UNDERSTANDING THE EFFECT OF CONFLICTING INFORMATION ON
MEDICATION ADHERENCE FOR VASCULITIS PATIENTS

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ABSTRACT

DELESHA M. CARPENTER: Understanding the Effect of Conflicting Information on
Medication Adherence for Vasculitis Patients
(Under the direction of Dr. Robert F. DeVellis)

Introduction. This dissertation represents the first quantitative investigation of the effect of

conflicting information on medication adherence in a sample of chronically ill patients.

Using the Information-Motivation-Behavioral Skills model as a theoretical guide, the

primary aim was to explore the relationships between conflicting information, adherence

support, outcome expectations for medications, adherence self-efficacy, and medication

adherence. A secondary aim was to describe patients' most frequently used information

sources, determine which sources patients perceived as credible, and investigate whether

there were gender differences in the use and perceived credibility of sources.

Methods. Vasculitis patients (n=232) completed two online questionnaires as part of the

Accessing Social Support in Symptom Treatment Study. A bootstrapping approach was used

to determine whether self-efficacy and outcome expectations mediated the effects of

conflicting information and adherence support on medication adherence. For the second aim,

MANCOVA tested the significance of a source*gender interaction term and follow-up

contrasts determined which sources male and female patients used differently. T-tests

compared patients' perceived credibility ratings.

Results. A majority of patients (51.3%) received conflicting medication information.

Conflicting information had a direct negative effect on medication adherence, which was not

mediated by self-efficacy or outcome expectations. Alternatively, self-efficacy mediated the positive effect of adherence support on medication adherence. Patients used physicians and the Internet most often to obtain medication information and also rated them as the two most credible information sources. Male patients consulted their spouse/partner more often and rated them as more credible than female patients. Female patients were more likely to use medication package inserts and the Internet and less likely to consult nurses than male patients.

Conclusion. Vasculitis patients seek medication information from multiple sources, which can result in the discovery of conflicting information. Patients who receive conflicting medication information are less adherent to their medication regimens. Policy initiatives to standardize medication practices may reduce the amount of conflicting information available to patients. Future research should attempt to uncover the determinants and outcomes, both immediate and distal, of receiving conflicting information and explore whether conflicting information is an issue for other disease populations.

DEDICATION

I dedicate this dissertation to my parents, Fred and Marsha Laroe. You are source of continual inspiration for me, both academically and spiritually. Thanks for all your love and support.

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CHAPTER 1: INTRODUCTION

1.1 Problem Statement

Vasculitis is a life-threatening autoimmune disease that can affect multiple organ systems. Over the course of the past four decades, the lives of vasculitis patients have been prolonged due to the continual evolution of medications and treatment regimens. Because patients' lives have been prolonged, this disease is now viewed more as a chronic illness as opposed to an acute condition. Although there is no cure for vasculitis, prescribed medications can induce remission, effectively treat disease symptoms, and aid in the prevention of future vasculitic "flares", thus decreasing financial burden for patients by reducing vasculitis-related hospitalizations (Cotch, 2000). Adherence to prescribed medications is critical because untreated patients have an 80% mortality rate within the first year of diagnosis (Walton, 1958). Unfortunately, vasculitis medications also are associated with serious side effects, including changes in mood, appearance, and organ function. In the most extreme cases, immunosuppressive medications can lead to severe infections and, ultimately, patient death (Langford et al, 1998).

Because vasculitis medications are associated with both positive and negative outcomes, it is important to understand what factors facilitate or hinder patients from taking medications as prescribed (medication adherence). The Information-Motivation-Behavior Skills (IMB) model offers a parsimonious theoretical framework with which to understand patient medication adherence (Fisher et al, 2003). The IMB model has been used to study

medication adherence for HIV/AIDS patients who, like vasculitis patients, take medications that prolong life and are associated with serious side effects. The IMB model posits that adherence-related information, motivation, and behavioral skills (self-efficacy) are determinants of medication adherence for patients living with a disease. A growing body of evidence suggests that the IMB model is effective at predicting medication adherence for HIV/AIDS patients (Fisher et al, 2006; Amico et al, 2009); however, the model assumes that patients receive homogenous adherence-related information.

To view information as a unidimensional, homogenous construct assumes that people are not receiving conflicting information from different sources regarding their medication regimens, which is not necessarily true. In fact, patients commonly consult multiple sources for medication information (Narhi, 2007; Rutten et al, 2005, Hesse et al, 2005), yet no published research has investigated whether receiving conflicting adherence-related information influences medication adherence for chronic disease patients. Preliminary evidence suggests that conflicting information affects patients' perceptions of care and increases anxiety (Zapka et al, 2004; Pollock et al, 2004; Han et al, 2006). Thus, conflicting information may better predict adherence self-efficacy and medication adherence than an information construct that is operationalized as factual knowledge.

1.2 Study Aims

This dissertation adds to the psychosocial literature in the field of vasculitis by determining if patients receive conflicting adherence-related information and whether receiving conflicting information influences patients' medication-taking behavior. In order to address the research gaps alluded to earlier, I developed five specific aims.

Aim #1: To describe the extent to which vasculitis patients receive conflicting

information about their medications.

Aim #2: To determine whether conflicting information and adherence support predict outcome expectations, adherence self-efficacy, and medication adherence.

Aim #3: To describe the sources of medication information that vasculitis patients use.

Aim #4: To determine which sources of medication information patients perceive as most credible.

Aim #5: To explore whether information source use varies for male and female vasculitis patients.

In order to address these aims, I collected primary data from a convenience sample of 232 vasculitis patients. Participants were recruited from four sources: 1) existing vasculitis studies at UNC Chapel Hill, 2) the Glomerular Disease Collaborative Network patient registry database, 2) recruitment announcements in vasculitis newsletters and websites, and 4) local vasculitis support groups. The study was longitudinal in nature and data were collected at two time points using web-based surveys. All data was analyzed with SAS Version 9.2.

1.3 Organization of the Dissertation

This dissertation comprises seven chapters. The introduction, which is the first chapter, is followed by the background and significance chapter. The third chapter presents the specific aims and associated research questions and hypotheses. The study's conceptual model also is included in that chapter. Chapter 4 discusses the questionnaire development process, including formative interviews, results of an expert panel review and cognitive interviews, as well as the psychometric properties for the final versions of the study measures. The results are summarized in two manuscripts. The first manuscript addresses

study aims #1 and #2, while the second manuscript addresses the remaining three aims. The final chapter is a general discussion of all study results and implications for future research. Last, all study materials, including the two web-based questionnaires, are included in the appendices.

CHAPTER 2: BACKGROUND AND SIGNIFICANCE

2.1 Overview

In this chapter, I begin by discussing the nomenclature, epidemiology, and symptomatology of vasculitis. Next, I describe the different vasculitis medications and their associated side effects. Third, I summarize the medication adherence literature with a specific focus on Information-Motivation-Behavior Skills (IMB) model variables and the empirical studies that have been conducted to test the relationships between the variables. Next, I identify existing research gaps, with a particular focus on the dearth of information about the effects of receiving conflicting information on patients' medication-taking behavior. Last, I provide a rationale for using the IMB model as the theoretical underpinning for my dissertation.

2.2 Vasculitis Nomenclature

Before discussing incidence and prevalence statistics, it is important to understand that there is disagreement among experts regarding how to classify the different types of vasculitis. Currently, there are two commonly used sets of criteria for vasculitis nomenclature: one put forth by the American College of Rheumatology (ACR) (American College of Rheumatology, 1990) and the other from the Chapel Hill Consensus Conference (CHCC) (Jennette et al, 1994). CHCC criteria are used frequently, despite the fact that the authors did not intend for their nomenclature system to be used to classify patients into different vasculitis disease categories.

Although there is overlap in the ACR and CHCC nomenclature criteria, some areas of contention exist. One major area of contention involves how to classify microscopic polyangiitis (MPA). The ACR has no criteria for MPA, whereas the CHCC defines MPA as necrotizing vasculitis that involves "microscopic vessels" and is associated with few or no immune deposits (Jennette et al, 1994). Thus, using the ACR criteria, MPA would be grouped with other types of vasculitis as opposed to being considered a stand-alone vasculitis category as defined by the CHCC. A second area of contention involves the classification of Wegener's Granulomatosis (WG) patients. According to the ACR criteria, a true case of WG must involve at least two of the following: 1) nasal or oral inflammation, 2) abnormal chest radiograph, 3) active urinary sediment, or 4) granulomatous inflammation on biopsy (Leavitt et al, 1990). In contrast, according to CHCC criteria, a true WG patient must have granulomatous inflammation (Jennette et al, 1994). As noted by Hogan and colleagues (1996), these differences in criteria make it difficult to compare across studies because the types of patients included will vary based on which criteria were used. For example, a study that uses the ACR criteria to recruit WG patients may include a substantial number of patients that are classified as having MPA according to the CHCC criteria. For the purposes of this study, I will be using the CHCC criteria because it makes the distinction between MPA and WG patients.

2.3 Types of Vasculitis

The vasculitides (plural of vasculitis) are a family of rare diseases that cause inflammation in patients' blood vessels. The various types of vasculitis are categorized based on the size, number, and site of affected blood vessels. Three types of vasculitis attack the small blood vessels and are associated with anti-neutrophil cytoplasmic antibodies (ANCA).

These three types are referred to as ANCA-associated systemic vasculitis (AASV), which includes Wegener's granulomatosis (WG), microscopic polyangiitis (MPA), and Churg Strauss Syndrome (CSS) (Jennette et al, 1994). WG, CSS, and MPA are also known as the primary systemic small vessel vasculitides (Lane et al, 2005) and represent the most common vasculitis types.

There are several less common forms of vasculitis that differ from AASV in the types of blood vessels they attack. For example, Giant Cell Arteritis and Takayasu's Arteritis affect the medium and large blood vessels, including vessels as large as the aorta. Interestingly, Behcet's disease can affect both the small and large blood vessels (Vasculitis Foundation, 2006). Polyarteritis Nodosa (PAN), like AASV, can affect both the small and medium vessels, but is not commonly associated with ANCA. For the remainder of this section, I will focus on AASV, as these vasculitis types possess the largest epidemiological base in the literature.

AASV is not distributed evenly among races and across geographic locations. For example, the Vasculitis Foundation (2006) estimates that 97% of vasculitis patients are white, 2% are black, and 1% are of other races. In contrast, studies that have been conducted with predominately southeastern U.S. populations have found that approximately 10% of vasculitis patients are black {Hogan et al, 1996; Hogan et al, 2005). Unfortunately, large-scale AASV prevalence studies have not been conducted in the United States, so an accurate estimate of the racial distribution of the disease types does not exist.

Currently, the causes of AASV are unknown; however, preliminary evidence suggests that environmental influences such as hydrocarbon exposure, inhaled fumes and particulates, infections, drugs, allergy, vaccination, and farming may play a role in disease development

(Watts et al, 2005). In addition, latitude and exposure to silica (Watts et al, 2005; Lane et al, 2005) have been implicated as possible causes of the disease. Because latitude appears to be associated with vasculitis, the prevalence of vasculitis varies between countries. For example, in Europe, WG is more prevalent at higher latitudes, whereas MPA is more common at lower latitudes (Watts et al, 2001). Below is a brief description of each AASV type.

2.3.1 Wegener's Granulomatosis

WG is the most common of the three AASV types. To date, several prevalence/incidence studies of WG have been conducted in countries such as the United States (Cotch et al, 1996), Norway (Koldingsnes et al, 2000), England (Watts et al, 2005), Spain (Gonzalez-Gay et al, 2001), Germany (Reinhold-Keller et al, 2005), and France (Mahr et al, 2004). Prevalence estimates of WG vary by country. For example, the prevalence of WG is 23.7/million citizens in France (Mahr et al, 2004), 30 cases/million citizens in the United States (Cotch et al, 1996), and 95 cases/million citizens in Norway (Koldingsnes et al, 2000). Incidence also varies by country, with estimates from 2 new cases/million/year in the United States (Vasculitis Foundation, 1996) up to 55 new cases/million/year in Norway (Koldingsnes et al, 2000).

With regard to symptomatology, WG most often affects the upper airway, lungs, and kidneys; however, it may also affect the joints, muscles, eyes, skin, and other organs (Langford, 2005). No definite cause of WG has been identified; however, there is some evidence that cell-mediated immune responses may have a causal role (Molloy & Langford, 2006). WG affects men and women equally and is usually diagnosed in persons between the ages of 40-60, although it can manifest at any age (Vasculitis Foundation, 2006; Langford, 2005).

2.3.2 Microscopic Polyangiitis

Similar to WG, the incidence for MPA is low, ranging from 0.5 new cases/million/year in the United Kingdom to 24 new cases/million/year in Kuwait (Lane et al, 2005; Gonzalez-Gay et al, 2001). In Germany, Reinhold-Keller and colleagues (2005) documented an incidence rate of approximately 3 new cases/million/year. One prevalence study by Mahr and colleagues (2005) in France, reported a prevalence of 25.1/million adult citizens. No incidence or prevalence studies of MPA have been conducted in the United States.

Regarding symptomatology, MPA patients often experience kidney, lung, and peripheral nerve issues (Molloy & Langford, 2006) as well as gastrointestinal, upper respiratory, and joint/muscle problems (Belmont, 2006). Clinically, MPA is very similar to WG, except that there is less ear, nose, and throat involvement in MPA (Molloy & Langford, 2006). MPA typically manifests in middle age and predominantly affects white people (Vasculitis Foundation, 2006). Based on studies that group MPA patients separately from other vasculitis types, it appears that the disease affects men and women equally (Lane et al, 2005; Mohammad et al, 2007). Like other types of AASV, the cause of MPA is unknown.

2.3.3 Churg Strauss Syndrome

The estimated incidence for CSS is lower than that of WG and MPA, ranging from 0.5 new cases/million/year in Norway (Koldingsnes et al, 2000) to 4.2 new cases/million/year in the United Kingdom (Lane et al, 2005). The prevalence of CSS varies based on the country of study; however, the overall estimate for western Europe is between 2.4 to 6.8 cases/million people (Noth et al, 2003). At this time, no incidence or prevalence study of CSS has been conducted in the United States.

As for symptomatology, body systems commonly affected by CSS include the lungs, skin, ears, nose, and throat, as well as kidneys and gastrointestinal organs (Pagnoux et al, 2007). CSS patients typically experience allergic rhinitis, asthma, and high levels of circulating eosinophils (Jennette et al, 1994; Martin et al, 1999). The presence of asthma and eosinophils differentiates CSS from WG and MPA. CSS is also distinguishable from WG and MPA because ANCA-positivity is less common in CSS (approximately 50%) than in WGA (90%) or MPA (80%) (Hoffman et al, 2005). CSS patients who are ANCA-positive may experience more negative renal outcomes when compared with patients who are not ANCA-positive (Sable-Fourtassou et al, 2005).CSS affects men and women equally, and the mean age of diagnosis is 48 years old (Pagnoux, 2007). The cause of CSS is unknown.

2.4 Vasculitis Medications

Vasculitis is characterized by periods of disease activity (relapses or flares) followed by periods of remission. When a patient is experiencing symptoms of vasculitis, this is referred to as active vasculitis and treated with prescription medications. Vasculitis is also associated with chronic disease manifestations, such as end stage renal disease (de Lind et al, 2006) and hearing loss (Lidar et al, 2007), which result from prolonged inflammation and tissue death of the blood vessels. The medications discussed from this point forward are those used to treat active vasculitis as opposed to chronic disease manifestations.

Prescription medications are critical for patient survival because they induce remission in patients experiencing relapses as well as prevent subsequent relapses once remission is achieved. In fact, vasculitis medications are so key to survival that when a patient is left untreated there is an 80% mortality rate within the first year of diagnosis (Walton, 1958). Treatment with vasculitis medications improves the 5-year survival rate

between 70-90%; however, approximately 20% of patients do not respond to treatment, and 50% of responders will subsequently experience a disease relapse (Walsh & Jayne, 2007).

The types of vasculitis medications prescribed vary based on where the patient is in the relapse/remission cycle. When patients present with a relapse, they are most often prescribed immunosuppressive medications including high-dose corticosteroids as well as cytotoxic agents such as cyclophosphomide, and anti-metabolites (methotrexate, and mycophenolate mofetil). This combination of corticosteroids and immunosuppressive medications is known as induction therapy because it induces remission in 80% of patients who present with active vasculitis (Puechal, 2007). After achieving remission, many vasculitis patients are prescribed maintenance therapy drugs, which reduce the rate of subsequent relapses (Puechal, 2007). The following medications are often prescribed to maintain remission: immunosuppressives like prednisone, azathioprine, mycophenolate mofetil or methotrexate, and the antibiotic co-trimoxazole. Sometimes patients are able to stop taking medications completely after a 6-12 month maintenance period, while others have to stay on maintenance medications for the rest of their lives.

Although induction of remission and additional years of life are major benefits of vasculitis medications, medical treatment also carries certain burdens, including serious medication side effects, loss of income due to missed days of work, alteration of routine, and symptom monitoring (Hoffman et al, 1998). Examples of commonly experienced medication side effects include: higher risk for infection, hair loss, and nausea/vomiting (Langford et al, 1998). Moreover, medication-induced infections are a serious issue in vasculitis treatment. For example, in a study of 229 ANCA-associated vasculitis patients in England, Harper and Savage (2005) found that the risk of death increased by 58% when patients had an infection.

Additionally, older patients were more likely to die from an infection than younger patients.

Less common but more severe side effects include leukemia, cancer, and permanent kidney damage (Langford et al, 1998). In addition to these physical side effects, patients also experience psychological side effects from medications including mood swings and depression. Side effects are medication-specific. For example, osteoporosis and diabetes are associated with prolonged corticosteriod use, whereas bladder cancer and hair loss are side effects of cyclophosphamide. It is also important to note that some patients do not experience any side effects when taking vasculitis medications. Table 2.1 presents a list of vasculitis medications and their associated side effects.

Table 2.1: List of vasculitis medications and their associated side effects

Medication Name (Brand Name)	Medication Type	Short-term Side Effects*	Severe Side Effects*
Co-trimoxazole (Bactrim)	Antibiotic	Dizziness/Headache Fatigue/lethargy Diarrhea Abnormal taste Nausea/vomiting/anorexia Rash Anemia	Jaundice
Corticosteroids (Prednisone, Methylprednisolone)	Corticosteroid	Increased risk of infection Dizziness/Headache Upset stomach Trouble sleeping Weight gain Mood changes	Convulsions Diabetes Pancreatitis Irregular menstruation Osteoporosis Cataracts Joint damage
Azathioprine (Imuran)	Immunosuppresive	Increased risk of infection Nausea/vomiting/anorexia Fatigue Hair loss Joint pain Diarrhea	Bone marrow toxicity Leukemia Lymphoma Liver toxicity Pancreatitis
Cyclophosphamide-IV or oral (Cytoxan)	Immunosuppressive	Increased risk of infection Nausea/vomiting/anorexia Diarrhea/ abdominal pain Rash/hives/sweating Headache Swollen lips/mouth sores Hair loss	Bladder cancer & fibrosis Hemorrhagic cystitis Sterility Cataracts Kidney failure

Table 2.1 continued

Medication Name (Brand Name)	Medication Type	Short-term Side Effects*	Severe Side Effects*
Cyclosporin	Immunosuppresive	Increased risk of infection Nausea Cramps/diarrhea Headache Hair growth Acne Tremors Swollen gums	Kidney problems High blood pressure
Methotrexate (Trexall, Rheumatrex)	Immunosuppresive	Mouth sores Nausea/vomiting Low white blood cell counts Dizziness/headache/drowsiness Skin rash/itch Hair loss	Bone marrow toxicity Pneumonitis Hepatic fibrosis
Mycophenolate mofetil (Cellcept)	Immunosuppresive	Dizziness/headache/drowsiness Nausea/vomiting Diarrhea/gas Sweating/flushing/tremors Insomnia Pain Rash Mood changes Vision changes	Anemia Gastrointestinal bleeding
Rituximab (Rituxan)	Immunosuppressive	Fever/chills Nausea/vomiting Hives/itching Fatigue Headache Runny nose Decreased blood pressure Vision changes	Increased risk of infection Anemia

2.5 Medication Adherence

When a person is diagnosed with a chronic disease, medical professionals often suggest a myriad of lifestyle changes, including changes in diet and exercise, as well as the implementation of new behaviors, such as symptom monitoring and starting a medication regimen. Of all the behaviors a newly diagnosed patient is asked to engage in, taking prescribed medications may seem the easiest to perform. However, the seemingly simple act

of taking medications is associated with multiple tasks, such as getting prescriptions filled and refilled, remembering how and when to take medications, and monitoring positive and negative medication effects. In addition to the logistical aspects of starting a medication regimen, patients must adapt to new psychosocial demands, which, depending on the disease, may include feeling stigmatized by taking medications and dealing with the disruptions medication-taking may cause to one's routine.

Given that medication-taking is not as simple as it seems, it is unsurprising that patient medication adherence is a major issue that spans all ages and diseases. Medication adherence is defined as, "the extent to which patients follow the instructions they are given for a prescribed treatment" (Haynes et al, 2005) (p. 2). The term "medication compliance" was originally used to describe adherence to a prescribed medication regimen; however, many researchers stopped using this term because they felt that adherence was a more non-judgmental term that implied that the doctor was not the sole arbiter of what was best for a passive patient (Gerber, 1986). Over the years, as understanding increased of how patients actively self-manage (Clark et al, 2001) their diseases, the term "medication adherence" began to supplant the term "compliance"; although both terms are still used today. For the remainder of this chapter, I will use medication adherence to describe the extent to which a patient's medication-taking behavior matches what is prescribed or mutually determined as best by the patient and his/her physician.

There are three different types of nonadherence (Schlenk et al, 2001). The most common type is erratic nonadherence, which has been defined as patients failing to follow therapy, "because it is difficult, complicated, or disruptions interfere with following the regimen" (Schlenk et al, 2001) (p.59). This type of adherence is most often due to patients'

forgetting their medications because of changes in their schedules or psychological distress.

A second type of nonadherence is unwitting nonadherence. This type of adherence occurs when a patient misunderstands their physician's directions and unintentionally takes their medications improperly. There are many reasons that patients misunderstand medication instructions, including language barriers, cognitive impairment, or simple miscommunication. In contrast, intentional nonadherence, a third type of nonadherence, occurs when a patient, "makes a clear decision to alter or discontinue therapy" (Schlenk et al, 2001) (p. 61). The most commonly cited reasons for this type of nonadherence are feeling better, side effects, low perceived medication effectiveness, complexity of the regimen, fear of addiction, and prohibitively high medication costs.

Because there are several ways to be nonadherent to medication regimens, it is unsurprising that many studies have documented that patients do not take their medications as prescribed. For example, several decades of research has demonstrated that patient adherence to medication regimens is suboptimal, with adherence rates ranging from 7% to 85% (Haynes et al, 2005). Medication adherence for persons with chronic disease is no exception, with one review article reporting an average medication nonadherence rate of 24.8% (DiMatteo, 2004a). Other researchers (Schlenk et al, 2001) have documented an average medication nonadherence rate of 50% for chronic conditions like asthma and hypertension.

Similar findings have been reported for rheumatic disease patients. For example, one study found that a majority of lupus and rheumatoid arthritis patients (both of which, like vasculitis, are systemic and inflammatory) reported multiple occasions when they did not take their medication as prescribed (Popa-Lisseanu et al, 2005). To date, only one study has

investigated whether medication adherence is an issue for vasculitis patients. In this study, Thorpe (2006) documented a mean self-reported medication adherence rate of 4.5 on a 5.0 scale. In other words, the average vasculitis patient was nonadherent 10% of the time.

The consequences of nonadherence are multiple and substantial: including medical complications, hospitalizations, and increased financial burden for families and the health care system (Gallant, 2003). As noted earlier, medication nonadherence can lead to continued escalation of vasculitic symptoms, eventually resulting in organ failure and death (Puechal, 2007). In addition to the toll nonadherence takes on health, Cotch (2000) documented the financial burden of vasculitis, with the average cost of a vasculitis-related hospitalization for a WG patient being $12,023 between the years of 1986-1990. When those numbers are extrapolated to the United States as a whole, total charges for vasculitis-related hospitalizations are approximately $150 million. Because taking prescribed medications can help reduce vasculitis relapses, adherence can lead to a potential cost-savings by reducing the number of vasculitis-related hospitalizations.

2.6 Factors Related to Medication Adherence

As medications have proven to be pivotal for increasing lifespan and quality of life for vasculitis patients, it is important to know what factors help or hinder patients' ability to adhere to their prescribed medication regimens. To date, a plethora of studies have been conducted to learn which factors best explain variation in medication adherence. In 1976, Haynes documented 59 factors that had been studied in relation to patient adherence. He organized these factors into six categories:

> 1) demographic features of patients;
> 2) features of the disease;
> 3) features of the therapeutic regimen;
> 4) features of the therapeutic source;

5) features of the patient-therapist interaction; and
6) sociobehavioral features of patients.

Overall, there was no strong evidence to support that demographic features of the patients (e.g. age, sex, education, SES) were significantly associated with treatment adherence. Similarly, only diagnosis was significantly related to adherence in the "features of disease" category. Specifically, patients with a psychiatric diagnosis, especially schizophrenia, were less adherent than persons with nonpsychiatric diagnoses. With regard to "features of the therapeutic regimen", three factors were related to adherence: complexity, degree of behavioral change, and duration. Patients with more complex drug regimens were less adherent than patients with simpler regimens. Additionally, patients who were asked to acquire new habits (such as taking medication) were generally more adherent than patients who were asked to change old behaviors, such as eating habits. Thus, the more behavioral change a patient was asked to engage in, the less adherent they were. Third, as the duration of therapy increased, patients generally demonstrated less adherence with time. Like demographic and disease features, "features of the therapeutic source" were not significantly related to medication adherence. In the category of "patient-therapist interaction", level of supervision and patient satisfaction were both significantly related to adherence. Patients who were supervised (in-patients at the hospital) were more adherent than unsupervised outpatients. Last, patients who were more satisfied with their therapist and clinic were more adherent than unsatisfied patients.

Multiple sociobehavioral features of the patient were associated with adherence. The factors most strongly related to nonadherence were higher perceived disease severity and susceptibility, history of nonadherence with other regimens, and family instability. Patients who perceived their disease as more serious and felt more susceptible to the disease [two key

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components of the Health Belief Model (Hochbaum, 1958)] were more adherent than patients who did not possess these beliefs. Thus, Haynes (1976) concluded that there was support for the Health Belief Model in the area of adherence; although, prospective studies generally reported weaker associations than retrospective studies. Additionally, patients who demonstrated adherence to other regimens were more likely to adhere to newly prescribed regimens. Last, patients with more supportive families were more adherent than patients with less supportive families.

Since Haynes' review, additional review papers have been published that document factors related to adherence (DiMatteo, 2004a; DiMatteo, 2004b, DiMatteo et al, 2007, Gallant, 2003) and the effectiveness of adherence interventions (Haynes et al, 2006; Kriplani et al, 2007). An inspection of these papers reveals that there has been increased focus on intrapersonal and interpersonal adherence-related factors. Researchers also have sought to better understand how medication characteristics relate to adherence. A brief description of findings related to each of these adherence factor groups (intrapersonal, interpersonal, medication characteristics) is found below. It should be noted that although researchers have continued to investigate the relationship between demographic factors and adherence, there is still no consistent evidence that these factors predict medication adherence (Vermeire et al, 2001).

2.6.1 Intrapersonal factors

A substantial body of research about intrapersonal adherence-related factors has accumulated over the past 30 years. Most of the factors that have been studied come from widely used health behavior theories, including the Health Belief Model (Hochbaum, 1958), the Theory of Reasoned Action/Planned Behavior (Fishbein &Ajzen, 1975), and Social

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Cognitive Theory (Bandura, 1989). The vast majority of research in this area has identified

three intrapersonal factors that are strongly related to medication adherence: 1) patient

medication beliefs and attitudes, 2) self-efficacy, and 3) depression. In addition to these three

factors, perceived medication effectiveness (Gordon et al, 2007; Popa-Lisseanu, 2005) and

knowledge about medications (Haynes, 1976; Munro et al, 2007) have received mixed

support regarding whether they are significant predictors of adherence. Unfortunately, no

published studies have investigated whether intrapersonal factors are predictors of

medication adherence for vasculitis patients.

2.6.1.1 Patient medication beliefs and attitudes

Patient medication beliefs and attitudes encompass: 1) perceived disease severity, 2)

beliefs about the necessity of medications, and 3) concerns about medications. In a meta-

analysis of 116 articles, DiMatteo (2007) found that perceived disease severity threat, defined

as, "the patient's belief in the severity of the disease to be prevented or treated" (p. 523), was

significantly positively correlated with adherence. In fact, there was a 22% higher risk of

nonadherence for patients who did not perceive their illness as a severe threat when

compared with patients who did perceive their illness as a severe threat. DiMatteo (2007)

also explored the relationship between self-reported and objective disease severity (i.e.

patient health status) and adherence. Those analyses revealed that patients with serious

conditions (HIV, end stage renal disease, heart failure) who self-reported higher disease

severity (poorer health) were *less* likely to be adherent than patients with lower self-rated

disease severity (better health). In addition to self-reported disease severity, when using

measures of objective severity, she found that patients with serious conditions who had

higher objective disease severity were at 11% greater risk of nonadherence than patients who

were less severely ill. These findings indicate that patients with serious illnesses who are in poorer health (subjectively and objectively) and do not perceive their disease as a serious threat are at greater risk of nonadherence.

In addition to perceived disease severity, medication concerns and beliefs about the necessity of medications have been related to adherence. In 1999, Horne and colleagues created the Beliefs about Medicines Questionnaire (BMQ) to measure both medication concerns and perceived necessity of medications. The necessity construct represents, "the perceived role of medication in protecting against deterioration of present and future health status of the patient," while medication concerns represent the emotional (being worried) and cognitive (medications being a mystery) consequences of taking medications (p. 20) (Horne et al, 1999). Results from this questionnaire have been reported by researchers in the fields of rheumatoid arthritis (Neame & Hammond, 2005; Treharne et al, 2006) and HIV/AIDS (Gonzales, 2007b). In a study of 328 rheumatoid arthritis patients, Neame and Hammond (2005) found that nonadherent patients reported higher medication concerns than adherent patients; however, they did not find any difference in necessity beliefs between adherent and nonadherent patients. In conflict with Neame and Hammond's findings, Treharne and colleagues (2006) have reported that rheumatoid arthritis patients with higher necessity beliefs are more adherent than patients with lower necessity beliefs. In a study of 325 HIV-infected patients, Gonzales (2007b) reported that necessity was significantly positively related to adherence, while concerns were significantly negatively related to medication adherence. These findings lend overall support to the idea that necessity and concerns are important predictors of medication adherence for patients with chronic illnesses.

2.6.1.2 Self-efficacy

Self-efficacy is defined as a person's confidence in their ability to perform a specific behavior (Bandura, 1989). For persons with chronic illness, high self-efficacy has predicted better psychological functioning and adherence to health recommendations (Marks et al, 2005). For example, in a study of rheumatoid arthritis patients (Brus et al, 1999), self-efficacy was a significant predictor of medication adherence in a logistic regression analysis even when controlling for other variables like age, sex, education, and outcome expectations. Burge and colleagues (2005) also found that there was a significant positive correlation between self-efficacy and medication adherence for chronically ill patients. There is also strong evidence from the field of arthritis to support that increasing self-efficacy leads to better self-management behaviors (Lorig et al, 1989; Lorig & Holman, 1993). It has been posited that self-efficacy may have an indirect effect on adherence through increasing patient motivation (Marks et al, 2005b).

2.6.1.3 Depression

Depression is the third intrapersonal factor that has been associated with medication adherence for persons with chronic disease. In a study of Type II diabetes patients, Gonzales (2007a) found that persons defined as having probable major depression reported significantly fewer adherent days to diet, exercise, and glucose self-monitoring when compared with non-depressed patients. Additionally, logistic regression models revealed that major depression was associated with a 2.3-fold increase in the odds of missing at least one medication dose in the previous seven days. Additional support for depression as a predictor of nonadherence comes from a review of cross-sectional medication adherence studies conducted with older adults (Briesacher et al, 2007). In six of the seven studies that investigated depression, poor mental health was a statistically significant predictor of cost-

related medication nonadherence. Because depression is often associated with other variables like income, age, and gender; it is often included as a covariate in medication adherence regression analyses.

2.6.2 Interpersonal factors

Similar to research on intrapersonal factors, there has been a growing body of research about how interpersonal factors affect self-management behaviors like medication adherence. Much of this research has focused on social support and aspects of the physician-patient relationship. Again, no published studies have determined whether interpersonal factors are predictors of medication adherence for persons living with vasculitis. Below is a brief synthesis of research findings regarding social support, the doctor-patient relationship, and medication adherence.

2.6.2.1 Social support

Studies about social support and medication adherence have focused on two main areas: types of support (functional support) and sources of support (structural support). A major meta-analysis of 122 studies by DiMatteo (2004a) investigated the effects of both functional and structural support on adherence to treatment regimens for chronic disease patients. Overall, she found that functional support was a stronger predictor of adherence than structural support. For example, practical support, defined as the provision of instrumental support and assistance (like reminders), was the most significant predictor of treatment adherence. In fact, standardized odds ratios revealed that the odds of adherence were 1.60 times higher for persons that received practical support when compared with persons that did not receive practical support. Emotional support was also a significant predictor of adherence, with the risk of nonadherence 1.35 times higher for patients who do

not receive emotional support. The third functional support factor, family cohesiveness, was also significantly related to adherence, with patients in cohesive families having 2.03 higher odds of adhering when compared with patients who are not in cohesive families.

With regard to sources of social support, numerous studies have shown that members of a patient's social network can influence the patient's psychological affect and decision to engage in self-management behaviors, including medication adherence (DeVellis et al, 2003, Gallant, 2003, Lewis et al, 2002, Lewis & Butterfield, 2005, Lewis et al, 2007). As Gallant (2003) elegantly stated, "chronic illness self-management does not occur in a vacuum, but rather in a context that includes formal health care providers, informal social network members, and the physical environment" (p. 171). As illustrated above, social network members may influence adherence, and ultimately other health outcomes, via the provision of practical support. Practical support may be provided in a variety of ways, including giving advice, tangible support (such as assistance with transportation), and direct assistance with self-management activities (Gallant, 2003).

Studies of supportive others often have been limited to assessments of one source of support, most commonly the patient's spouse. For example, DiMatteo (2004b) found that married patients were more adherent to their treatment regimen than unmarried patients. Of studies that have been conducted on source differences, most have focused on socially-isolated individuals or persons with conditions other than auto-immune diseases. For example, a study by Dean et al (1990) found that social support from friends and spouses significantly reduced depression for elderly persons but found no significant effects for support provided by adult children and other family members. The authors have stated that "further research is needed to discern the conditions under which the various sources may be

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differentially significant, such as illness and disability." A decade later, in a study of HIV medication adherence, Meredith and colleagues (2001) asked patients to report what sources have been important in their decisions about using HIV medications. The physician was ranked most important, followed by others with HIV, friends, medical journals, and the Internet. Five years later, a subsequent study of HIV medication adherence found the only significant variable associated with perfect medication adherence was the caregivers' perceptions of medication hassles, with higher perceived hassle being associated with lower patient adherence (Beals et al, 2006). A more detailed review of how different sources of medication information affect medication adherence is presented in section 2.9 of this chapter.

Researchers have expressed a need for additional study of how different social network members affect patients' treatment adherence. For example, a recent study of spousal support and cardiac rehabilitation behaviors stated, "it would be useful to investigate the extent to which other important members of a patient's social network engage in similar or dissimilar support and control efforts, and to evaluate how these efforts jointly affect the patient's health outcomes" (Franks et al, 2006). Additionally, Penninx et al (1998) stated, "the question for future research is to specify in more detail for whom, from whom, and under what circumstances various types of social support and personal coping resources can be expected to influence health (p. 558)." Additionally, studying sources of support beyond partners and spouses is justified according to a review of family social support interventions to increase chronic disease management (Martire et al, 2004). In this review, the authors found that family interventions reliably decreased mortality when they involved a mixed group of family members as opposed to only spouses.

2.6.2.2 Physician-patient relationship

Although there is a paucity of research that directly compares sources of social support, the effect of the physician-patient relationship on adherence has been studied extensively. O'Brien and colleagues (1992) provide a detailed review of this area. Overall, physician trust (Briesacher, 2007), physician-patient communication, and patient satisfaction have been consistently related to adherence. Briesacher (2007) found that patients who trust their physicians were more adherent to their medications when compared with patients who did not trust their physicians. This finding has been corroborated by other research (Haynes, 1976; Ockene, 2001). Good physician-patient communication has also been associated with better medication adherence (O'Brien et al, 1992). For example, physicians who use understandable language, encourage open exchange of information in a friendly environment, and encourage patients to be active in their medical care promote better medication adherence more so than doctors who do not do these things (O'Brien et al, 1992). Last, patient satisfaction, including satisfaction with health care providers and the information received from health care providers, has been related to medication adherence, with more satisfied patients reporting better medication adherence (Lyons & Chamberlain, 2006).

2.6.3 Medication characteristics

In addition to intrapersonal and interpersonal factors, specific characteristics of medications, including side effects (Popa-Lisseanu et al, 2005, Gordon et al, 2007), number (Burge et al, 2005), cost (Briesacher, 2007), and type (Treharne et al, 2006), have been associated with adherence. For example, in a qualitative study of rheumatoid arthritis and lupus patients, Popa-Lisseanu and colleagues (2005) reported that fear of side effects was the most commonly reported barrier to medication adherence. Patients were most concerned

about organ damage, leading several to discontinue treatment completely without consulting

their physicians first. Similarly, another study (Gordon et al, 2007) found that medication

side effects caused cardiovascular patients to adjust or miss medication doses or stop the

medications altogether. Regarding number and costs of medication, increasing number

(Burge et al, 2005) and costs (Briesacher, 2007) of medications have been associated with

poorer medication adherence for patients with chronic disease. Last, adherence has been

shown to vary based on the type of medication being taken. For example, with rheumatoid

arthritis patients, adherence rates vary for non-steroidal anti-inflammatory drugs (NSAIDs)

and disease modifying and anti-rheumatic drugs (DMARDs) (Treharne et al, 2006). Thus, it

cannot be assumed that if a patient is adherent with one type of medication, they will be as

adherent with other types.

2.7 The Information-Motivation-Behavioral Skills Model

Based on the review of literature provided above, it is obvious that many factors are

related to medication adherence. Several organizing frameworks/models/theories exist with

which to structure relationships among and between these factors and adherence, including

the Health Belief Model (Hochbaum, 1958), the Theory of Reasoned Action and Planned

Behavior (Fishbein &Ajzen, 1975), Social Cognitive Theory (Bandura, 1989), Protection

Motivation Theory (Rogers, 1975), the Transtheoretical Model (Prochaska & DiClemente,

1983), and the Information-Motivation-Behavioral Skills model (Fisher & Fisher, 1992). In a

recent review of behavior change theories, Munro and colleagues (2007) noted that, "there is

no clear evidence yet for the support of any of these theories within the field of adherence

behaviors" (p. 11). However, of these theories and models, the Information-Motivation-

Behavioral Skills (IMB) model is the least studied, probably due to its relatively recent

development in the field of behavioral psychology. Despite its newness, the IMB model has been labeled a "promising model for promoting adherence" (Munro et al, 2007, p. 8).

The IMB model was originally developed to account for the psychological determinants of HIV risk and preventive behavior and has been used to study medication adherence for HIV patients since 2001. The parsimonious IMB model causally relates three constructs (adherence-related information, motivation, and behavioral skills) to explain medication adherence. The model posits that a better informed, more motivated patient with requisite behavior skills will initiate and maintain health-promoting behaviors (like taking medications) more than patients who are uniformed, unmotivated, and lacking of requisite behavior skills. Figure 2.1 is a graphical representation of the model.

Figure 2.1: The IMB model applied to medication adherence
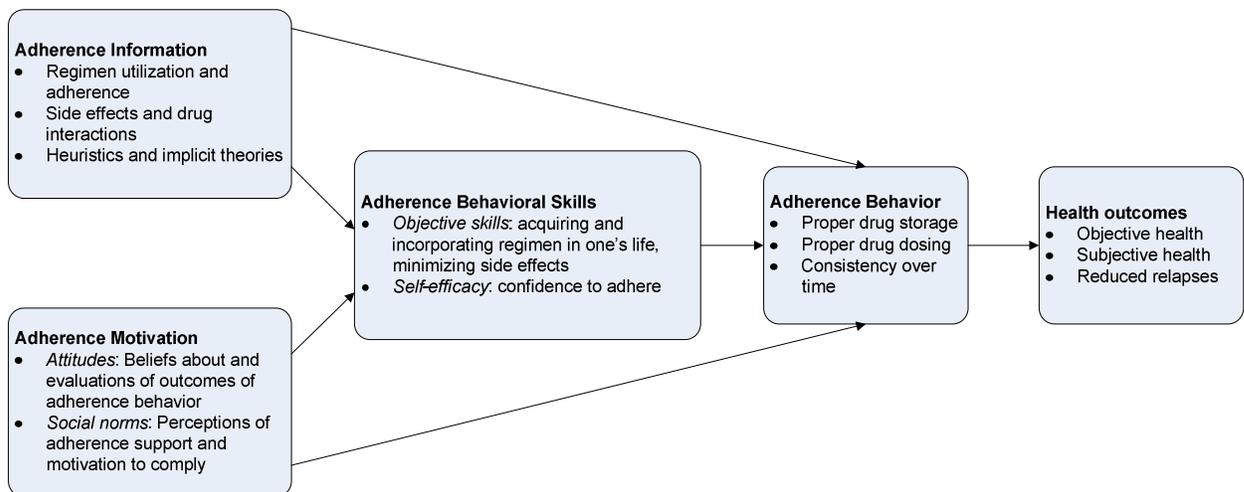
adapted from Fisher et al (2006)

Before discussing the extent to which the IMB model predicts medication adherence, it is important to understand how each construct is defined. Beginning with the left side of the model, adherence information is defined as relevant facts about: 1) when and how to take

medications correctly, 2) side effects, 3) adequate adherence levels (what happens when one is adherent 50% versus 100% of the time), and 4) drug interactions (Fisher et al, 2003). In addition to basic facts, adherence-related heuristics are an important component of the information construct. Heuristics are simple rules which permit cognitively effortless behavior and may be at odds with correct adherence (Fisher et al, 2003). An example of a faulty adherence-related heuristic is, "if I'm feeling well, then missing a few doses of my medication doesn't really matter" (Amico et al, 2005). Additionally, implicit theories are a part of the information construct. Implicit theories are, "more complex sets of beliefs that require cognitive effort to apply adherence decision making" (Fisher et al, 2006) (p. 463). An example of an implicit theory provided by Fisher and colleagues (2006) is, "skipping my medication from time to time will eventually teach my immune system to fight the virus by itself." Looking at the causal relationships in the model, adherence-related information is shown to affect adherence behavior directly and indirectly through adherence behavioral skills.

Adherence motivation is the second construct located on the left-hand side of the model and comprises personal attitudes and social norms. Attitudes towards adherence are, "based upon perceptions of the outcomes of adherent behavior and evaluations of these outcomes" (Fisher et al, 2003) (p. 100). For example, if a patient believes that taking medications properly will increase his/her quality of life and he/she values improved quality of life, then he/she is more likely to be adherent. In addition to personal motivation to adhere, the IMB model asserts that social motivation can affect adherence behavior. Social motivation involves the patient's perceptions of adherence support from significant others. Moreover, social motivation is affected by a patient's willingness to comply with the wishes

significant others. Thus, a patient that perceives that his/her significant others (spouse, friends) are supportive of taking medication as prescribed and desires to take medications correctly because his/her significant others approve, is more socially motivated to be adherent. However, there is also the possibility of a negative effect, whereby significant others are not supportive of a patient's adherence and the patient becomes less adherent in an effort to comply with their wishes. Like adherence information, the adherence motivation construct is shown to affect adherence directly and indirectly through adherence behavioral skills. Overall, the motivation construct draws heavily upon the Theory of Reasoned Action (Fishbein & Ajzen, 1975).

Moving to the right, behavioral skills is the next construct in the IMB model. Behavioral skills comprise objective abilities (e.g. ability to take and store medications properly, incorporate medication taking into one's daily routine, minimize side effects) and self-efficacy to perform adherence behaviors (Fisher et al, 2003). According to the model, patients who have both the ability and confidence to perform adherence-related tasks will be more adherent and, ultimately, will have better health outcomes. It is important to note that when the medication regimen is complicated, as is often the case for vasculitis patients, the effects of adherence information and motivation are mostly mediated by behavioral skills. Following this logic, it is possible that a patient can be both informed and motivated to be adherent, but if he/she lacks adherence-related behavioral skills, then he/she is ultimately more likely to be nonadherent. Thus, with complex regimens, direct effects of information and motivation on adherence are less likely.

The right-most constructs of the IMB model are medication adherence and health outcomes. Medication adherence represents the behaviors necessary to be adherent to one's

medication regimen, including storing medications properly, taking the correct amount of medication at the correct times, and being consistent with the regimen (Fisher et al, 2003). If a patient is adherent, then health outcomes are likely to be affected. For example, with vasculitis patients, taking medications correctly may increase quality of life by alleviating disease symptoms and preventing vasculitic flares.

2.7.1 Empirical support for the IMB model

To date, four published studies have empirically investigated whether the IMB model predicts medication adherence for HIV/AIDS patients. The results of three of these studies (Amico et al, 2005; Starace et al, 2006; Kalichman et al, 2001) were included in a review article by Fisher and colleagues (2006). The fourth study was published by Amico and associates in 2009. Overall, the results of these studies lend strong cross-sectional support for the IMB model in predicting adherence to antiretroviral medications for HIV/AIDS patients. Table 2.2 synthesizes the results from these studies. Each study is described in greater detail below.

The first study to test whether the relationships proposed in the IMB model were applicable to medication adherence was conducted by Kalichman and associates in 2001. In this study, a convenience sample (*n*=112) of predominantly African American, HIV-positive women in the United States completed a self-administered questionnaire that asked about IMB model constructs and HIV treatment adherence. Respondents were considered adherent if they had not missed a dose of their antiretroviral medications in the previous week. Using structural equation modeling, the authors found some support for the relationships proposed in the IMB model. More specifically, the authors found significant relationships between: 1) motivation and behavioral skills (self-efficacy) and, 2) behavioral skills (self-efficacy) and

treatment adherence. However, the authors did not find a significant relationship between adherence information and behavioral skills. Fisher and colleagues (2006) suggest that this insignificant finding occurred because the authors measured factual information (i.e. "Is AZT a protease inhibitor?") instead of adherence-related information (i.e. "I know what to do if I miss a dose of any of my HIV medications"). Although the authors found a significant relationship between information and motivation, this finding was not discussed in the article. Last, the authors also found that depressed respondents were more likely to be nonadherent than respondents who were not depressed.

A second test of the IMB model was conducted by Amico and associates in 2005. In this study, a convenience sample of 200 HIV-positive patients were recruited from clinics in Puerto Rico. Respondents were asked to complete a Spanish version of the IMB ART questionnaire, which asks about IMB model constructs in relation to antiretroviral medication adherence. Respondents were categorized into two groups: those who were optimally adherent (adherent 95% or more of the time) and suboptimally adherent (adherent less than 95% of the time). Using this cutoff point, 20% of respondents were categorized as suboptimally adherent. Structural equation modeling revealed complete support for the IMB model relationships. Specifically, significant positive relationships were found between: 1) information and behavioral skills, 2) motivation and behavioral skills, and 3) behavioral skills and adherence. Also, the authors found support for the idea that the effects of information and motivation on medication adherence are primarily mediated by behavioral skills. Thus, they did not find significant direct effects of information or motivation on adherence. Moderators of these relationships were not investigated.

Starace and colleagues (2006) published a third test of the IMB model. This study

was conducted in Italy with a convenience sample of 100 HIV-positive patients. All participants were white and completed the Italian version of the IMB ART questionnaire. Like Amico and associates (2005), Starace and colleagues defined optimally adherent respondents as those who took their antiretroviral medications correctly 95% or more of the time. Using this definition, 48% of respondents were categorized as optimally adherent. Structural equation modeling revealed full support for the proposed relationships in the IMB model. To be exact, the authors found significant positive relationships between: 1) adherence information and behavioral skills, 2) adherence motivation and behavioral skills, and 3) behavioral skills and adherence. Similar to Amico and associates (2005), the authors concluded a fully-mediated model, in which the effects of information and motivation on medication adherence are mediated by behavioral skills, was preferable to a model in which information and motivation have direct effects on adherence. Last, although a test of moderation was not conducted, the authors found that suboptimally adherent patients were more likely to be depressed.

The most recent investigation of the IMB model was published by Amico and associates in 2009. In this study, a convenience sample (*n*=149) of HIV-positive patients was recruited from a clinic in Mississippi and asked to complete a computerized version of the IMB ART questionnaire. Forty-two percent of respondents were female and 85% were African American. Unfortunately, the authors did not discuss whether the study measures were valid in this primarily African-American sample; however, the internal consistency reliability was moderate to good, ranging from 0.70 to 0.88. The authors used the same definition of adherence as their 2005 study to categorize optimally and suboptimally adherent patients. Unlike previous studies, Amico and her colleagues decided to represent the two

components of the motivation construct (attitudes and social norms) as separate variables in their structural equation model. Despite this difference in their structural equation model, the authors still found strong support for the relationships among IMB model constructs. To illustrate, significant relationships were found between: 1) information and behavioral skills, 2) attitudes and behavioral skills, 3) social norms and behavioral skills, and 4) behavioral skills and adherence. In addition, information was significantly related to both attitudes and social norms. Like the two previously discussed studies, the authors concluded that the effects of information and motivation on adherence are mediated through behavioral skills rather than exerting direct effects on adherence. Again, the authors did not investigate whether any variables moderated the model relationships.

Table 2.2: Empirical evidence to support the IMB model relationships*

Article	Info to Mot	Info to BS	Mot to BS	BS to MA	Info to MA	Mot to MA	Model fit for fully mediated model
Kalichman et al (2001)	✓	ns^a	✓	✓	ns^a	✓	Not reported
Amico et al (2005)	ns^a	✓	✓	✓	ns^a	ns^a	$\chi^2(2,n=200)=5.063$, ns, CFI=0.958 RMSEA =0.08
Starace et al (2006)	ns^a	✓	✓	✓	ns^a	ns^a	$\chi^2(2,n=100)=2.153$, ns, CFI=0.996 RMSEA =0.03
Amico et al (2009)	✓	✓	✓	✓	ns^a	ns^a	$\chi^2(50,n=149)=65.80$, ns, CFI=0.988, RMSEA =0.05

*adapted from Fisher et al (2006)

Note. A checkmark indicates a significant effect demonstrated in the anticipated direction.

Info= information; Mot = motivation; BS= behavioral skills; MA=medication adherence

CFI = comparative fit index; RMSEA = root mean-square error of approximation

[a] Effects of the variable when the effects of the remaining model variables are statistically controlled

2.8 Current Limitations of the IMB Model

Given that empirical studies of the IMB model and medication adherence began in 2001, it is not surprising that there are limitations and gaps in the existing research. For

example, the model has been exclusively tested in samples of HIV positive patients. Thus, it is unknown how well the model will generalize to other populations. Second, all mulitivariate tests of the model have been conducted using cross-sectional research; hence; it is unknown whether the relationships among variables are causal. Third, the information construct in the model assumes that patients receive consistent information about their medications and that information from different sources is equally weighted and can be pooled into a global construct. Last, there are limitations in how model constructs have been operationalized. For example, in all studies reported in Table 2.2, social motivation was measured using one item, "Most people who know I'm HIV positive support me in taking my HIV medication." Measuring constructs with single items limits the ability to determine whether one is validly and reliably measuring the desired construct versus a conceptually similar construct (DeVellis, 2003).

Despite its limitations, I used the IMB model as an organizing framework to explore the effect of receiving conflicting information on vasculitis patients' medication adherence. In order to address some of the limitations described above, I included multiple sources of information, like doctors, spouses/partners, and the Internet, to better understand the information seeking behavior of vasculitis patients. Additionally, I conducted a longitudinal, as opposed to a cross-sectional, study to help determine whether information and support are causally related to behavioral skills (self-efficacy) and medication adherence. Last, I used multi-item measures for main variables of interest like adherence support.

The following two sections (Sections 2.9 and 2.10) provide an overview of topics that are covered in greater detail in Chapters 5 and 6. Specifically, the sections address commonly used sources of medication information and an overview of the determinants and effects of

receiving conflicting health information. These two sections are included here for the

purpose of clarifying the present study's rationale (Section 2.11).

2.9 Sources of Medication Information

Currently, the information construct of the IMB model has been operationalized as a

global construct in which information from all possible sources is pooled together. This may

not make sense given that the availability of medication information has increased

dramatically over the past few decades, with patients often obtaining medication information

from multiple sources. The increase in information availability from different sources is due

to a number of factors, including the growth of health-related websites on the Internet (Fox &

Rainie, 2003; Cline & Haynes, 2001), direct-to-consumer drug advertisements (Khanfar et al,

2007), policy changes to improve medication package inserts (Amery, 1999), and increased

patient advocacy and consumerism (Dutta-Bergman, 2005). Given the growing number of

information sources, the variability in quality across sources (Berland et al, 2001; Thompson

& Graydon, 2009), and the relationship between information and positive patient outcomes

(Rutten et al, 2005), it is important to understand variability in source use, rather than lump

all sources together as exerting equal influence on patients.

There is little consistency among health information studies about which source

patients trust and/or consult most often, though physicians are generally ranked as one of the

most trusted sources. In a comprehensive review of cancer patients' information needs,

Rutten and colleagues (2005) determined that physicians were frequently consulted by

patients during both the diagnosis/treatment and post-treatment phases of illness. Moreover,

the Health Information National Trends Survey (HINTS), a national U.S. survey of cancer

information-seeking behavior, found that physicians were the most preferred *and* most

trusted source of information (Mayer et al, 2007; Hesse et al, 2005). This finding has been

replicated in at least two other countries, with asthma patients in the United Kingdom

(Trewin & Veitch, 2003) and the general medication-taking population in Norway (Narhi,

2007) rating the general practitioner as their preferred or most reliable source of medication

information, respectively.

Even though physicians are often patients' preferred source for health information,

that does not mean that they are the most frequently used source. The HINTS study offers an

excellent example; patients trusted physicians most but used the Internet more often to find

cancer-related information (Hesse et al, 2005). Likewise, Narhi (2007) found that patients

consulted information leaflets more often than physicians, even though physicians were rated

as the most reliable source of medication information. Additionally, Sleath and colleagues

(2003) found that physicians were the second-most commonly used source of antidepressant

information for patients living in the United States. In this case, patients consulted

pharmacists more often than physicians.

In addition to the Internet (Narhi, 2007; Hesse et al, 2005) and pharmacists (Sleath et

al, 2003, Trewin and Veitch, 2003), other frequently consulted health information sources

include written materials like patient information leaflets (Narhi, 2007, Rutten et al, 2005),

books (Hesse et al, 2007) and newsletters (Huber & Cruz, 2000), non-physician health

professionals like nurses (Mills & Davidson, 2002; Luker et al, 1996, Rutten et al, 2005), and

mass media sources such as newspapers, magazines, and television (Cunnigham et al, 1999;

Huber & Cruz, 2000; Narhi, 2007, Rutten et al, 2005). Family and friends also are important

sources of health information for patients (Huber & Cruz, 2000; Sleath et al, 2003, Rutten et

al, 2005).

Multiple factors, including age, education, race, and phase of illness, can influence patients' information-seeking behavior, which may explain why there is a great deal of variability in patients' source preferences. In general, younger patients are more likely to search for health information (Rutten et al, 2006), as well as trust (Hesse et al, 2005) and use (Narhi, 2007, Sleath, 2003) the Internet more than older patients. To be specific, persons aged 18-34 were 10.3 times as likely to trust cancer information on the Internet than persons older than 65 (Hesse et al, 2005). Education is also positively associated with information seeking, with patients who have greater than a high school education being more likely to seek health information than patients with less than a high school education (Mayer et al, 2007, Rutten et al, 2005). Moreover, college graduates trust health information provided by physicians, the Internet, and newspapers more than non-college graduates (Hesse et al, 2005), while less educated patients are more likely to obtain information from family and friends (Cunnigham et al, 1999; Sleath, 2003). Although the findings regarding race and source preference have been mixed (Rutten et al, 2005), whites are much less likely than blacks to consult religious organizations for health information (Williams et al, 2007; Cunningham et al, 1999). Source preference also varies with phase of illness; patients prefer written materials in the early stages of their disease, whereas family and friends become more important sources as the disease progresses (Rutten et al, 2005).

Gender also affects health seeking behavior. Female patients have consistently sought information more frequently and from more sources than male patients (Mayer et al, 2007, Rutten et al, 2005, Huber & Cruz, 2000). Women trust information from physicians, television, family/friends, magazines, newspapers, and the radio more than male patients (Hesse et al, 2005). However, Mills and Davidson (2002) found that female patients rated the

quality of cancer information from television and radio lower than male patients.

The differences in source use outlined above provide a clear rationale for analyzing information sources separately as opposed to lumping them together as part of a global information construct. Particularly, because patients' level of trust varies across sources, it is likely that more trusted sources exert a stronger effect on behaviors, such as medication adherence. Furthermore, information given by different sources may be conflicting, which would further undermine grouping all information sources together within a single information construct. Section 2.10 provides a more detailed description of the possible negative effects of conflicting information.

2.10 The Problem of Conflicting Information

Because patients often consult multiple sources for health information, the opportunity to encounter conflicting information may arise. Conflicting information further undermines the operationalization of information as a unidimensional construct. A burgeoning, primarily qualitative, literature has begun to document the extent to and conditions under which chronic disease patients receive conflicting information. The results from these studies demonstrate that people living with chronic conditions, such as cancer (Mills & Davidson, 2002; Gray et al, 1999), cardiopulmonary disease (Trewin & Veitch, 2003), rheumatic disease (Lim et al, 2007), low back pain (McIntosh et al, 2003) as well as mental illness (Pollock et al, 2004) receive conflicting health-related information about their illness and its management.

Several studies have documented that patients receive conflicting information about their medications. For example, conflicting information was the second-most common system-level factor related to medication discrepancies between patients and doctors in a

sample of older adults who had recently been discharged from a U.S. hospital (Coleman et al, 2005). Moreover, in a study conducted in the United Kingdom, one out of every four rheumatic disease patients reported receiving conflicting information about their medications (Lim et al, 2007). This finding has been replicated in other countries, with approximately one-fifth to one-quarter of patients with multiple chronic conditions or acute health problems in Australia, Canada, New Zealand, United Kingdom, and the United States reporting that they had received conflicting information from different doctors or health professionals (Belndon et al, 2003). Unfortunately, no published research has documented whether patients with rare health conditions encounter conflicting information.

Few studies have documented whether receiving conflicting information results in negative outcomes. Preliminary evidence, however, suggests receipt of conflicting information may negatively influence patients' perceptions of care and increase anxiety. For example, Zapka and colleagues (2004) interviewed women who had abnormal mammograms or Pap smears and found that 7% and 14%, respectively, had received conflicting or confusing information about their abnormal test. Women who had received conflicting or confusing information were significantly more likely to report that their medical care could be better when compared to women who did not receive conflicting information. Additionally, low back pain patients who had received conflicting information found it more difficult to assess which information source was most reliable or trustworthy (McIntosh et al, 2003); whereas, mental health inpatients experienced anxiety and uncertainty when they received conflicting medication information from different sources. Similarly, caregivers of patients also have reported feeling overwhelmed and confused when encountering conflicting information (Gray et al, 1999).

2.11 Rationale

Unfortunately, no published research has explored the relationship between conflicting information and medication adherence in a sample of chronically ill patients. Given that conflicting information has been associated with psychological outcomes such as anxiety in previous studies, it is important to determine if it is also related to behavioral outcomes. Unfortunately, no theoretical models incorporate a conflicting information construct. Thus, the IMB model is a logical model to guide the current dissertation research because it is the theory that most explicitly defines the relationship between information and medication adherence.

CHAPTER 3: RESEARCH AIMS AND HYPOTHESES

The overarching goal of this study is to determine whether receiving conflicting medication information influences vasculitis patients' medication-taking behaviors. Based on the review of the literature and discussion of the Information-Motivation-Behavioral Skills (IMB) model presented in Chapter 2, I have developed five specific aims that attempt to determine whether conflicting information affects vasculitis patients' medication adherence as well as describe the information-seeking behavior of patients. I present specific aims and their associated research questions and hypotheses below. Manuscript #1 includes two aims which: 1) describe the extent to which patients receive conflicting information and, 2) determine whether conflicting information and adherence support predict outcome expectations, adherence self-efficacy, and medication adherence. Three aims are included in Manuscript #2, which focuses on patients' use and perceived credibility of medication information sources as well as gender differences in information source use. Figure 3.1 summarizes the hypothesized relationships among variables in graphical form.

Manuscript #1

Specific Aim #1: To describe the extent to which vasculitis patients receive conflicting information about their medications.

RQ$_1$: Do patients report receiving conflicting information about their vasculitis medications?

H$_{1.1}$: A majority of patients will report receiving conflicting information about some

aspect of their vasculitis medications.

Specific Aim #2: To determine whether conflicting information and adherence support predict outcome expectations, adherence self-efficacy, and medication adherence.

RQ$_2$: Does adherence self-efficacy mediate the effects of conflicting information and adherence social support on medication nonadherence?

H$_{2.1}$: Adherence self-efficacy will partially mediate the relationship between conflicting information and medication nonadherence such that receipt of conflicting information will decrease adherence self-efficacy which, in turn, will increase medication nonadherence.

H$_{2.2}$: Adherence self-efficacy will partially mediate the relationship between adherence support and medication nonadherence such that more adherence support will increase self-efficacy which, in turn, will decrease medication nonadherence.

RQ$_3$: Do outcome expectations for medications mediate the effects of conflicting information and adherence social support on medication nonadherence?

H$_{3.1}$: Outcome expectations will partially mediate the relationship between conflicting information and medication nonadherence such that receipt of conflicting information will lead to less positive outcome expectations for medication which, in turn, will increase medication nonadherence.

H$_{3.2}$: Outcome expectations will partially mediate the relationship between adherence support and medication nonadherence such that receipt of adherence support will lead to more positive outcome expectations for medication which, in turn, will decrease medication nonadherence.

RQ$_4$: Does adherence self-efficacy predict medication nonadherence for vasculitis patients?

H$_{4.1}$: Adherence self-efficacy will be significantly, negatively associated with medication nondherence for vasculitis patients.

RQ$_5$: Do outcome expectations predict medication nonadherence for vasculitis patients?

H$_{5.1}$: Outcome expectations will be significantly, negatively associated with medication nondherence for vasculitis patients.

Manuscript #2

Specific Aim #3: To describe the sources of medication information that vasculitis patients use.

RQ$_6$: Which sources do vasculitis patients use most often to obtain medication information?

H$_{6.1}$: The physician will be the primary source of medication information followed by the pharmacist and the Internet.

H$_{6.2}$: The spouse/partner, family member, and person living with vasculitis will not be major sources of medication information for patients.

Specific Aim #4: To determine which sources of medication information patients perceive as most credible.

RQ$_7$: Which sources of medication information do patients perceive as credible?

H$_{7.1}$: Physicians and pharmacists will be perceived as the most credible sources of medication information followed by the Internet, persons living with vasculitis, spouses/partners, and family members.

Specific Aim #5: To explore whether information source use varies for male and female vasculitis patients.

RQ$_8$: Do male and female patients differ in their use of medication information sources?

$H_{8.1}$: Female patients will obtain medication information more frequently than male patients.

$H_{8.2}$: Female patients will use family and friends as medication information sources more often than male patients.

Figure 3.1: The hypothesized relationships among conflicting information, adherence support, outcome expectations, medication adherence self-efficacy and medication nonadherence
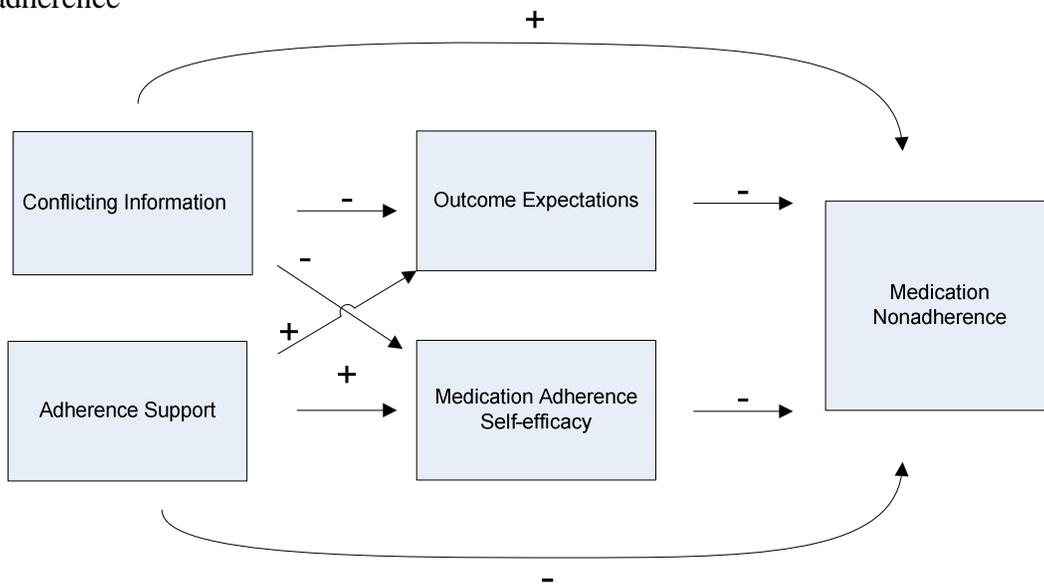
CHAPTER 4: QUESTIONNAIRE DEVELOPMENT

4.1 Overview

      I conducted a three-phased research study in order to address the specific aims discussed in the previous chapter. The first phase was formative, during which I conducted interviews with four vasculitis patients to learn more about their mediation-seeking behavior, especially the concept of conflicting information. The second phase of the study, which included an expert review and cognitive interviews, determined the appropriateness and usability of the study's data collection instruments: two web-based surveys. After the first two phases were completed, I began recruitment for the third phase, which was the main data collection effort for the dissertation. In this chapter, I discuss the formative study (Phase 1), describe changes made to the study instruments as a result of the expert review and cognitive interviews (Phase 2), and then summarize the psychometric properties for the final version of the study measures (Phase 3).

4.2 Phase 1: Formative Research

      Because there was a paucity of data available about the effect of receiving conflicting medication information, I conducted four telephone interviews with vasculitis patients to learn more about this construct. The interviews took place in April and May of 2008 and lasted approximately 30 minutes. Participants signed an informed consent form and received a $20 gift card incentive. Each interview was digitally recorded and the files were transcribed by a professional transcriptionist. I also took notes during each interview.

The discussion guide (Appendix A) contained eight questions that asked which information sources patients used to obtain medication information and which sources they trusted most. I specifically asked participants whether they had ever received conflicting information about their vasculitis medications; follow-up questions asked how patients handled situations in which conflicting information was given and about the types of conflicting information received (side effects, drug interactions, medication effectiveness, medication costs, etc.). The interview transcripts are located in Appendix B.

4.2.1 Formative interview results

I analyzed the interviews thematically (Patton, 1990) to identify important domains of patients' information-seeking behavior. The analysis revealed that participants most commonly used their doctors and the Internet to obtain information about their vasculitis medications. Participants also listed other patients/support groups, articles and books, and medication package inserts as information sources. Mass media sources like television, radio, magazines, and newspapers were not mentioned as sources by any of the participants. Moreover, pharmacists, family members, and friends were not frequently used because they were not viewed as knowledgeable about vasculitis medications, as illustrated in the quotation below.

> *I can talk to my family and friends about it, but these medicines are all medicines they've never heard of. They have no idea what I'm talking about! There are a lot of barriers talking to a pharmacist. You have to be able to get them to come to the window, it's not private, and they don't know these medicines- at least, the community pharmacists don't know them very well.*

All four interview participants (100%) said that their doctors were their most trusted source of medication information. The Internet, other patients, the *Physicians' Desk Reference*, and pharmacists were also mentioned as trusted sources of information. For

example, one participant's quotation about the different information sources reads:

> *I use my doctor because I trust him. He knows the drugs, he knows me, and he can kind of put the two together. I use the Internet because I tend to get more complete information from all the possibilities- more information about the drug, in more depth, and can sit down and read it at my speed. I read the books because they have stories about how people have dealt with it. I guess another source that I didn't mention- the Vasculitis Support Group- linked me to other patients about their experiences with the drugs and how they take them.*

Only two participants (50%) reported receiving conflicting medication information when asked directly. However, follow-up questions revealed that all four participants (100%) had received conflicting information about some aspect of their medications at least once during the course of their treatment. In other words, it took some probing to help patients remember particular instances in which they had received conflicting information from different sources.

All participants (100%) reported receiving conflicting information about how to take their vasculitis medications (timing, with food) and side effects (types and severity); however, most patients resolved these situations by contacting their primary physician. In two participants' words:

> *It's just a matter of whether to take something in the morning or take it at night. Where one (doctor) will say it's best to take it in the morning, another will say it's best to take it at night. If I do get a conflicting thing, I'll say, 'Well, Dr. so-and-so said for me to take it in the morning.' And they'll say, 'well, you can take it in the morning- that's fine.'*

> *A package insert might say not to take it with food, but if I take it without food, it makes me sick. I talk to the doctor, and the doctor says, 'It's okay to take it with food.'*

In addition, one participant (25%) mentioned that they had received conflicting information about the effectiveness and costs of their vasculitis medications.

In most instances, participants obtained conflicting information after a problem, like a

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side effect or unexpected drug interaction, had developed. Thus, omission of information from one source, such as a doctor not telling a patient about a specific side effect, often led to the discovery of conflicting information because patients would consult other sources to determine the cause of their problem. For example:

> *With the steroids, I found out about muscle weakness as an issue. I had actually run into the problem without realizing that was what the problem was. This was just after I had started the IV steroids, and I remember trying to go up a flight of stairs and couldn't make it. I talked to the doctor about it later and she said, 'Well, were you short of breath?' I said, 'No, I wasn't short of breath, I just couldn't make it; couldn't get up.' She didn't say anything more about it, but I continued to have trouble, and fell down in a parking lot and couldn't get back up until this guy helped me. At that point, I started researching it and saw that it was a side effect of the steroids. My doctor referred me to a rheumatologist who referred me to a physical therapist who said later, 'Yeah, it's the steroids that cause the muscle weakness in the legs.'*

4.3 Phase 2: Expert Review and Cognitive Interviews

Before testing the survey instruments with autoimmune disease patients, a panel of five expert reviewers was asked to examine the survey for face validity, content validity, readability, relevance, and usability. These reviewers included two psychologists with expertise in chronic disease and social support, an epidemiologist knowledgeable about vasculitis, and a medical doctor who works with vasculitis patients. Additionally, a pharmacist provided input about the pharmacy and pharmacist-related section of the first survey. I used the panel's feedback to improve the clarity of question wording, format and layout, and instructions of the survey. The reviewers did not recommend any major changes to the survey's content such as the elimination or addition of questions.

The revised survey instruments were then completed by a convenience sample of five individuals with chronic autoimmune diseases, including two multiple sclerosis, one glomerulonephritis, one Crohn's disease, and one vasculitis patient. Because there were a limited number of vasculitis patients who I could access for my main data collection effort, I

decided to enroll other autoimmune disease patients for the cognitive interviews so as to not further limit my Phase 3 sample. All cognitive interview participants signed an informed consent form; participants did not receive an incentive. The interviews lasted approximately one hour. I interviewed participants while they completed the survey instruments and also solicited participants for written feedback about their survey experience.

Most of the improvements made to the survey as a result of the cognitive interviews were minor in nature, including changes in instruction wording, the addition of a "back" button to aid with navigation and a warning screen that notified participants that they had to navigate to the last page of the survey or their responses would not be recorded. Additionally, I added transition screens between measures to inform participants that the topic of inquiry was about to change.

Although most changes based on the cognitive interview results were minor, I did make five major modifications to the survey instruments. First, I eliminated three of the five McCroskey and Teven (1999) Credibility Scale questions. Respondents found these questions redundant and could not effectively differentiate between how trained, how informed, and how competent a source was. The two questions that resonated best with respondents, how knowledgeable and how expert a source was about vasculitis medications, were retained in the final version of the credibility measure.

Second, I eliminated two questions from the adherence social support measures. Three of the five cognitive interview participants did not believe that a source telling them that their vasculitis medications were "helping them" or "hurting them" were relevant. The other social support items were deemed relevant by participants and retained in the final version of the questionnaire. Thus, the final versions of the support scales included four

overlapping items. Third, because the extent to which respondents interacted with different information sources (i.e. a pharmacist and a spouse) varied, I added a "N/A" option to the social support scale. Otherwise, some respondents indicated that they would leave those social support questions blank.

Last, I made changes to the response scales of two other measures. Because respondents had difficulty differentiating between "usually" and "often" on the sources of information measure, I eliminated the "usually" option. Thus, the final scale for this measure ranged from 1= '*never*' to 5= '*always*'. Moreover, respondents recommended that I add a '*don't remember*' option to the conflicting information scale. Some respondents had difficultly remembering if they had received conflicting information about a given topic and would leave the question blank if a '*don't remember*' option was not included. The addition of this response option may also help reduce recall bias.

4.4 Phase 3: Main Study

4.4.1 Recruitment and eligibility criteria

I discuss recruitment procedures and eligibility criteria in the first and second manuscripts, located immediately after this chapter.

4.4.2 Data collection procedures

Persons who expressed interest in completing the study and met eligibility criteria were given a study ID number, which was assigned in chronological order so that the first participant to enroll in the study was assigned a "1", the second a "2", and so forth. Data were collected at two time points (Time 1 and Time 2). In order to maintain confidentiality, participants were asked to log in to the survey using their ID number; not their names. No identifying information was collected in either survey.

The first page of the Time 1 survey was a study fact sheet. After reading the fact sheet, participants checked a box stating that they had read and understood the study procedures and agreed to participate. On average, it took participants approximately one hour to complete the first survey. If participants had not completed the survey within two weeks of receiving the survey link, they received a follow-up email which asked if they had encountered problems. I contacted nonrespondents up to ten times to ask them to complete the survey. After ten contacts, I dropped nonrespondents from the study. Manuscript #1 contains a summary of participants who were dropped at Time 1.

Approximately three months after completion of the first survey, I emailed participants the link to the second (Time 2) survey. The Time 2 survey was completed in the same manner as the Time 1 survey, but took less time because it contained fewer questions. On average, participants took approximately 30 minutes to complete the survey. Again, I attempted to contact nonrespondents up to ten times if the survey had not been completed within two weeks of sending the initial link. After ten contacts, I dropped persistent nonresponders from the study; a summary of these non-responders is presented in Manuscript #1.

Once participants completed the Time 2 survey, I sent them a thank you letter and $10 gift card. Participants' gift card choices included Target, British Petroleum gas station, or Applebees restaurants.

4.4.3 Survey instruments

Both survey instruments were web-based; I did not create paper versions of the surveys. I used the Qualtrics software program, which is available free-of-charge to UNC students and faculty, to create the online questionnaires and collect data.

4.5 Measures

Table 4.1 summarizes the study measures, including name, number of questions, and psychometric properties of the measure. The main outcome variable for the study is medication adherence, with outcome expectations and adherence self-efficacy acting as mediating variables. There are also two independent variables: conflicting information and adherence support. Medical credibility and medication information sources (i.e. doctors, pharmacists, spouse/partner) are also main variables of interest, even though they were only used in a descriptive fashion. Last, I measured several control variables, including age, gender, race, education, insurance status, illness phase, and disease duration.

Table 4.1: Overview of psychometric properties for study measures

Variable	Assessment tool	# of Items	Dimensionality	Cronbach α
Independent Variables				
Adherence information	Frequency of source use	1 /source	-	-
Adherence support	Newly developed scale	4	1 factor	0.80
Perceived medical credibility	Modified McCrosky & Teven Credibility Scale	2 / source	-	0.81-0.92 (inter-item r's)
Conflicting information	Newly developed scale	6	1 factor	0.75
Mediating Variables				
Adherence self-efficacy	Difficulty subscale (SEAMS)	7	1 factor	0.88
Outcome expectations	Specific- Necessity Subscale (BMQ)	5	1 factor	0.80
Outcome Variable				
Medication nonadherence	Vasculitis Self-Management Medication Adherence scale	7	1 factor	0.89

4.5.1 Medication adherence

I used the Vasculitis Self-Management Survey (VSMS) medication adherence subscale (Thorpe, 2006) to assess medication adherence. The VSMS medication adherence scale consists of seven items measured on a five-point Likert scale ranging from 1= "none of the time" and 5 = "all of the time" with the exception of one question that ranges from 1 = "0-24%" and 5 = "100%." Example items from the VSMS medication adherence subscale read, "*I skipped a dose of my medication*," and "*during the past 4 weeks, how often did you have a hard time taking your recommended medication(s) exactly as directed*?"

The VSMS medication adherence subscale has demonstrated acceptable internal consistency (Cronbach's α = 0.77-0.87) and a test-retest reliability of 0.60. Thorpe (2006) used this medication adherence subscale in a sample of 191 vasculitis patients and found a mean medication adherence of 4.5/5.0.

In order to explore the psychometric properties of the medication adherence measure, I conducted a principal components analysis, a parallel analysis, and calculated Cronbach's alpha coefficient. More detail about these statistical procedures is presented in section 4.7 of this chapter. In the present study, both the principal components factor analysis and parallel analysis suggested a one-factor solution. Internal consistency for the medication adherence measure was also high (Cronbach's α = 0.89). The parallel analysis graphic is presented below in Figure 4.1 while the actual and simulated eigenvalues are presented in Table 4.2.

Figure 4.1: Parallel analysis for medication adherence measure (1000 iterations)

Parallel Analysis -P95 Simulated Eigenvalues

7 Variables, 1000 Iterations, 232 Observations
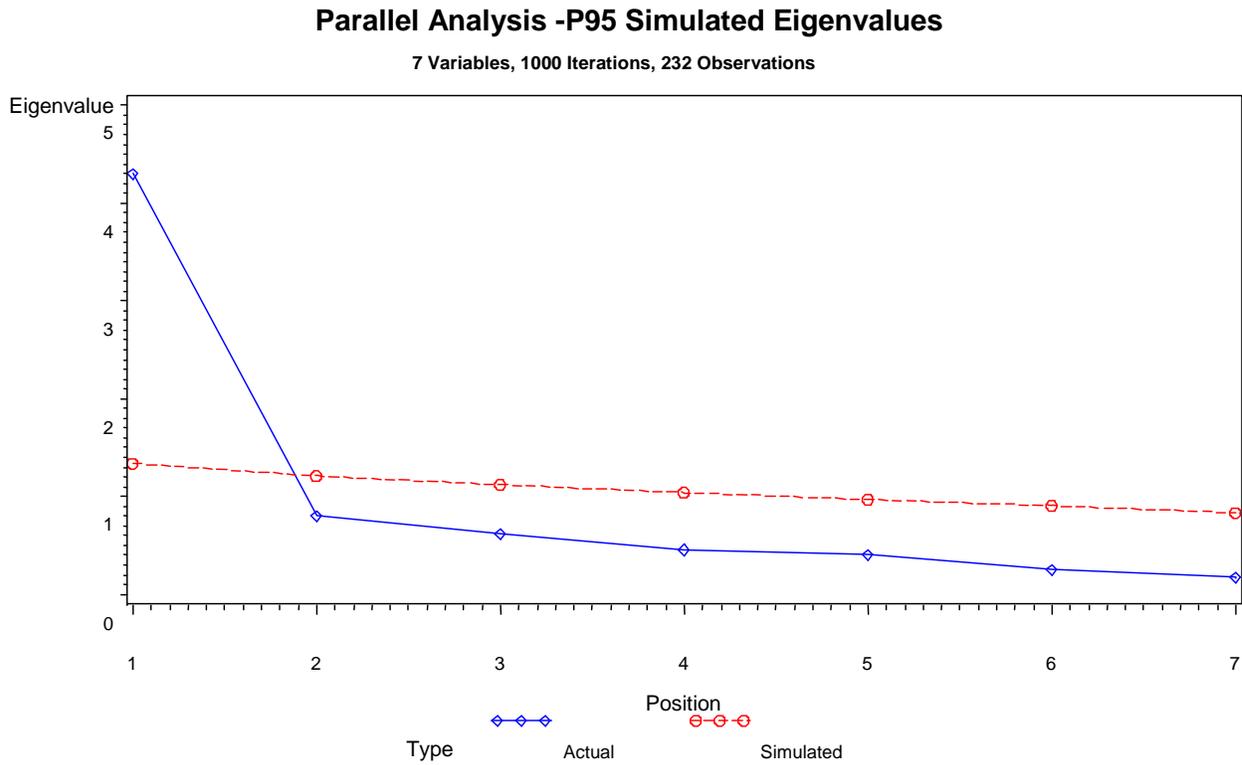
Table 4.2: Actual and simulated Eigenvalues for the medication adherence parallel analysis

Actual Eigenvalue	Simulated Eigenvalue
4.30	1.34
0.80	1.21
0.61	1.12
0.46	1.04
0.41	0.97
0.25	0.91
0.17	0.83

4.5.2 Medication adherence self-efficacy

I used the difficulty subscale from the Self-Efficacy for Appropriate Medication Use

Scale (SEAMS; Risser et al, 2007) to measure adherence self-efficacy. The SEAMS was

developed to measure adherence self-efficacy in a sample of low literacy, predominantly

African American, coronary heart disease patients who lived in the United States. The

original measure consisted of two subscales that asked respondents to rate their level of confidence to take medications correctly in a number of different circumstances, including when they have a busy day planned or when a doctor changes their medicines. The original SEAMS items were measured on a three-point Likert-scale ranging from 1 = "not confident" to 3 = "very confident." I changed the response scale from three points to five points to potentially capture greater variability in adherence self-efficacy. The modified scale ranged from 1= "not at all confident" to 5= "very confident."

In order to determine the validity of SEAMS, Risser and colleagues (2007) conducted a principal components analysis (PCA) with varimax rotation, which yielded a two-factor solution. Seven items loaded on the first factor, which was called self-efficacy under difficult circumstances. This factor essentially captured patients' confidence to remain adherent when their normal routine was disturbed and accounted for 36% of the total variance. Internal consistency reliability was decent for the difficult circumstances subscale, Cronbach's alpha =0.86. Moreover, the SEAMS measure correlated highly with the Morisky medication adherence scale (Spearman's ρ = .51), thus demonstrating criterion-related validity.

In the present study, both the principal components factor analysis and parallel analysis suggested a one-factor solution for the difficulty subscale. Additionally, internal consistency for the difficulty subscale was good (Cronbach's α = 0.88). The parallel analysis graphic is presented below in Figure 4.2 while the actual and simulated eigenvalues are presented in Table 4.3.

Figure 4.2: Parallel analysis for the adherence self-efficacy measure (1000 iterations)

Parallel Analysis -P95 Simulated Eigenvalues

7 Variables, 1000 Iterations, 232 Observations
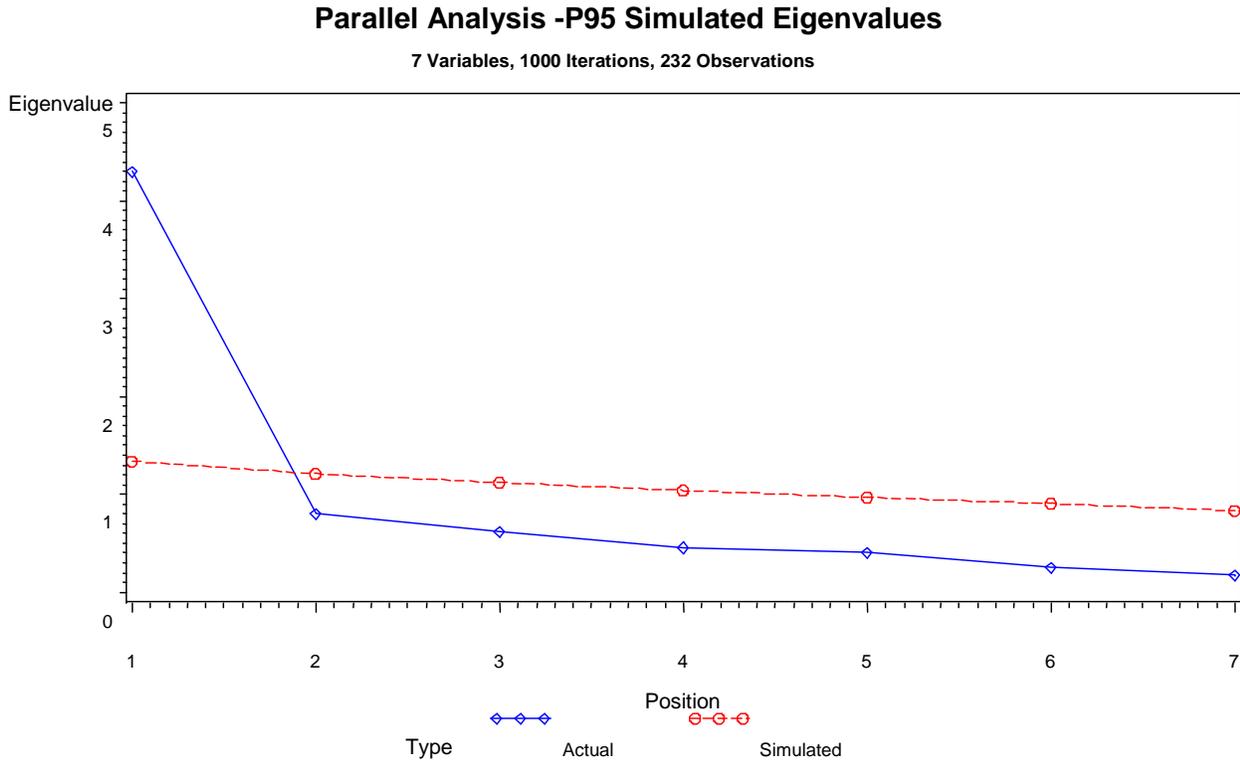
Table 4.3: Actual and simulated Eigenvalues for the self-efficacy parallel analysis

Actual Eigenvalue	Simulated Eigenvalue
4.07	1.35
1.00	1.21
0.58	1.12
0.44	1.04
0.38	0.97
0.33	0.90
0.20	0.83

4.5.3 Outcome expectations

Patients' medication-related outcome expectations were measured using the specific-necessity subscale of the Beliefs about Medicines Questionnaire (BMQ) (Horne et al, 1997). The BMQ is a 20-item scale measured on a five-point Likert scale that ranges from 1 = "strongly disagree" to 5 = "strongly agree." The BMQ consists of four subscales: 1) specific

beliefs about the necessity of one's medications (specific-necessity); 2) specific concerns about one's medications (specific-concerns); 3) general beliefs about the harm of taking medications (general-harm); and 4) general beliefs about the overuse of medications (general-overuse). The specific-necessity subscale consists of five items that, "represent the perceived role of medication in protecting against deterioration of present and future health status of the patient" (Horne et al, 1997) (p. 20). In this way, this subscale represents a logical operationalization of outcome expectations. Example items from the specific-necessity scale read, "*my health, at present, depends on my medicines,*" and "*without my medicines I would be very ill.*"

In a sample of 90 general medical patients, the BMQ specific-necessity subscale demonstrated good internal consistency (Cronbach alpha = 0.86). The scale also demonstrated good test-retest reliability (0.77) in a sample ($n = 31$) of asthmatic patients (Horne et al, 1997).

In the present study, both the principal components factor analysis and parallel analysis suggested a one-factor solution for the specific-necessity subscale. Additionally, internal consistency for the subscale was decent (Cronbach's $\alpha = 0.80$). The parallel analysis graphic is presented below in Figure 4.3 while the actual and simulated eigenvalues are presented in Table 4.4.

Figure 4.3: Parallel analysis for the outcome expectations for medications measure (1000 iterations)

Parallel Analysis -P95 Simulated Eigenvalues

5 Variables, 1000 Iterations, 232 Observations
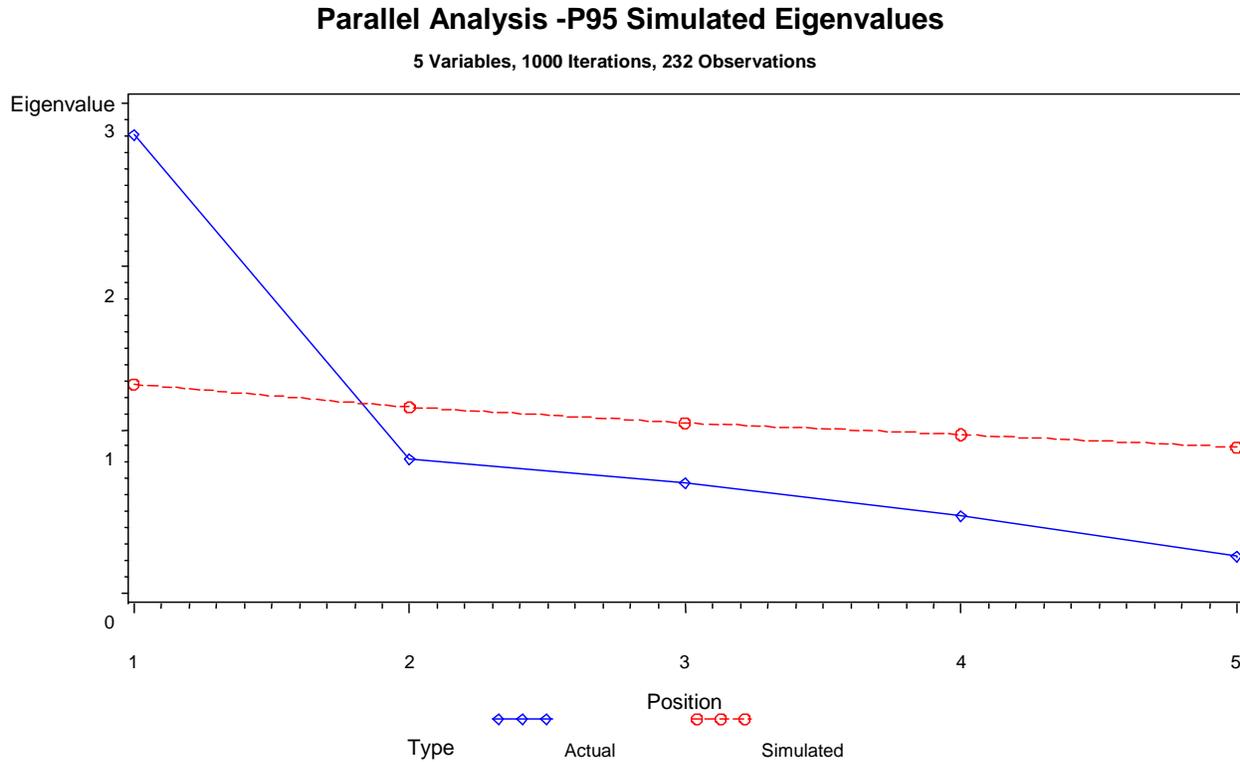
Table 4.4: Actual and simulated Eigenvalues for the outcome expectations parallel analysis

Actual Eigenvalue	Simulated Eigenvalue
2.80	1.28
0.82	1.14
0.68	1.04
0.47	0.97
0.23	0.89

4.5.4 Adherence support

In previous studies (Fisher et al, 2006; Amico et al, 2009), adherence support was measured using one item: "*Most people who are important to me who know I have (disease) support me in taking my medications as prescribed.*" In order to avoid the limitations of measuring a construct with a single item, I developed five new source-specific scales to

measure adherence social support from doctors, spouse/partners, family members/friends, pharmacists, and other vasculitis patients. These five scales measured specific ways in which significant others supported a patient in taking their vasculitis medications. Four items overlapped between the five scales; how often does this person "*support you in taking your vasculitis medicines*," "*share new information about vasculitis medicines with you*," "*provide helpful hints about how to deal with your vasculitis medicine's side effects*," and "*give you enough support when it comes to taking your vasculitis medicines as prescribed*." Response options ranged from 1= "does not do this" to 5= "does this a lot." Respondents could also select "*N/A*" if they thought the question did not apply to their situation. In these cases, we recoded *N/A* as a "1" because the source did not provide that type of support.

In order to maximize power for the statistical analyses discussed in Chapter 5, I limited my examination of adherence support to focus on doctor support. I did this because every participant reported having a doctor; hence, this was the only source of support that allowed me to use the full sample. Figure 4.4 and Table 4.5 present the graphical depiction and actual and simulated eigenvalues, respectively, for the doctor support variable. Internal consistency for doctor support was decent (Cronbach's $\alpha = 0.80$).

Figure 4.4: Parallel analysis for the doctor support measure (1000 iterations)

Parallel Analysis -P95 Simulated Eigenvalues

4 Variables, 1000 Iterations, 232 Observations
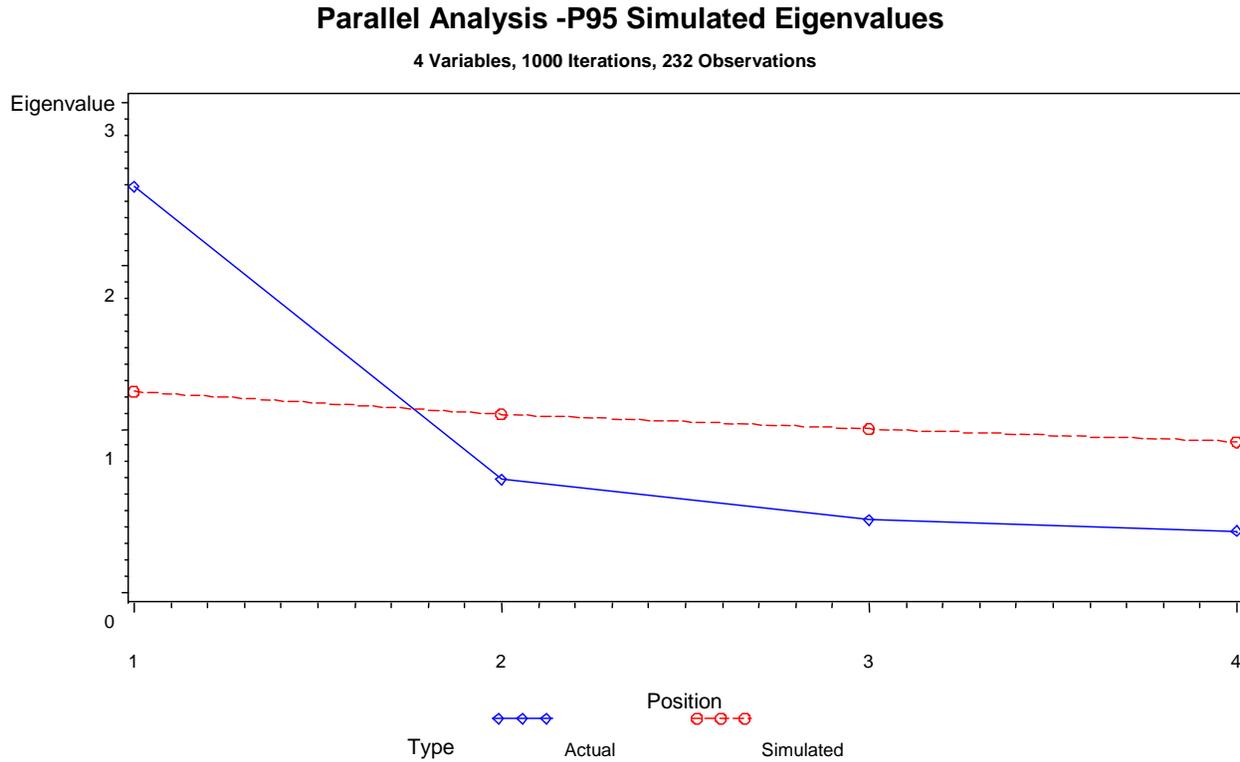
Table 4.5: Actual and simulated Eigenvalues for the doctor support parallel analysis

Actual Eigenvalue	Simulated Eigenvalue
2.49	1.23
0.69	1.09
0.44	1.00
0.38	0.92

4.5.5 Conflicting information

Because a conflicting medication information scale has never been reported in the literature, I conducted cognitive interviews to assist in the development of a new scale to measure this construct. I developed six items that asked respondents to report whether they had ever received conflicting information about: the time of day to take their medications, how to take their medications, proper dosing, duration (i.e. 6 months versus 1 year), side effects, and side effect severity. Respondents could choose between the following response

options: '*have not received conflicting information*', '*have received conflicting information*',

or '*don't remember.*'

We recoded "don't remember" responses as missing and then calculated a summary

score by adding the six items. Using tetrachoric correlations, we found that all scale items

loaded at 0.70 or greater onto one factor, which indicated a one-factor solution. KR-20 was

0.75. Figure 4.5 and Table 4.6 present the graphical depiction and actual and simulated

eigenvalues, respectively, for the conflicting information variable. Table 4.7 displays the

factor loadings using the tetrachoric correlations.

Figure 4.5: Parallel analysis for the conflicting information measure (1000 iterations)

Parallel Analysis -P95 Simulated Eigenvalues

6 Variables, 1000 Iterations, 232 Observations
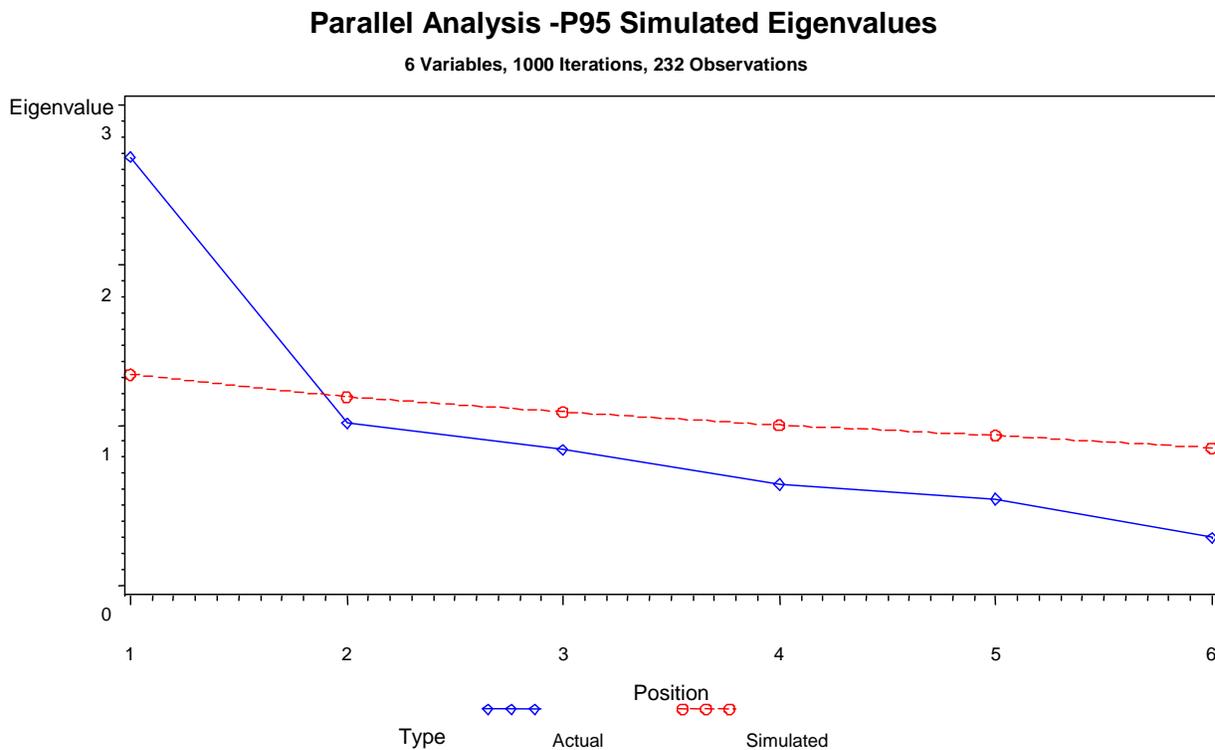
Table 4.6: Actual and simulated Eigenvalues for the conflicting information parallel analysis

Actual Eigenvalue	Simulated Eigenvalue
2.68	1.32
1.00	1.18
0.85	1.08
0.63	1.00
0.54	0.94
0.30	0.86

Table 4.7: Factor loadings for the one-factor solution using tetrachoric correlations for the conflicting information measure

Item	Factor Loading
coninfo1	0.80
coninfo2	0.74
coninfo3	0.70
coninfo4	0.74
coninfo5	0.84
coninfo6	0.87

4.5.6 Adherence information- Frequency of source use

During the cognitive interviews, I asked vasculitis patients which sources they used to obtain vasculitis medication information. Based on their responses as well as a review of the literature, I identified 12 information sources, which included doctors, pharmacists, nurses, brochures and pamphlets, medicine package inserts, articles and books, the Internet (information websites), support groups (online or in-person), spouse/partner, family members other than their spouse, friends, and newsletters. For each source, patients answered one item about how often they had obtained vasculitis medicine information during the past year, ranging from 1= '*never*' to 5= '*always*.'

4.5.7 Perceived medical credibility

Perceived medical credibility is defined as how credible respondents perceive a source to be with regard to their vasculitis medications. If respondents reported that they had obtained information about vasculitis medicines from any one of six sources (doctors, pharmacists, spouses, family members/friends, other vasculitis patients, Internet), then they were asked to rate the perceived credibility of that source. Hence, if respondents did not report obtaining vasculitis medication information from the pharmacist, they did not complete perceived credibility items about the pharmacist. Credibility was measured by two items that were derived from the competence subscale of the McCroskey and Teven Credibility Scale (1999). The first item asked how knowledgeable (1= '*not at all knowledgeable*' to 9= '*extremely knowledgeable*') a source was about vasculitis medicines, while the second item asked how expert (1= '*not at all expert*' to 9= '*extremely expert*') the source was about vasculitis medicines.

Because the credibility measure only possessed two-items, I did not conduct a factor analysis, parallel analysis, or calculate a Cronbach's alpha coefficient. Instead, I inspected the inter-item correlations for each of the six subscales; the correlations ranged from 0.92 for family credibility to 0.81 for Internet credibility. A summary score was created for each source by averaging the two items. Table 4.8 presents the inter-item correlations for the six sources.

Table 4.8: Inter-item correlations by source for the perceived medical credibility measure

Source	Inter-item correlation
Family	0.92
Pharmacist	0.90
Partner	0.89
Other vasculitis patient	0.89
Doctor	0.88
Internet	0.81

4.5.8 Control variables

In addition to the main study variables discussed above, I included several control variables on the questionnaires. Most of the control variables were demographic, such as gender, age, race, insurance status, and educational level, which were measured using single items. Several disease and medication regimen-related variables, including years living with disease (disease duration) and number of medications, also were assessed using single items. Individual items for the baseline and follow-up questionnaires are located in Appendix C and D, respectively.

4.6 Data Management

I downloaded survey data directly from the Qualtrics website as a SPSS data file. Downloading data directly from the website ensured that the only source of data entry error was from the respondent (respondent entered an incorrect number). After downloading the data into SPSS, I exported the data file to SAS Version 9.2. I used the participant identification number (PID) to identify participants on both the Time 1 and Time 2 surveys; thus, I was able to link the data from Time 1 and Time 2. To ensure that I did not have matching issues between the two surveys, I emailed participants their ID number at Time 2 and added a macro to the website that does not allow a person to complete the survey unless they entered their login ID number.

4.7 Psychometric Properties of the Study Measures

4.7.1 Exploratory factor analyses

Because I developed two new measures for this study, *conflicting information* and *adherence support,* a logical first step was to determine how many factors underlie these measures. In order to accomplish this, I conducted exploratory factor analyses (EFA) on

these scales. More specifically, I conducted a principal components analysis (PCA) on both newly developed measures. The first step of a PCA is to determine the optimal number of factors that underlie each latent construct. In order to assess the number of factors, I analyzed Cattell's scree plots (Cattell, 1966) for "elbows." In a scree plot, eigenvalues for factors are plotted from highest to lowest, with lower eigenvalues representing "scree" or factors that do not capture much additional variance in the set of items (DeVellis, 2003). The number of factors that are above the "elbow" is considered the optimal number of factors that should be retained for future analyses.

The next step in the PCA is to rotate retained factors to determine how items best load on each common factor. I conducted an oblique (promax) rotation, which allowed factors to correlate with one another. After rotating the factors, I analyzed the factor loading matrix to determine the pattern of item loadings. Items that possessed loadings greater than 0.40 on one factor and no loadings greater than 0.20 on other factors were retained for analysis.

4.7.2 Parallel analysis

I also conducted a parallel analysis (Horn, 1965) to determine how many factors underlie each multi-item study measure. Parallel analysis compares the actual eigenvalues from the study data set to simulated eigenvalues. The simulated eigenvalues are calculated by conducting an exploratory factor analysis on a specific number of randomly generated datasets, which possess the same sample size and number of variables as the actual or true data set. For this dissertation, I generated 1,000 random data sets. I compared the simulated eigenvalues produced by these 1,000 random datasets to the actual eigenvalues produced by the study data. Parallel analysis defines the number of factors that underlie the solution as the number of actual eigenvalues that exceed the simulated, or randomly-produced, eigenvalues.

This approach takes into account the effect of sampling error (Hayton et al., 2004). In this study, I used a parallel analysis macro created by Kabacoff (2003) to compare the actual eigenvalues to the 95th percentile simulated eigenvalues produced from 1,000 randomly generated datasets.

4.7.2 Internal consistency

Internal consistency, as measured by Cronbach's alpha, was calculated for all measures. Cronbach's alpha is a coefficient of reliability that indicates how much variability in a set of items is accounted for by the latent construct. If the alpha coefficient was greater than .70, then the set of items is deemed to have decent internal consistency reliability (Nunnaly, 1978).

CHAPTER FIVE: THE EFFECT OF CONFLICTING MEDICATION INFORMATION AND DOCTOR SUPPORT ON MEDICATION ADHERENCE FOR CHRONICALLY ILL PATIENTS

To be submitted to *Patient Education & Counseling*

Abstract

Objective. This is the first quantitative investigation of the effect of conflicting information on medication adherence in a sample of chronically ill patients. We specifically investigated whether conflicting information and doctor support had a direct effect on medication adherence or whether the effect was mediated by adherence self-efficacy and outcome expectations for medications.

Methods. Vasculitis patients (n=228) completed two online questionnaires that contained measures of conflicting information, adherence self-efficacy, outcome expectations, doctor support, and medication adherence. We used a bootstrapping approach to generate 95% confidence intervals to test for the significance of each mediated effect.

Results. A majority of patients (51.3%) reported receiving conflicting medication information. Conflicting information had a direct negative effect on medication adherence, which was not mediated by self-efficacy or outcome expectations. Alternatively, self-efficacy did mediate the positive effect of doctor support on medication adherence.

Conclusion. Patients who encounter conflicting medication information are less adherent to their medication regimens. The presence of a supportive doctor may counteract the negative effect of conflicting medication information.

Practice Implications. Physicians should initiate conversations about conflicting medication information with their patients. Policy initiatives to standardize medication practices may also reduce the amount of conflicting information available to patients.

Introduction

Health-related information helps patients cope with illness by increasing knowledge, reducing feelings of uncertainty, and enhancing emotional and social adjustment (Johnson, 1997). When seeking information, patients have a number of sources from which to choose, including health professionals like physicians (Rutten et al, 2005; Trewin and Veitch, 2003, Narhi, 2007; Hesse et al, 2005), pharmacists (Sleath et al, 2003, Trewin and Veitch, 2003), and nurses (Mills & Davidson, 2002; Luker et al, 1996, Rutten et al, 2005), health-related websites (Hesse et al, 2005, Narhi, 2007), patient information leaflets (Narhi, 2007), mass media sources such as newspapers, magazines, and television (Narhi, 2007, Rutten et al, 2005; Hesse et al, 2005), and family and friends (Huber & Cruz, 2000; Sleath et al, 2003, Rutten et al, 2005). When patients consult more than one source for health information, the opportunity to encounter conflicting information arises.

Conflicting information may represent a negative side of information seeking. A burgeoning, primarily qualitative, literature has begun to document the extent to and conditions under which chronic disease patients receive conflicting information. The results from these studies demonstrate that people living with chronic conditions, such as cancer (Mills & Davidson, 2002; Gray et al, 1997), cardiopulmonary disease (Trewin & Veitch, 2003), rheumatic disease (Lim et al, 2007), low back pain (McIntosh et al, 2003) as well as mental illness (Pollock et al, 2004) receive conflicting information about their illness and its management. Furthermore, several studies have documented that up to 25% of patients receive conflicting information about their medications (Coleman et al, 2005; Lim et al, 2007; Blendon et al, 2003), although no published research has focused specifically on patients with rare health conditions.

Preliminary evidence suggests that receipt of conflicting information may negatively influence patients' perceptions of care (Zapka et al, 2004), increase anxiety (Pollock et al, 2004), alter risk perceptions (Han et al, 2006), and complicate patients' ability to assess the reliability of information sources (McIntosh et al, 2003). Although the relationship between conflicting information and medication adherence has not been tested in the literature, health behavior models like the Information-Motivation-Behavioral Skills (IMB) Model (Fisher et al, 1992) offer insight into the potential mechanisms through which conflicting information may affect adherence. Specifically, the IMB model posits that adherence information has a positive effect on both adherence self-efficacy and medication adherence and that self-efficacy acts as a mediator of the relationship between information and adherence. The IMB model also postulates that motivation (i.e. perceptions of social support and adherence outcome expectations) influence adherence directly and indirectly through increased self-efficacy. Four cross-sectional tests of the model lend support to these theorized relationships (Amico et al, 2005; Amico et al, 2009; Starace et al, 2006; Kalichman et al, 2001), although self-efficacy appears to mediate the majority of the effect of information on medication adherence.

Significance

To our knowledge, this study represents the first quantitative investigation of the relationship between conflicting information and medication adherence in a sample of chronically ill patients. The IMB model served as the organizing framework for our conceptual model (Figure 1), in which we hypothesize that greater amounts of conflicting information will result in more medication nonadherence. Additionally, we believe that self-efficacy and outcome expectations will partially mediate the relationship between conflicting

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information and nonadherence. Specifically, we posit that patients who receive more conflicting information will have decreased self-efficacy and more negative outcome expectations for medications, which will result in more nonadherence. Moreover, we hypothesize that social support from patients' physicians will result in less medication nonadherence and that this effect will be partially mediated through increased self-efficacy and more positive outcome expectations for medications.

Methods

Overview

All data were collected as part of the Accessing Social Support in Symptom Treatment (ASSIST) Study, which was designed to assess the information seeking behaviors of vasculitis patients. Vasculitis is a rare autoimmune disease that causes blood vessel inflammation and is characterized by an unpredictable course of relapses ("flares") and remission. The ASSIST Study consisted of two online questionnaires administered three months apart. To be eligible for participation, all patients had to have a self-reported diagnosis of vasculitis, be at least 18 years of age, be able to read and write in English, have access to the Internet, and currently be taking at least one medication to treat their vasculitis. This study was approved by the Institutional Review Board at the University of North Carolina at Chapel Hill.

We recruited participants for the ASSIST Study in four ways. First, we distributed study brochures at the 2008 Vasculitis Foundation Conference in Rochester, Minnesota. This recruitment method yielded 45 interested patients, 39 of whom were eligible and interested. Second, we mailed study announcement letters to known vasculitis patients (*n*=361) who were part of the Glomerular Disease Collaborative Network (GDCN). The GDCN is a

collaboration of the University of North Carolina and community nephrology offices across the southeastern United States. Of the 67 GDCN patients who returned correspondence, 38 were eligible to participate. For our third recruitment method, we contacted physician-diagnosed vasculitis patients (n=124) who were part of the Partners Adjusting to Illness with Relationship Support (PAIRS) or Vasculitis Self-Management (VSM) studies at the Thurston Arthritis Research Center; 29 of the 39 (74%) patients who responded were eligible and interested. Our last recruitment method involved posting general recruitment announcements (including a study podcast) on vasculitis websites and in patient newsletters. Information about the study was also distributed at local support group meetings and circulated on eight vasculitis email groups and listservs; 147 of the 155 patients who contacted us in response to these general announcements were eligible.

Thus, 306 patients, 253 (83%) of whom were eligible and interested, responded to our various recruitment efforts. Reasons for ineligibility included not taking vasculitis medications (n=25), patient death (n=9), not having access to the Internet (n=9), being too busy to participate (n=4) and not having a diagnosis of vasculitis (n=1). An additional five patients refused to participate after learning more about the study.

Once participants were enrolled in the study, we emailed them a questionnaire link that directed them to the study fact sheet. After reading the fact sheet, participants were directed to the baseline questionnaire, which took approximately one hour to complete. Three months later, we emailed the link to the 30-minute follow-up questionnaire. Participants received a $10 gift card after completing the second questionnaire.

Two hundred thirty-two of the 253 eligible patients (91.7%) completed the baseline questionnaire. Reasons for non-completion included technical issues (n=7), being too sick

(*n*=4) or too busy (*n*=3) to participate, or never responding to study correspondence (*n*=7). When compared with completers, non-completers were not significantly different in terms of gender or self-reported vasculitis type.

Our three-month follow-up response rate was 98.2%; only four of the 232 participants did not complete the second questionnaire. One participant experienced technical difficulties and the remaining three did not respond to study correspondence.

Measures

The three-month follow-up questionnaire contained measures for our mediating variables (adherence self-efficacy, outcome expectations) and our outcome variable of interest (medication nonadherence). The independent variables (conflicting medication information and doctor support) and sociodemographic variables were measured as part of the baseline questionnaire.

Medication nonadherence. To measure medication nonadherence, we used the Vasculitis Self-Management Survey (VSMS) medication adherence subscale, which asks respondents to describe their medication taking behavior during the past four weeks (Thorpe, 2006). The seven scale items are measured on a five-point Likert scale; the response scale for six items ranges from 1= "none of the time" to 5 = "all of the time," while the seventh item (percentage of medication doses taken exactly as directed) ranges from 1 = "0-24%" to 5 = "100%." The VSMS medication adherence subscale has demonstrated acceptable internal consistency (Cronbach $\alpha = 0.77$) and test-retest reliability of 0.60 in a previous study of vasculitis patients (Thorpe, 2006). In order to create a summary medication adherence score, we reverse scored two items and then computed the average of the seven items. Higher summary scores indicate greater *nonadherence.* Cronbach's alpha coefficient was 0.89 in our

study.

Adherence self-efficacy. We used the difficulty subscale from the Self-Efficacy for Appropriate Medication Use Scale (SEAMS; Risser et al., 2007) to measure adherence self-efficacy. The difficulty subscale items ask respondents to rate their level of confidence to take medications correctly in a number of difficult situations, including when they have a busy day planned, are away from home, or have to take multiple medications. Originally, the seven difficulty items were measured on a three-point Likert-scale ranging from 1 = "not confident" to 3 = "very confident." We changed the response scale from three points to five points in an attempt to capture greater variability in adherence self-efficacy. The modified scale ranged from 1= "not at all confident" to 5= "very confident." We created a summary score by averaging item responses; higher scores represent greater levels of adherence self-efficacy. Internal consistency (α= 0.88) was good.

Outcome expectations. Patients' medication-related outcome expectations were measured using the specific-necessity subscale of the Beliefs about Medicines Questionnaire (BMQ) (Horne et al, 1997). The specific-necessity subscale includes five items representing "the perceived role of medication in protecting against deterioration of present and future health status of the patient" (p. 20) and has demonstrated good internal consistency and test-retest reliability in previous studies (Horne et al, 1997). Response options ranged from 1= "strongly disagree" to 5= "strongly agree." Again, we created a summary score by averaging item responses. In this case, higher summary scores indicated stronger patient beliefs that vasculitis medications were necessary to maintain health. The Cronbach alpha coefficient was 0.80.

Conflicting information. Because a conflicting medication information scale has not

been reported in the literature, we developed six items that asked respondents to report whether they ever received conflicting information about the time of day to take their medications, how to take their medications, proper dosing, duration (i.e. 6 months versus 1 year), side effects, and side effect severity. Respondents could choose between the following response options: "have not received conflicting information," "have received conflicting information," or "don't remember." We recoded "don't remember" responses as missing and then calculated a summary score by adding the six items. All scale items loaded at 0.70 or greater onto one factor, which indicated a one-factor solution. KR-20 was 0.75.

Doctor support. Participants completed four items about perceived adherence support from their primary vasculitis doctor. Specifically, participants indicated how often their doctor supported them in taking their vasculitis medications, shared new information about vasculitis medicines, provided helpful hints about how to deal with the side effects of vasculitis medicines, and provided enough support when it came to taking the medications as prescribed. Response options ranged from 1= "does not do this" to 4= "does this a lot." Respondents could also select "*N/A*" if they thought the question did not apply to their situation. In these cases, we recoded *N/A* as a "1" because the doctor did not provide that type of support. We created a summary score by averaging the four items; higher scores reflected more adherence support. Cronbach's alpha was 0.80 in our sample.

For the multiple-item scales described above, summary scores were not calculated if more than 25 percent of the scale items were missing. In those cases, participants' scores were treated as missing.

Socio-demographics. Participants answered various demographic and disease-related questions, including one item each about gender, race, age, education (in years), year of

vasculitis diagnosis, vasculitis type, and health insurance status (insured versus not insured).

Participants also reported the interval since their last vasculitis relapse or flare, with 1= "I am currently experiencing a flare-up or relapse", 2= "less than 1 year ago", 3= "more than 1 year ago", and 4= "I have never experienced a relapse or flare-up or relapse."

Data analysis

We used SAS version 9.2 to conduct all analyses. First, we calculated descriptive statistics, including skewness and kurtosis. Then, we used a bootstrapping approach (Preacher & Hayes, 2008) to determine whether self-efficacy and outcome expectations mediated the effects of conflicting information and doctor support on medication adherence, controlling for age, gender, education, and time since last flare. Bootstrapping is a nonparametric procedure that does not impose the constraint of multivariate normality and allows for the statistical comparison of multiple indirect effects. In this study we calculated an overall point estimate and 95% confidence interval for each mediated (indirect) effect by generating a sampling distribution from 5,000 samples (with replacement) of size n from the full data set. Bootstrapping also produces contrasts to test the relative strength of each specific indirect effect. We used bias-corrected confidence intervals to determine whether the point estimates for each indirect effect were significant; estimates were considered significant if the confidence interval did not contain zero.

Results

Sample characteristics

Table 1 summarizes the demographic and clinical characteristics of the final study sample (*n*=228). A majority of participants were female (70%), white (91%), and had a diagnosis of Wegener's Granulomatosis (59%). On average, participants were middle-aged

(M= 51.0 years) and reported some college education (M= 15.6 years). Patients had been living with vasculitis for an average of 6.4 years and 28.4% were experiencing a relapse or flare at the time of the baseline survey. Ninety-three percent of patients reported having health insurance.

Descriptive statistics

Descriptive statistics also are presented in Table 1. On average, patients' reported fairly low levels of medication *nonadherence* (1.7 on a 5-point scale), whereas their adherence self-efficacy was quite high (M=4.0, sd=0.9). Patients also had very positive outcome expectations for their medications, with a mean of 4.4 on a 5-point scale. Additionally, patients' physicians provided them with a fair amount of adherence support (M=3.1, sd=0.7).

More than half of patients (51.3%) reported receiving conflicting information about at least one aspect of their vasculitis medications. In terms of the amount of conflicting information, 32.5% received no conflicting medication information, 36.4% received conflicting information about 1-3 medication topics, 14.9% received conflicting information about 4-6 medication topics, and 16.2% could not remember if they had received conflicting medication information. Patients were most likely to receive conflicting information about the severity of medication side effects (35.5%), the duration of treatment (30.7%), and the types of side effects associated with their vasculitis medications (29.4%), whereas conflicting information about correct dosage (24.1%), correct timing (21.9%), and how to take medications correctly (with or without food) (16.6%) was encountered less often (Figure 2).

Mediation analyses

Table 2 displays the point estimates and *p*-values for the hypothesized relationships in

our conceptual model. The model explained approximately 25% of the total variance in medication adherence (adjusted $R^2 = 0.25$). There were no significant relationships between conflicting information and outcome expectations (B= -0.0066, p= 0.83) or adherence self-efficacy (B= -0.0185, p= 0.65). In contrast, physician support was significantly positively related to self-efficacy (B= 0.2762, p <0.01) but not outcome expectations (B= -0.0029, p= 0.97). Both outcome expectations and self-efficacy were significantly related to medication nonadherence; however, outcome expectations (B= 0.1621, p= 0.02) were positively associated with nonadherence while self-efficacy (B= -0.2795, p <0.001) had a negative association. The direct effect of conflicting information (B= 0.0619, p= 0.03) on nonadherence was significant, whereas physician support was not (B= -0.0422, p= 0.54). Only one covariate, gender (B= 0.2063, p= 0.04), was significantly associated with nonadherence; women (M=1.73, sd=0.7) were more nonadherent than men (M=1.49, sd=0.7).

A more detailed examination of the mediated effects is presented in Table 3. As demonstrated by the confidence intervals, neither outcome expectations [95% CI (-0.0140, 0.0082)] nor self-efficacy [95% CI (-0.0161, 0.0303)] were significant mediators of the relationship between conflicting information and nonadherence. Alternatively, self-efficacy [95% CI (-0.1491, -0.0231)] did significantly mediate the relationship between physicians support and nonadherence. Moreover, the significant contrast [95% CI (0.0155, 0.1470)] indicates that self-efficacy is a stronger mediator of physician support on nonadherence than outcome expectations.

Discussion and Conclusion

Discussion

This is the first quantitative study to explore whether conflicting information and doctor support affect medication adherence for patients living with a chronic illness. A majority (51.3%) of patients in our sample encountered conflicting information about their medications. Patients were most likely to receive conflicting information about the severity of medication side effects (35.5%) and treatment duration (30.7%) and were least likely to receive conflicting information about how to take their medications correctly (16.6%). Patients who received conflicting information were less adherent to their medication regimens than patients who did not receive conflicting information.

Based on the IMB Model, we hypothesized that self-efficacy would mediate the relationship between conflicting information and medication adherence. There are several potential explanations why we did not find this significant mediating effect. First, because conflicting information is conceptually different from information, it may work through pathways other than self-efficacy to affect behavior. If this is true, than the IMB model may not be the best model to explore the effects of conflicting information. To our knowledge, no theoretical model attempts to explain the effects of conflicting information on behavior. Hence, we should integrate what is known from other theories to better understand the mechanisms through which conflicting information works to affect medication adherence. Specifically, the Cognitive-Social Health Information Processing (C-SHIP) model might offer a useful starting point (Miller et al, 1996).

Within the C-SHIP model (Miller et al, 1996), patients' information seeking style (categorized as "monitors" or "blunters"), may moderate the effect of conflicting information on adherence. Patients who are monitors actively scan for threatening health information, which can result in increased anxiety and, ultimately, avoidance behavior (Miller et al, 1996).

It is likely that monitors would actively seek information about medication side effects, increasing the chances that they would encounter conflicting information about the types and severity of side effects. In these cases, patients may become anxious about conflicting information and possibly less adherent. In contrast, blunters tend to deny the existence of health risks and may be less likely to seek information from alternative sources. When confronted with conflicting information, blunters may defer to the source they believe is most credible, especially if that source provides positive information and assessments (Viscusi, 1997). If patients view their physicians as the most credible source of medication information, which has been demonstrated in previous studies (Mayer et al, 2007; Hesse et al, 2005; Carpenter et al, under review), then they may ignore conflicting information they find on the Internet, for example, and adhere to their physicians' advice. Moreover, if blunters truly ignore other sources of information, then their self-efficacy may be essentially unaffected. Thus, conflicting information may affect the self-efficacy of monitors but not blunters. Future studies should determine whether conflicting information and information seeking style interact to influence self-efficacy and medication adherence.

As we hypothesized, patients with supportive physicians felt more confident that they could take their medications in different difficult situations. This, in turn, led to greater medication adherence. This suggests that physicians who specifically discuss medications, including how to cope with side effects, increase patients' adherence self-efficacy. Because physicians are typically viewed as the most credible health information source (Mayer et al, 2007; Hesse et al, 2005), it may be especially important for them to discuss adherence with patients.

The finding that positive outcome expectations for medications were associated with

worse medication adherence was unanticipated and may be due to the variable's lack of variability. As noted earlier, patients' outcome expectations for medications were very high (4.4 on a 5.0 scale). This is unsurprising given that vasculitis medications are critical to patient survival; there is 80% mortality rate for untreated vasculitis within the first year of diagnosis (Walton, 1958). Alternatively, patients who hold the strongest beliefs that their medications are essential for the maintenance of health may be more likely to remember instances in which they did not take their medications correctly than patients who do not belief that their medications are health-protective. Thus, patients with the most positive outcome expectations for medications may also be the most likely to recall instances of nonadherence.

Gender was the only significant covariate in our regression analyses. Women reported greater levels of nonadherence than men. Previous research about the effect of gender on medication adherence has been mixed (Haynes, 1976). However, it is well-known that women seek more health information than men (Mayer et al, 2007; Rutten et al, 2005; Huber & Cruz, 2000). In fact, our own research has demonstrated that female vasculitis patients consult more sources for medication information than male patients (Carpenter et al, under review). Thus, women may encounter conflicting information more often than men, which may ultimately result in greater nonadherence.

Limitations

Our study findings should be interpreted with caution for several reasons. First, patients tend to over-report medication adherence on self-reported questionnaires (Treharne et al, 2006). However, this likely biased our results by weakening the relationship between conflicting information and adherence. Additionally, patients in our sample may be more

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likely to encounter conflicting information because they use the Internet. Thus, the results cannot be generalized to other patient populations. The relative lack of diversity (well-educated, 70% female) further limits the study's generalizability. Future research should attempt to recruit more educationally diverse samples and determine whether non-Internet users encounter conflicting information to the same degree as Internet users. Third, even though our study is longitudinal in nature, we cannot say that conflicting information is a cause of medication nonadherence. However, it is unlikely that poor adherence leads patients to encounter conflicting medication information. Controlling for baseline adherence levels would address this limitation.

Last, our conflicting information measure possesses several shortcomings. First the reliability and validity for this measure has not been established, although our factor analysis suggests a one-factor solution. Second, our measure about lifetime receipt of conflicting information was subject to recall bias; we conservatively treated the 14.9% of patients who could not remember if they had received conflicting information as missing. It is also possible that conflicting information received several years ago is less salient than recently received conflicting information in terms of self-efficacy and medication adherence. These limitations could be addressed by designing a prospective study that tracks patients' information seeking behavior over a several month period after receiving a new prescription.

Conclusion

Conflicting medication information is a clear threat to patient medication adherence. If vasculitis patients receive conflicting medication information, then it is almost certain that patients with more common diseases encounter just as much, if not more, conflicting information, especially from media sources and family and friends (Rutten et al, 2005). For

this reason, researchers should assess the extent to which patients with more common diseases, like cancer, diabetes, arthritis, and asthma, encounter conflicting medication information. Moreover, qualitative research that explores how patients resolve situations in which conflicting information is encountered is warranted. For example, it is possible that patients defer to their most trusted source or they may develop some type of hybrid medication taking behavior that incorporates advice from multiple trusted sources. This type of research could guide the development and refinement of theoretical models that explain how conflicting information affects self-management behavior. Lastly, supportive physicians can increase patients' adherence self-efficacy by offering adherence-related advice and providing reliable secondary information sources.

Practice implications

In an ideal world, physicians would thoroughly discuss medications with patients as well as provide them with a list of high quality information sources, such as medication websites and written materials. In-depth physician-patient discussion about medications and alternative information sources would have the double benefit of increasing patients' perceptions of physician support, which increases self-efficacy, as well as potentially reducing the direct negative impact of conflicting information on medication adherence. Given the time constraints and range of topics that must be covered during a typical office visit, it may be impractical to ask physicians to devote extra time to this issue.

It may be more practical for other medical staff, like nurses or receptionists, to direct patients to high quality secondary information sources. An intervention of this type may require additional vasculitis-specific education for office staff. Additionally, identifying high quality sources may be more difficult than it seems because there are often inconsistencies in

medication treatment guidelines at the physician level (Vidal et al, 2005). Expert panels of

physicians, pharmacists, nurses, and patient advocates may need to convene to create

consensus-based treatment guidelines. This may curb any 'trickle down' effect of physician-

level conflicting information to the patient.

Table 5.1: Participant characteristics (*n*=228)

Characteristic	Mean (*SD*) or %	Skewness	Kurtosis
Socio-demographic			
Age	51.0 (13.3)	-0.14	-0.71
Male	30.3%	-	-
White	91.3%	-	-
Education (in years)	15.6 (2.8)	-0.24	1.74
Disease			
Self-reported disease type			
Wegener's Granulomatosis	59.2%		
Churg Strauss Syndrome	12.7%		
Microscopic Polyangiitis	7.9%	-	-
Takayasu Arteritis	4.8%		
Other	15.4%		
Years with disease	6.4 (6.2)	-2.03	5.19
Currently experiencing flare/relapse	28.4%	-	-
Clinical			
Have health insurance	93.4%	-	-
Other			
Medication adherence	1.7 (0.7)	1.22	1.59
Adherence self-efficacy	3.99 (0.9)	-0.58	-0.44
Outcome expectations	4.4 (0.6)	-1.30	1.63
Conflicting information	1.6 (1.8)	0.83	-0.42
Physician support	3.1 (0.7)	0.13	-0.84

Table 5.2: Summary of mediation results for the effect of conflicting information and doctor support on medication nonadherence (5000 bootstrap samples)

	Estimate (*SE*)	*t*-statistic	*p*-value
Independent variables to mediating variables			
Conflicting Information→ Outcome expectations	-0.0066 (0.0308)	-0.21	0.83
Conflicting Information→ Self-efficacy	-0.0185 (0.0412)	-0.45	0.65
Physician support→ Outcome expectations	-0.0029 (0.0740)	-0.04	0.97
Physician support→ Self-efficacy	0.2762 (0.0990)	2.79	<0.01
Mediating variables to dependent variable			
Outcome expectations→ Medication nonadherence	0.1621 (0.0697)	2.32	0.02
Self-efficacy→ Medication nonadherence	-0.2795 (0.0522)	-5.36	<0.0001
Independent variables to dependent variable (direct effects)			
Conflicting Information→ Medication nonadherence	0.0619 (0.0279)	2.22	0.03
Physician support→ Medication nonadherence	-0.0422 (0.0684)	-0.62	0.54
Covariates			
Age	-0.0030 (0.0037)	-0.81	0.42
Gender (females vs. males)	0.2063 (0.0976)	2.11	0.04
Education (years)	-0.000 (0.0163)	-0.00	1.00
Time since last relapse/flare	0.0492 (0.0450)	1.09	0.28
	Adjusted R^2=0.25		

Table 5.3: Specific indirect effects of conflicting information and doctor support on medication adherence

| | | Bias-corrected 95% CI | |
| | | | |
Specific indirect effect	Point estimate (SE)	*Lower*	*Upper*
Conflicting Information			
Outcome expectations	-0.0011 (0.0132)	-0.0140	0.0082
Self-efficacy	0.0052 (0.0117)	-0.0161	0.0303
Total	0.0041 (0.0132)	-0.0198	0.0326
Contrast			
Outcome expectations vs. self-efficacy	-0.0062 (0.0124)	-0.0325	0.0169
Doctor support			
Outcome expectations	-0.0005 (0.0136)	-0.0245	0.0300
Self-efficacy	-0.0772 (0.0319)	-0.1491	-0.0231
Total	-0.0777 (0.0356)	-0.1554	-0.0133
Contrast			
Outcome expectations vs. self-efficacy	0.0767 (0.0338)	0.0155	0.1470

Figure 5.1: Predicted relationships among conflicting information, doctor support, outcome expectations, adherence self-efficacy, and medication nonadherence
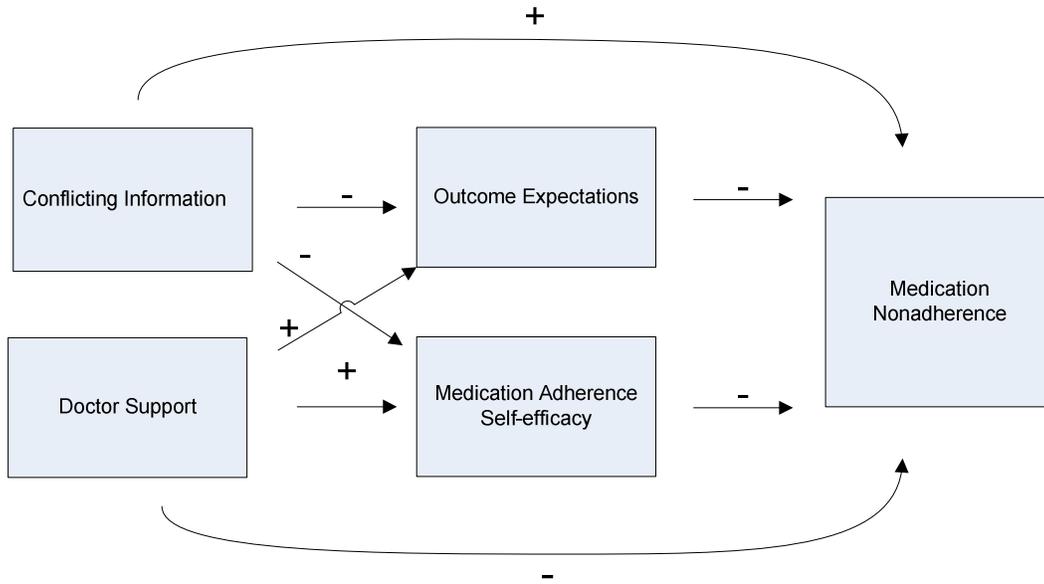
Figure 5.2: Percentage of patients receiving conflicting information by medication topic
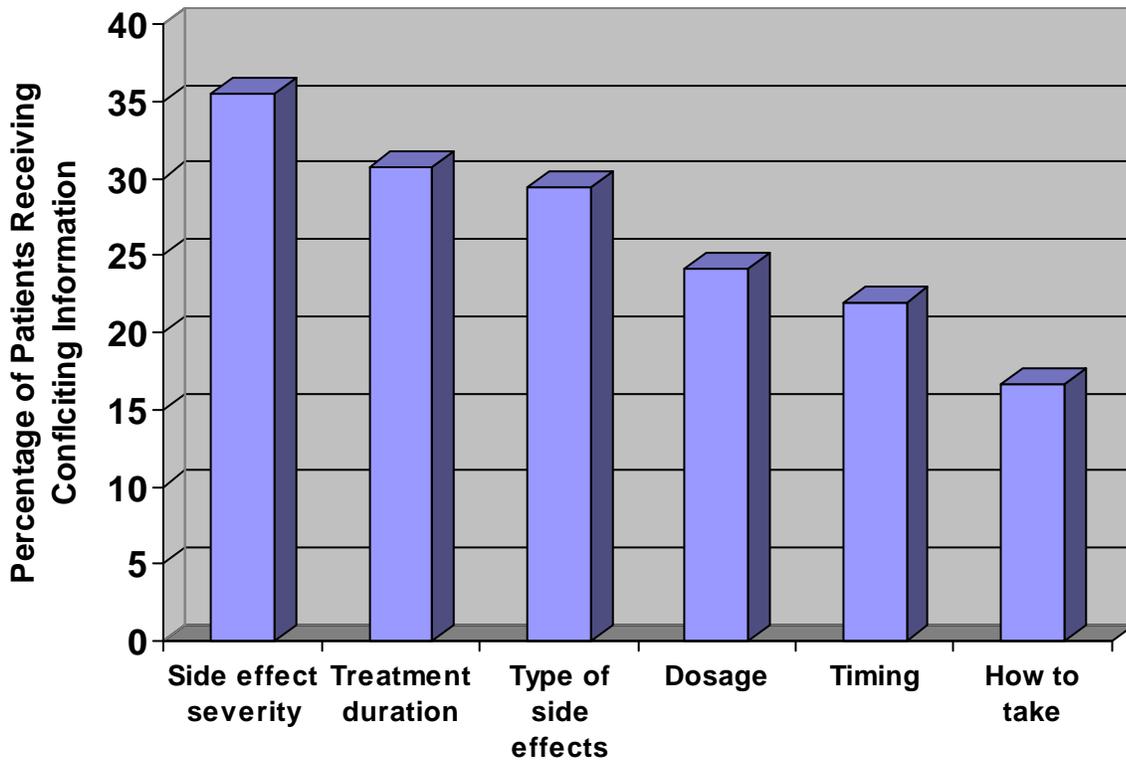
Figure 5.3: Reduced model for the relationships among conflicting information, doctor support, outcome expectations, adherence self-efficacy, and medication nonadherence
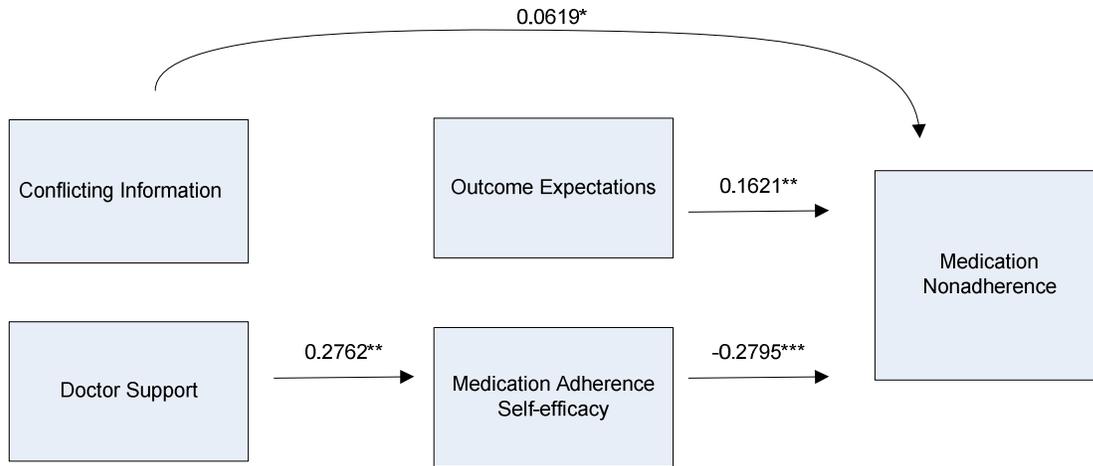
* p<0.05, ** p<0.01, ***p<0.001

Covariates include: age, gender, education, and time since last flare

CHAPTER SIX: USE AND PERCEIVED CREDIBILITY OF MEDICATION INFORMATION SOURCES FOR VASCULITIS PATIENTS: DIFFERENCES BY GENDER

Submitted to *Arthritis Care & Research*

Abstract

Objective. The information sources that vasculitis patients use may be appreciably different from other disease groups. This article's purpose is to describe vasculitis patients' most frequently used medication information sources and determine which sources patients perceive as credible. We also investigate whether there are gender differences in the use and perceived credibility of information sources.

Methods. Using an online questionnaire, vasculitis patients ($n=232$) indicated how often they obtained medication information from 12 sources during the previous year and rated the credibility of six sources. MANCOVA tested the significance of a source*gender interaction term, controlling for important demographic and clinical variables. After finding a significant interaction, we calculated follow-up contrasts to determine which sources male and female patients used differently. We used t-tests to compare patients' perceived credibility ratings.

Results. Patients used physicians and the Internet most often to obtain medication information. Moreover, the doctor and the Internet were rated as the two most credible information sources. Male patients consulted their spouse/partner more often and rated them as more credible than female patients. Female patients were more likely to use medication package inserts and the Internet and less likely to consult nurses than male patients.

Conclusion. Vasculitis patients, like other patient populations, seek medication information from multiple sources. Non-physician health professionals, such as pharmacists and nurses, may be underutilized by this population. Because male patients view their spouse/partner as a credible source from whom to obtain medication information, providers may want to involve the spouse/partner in prescription decision-making.

INTRODUCTION

The availability of medication information has increased dramatically over the past few decades. This increase is due to a number of factors, including the growth of health-related websites on the Internet (Fox & Rainie, 2003; Cline & Haynes, 2001), direct-to-consumer drug advertisements (Khanfar et al, 2007), policy changes to improve medication package inserts (Amery, 1999), and increased patient advocacy and consumerism (Dutta-Bergman, 2005). Given the growing number of information sources, the variability in quality across sources (Berland et al, 2001; Thompson & Graydon, 2009), and the relationship between information and positive patient outcomes (Rutten et al, 2005), it is important to understand where patients obtain information about their medications.

There is little consistency among health information studies about which source patients trust and/or consult most often, though physicians are generally ranked as one of the most preferred and trusted sources (Mayer et al, 2007; Hesse et al, 2005; Trewin & Veitch, 2003; Narhi, 2007, Rutten et al, 2005). Even though physicians are often preferred, that does not mean that they are the most frequently used source. For example, studies have found that patients consulted the Internet (Hesse et al, 2005) and pharmacists (Sleath and colleagues, 2003) more often than physicians.

In addition to the Internet and pharmacists, other frequently consulted health information sources include written materials like patient information leaflets (Narhi, 2007, Rutten et al, 2005), books (Hesse et al, 2005) and newsletters (Huber and Cruz, 2000), non-physician health professionals like nurses (Mills & Davidson, 2002; Luker et al, 1996, Rutten et al, 2005), and mass media sources such as newspapers, magazines, and television (Cunnigham et al, 1999; Huber & Cruz, 2000; Narhi, 2007, Rutten et al, 2005). Family and

friends also are important sources of health information for patients (Huber & Cruz, 2000; Sleath et al, 2003, Rutten et al, 2005).

Multiple factors, including age (Rutten et al, 2006; Hesse et al, 2005; Narhi, 2007; Sleath et al, 2003), education (Mayer et al, 2007; Rutten et al, 2005), race (Rutten et al, 2005, Williams et al, 2007; Cunnigham et al, 1999), and phase of illness (Rutten et al, 2005), can influence patients' information-seeking behavior, which may explain why there is a great deal of variability in patients' source preferences. Gender also affects health seeking behavior. Female patients have consistently sought information more frequently and from more sources than male patients (Mayer et al, 2007, Rutten et al, 2005, Huber & Cruz, 2000).

Although not tested empirically, it is reasonable to assume that the availability of health information has not increased equally for all patient groups, especially groups who have a rare illness. Vasculitis patients represent one such group; the prevalence of anti-neutrophil cytoplasmic antibodies (ANCA)-associated granulomatosis vasculitis (formerly known as Wegeners Granulomatosis) (Woywodt & Matteson, 2006), the most common form of vasculitis, is 30 cases/million U.S. citizens (Cotch et al, 1996). Although vasculitis patients may be just as motivated to obtain medication information as cancer patients, these patients do not have access to the same types of information sources. For example, it is unusual to hear vasculitis discussed on television. Moreover, popular print media sources, like newspapers and magazines, do not publish articles about vasculitis with nearly the same frequency as more common diseases. Partially due to vasculitis' lack of exposure in the media, the general public's awareness of the disease is low. For this reason, family and friends, which cancer (Rutten et al, 2005) and HIV patients (Huber & Cruz, 2000) commonly use for disease-related information, are unlikely to have valuable vasculitis-specific

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information to share, unless they search for this information themselves.

Because the information sources used by vasculitis patients may be appreciably different from other disease groups, the primary goal of this article is to describe vasculitis patients' most commonly used sources of medication information and determine which sources patients perceive as most credible. A secondary goal is to investigate whether there are gender differences in source use and perceived credibility of information sources. Specifically, patients' use of twelve sources, including doctors, pharmacists, nurses, brochures and pamphlets, medicine package inserts, articles and books, the Internet, vasculitis support groups, spouse/partner, family members, friends, and patient newsletters, are explored.

PARTICIPANTS AND METHODS

Overview

All data were collected as part of the Accessing Social Support in Symptom Treatment (ASSIST) Study. The ASSIST Study consists of two online questionnaires administered three months apart. To be eligible for participation, all patients must have a self-reported diagnosis of vasculitis, be at least 18 years of age, be able to read and write in English, have access to the Internet, and currently be taking at least one medicine to treat their vasculitis. We e-mailed eligible participants a questionnaire link, which directed them to the study fact sheet. After reading the fact sheet, participants were directed to the baseline questionnaire, which took approximately one hour to complete. Participants received a ten dollar gift card after completing the 30-minute three-month follow-up questionnaire. Because questions regarding sources of medication information were included only on the baseline

questionnaire, we did not analyze three-month follow-up data for this article. This study was approved by the Institutional Review Board at the University of North Carolina at Chapel Hill.

Sample

We recruited participants for the ASSIST Study in four ways, including distributing study brochures at the 2008 Vasculitis Foundation Conference in Rochester, Minnesota. A total of 45 patients approached us to enroll in the study; 39 were eligible to participate. Four patients were ineligible because they did not having access to the Internet and two refused to participate after learning more about the study.

We also mailed recruitment letters to known vasculitis patients (n=361) who agreed to be notified about research studies and were part of the Glomerular Disease Collaborative Network (GDCN). The GDCN is a collaboration of the University of North Carolina and community nephrology offices across the southeastern United States. Of the 67 GDCN patients who returned correspondence, 38 were eligible to participate. Twenty-nine patients were ineligible because they were not currently taking vasculitis medications (n=14), they had died (n=8), they were too busy to participate (n=4), or they did not have access to the Internet (n=3).

Additionally, we contacted vasculitis patients (n=124) who were participants in the Partners Adjusting to Illness with Relationship Support (PAIRS) or Vasculitis Self-Management (VSM) studies conducted at the Thurston Arthritis Research Center. All PAIRS and VSM participants had expressed interest in learning about future research studies and had their vasculitis diagnosis confirmed by a physician. Of the 39 patients who responded, 29 (69%) were eligible and interested in participating; reasons for ineligibility included not

taking vasculitis medications (*n=4*), not having access to the Internet (*n=2*), no longer having a diagnosis of vasculitis (*n=1*), and patient death (*n=1*). An additional two participants refused to participate after learning more about the study.

We also posted general recruitment announcements (including a study podcast) on vasculitis websites and in patient newsletters. Information about the study was also distributed at support group meetings nationally and circulated on eight vasculitis email groups and listservs. A total of 155 patients contacted us in response to these general announcements. Seven patients were ineligible because they were not taking vasculitis medicines and one patient was not interested after learning more about the study. Thus, 306 patients, 253 (83%) of whom were eligible and interested, responded to our various recruitment efforts.

Measures

All study measures described below were completed as part of the online ASSIST baseline questionnaire.

Socio-demographics. Before completing main study measures, participants answered various demographic and disease-related questions, including one item each about gender, race, age, education (in years), year of diagnosis, vasculitis type (Wegener's Granulomatosis, Microscopic Polyangiitis, Churg Strauss Syndrome, Takayasu Arteritis, other), phase of illness (currently experiencing relapse/flare vs. not currently experiencing relapse/flare), and health insurance status (insured versus not insured). A disease duration variable was created by subtracting the year in which the patient was diagnosed with vasculitis from the midpoint of our data collection year (2008.5). Additionally, participants indicated whether they lived within or outside the United States (US, International).

Frequency of medication source use. We asked patients how often they obtained vasculitis medicine information from twelve sources, including doctors, pharmacists, nurses, brochures and pamphlets, medicine package inserts, articles and books, Internet (information websites), support groups (online or in-person), spouse/partner, family members other than their spouse, friends, and newsletters. For each source, patients answered one item about how often they had obtained vasculitis medicine information during the past year, ranging from 1= 'never' to 5= 'always.'

Source credibility. If patients reported that they had obtained information about vasculitis medicines from any one of six sources (doctors, pharmacists, spouses, family members/friends, other vasculitis patients, Internet), then they were asked to rate the perceived credibility of that source. Hence, if patients did not report obtaining vasculitis medication information from the pharmacist, for example, they did not complete perceived credibility items about the pharmacist. Credibility was measured by two items that were derived from the McCroskey and Teven Credibility Scale (1999). The first item asked how knowledgeable (1= '*not at all knowledgeable*' to 9= '*extremely knowledgeable*') a source was about vasculitis medicines, while the second item asked how expert (1= '*not at all expert*' to 9= '*extremely expert*') the source was about vasculitis medicines. Inter-item correlations ranged from .92 for family credibility to .81 for Internet credibility. A summary score was created for each source by averaging the two items, with higher scores reflecting greater perceived credibility.

Data analysis

We used SAS Version 9.2 to generate univariate statistics (means, standard deviations, skewness, kurtosis) to characterize the sample. We then calculated descriptive

statistics for male and female patients on the key study variables (frequency of source use, perceived credibility). In order to determine whether there were differences in how often men and women used medication information sources during the past year, we ran a multivariate analysis of covariance (MANCOVA) model using PROC MIXED to determine whether there was a significant source*gender interaction. In this analysis, subject (participant) was treated as a random effect, and information source and gender were treated as fixed effects. The twelve frequency-of–source-use variables were the dependent variables, information source (e.g. doctor, pharmacist, spouse) and patient gender were treated as the primary independent variables and age, education, race (white vs. nonwhite), participant type (international vs. domestic), self-defined vasculitis type, insurance status, phase of illness and disease duration were the control variables. If the source*gender interaction term was significant ($p<0.05$), we proceeded by contrasting men and women for each of the twelve information sources. In order to contrast men and women, we created a male and female category for each source, which resulted in 24 different categories. For example, doctor (source 1) was split into two categories (g1 s1 and g2 s1) where g1= males and g2=females and s1=source 1. This procedure was repeated for each of the twelve sources; thus, our F-tests for contrasts had 2,374 degrees of freedom and were considered significant if the *p*-value was less than 0.01.

For our perceived credibility analyses, we used independent sample *t*-tests to compare men and women's ratings of six sources: doctors, pharmacists, spouses, family members, other vasculitis patients, and the Internet. We applied the Bonferroni correction to our *t*-test results; thus, individual *t*-tests were only considered significant if *p*-value was less than 0.008 (i.e., 0.05/6).

RESULTS

Sample characteristics

Twenty-one patients did not complete the baseline questionnaire. Reasons for non-completion included technical issues (n=7), being too sick (n=4) or too busy (n=3) to participate, or never responding to study correspondence (n=7). Thus, 232 of 253 eligible patients (92%) completed the questionnaire. When compared with completers, non-completers were not significantly different in terms of gender or vasculitis type; we did not have any additional variables with which to compare completers and non-completers.

Table 1 summarizes the demographic and clinical characteristics of the study sample. A majority of participants were women (69%), white (91%), married (81%) and had a diagnosis of ANCA-associated granulomatosis vasculitis (59%). On average, participants were middle-aged (mean= 51.0 years) and reported some college education (mean= 15.6 years of education). Forty-eight (21%) participants resided outside the United States. Patients had been living with vasculitis for an average of 6.5 years and 27.6% were currently experiencing a relapse or flare. Nine patients (4%) had a kidney transplant and two patients (1%) were currently on dialysis. Ninety-four percent of patients reported having health insurance.

Sources of medication information

During the past year, doctors were the most frequently used medication information source for both men (M=4.20, sd=0.9) and women (M=4.01, sd=1.1), while the Internet was the second most used source (male M=3.27, sd=1.2; female M= 3.84, sd=1.1) of information (Figure 1, Table 2). Patients also obtained medication information from medication package inserts (male M=2.94, sd=1.2; female M= 3.52, sd=1.3), but used other written materials like

books and articles (male M=2.67, sd=1.0; female M= 2.92, sd=1.2), brochures and pamphlets (male M=2.57, sd=1.0; female M= 2.87, sd=1.2), and newsletters (male M=2.55, sd=1.2; female M= 2.59, sd=1.3) less often. Support groups (male M=2.66, sd=1.3; female M= 3.05, sd=1.3) and non-physician health professionals, like nurses (male M=2.65, sd=1.2; female M= 2.14, sd=1.1) and pharmacists (male M=2.6, sd=1.3; female M= 2.78, sd=1.4) were not consulted frequently during the past year by patients. Two of the least consulted sources were non-health professionals, like family members other than the spouse (male M=1.76, sd=1.1; female M= 1.75, sd=1.0) and friends (male M=1.50, sd=0.7; female M= 1.64, sd=0.9). The spouse/partner was the third most frequently used source for men, but the absolute least used source for women (male M=3.11, sd=1.9; female M= 1.62, sd=1.1). These differences are discussed in greater detail below.

Gender differences in source use

The source*gender interaction term ($F_{[1,2374]}$ = 12.76, p<0.0001) was significant in the multivariate model, controlling for age, education, race, vasculitis type, international participant status, health insurance status, time since last relapse/flare, and disease duration. Besides a main effect for information source ($F_{[1,2374]}$ = 78.20, p<0.0001), there were no other significant variables in the model. Follow-up contrasts revealed that the largest gender difference was seen for the spouse/partner ($F_{[1,2374]}$ = 70.72, p<0.0001), with men using this source more often than women. Patients also differed in their use of the Internet, with women obtaining information from this source more often than men ($F_{[1,2374]}$ = 12.39, p<0.001). The third largest gender difference in source use was seen for medication package inserts ($F_{[1,2374]}$ = 11.70, p<0.001); women were more likely to obtain information from this source than men. Alternatively, men were more likely to consult nurses ($F_{[1,2374]}$ = 7.67, p<0.01) for

medication information than were women. We did not find any other significant differences in source utilization.

Perceived credibility of medication information sources

On a scale from one to nine, the two most credible sources for both men and women were doctors (male M=8.16, sd=1.3; female M= 7.74, sd=1.6) and the Internet (male M=7.07, sd=1.2; female M= 7.12, sd=1.5). Although not rated as highly, pharmacists (male M=6.60, sd=2.1; female M= 6.41, sd=1.7) and other vasculitis patients (male M=5.69, sd=2.1; female M= 6.57, sd=2.0) were perceived as fairly credible information sources. Men (M=4.31, sd=2.4) rated family members as the least credible source while women (M= 4.18, sd=2.4) rated them as the second least credible source. Similar to our previous finding with the source frequency variable, there was a discrepancy between men and women in terms of how credible they viewed their spouse/partner, with men rating their partners as fairly credible (M=6.10, sd=2.4) while women rated their partners as the least credible of the six sources (M=4.13, sd=2.3).

Gender differences in source credibility

The Bonferroni-corrected t-test revealed that the gender difference in spouse/partner credibility was significant ($t_{(185)}$=5.45, p<0.0001). No other significant gender differences in source credibility were found, although the t-test for other vasculitis patients trended towards significance ($t_{(174)}$=-2.52, p=0.01). In this case, women rated other vasculitis patients as more credible sources than men did.

DISCUSSION

To our knowledge, this is the first study to describe vasculitis patients' medication

information-seeking behavior. Our results revealed that, in some ways, vasculitis patients possess source preferences and credibility ratings that are similar to those of other patient groups. For example, cancer patients, like vasculitis patients, sought information most often from health care providers and the Internet (Rutten et al, 2005), with physicians rated as their most trusted information source (Hesse et al, 2005). Additionally, vasculitis patients' use of written materials, such as medication package inserts and books, mirrors that of other patient populations (Rutten et al, 2005, Huber & Cruz, 2000).

There may also be important differences in the types of sources that vasculitis patients consult when compared with other patient groups. For example, when compared to HIV (Huber & Cruz, 2000) and cancer patients (Rutten et al, 2005), vasculitis patients appear to use support groups more often and family and friends less often. Specifically, patients in our study ranked support groups as their fourth most frequently used source, while family and friends (other than the spouse) were ranked among the least used sources; other studies have found that family and friends are used more often than support groups (Huber & Cruz, 2000; Rutten et al, 2005). The fact that vasculitis is a rare disease could partially explain this finding. Whereas a high percentage of people living in the United States probably know someone with cancer or have seen a story about an HIV-positive person, it is unlikely that they know someone living with vasculitis. In the absence of family and friends who are knowledgeable about the disease, patients may view vasculitis support groups as more reliable sources of medication information.

We found that vasculitis patients may underutilize non-physician health professionals such as nurses and pharmacists for medication information. Even though patients rated pharmacists as fairly credible information sources, they were only consulted rarely to

sometimes during the past year. Nurses were consulted even less frequently, which makes sense given that most medical practices and hospitals do not have nurses specifically trained in vasculitis care. It is unclear whether patients did not use pharmacists and nurses because they obtained the medication information they needed from other sources, like doctors and the Internet, or because there were access issues, whereby it was difficult to contact nurses or pharmacists. Future studies that are qualitative in nature may help elucidate why vasculitis patients are not consulting non-physician health professionals for medication information.

We were surprised by the magnitude of the gender difference in how vasculitis patients view and use their spouse/partner as an information source. Male patients ranked their spouse/partner as their third most used and fourth most trusted source of medication information. In contrast, female patients ranked their spouse/partner as their least used (out of a list of twelve sources) and least credible (out of a list of six sources) source of information. There are several possible explanations for this finding. First, women seek more health information from more sources than men (Mayer et al, 2007; Rutten et al, 2005; Huber & Cruz, 2000). Hence, for women, the relative credibility of partners may decrease when compared with information from more objective sources such as pharmacists, written materials, and the Internet. On the other hand, if men seek information from fewer sources, then the relative credibility of their spouse may increase.

Gender roles and socialization also may explain why male and female patients have dramatically different opinions of their spouse/partner as a source of medication information. In Western societies, women often take on a nurturing role, which may make them feel responsible for the health of their family members, including partners (Gabriel, 1999). Hence, women may feel it is their duty to research multiple aspects of their partner's disease,

including its treatment. Alternatively, men are socialized to be "strong" and resistant to illness (Lee & Owens, 2002), which may make them less likely to seek medical services and information (Verbrugge, 1985). Because we did not ask participants to report their spouse/partner's gender, we cannot verify that all spouses of male patients were female.

Medication package inserts, the Internet, and nurses represent three other sources that men and women used differently. Women consulted package inserts and the Internet more often than men did, whereas men were more likely than women to consult nurses. Again, we believe the fact that women search for information from more sources than men may explain why they used package inserts and the Internet more frequently. However, we do not have an explanation for why men seek health information from nurses more frequently than women. In an effort to reduce respondent burden, we did not ask participants to rate the perceived credibility of all twelve sources. It could be that men believe nurses are more credible sources of information than women do; thus, they consult them more often. Future studies should ask participants to rate the credibility of all sources in order to determine whether credibility is the driving force behind gender differences in source use.

None of the demographic and clinical variables that we included in our multivariate model had a significant effect on how often patients' consulted different information sources. The relative homogeneity of our study sample made it difficult to assess the effect of additional moderating variables such as race, age, and education; these variables have been associated with source preferences and information seeking behavior in previous studies (Rutten et al, 2005) and should be considered as moderators in more diverse samples. Also, because we did not have many international participants (n=48), it is also possible that there are inter-country differences in information seeking that we did not have sufficient power to

capture. Moreover, information theories, such as the Comprehensive Model of Information Seeking (Johnson, 1997), can help guide researchers in the selection of other pertinent variables that may influence patients' information seeking behavior.

Because we used an online survey to collect data, the results of our study, especially findings regarding the Internet, should not be generalized to the greater vasculitis population. It is likely that non-Internet users have markedly different opinions about the credibility of Internet sources. Researchers who are interested in non-Internet using patients could employ pen-and-paper surveys or telephone interviews to capture the information source preferences of this group.

Our questionnaire asked participants to report their medication information source use during the past year. This retrospective examination of information seeking is a limitation of our study that is subject to recall bias. Longitudinal studies which examine patients' information seeking behavior over the course of their disease are a logical next step, particularly because source use has been shown to change over time (Luker et al, 1996, Rutten et al, 2005, Squiers et al, 2007). Moreover, our assertion that vasculitis patients differ from other patient groups is speculative at this point. Additional research should recruit samples of patients with different diseases to determine whether disease type truly influences information source use and preference. A comparison of a common disease, like diabetes or breast cancer, with a rare disease, like vasculitis, may be particularly enlightening.

Implications for practitioners

Vasculitis patients consult multiple sources for medication information. The number of sources that patients consult may be more limited when compared to diseases like cancer or diabetes, which makes the information provided by the physician particularly valuable to

patients. In the eyes of patients, physicians are their most credible source of medication information. However, patients also rated the Internet as a very credible source. Because medication information on the Internet is not necessarily accurate or presented in a patient-friendly manner (Thompson & Graydon, 2009), physicians may want to direct their vasculitis patients to high quality websites. Moreover, because the social networks of vasculitis patients are likely to be devoid of family and friends who are knowledgeable about vasculitis, physicians should consider referring patients to organizations like the Vasculitis Foundation, which can help guide patients to online and local support groups.

Because male patients think of their spouse/partner as a trusted source of medication information, physicians should attempt to include male patients' partners in the disease management process. Previous studies have found that partners undergo a pattern of information seeking that is comparable, if not more thorough, than the patient (Echlin & Rees, 2002). For this reason, it is particularly important that physicians and other health care professionals equip patients and their partners with accurate medication information.

Table 6.1: Participant characteristics

Characteristic	N	Mean (*SD*) or %	Skewness	Kurtosis
Socio-demographic				
Age	232	51.0 (13.5)	-0.14	-0.68
Male	232	30.6%	-	-
White	232	91.0%	-	-
Education (in years)	224	15.6 (2.9)	-0.21	1.59
International participant	230	20.9%	-	-
In committed relationship	232	81%	-	-
Disease				
Disease type	232		-	-
Wegener's Granulomatosis		59.2%		
Churg Strauss Syndrome		12.5%		
Microscopic Polyangiitis		7.7%		
Takayasu Arteritis		5.2%		
Other		15.5%		
Years with disease	232	6.5(6.1)	2.0	5.1
Clinical				
Health insurance	230	93.5%		
Kidney transplant	232	3.9%		
Currently on dialysis	230	0.8%		
Currently experiencing flare/relapse	228	27.6%		

Figure 6.1: Sources of medication information for male and female vasculitis patients during past year ($n = 232$)
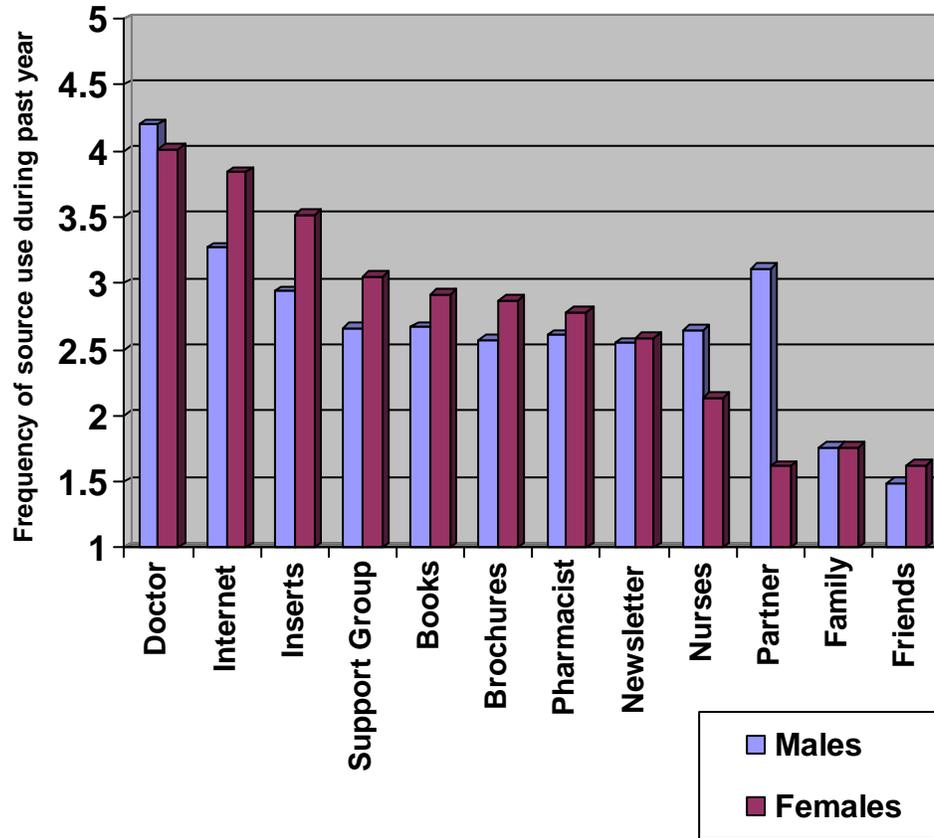
Responses ranged from 1= 'never' to 5= 'always'

Table 6.2: ANCOVA results contrasting frequency of use for male and female vasculitis patients for 12 different medication information sources

Source	Males (n=71) Mean (SD)	Females (n=159) Mean (SD)	F	P
Spouse/partner	3.11(1.9)	1.62(1.1)	70.73	<0.0001
Internet	3.27(1.2)	3.84(1.1)	12.39	<0.001
Package inserts	2.94(1.2)	3.52(1.3)	11.70	<0.001
Nurses	2.65(1.2)	2.14(1.1)	7.67	<0.01
Support groups	2.67(1.3)	3.05(1.3)	4.33	0.04
Brochures	2.57(1.0)	2.87(1.2)	3.31	0.07
Books & articles	2.67(1.0)	2.92(1.2)	2.82	0.09
Pharmacist	2.61(1.3)	2.78(1.4)	2.37	0.12
Friends	1.49(0.7)	1.64(0.9)	1.04	0.31
Doctor	4.20 (0.9)	4.01(1.1)	0.69	0.41
Newsletters	2.55(1.2)	2.59(1.3)	0.35	0.55
Family members	1.76(1.1)	1.75(1.0)	0.22	0.58

Responses ranged from 1= 'never' to 5= 'always'

Figure 6.2: Perceived credibility ratings of six sources for male and female vasculitis patients

(*n*=232)
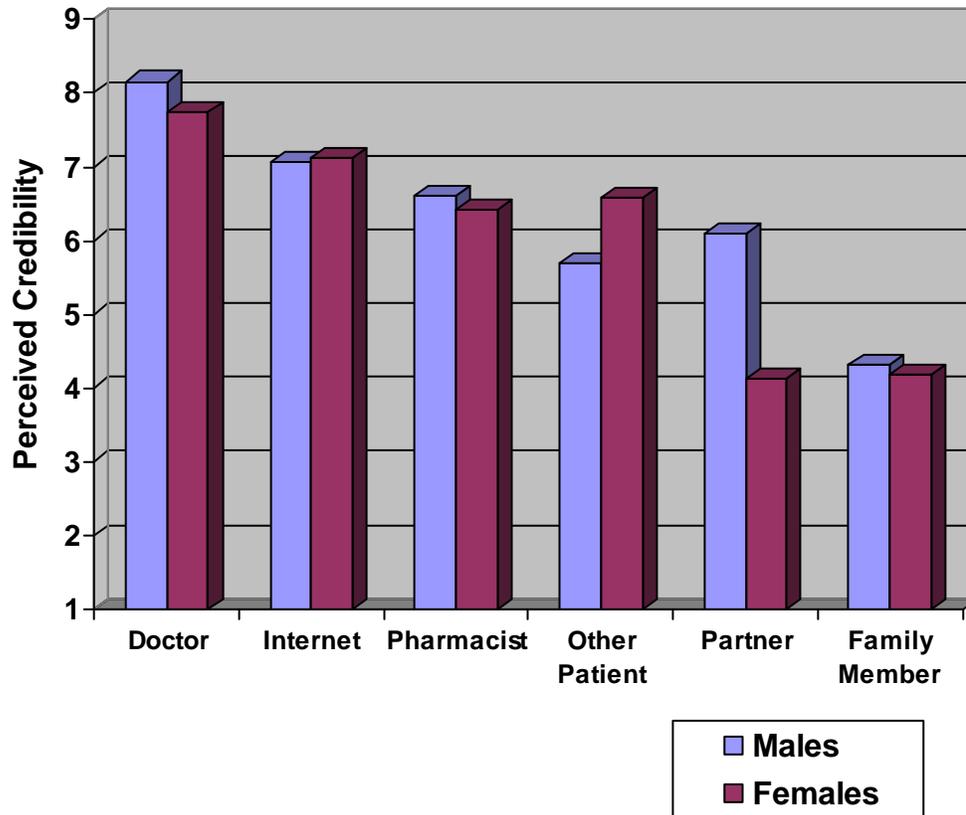
CHAPTER SEVEN: SUMMARY AND DISCUSSION

7.1 Summary of Findings

In summary, my hypotheses regarding the effects of conflicting information and the information seeking behavior of vasculitis patients were partially supported. Table 7.1 summarizes the results for each research question. For the first research question, I correctly hypothesized that a majority of patients would report receiving conflicting information; 51.3% of patients received conflicting information about at least one aspect of their medications. As described in Chapter 5, the percentage of patients receiving conflicting information varied considerably (16.6% to 35.5%) depending on the specific medication topic. Patients were most likely to receive conflicting information about the severity of medication side effects (35.5%) and treatment duration (30.7%) and were least likely to receive conflicting information about how to take their medications correctly (16.6%).

The second research question, which was addressed in Chapter 5, explored the relationships between conflicting information, adherence support, adherence self-efficacy, outcome expectations for medications, and medication adherence. The first hypothesis was not supported; adherence self-efficacy did not mediate the effect of conflicting information on medication adherence. Instead, conflicting information had a direct positive association with nonadherence such that patients who received more conflicting information were more nonadherent than patients who received less conflicting information. In contrast, the second

hypothesis was supported; adherence self-efficacy did mediate the effect of adherence

support on medication adherence. Specifically, more support from the physician increased

patient self-efficacy, which in turn decreased nonadherence.

Similar to the first hypothesis for research question #2, the hypothesis for research

question #3 also was incorrect; outcome expectations for medications did not mediate the

relationship between conflicting information and medication adherence. The relationship

between outcome expectations and adherence support from the physician also was

insignificant.

As hypothesized in research question #4, there was a strong positive relationship

between adherence self-efficacy and medication adherence. In fact, this relationship

remained significant even after controlling for patient demographic and clinical

characteristics such as age, gender, race, education, and time since last flare. This finding

was unsurprising given the extensive literature base that has documented a positive

relationship between self-efficacy and health-promoting behaviors (Marks et al, 2005;Brus,

1999; Burge, 2005; Lorig et al, 1989; Lorig & Holman, 1993).

In contrast to our hypothesis for research question #5, outcome expectations were

significantly *positively* correlated with medication nonadherence, meaning that patients with

more positive outcome expectations for medications were more *nonadherent*. Chapter 5

addresses some of the possible reasons I found a significant relationship that was in the

opposite direction of what was hypothesized.

Chapter 6 presents the results for the remaining three research questions, which

focused on the information-seeking behaviors of vasculitis patients during the past year. The

hypotheses for research question #6 were partially supported; the physician was the primary

source of medication information for patients. However, the Internet, not the pharmacist, was the second most commonly used information source. Although I hypothesized that patients would frequently consult pharmacists because they are "professional" sources of medication information, patients only consulted them rarely to sometimes during the past year. Contrary to my expectations, other patients with vasculitis (in the form of support groups) were fairly frequently used sources of medication information for patients. Family members, on the other hand, were not commonly consulted sources for medication information, which was in line with my hypothesis. Last, I posited that patients would not use their spouses often as sources of medication information. This hypothesis was partially supported because female patients rated their spouse as their least used information source. However, male patients rated their spouse as their third most used information source. Because of the magnitude of this gender difference, it is unproductive to discuss spouses as information sources in a global manner.

The hypotheses for the seventh research question regarding perceived credibility also were partially supported by the study data. Patients rated physicians as their most trusted source for medication information followed by the Internet. I had speculated that pharmacists also would be rated as a highly credible source; however, patients rated them at approximately the same credibility level as other vasculitis patients, around 6.5 on a 9-point scale. As expected, family members other than the spouse were rated among the least credible sources of medication information. Male and female patients differed in their perceptions of spouse credibility, with male patients rating their spouse as fairly credible and female patients rating them as the least credible of six sources. Again, the magnitude of this difference limits the ability to discuss an overall result for spouse credibility.

The eighth and final research question explored gender differences in information

source use. As alluded to earlier, there were substantial differences in which sources male

and female vasculitis patients consulted. I hypothesized that female patients would obtain

medication information more frequently than male patients. Moreover, I posited that females

would consult their family and friends for medication information more often than males.

Indeed, female patients used eight of the twelve information sources more frequently than

male patients. However, only two source differences were statistically significant, with

women obtaining information from the Internet and medication package inserts more than

men. Contrary to my hypothesis, women did not use family and friends as information

sources more often than men. Unexpectedly, men consulted their spouses and nurses more

frequently than women. However, it was the magnitude of the gender difference in spouse

use that was most striking, with men using their spouse as an information source much more

frequently than women.

Table 7.1: Support for research questions and hypotheses

RQ	Hypothesis	Support for Hypotheses
Specific aim #1		
RQ$_1$	H$_{1.1}$: A majority of patients will report receiving conflicting information about some aspect of their vasculitis medications.	Supported
Specific aim #2		
RQ$_2$	H$_{2.1}$: Adherence self-efficacy will partially mediate the relationship between conflicting information and medication nonadherence such that receipt of conflicting information will decrease adherence self-efficacy which, in turn, will increase medication nonadherence.	Partially supported Adherence self-efficacy mediated the relationship between social support and medication nonadherence
	H$_{2.2}$: Adherence self-efficacy will partially mediate the relationship between adherence support and medication nonadherence such that more adherence support will increase self-efficacy which, in turn, will decrease medication nonadherence.	

RQ	Hypothesis	Support for Hypotheses
RQ$_3$	H$_{3.1}$: Outcome expectations will partially mediate the relationship between conflicting information and medication nonadherence such that receipt of conflicting information will lead to less positive outcome expectations for medication which, in turn, will increase medication nonadherence.	Not supported
	H$_{3.2}$: Outcome expectations will partially mediate the relationship between adherence support and medication nonadherence such that receipt of adherence support will lead to more positive outcome expectations for medication which, in turn, will decrease medication nonadherence.	
RQ$_4$	H$_{4.1}$: Adherence self-efficacy will be significantly, negatively associated with medication nondherence for vasculitis patients.	Supported
RQ$_5$	H$_{5.1}$: Outcome expectations will be significantly, negatively associated with medication nondherence for vasculitis patients.	Not supported Outcome expectations were positively associated with nonadherence
Specific aim #3		
RQ$_6$	H$_{6.1}$: The physician will be the primary source of medication information followed by the pharmacist and the Internet.	Partially supported The physician and the Internet were frequently used sources and family members were not.
	H$_{6.2}$: The spouse/partner, family member, and person living with vasculitis will not be major sources of medication information for patients.	
Specific aim #4		
RQ$_7$	H$_{7.1}$: Physicians and pharmacists will be perceived as the most credible sources of medication information followed by the Internet, persons living with vasculitis, spouses/partners, and family members.	Partially supported The physician was perceived as the most credible source.
Specific aim #5		
RQ$_8$	H$_{8.1}$: Female patients will obtain medication information more frequently than male patients.	Partially supported Women obtained medication information more frequently than men.
	H$_{7.2}$: Female patients will use family and friends as medication information sources more often than male patients.	

7.2 Implications

Medication nonadherence is associated with negative sequelae, including more vasculitic flares, increased health care costs, and patient death (Puechal, 2007; Cotch, 2000). Because conflicting medication information negatively impacts patients' medication adherence, it should be targeted for public health intervention.

7.2.1 Intervention implications

The major implications from this study concern how to deliver information about vasculitis medications. Physicians are the most trusted and used sources of medication information for vasculitis patients, making them the ideal health professionals to discuss medications with patients. In-depth physician-patient discussions about medications as well as high quality secondary information sources would have the double benefit of increasing patients' perceptions of doctor support, which increases self-efficacy, as well as reducing patients' opportunity to encounter information that is at odds with physician recommendations.

Unfortunately, given the time constraints and range of topics that must be covered during a typical office visit, it may be unreasonable to ask physicians to spend additional clinical time discussing medication issues with patients. Instead, ancillary materials about vasculitis medications could be developed to assist patients and physicians in having productive discussions about medication issues. Moreover, relevant and accurate materials about medications may increase patient's self-efficacy and reduce anxiety about side effects, ultimately reducing the amount of time that patients wish to discuss medications with their physicians. Alternatively, other medical staff, such as nurses, could be made responsible for discussing medications with patients and directing them to high quality secondary sources.

7.2.1.1 Identification of high quality medication information sources

Because patients consult multiple sources for vasculitis medication information, it is important to identify secondary information sources beyond the physician that are accurate and user-friendly. Identifying high quality medication websites should be a first priority because patients use and trust Internet sources almost as much as their physicians. A panel consisting of vasculitis experts, including physicians, nurses, and pharmacists as well as patient advocates could convene to rate the quality of existing medication websites. Once the panel reaches consensus about which websites are best, the URLs of these websites should be distributed to health care professionals who work with vasculitis patients, nonprofit organizations like the Vasculitis Foundation, and vasculitis patient listservs. A similar method has been used previously to identify high quality websites for methotrexate information and could be used as a benchmark by the expert panel (Thompson & Graydon, 2009).

Alternatively, if the panel does not identify any suitable websites for vasculitis medication information, then a new website may need to be created. Ideally, this website would contain information about each vasculitis medication, including how to take and store medications properly as well as the medications' side effects. Patients may be particularly interested in actions they can take to minimize the impact of side effects; a discussion forum in which health care professionals respond to patients' questions may be an effective way to address patients' concerns. Moreover, to enhance comprehension of the website's content, it should be visually appealing and contain text that is written at or below a sixth-grade reading level.

In addition to websites, written materials about vasculitis medications, their side

effects, and how to cope with side effects should be developed. These materials probably would be most beneficial for patients who do not have access to a computer or the Internet. The same expert panel could identify existing written materials that are appropriate, and if need be, recommend that new materials specific to vasculitis medications be developed. Again, these materials should be visually appealing and written at or below a sixth grade reading level. The Vasculitis Foundation could distribute these written materials as part of their new patient education packet.

Pending additional research that confirms that other health care professionals, like pharmacists and nurses, are accurate and reliable sources of vasculitis medication information, additional materials should be developed to direct patients to these under-utilized sources. As noted in Chapter 6, pharmacists are viewed as fairly knowledgeable sources of medication information, yet patients do not consult them often. Educational resources that describe how to initiate conversations with pharmacists and nurses may help patients make use of these professional health resources.

7.2.1.2 Development of materials about conflicting information

Because more than half of vasculitis patients reported receiving conflicting medication information, educational materials addressing this topic are warranted. Patients were most likely to receive conflicting information about side effects, which may reflect that this is the topic they research the most. Even though patients' outcome expectations for their vasculitis medications were high (i.e. they believed that their medications were essential for their health), these medications are also associated with severe side effects. Experiencing side effects coupled with receiving conflicting information about side effects may have an additive or multiplicative negative impact on medication adherence. Thus, tips about how to

handle conflicting side effect information may be especially salient to patients. Again, a panel of health professionals, health educators, and patients may need to convene to identify what the best methods are for resolving conflicting information. I would speculate that discussing conflicting information with the primary vasculitis physician would be the method that is most appealing to patients.

7.2.1.3 Development of targeted educational materials

As discussed in Chapter 6, male and female vasculitis patients exhibit different patterns of information seeking. Thus, educational materials about medications may be more useful to patients if they are specifically targeted for men and women. Because female patients cast a wider net when seeking information about medications, their materials should cover a broad range of sources, including where to find the most reliable written and web-based medication information. Women may also find guidelines for interpreting medication package insert information useful because they consult this source frequently. An additional section entitled "top five medication-related questions to ask your doctor" may assist women with obtaining the important information they need from their physicians. Moreover, because male patients often rely on their spouses for medication information, it may be important to direct female spouses to high quality information sources. These materials could contain sections about where to locate accurate medication information and ways to share this information with a spouse.

Materials targeted towards men should also contain information about how to effectively communicate with physicians as well as where and how to locate reliable medication information on the Internet. Unlike materials for female patients, male-focused materials should contain a section about how to involve their spouse in information searches.

For example, they could schedule 30 minutes to sit down as a couple to look for information on the Internet or go to the bookstore to find relevant books. This may encourage men to take a more active role in information seeking specifically and their own disease management more generally.

7.2.1.4 Educating patients about how to assess information quality

Teaching patients how to evaluate information sources represents a third intervention option, although this may be more time consuming and cost intensive than the intervention options discussed previously. There are many dimensions to assess when evaluating the quality of educational materials, which could seem like a daunting task for patients. At a minimum, vasculitis websites could add a webpage that lists the main criteria to assess when obtaining information from the Internet. Thompson and Graydon (2009) developed criteria for evaluating the quality of methotrexate websites; their criteria could be adapted for application for vasculitis medications. If a more intensive intervention is desired, a health educator could hold a seminar (in-person or online) about evaluating the quality and usefulness of medication information materials.

7.2.2 Practice and policy implications

It is possible that the presence of disparate medication information reflects best practice issues. Patients may receive conflicting information from multiple health care providers because there is a lack of consensus among professionals about what medications are best to use and the types of side effects associated with these medications. Other studies have found that professional resources contain discrepancies about how to taper rheumatic medications (Vidal et al, 2005). Physicians who are not associated with institutions that conduct vasculitis research, like UNC and the Cleveland Clinic, may have greater difficulty

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selecting a course of treatment for vasculitis patients if they encounter discrepancies in professional resources. Thus, these physicians may defer to an outdated source and recommend treatment options that would not be considered at more established vasculitis clinics that are more up-to-date with current vasculitis research. In these cases, patients of a general practice physician may visit the Cleveland Clinic website, for example, when searching for information and wonder why their doctor prescribed a course of therapy that was not recommended by the experts at Cleveland Clinic. This may lead the patient to question and be less adherent to his/her physician's recommendations.

For these reasons, medication treatment guidelines specific to vasculitis patients should be developed in order to help standardize medication usage. Vasculitis experts have already met to establish criteria for patient classification (Jenette et al, 1994), so creating uniform treatment guidelines is a logical next step. Although establishing treatment guidelines is a gargantuan task, it would reduce ambiguity related to proper vasculitis treatment for physicians who are unfamiliar with the disease. It is important that these guidelines are readily available to all physicians because it is financially unreasonable for many patients to obtain treatment at practices that specialize in vasculitis.

Alternatively, a quality label could be created to inform patients that a particular information source meets minimum credibility standards. Not unlike healthy food labels, this label could be branded and placed on high quality products. This would enable physicians and patients to quickly identify which information sources are credible and which are not. Unfortunately, a massive media campaign would need to be launched in order to educate health care providers and patients about the quality label. This would cost millions of dollars; therefore, it is probably only feasible if the quality label is applied to information sources for

other more common diseases, like arthritis, diabetes, and cancer.

7.2.3 Implications for health behavior theory

A major assumption that motivated this study was that information is a complex construct that can be conceptualized as more than factual knowledge. The results from this dissertation suggest that vasculitis patients do not view all information sources as equally credible and that conflicting information directly influences behavior. Thus, possessing factually correct information may not be as important for behavior when patients encounter conflicting information. Moreover, because conflicting information did not affect self-efficacy, it may work through theoretical pathways that are different than factual knowledge.

If additional research replicates the findings discussed in Chapter 5, then theories that incorporate an information construct, like the IMB model, may want to refine how they define information. The most persuasive rationale for this change is that one cannot assume that all information is equal in the eyes of patients, especially when they are presented with conflicting information.

Instead of attempting to create new theories that incorporate a conflicting information construct, researchers should draw upon what is known from economic, information seeking, and risk communication theories. Specifically, integrating determinants of information seeking (from the information seeking literature) with a deeper understanding of how patients process conflicting information (from the economic literature) may result in a more holistic understanding of the interplay between information and immediate psychological outcomes. Last, drawing from health behavior theories, the immediate psychological outcomes could be linked with behavioral outcomes, like medication adherence. As discussed in Chapter 5, the Cognitive-Social Health Information Processing (C-SHIP) model may be a particularly

useful starting point for better understanding the outcomes of receiving conflicting

information (Miller et al, 1996).

7.3 Study Limitations and Strengths

This dissertation possesses several limitations, some of which have been discussed in

Chapters 5 and 6. Namely, the medication adherence measure only captures intentional and

erratic nonadherence (Schlenk, 2001). Because patients may have been unintentionally

nonadherent, it is likely that the true nonadherence rate was higher than what respondents

reported. In this case, the relationship between receiving conflicting information and

medication adherence is likely biased towards the null. Moreover, our self-report measure is

also subject to recall bias, so our adherence rate also may be underestimated if patients forgot

specific instances of incorrect medication-taking behavior during the past month. Previous

studies (Treharne et al, 2006) have found that self-reported medication adherence is usually

higher than more objective measures of adherence. Although alternative methods of

measuring medication adherence exist (e.g. electronic pill bottles), they may not be well-

suited for vasculitis patients who often take injected medications.

Recall bias also is a limitation of the conflicting information measure, which asks

patients to indicate whether they have *ever* received conflicting information about six aspects

of their vasculitis medicines. Some patients in our sample have been living with vasculitis for

over 30 years, which may make it difficult to remember specific instances in which they

received conflicting information. In anticipation of this issue, we included a "don't

remember" response option for patients, of which 14.9% chose this option. Because we

cannot confirm whether patients over or underreported conflicting information, it is difficult

to know whether our estimates of the relationship between conflicting information and self-

efficacy and medication adherence are over or underestimated.

Additionally, conflicting information received several years ago is probably not as salient as recently received conflicting information in terms of self-efficacy and medication adherence. These limitations could be addressed by designing a study in which patients' information seeking behavior is tracked prospectively over a several month period after receiving a new prescription.

Second, the use of a convenience sample limits the study's external validity. Results cannot be generalized to the greater vasculitis population because our recruitment criteria (having access to a computer and time to take the survey) likely resulted in an unusually well-educated and affluent sample. Additionally, participants may possess health characteristics that are unlike other vasculitis patients. For example, unhealthy patients probably self-selected out of the study because they did not feel well enough to complete an hour-long survey. Although it is important to note that 28.4% patients reported currently experiencing a flare, so the healthy participant bias may not be extremely influential in our sample.

Third, I included two newly-developed measures for which validity and reliability have not been established: conflicting information and adherence support. Chapter 4 describes the results from the reliability and validity analyses. In summary, both measures resulted in one-factor solutions and internal consistency was acceptable (0.75-0.80). More rigorous tests of these measures' properties, including establishing test-retest reliability and construct validity, would further reinforce that these measures are psychometrically sound. Unfortunately, a "gold standard" measure of conflicting information does not exist, which means that we cannot test for criterion-related validity.

A fourth limitation concerns the three-month time interval between the baseline and follow-up questionnaire. Because the psychological timeline between receiving conflicting information and patient outcomes has not been established, there is no evidence that three months is an adequate amount of time to allow the independent variable (conflicting information) to work through the mediating variable (self-efficacy) to affect the dependent variable (medication adherence). Moreover, it is possible that patients experience greater anxiety and lower self-efficacy closer to the time of receiving conflicting information. Thus, a three-month interval may be too long to examine the effects of receiving conflicting information. This limitation is difficult to address; lab-based studies may be a first step for determining how long it takes patients to process conflicting information and whether this results in immediate psychological outcomes, like increased anxiety.

Last, although this study was longitudinal in nature, temporality is not sufficient to prove causality. However, it is unlikely that having a high level of medication adherence results in receiving conflicting information. To address the issue of causality, I could control for baseline levels of medication adherence in my statistical model. If conflicting information continues to predict medication adherence after controlling for baseline adherence, that would reinforce that conflicting information is causally related to medication adherence. Moreover, collecting data at additional time points (6-month and 12-month follow-up) would help establish whether the effects of conflicting information persist over time.

Despite its limitations, this dissertation also possesses several strengths. The overall response rates at Time 1 and Time 2 were good, 91.7% and 98.2%, respectively, which means that attrition probably did not affect the study results. Also, even though causality cannot be established, collecting data at two time points (baseline and 3-month follow-up)

establishes a temporal order between conflicting information and medication adherence. A third strength is that the study's conceptual model is based upon a theoretical model (the Information-Motivation-Behavioral Skills model). Additionally, the final sample size of 228 provided enough power to detect significant relationships between the study variables (Cohen, 1992). Last, our statistical methods were well-suited to the research questions; the innovative bootstrapping technique produced estimates and confidence intervals for each indirect effect so that we could test the significance of multiple mediators (Preacher & Hayes, 2008).

7.4 Directions for Future Research

This dissertation provided answers to several questions regarding the receipt of conflicting information and the information seeking behavior of vasculitis patients. However, these answers lead to more questions, particularly about other psychological and behavioral outcomes that may result from receiving conflicting information. I believe that this dissertation points to three main areas for future research: 1) qualitative and lab research that focuses on the psychological outcomes of receiving conflicting information, 2) additional survey research that determines whether conflicting information is encountered by patients with other diseases and whether this affects other health behaviors, and 3) intervention research aimed at reducing the amount of conflicting information in the public domain.

7.4.1 Qualitative research

At this point, it is unclear how patients resolve situations in which they encounter conflicting medication information. They may defer to their most trusted source, which is likely to be a physician, or develop some type of hybrid medication-taking behavior that incorporates recommendations from multiple sources. Qualitative research that explores

patients' reactions to conflicting information is a logical first step to answering these questions. Because reactions to conflicting information may be highly individualized, one-to-one interviews, as opposed to focus groups, are probably the best method for assessing patient reactions.

7.4.2 Lab-based research

Simultaneous to qualitative research, researchers could conduct lab-based studies that focus on patients' reactions to conflicting information. Previous research from the fields of economics and risk communication offer insight into the mental processes that occur when conflicting information is received. For example, Han and colleagues (2006) found that conflicting information leads to greater ambiguity and that patients often attempt to avoid ambiguity. Another study by Cameron (2005) demonstrated that people are prone to revert to their original beliefs if they encounter conflicting information. Cameron's study is particularly intriguing because she developed mathematical formulas to determine how people process conflicting information. This lab-based study could be adapted from the economic setting to the public health setting. Specifically, we could mathematically test whether patients resort to Bayesian updating, alarmist learning, or ambiguity avoidance when conflicting information is encountered. Furthermore, we could alter the experiment in order to determine whether there is a dose-response relationship between conflicting information and medication adherence.

7.4.3 Survey research

There are several high priority areas for future survey research about conflicting information; some have been discussed previously in Chapters 5 and 6. First, future studies should determine whether patients receive conflicting information in other self-management

domains and how this affects their self-efficacy and self-management behavior. A previous study (Thorpe, 2006) found that vasculitis patients were most adherent to their medications and were less adherent to physician recommendations for symptom monitoring, exercise, and dietary adjustments. Conflicting information may contribute to patients' nonadherence in these other areas of self-management. Future surveys should specifically determine where patients obtain information about proper diet and exercise, for example, and how much conflicting information they have received about these topics.

Second, researchers should determine whether conflicting information is an issue for other disease populations. It is likely that patients with more common chronic illnesses encounter greater amounts of conflicting medication information, which may enhance the negative impact of conflicting information on patient behavior, particularly if a dose-response relationship between conflicting information and behavior exists. Family, friends, and media sources are viewed as credible sources of self-management information for patients living with diseases such as cancer and HIV (Huber & Cruz, 2000; Sleath et al, 2003, Rutten et al, 2005). These additional sources, which are not commonly available to vasculitis patients, may be more likely to offer advice about medications that is in conflict with physician recommendations. Online surveys offer a cost-effective method for assessing the impact of conflicting information in these populations.

Last, researchers should use pen-and-paper or telephone surveys to assess the information seeking behaviors of patients who do not use the Internet. Non-Internet using patients may demonstrate significantly different patterns of information seeking than their Internet-using counterparts. It is possible that patients who do not use the Internet are less likely to encounter conflicting information. On the other hand, patients who do not seek

information online may be more likely to use other vasculitis patients as information resources. Given the variability in treatment between vasculitis patients, non-Internet using patients may be even more likely to encounter conflicting information.

7.4.4 Intervention research

In an ideal world, a substantial research base about the determinants and effects of conflicting information would be established before conducting intervention research. However, with the increasing focus on translational research and preliminary data that suggest that between one-fifth and one-fourth of patients receive conflicting information (Coleman et al, 2005), some effort should be invested in developing intervention materials that address this issue. Intervention implications are discussed more thoroughly in section 7.2.1 of this chapter.

7.5 Conclusion

This is the first study to examine the information seeking behavior of vasculitis patients. A majority of patients in our sample (51.3%) received conflicting medication information, and patients who received greater amounts of conflicting information were less adherent to their medications than patients who received less conflicting information. This finding underscores the importance of reducing the amount of conflicting information available in the public domain. There are several intervention strategies that could counteract the negative effect of conflicting information on medication adherence. Encouraging patient-provider communication about conflicting information represents a potentially effective intervention option because it may increase patients' perceptions of doctor support. In our sample, higher levels of doctor support were associated with greater adherence self-efficacy. Thus, in addition to reducing the direct negative effect of conflicting information on

medication adherence, more patient-provider communication may also increase patients' confidence to take medications correctly.

Additionally, educational materials should be developed that address patients' concerns about medications in addition to directing them to high quality information sources. Because male and female patients exhibited different patterns of information seeking, with male patients using their spouses much more often than female patients, materials targeted by gender may be particularly useful to married patients. Taken together, these results highlight the complexity of the relationship between information and behavior; a complexity that is not adequately accounted for in current health behavior theories and models. Future research should attempt to uncover the determinants and outcomes, both immediate and distal, of receiving conflicting information and explore whether conflicting information is an issue for other disease populations.

APPENDIX A:
PHASE I INTERVIEW GUIDE

Interview Questions

1. Studies with cancer and arthritis patients show that people get medication information from different sources, like their doctors, pharmacists, family, friends, and the Internet. Where do you get information about your vasculitis medicines?

[Probe the following sources: doctor, pharmacist, medicine leaflet/insert, Internet, spouse, family member, friends, vasculitis support group member]

2. Why do you use those sources?

3. Have you ever found out something new about your vasculitis medicines on the Internet?

4. Some people with other diseases, like diabetes, have reported receiving conflicting information from different people about their medicines. Overall, how consistent is all the information you get about your vasculitis medicines? For example, does the medicine information you get from your doctor, pharmacist, and Internet all match up exactly?

5. Please describe a time when you were presented with conflicting information about your vasculitis medicines and how you handled that.

6. If any of the situations have ever happened to you, please describe how you handled them:
   a) You experienced a side effect that you didn't know was associated with your vasculitis medicine
   b) Your vasculitis medicine side effects were more severe than you expected
   c) You had an unexpected drug interaction
   d) Your vasculitis medicine was more or less effective than you expected
   e) Someone suggested that you take your vasculitis medicine differently than prescribed
   f) Someone suggested you try a new medicine or treatment (either complementary/alternative/holistic or from a clinical trial)
   g) You found out that your vasculitis medicine cost more or less than you expected
   h) Have you ever had to change how you were taking your vasculitis medications to better meet your needs?
   i) Which source of medication information do you trust the most and why?
   j) Which source of medication information is easiest to understand?

Thank you so much for having this discussion with me. This was a very enlightening conversation and what you told me will be very helpful as I develop the vasculitis questionnaire. Do you have any questions or other comments?

APPENDIX B:
INTERVIEW TRANSCRIPTS

_____

Q: The first question is about where you get information about your vasculitis medicines. Studies with cancer and arthritis patients show that people get medication information from different sources like doctors, pharmacists, family, friends and the Internet. Where do you get your information?

A: From my doctor, from Internet sources – trusted ones, not ones that are not reliable. I go to WebMD, NIH sites, that kind of thing. But I get a lot of it from the little inserts when you get your drugs at the pharmacy. So I use that, especially if I'm looking for side effects, if I'm having one, or if it's a flare or whatever.

I guess also I get some information from other patients. People invariably ask, "Oh, what are you taking?" And, "Oh, well, I'm taking this." "Oh, really? Well, how is that working for you?" type of thing. I get calls a lot to talk with patients who are going to get [Rituxan] or who are thinking about CellCept, like it was _____ medicine from the Vasculitis Foundation.

Q: Those are actually some of the sources that have come up also with arthritis and cancer patients. Another thing that comes up is that people often give information to the patient even though they're not looking for it. Has anyone like a spouse or family member or friend offered information to you about your medications?

A: Oh, yes. [*Laughs.*]

Q: What kind of information do they offer you?

A: Cautionary, or, "Oh, I just read this study about...", or, "Oh, you're having that _____, well, is it the new drug you're trying?" I don't often get horror stories, so that's a good thing. But most of it, I think, is cautionary and, oh, have you heard about this, or did you read that.

Q: Okay, so you're actually getting medication information from a lot of different sources.

A: Yeah.

Q: But the one that you actively seek out are from the Internet and the medication inserts?

A: Yeah.

Q: And then you receive information from people like your doctor and other

patients.

A: Yeah.

Q: Okay. Why do you use the Internet and the medication insert information as a source of medication information?

A: Well, I want to see the possible side effects because this disease is so weird. You can have symptoms, and is this a flare, is this a drug reaction; what is it? So I want to have as much information as I can about the drugs that I'm taking. Very rarely have I consulted the pharmacist. I can count on the fingers of one hand how many times I've talked to the pharmacist about drugs.

Because I get all my drugs at one place, they check for interactions, and then [Ron] and [Brent, Sr.] are always looking at my chart to make sure that things are not overlapping. So I guess mostly to see information about side effects. And if I'm starting a new drug, or one that hasn't been tried a whole lot with me or a bunch of people, I just want to know sort of what the drug kind of looks like, what the profile is, any studies that they've done with it; that kind of thing.

Q: Okay. Overall are you just supplementing the information that you get from your doctor with these sources?

A: Yes.

Q: Okay. Are you ever able to use the information that you get from other sources like the friends and the family members and the spouse? Is that useful for you?

A: Not always. I think my primary are my doctors, the Internet and the drug inserts.

Q: Have you ever found out something new about your vasculitis medicines on the Internet? Something that wasn't told to you by your doctor?

A: I'm just going through the medicines I've taken… I don't think I have.

Q: Okay. So no surprising information or side effects that you didn't already know about?

A: No, I don't…I'm just trying to think, because I've been on CellCept for a while. Maybe once or twice, but very rarely. And it's not something awful, it's just oh, okay.

Q: Just additional information?

A: Yeah.

Q: Some people with other diseases like diabetes have reported receiving conflicting information from different people about their medicine. Overall, how consistent is the information that you get about your vasculitis medications from all sources?

A: It's pretty consistent. I don't think I've had a lot of conflicting information.

Q: Okay. If you have received conflicting information, is that more likely to come from a particular source?

A: Well, there was instance when I had…and it wasn't really conflicting information, it was more just in terms of when you take this medicine, because it was more than seven years ago, and I was on a bunch of medicines, and he tried to time everything out, you know, don't take with food, or lalala, and it was just getting really stupid. And some of my doctors, like my ENT doctor, said, "Just take it with your meal and you will get the benefit of the drug; it'll just take longer to do that." So it was sort of like, okay, all right, I will do that. But that's really the only time.

Q: I'm going to ask you about a list of situations that might have happened to you and how you handled them.

A: Okay.

Q: You experienced a side effect that you didn't know was associated with your vasculitis medicine.

A: Yes. Early on. The steroids. I didn't realize that they could make you quite as – [*laughs*] – unusual as you get when you're on a bunch of them.

Q: You mean, like the mood swings, or…?

A: Well, yes. Mood swings and sleeplessness. I thought I was just stressed because of the illness, and then I realized that it's not that, it's the side effects.

Q: And how did you realize that that was coming from the medications?

A: I did some reading on it.

Q: Oh, okay. So from your supplemental reading that you were doing?

A: Yes.

Q: How did you handle that information once you found out it was coming from the steroids?

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A: The one thing I switched when I took the medicine, I have a plan now that I use so that I know when I'm on a bunch of steroids that I take half to two-thirds early in the day and then the rest with my lunch, and then I'm not having any at night so that I can sleep.

Q: How did you come to the conclusion that this was what you needed to do? Is that something you discussed with your doctor or did you figure that out on your own?

A: I think I figured that out on my own.

Q: Okay. And then for a second situation you might have experienced, your medicine's side effects were more severe than you expected. Has that happened?

A: Yes.

Q: And how did you handle that?

A: Well, one of those drugs that you were not supposed to take with food, and I did, and I just threw up within ten minutes after breakfast. And I was on the floor in the kitchen, literally. It just knocked me flat. I was like, oh, my God, and then I went back and looked at the drug, and it was not "do not take this with food," it was two different types of drugs, don't take this drug within two hours of taking a drug that has this other thing.

And I didn't realize that they were that way, they were incompatible. And then I did it and I was just violently ill. So I called my doctor and I said, "What's going on?" I said I took this pill and he said, oh, well, that's the [symptom]. Oh, okay, so didn't do that again.

Q: Okay. That actually is the third situation – you had an unexpected drug interaction. But you handled that by calling your doctor?

A: Yeah.

Q: Okay. Have you ever experienced a situation where your vasculitis medicine was more or less effective than you expected?

A: Well, dosing is always an interesting issue. With CellCept, for me, if I take more than a thousand milligrams, I start to have GI problems. And we found that out by giving me 1,250, and I just couldn't do it, so we had to back down to 1,000.

Q: That was something that you handled together with your doctor?

A: Yeah.

Q: Okay. Did you do that during an appointment or did you call?

A: I think I emailed him.

Q: Oh, okay. Have you ever had a situation where someone suggested that you take your vasculitis medicine differently than it was prescribed?

A: No.

Q: Okay. Has someone suggested to you to try a new medicine or treatment, either an alternative or holistic medicine or suggest that you join a clinical trial?

A: You mean a clinical trial in the complementary medicine?

Q: Or just a new medicine.

A: Oh, yeah. I've been in a clinical trial.

Q: Who suggested that you join the clinical trial?

A: Patrick [Dockman].

Q: Oh, okay, your doctor?

A: Yeah, doctors.

Q: And you determined together with your doctors that this was a good fit?

A: Uh-huh.

Q: Have you heard from other patients or friends that there are new trials that you didn't hear about through your doctor or through reading Internet web sites?

A: Most of the clinical trials that are happening I hear about either through my doctor or through the Vasculitis Foundation – information newsletter, web site. I'm probably closer to the sources than…

Q: Most people, yes. Have you ever looked up information about alternative medicines or holistic treatments for vasculitis?

A: Ron suggested that I have massages, which I do. I had a facial nerve paralysis as a result of the vasculitis, and I had read that people with strokes benefited from acupuncture, and I figured this was like a stroke, and so I went to see an

acupuncturist. And what I got back of my face came back very quickly.

I didn't hear this information with my doctors. But it was an intense treatment for that, two and a half months, and after that I stopped. But the sensation and movement that I have back, my doctors say, gosh, you're healing a little faster than we thought. And I said, "Yeah, I am." And afterwards, of course, I told him, and he said, well, that was probably a good idea. [*Laughs.*]

Q: Oh, okay. So the doctor didn't initially suggest that you do it?

A: No.

Q: You read about it and then you tried it out and then it worked well for you?

A: Yeah.

Q: And then when they were curious about how well you were recovering, then…?

A: Yes. I'm also a bit of a medical pilgrim. I've tried a lot of things. Most of them I have told Ron about. I went to a healing service at a church. I went to see a Tibetan doctor, I guess, for lack of a better word. That was an unusual experience, for him and for me. The acupuncture. I also went to see a nutritionist who had a background in pharmacology to see if there were dietary supplements that would boost my energy, just help me have a more normal lifestyle, and that was very helpful.

Q: When you're looking through at these different treatments, where are you usually finding this information?

A: Because of things that I've heard that cancer patients use. I work at a cancer center, so I'm exposed to a lot of information about complementary medicines. I don't believe in alternative medicines. I think you need to go with the medicines that you're prescribed, and I wouldn't stop taking those. But if there's something that can help me maintain a more normal lifestyle or have more energy, then I'm all in favor. I guess I had read about those in studies. I just saw was [Jean] was doing with some of our cancer patients and I thought this might be helpful to me, so I made an appointment to go see him.

Q: You believe you were getting them from pretty credible sources if it was coming from studies?

A: Yeah.

Q: In the last situation that might have happened, have you ever found out that your vasculitis medicine costs more or less than you expected?

A: Well, I think at that point you're going to get into health insurance and coverage and drug co-pays, so I think it sort of varies. When they changed and some of the medicines that I'm on are not on the approved list…because the medicines that I take, for the most part, most of them don't have generic equivalents. Yeah, it's sometimes more expensive than I think it's going to be, but what are you gonna do?

Q: So when that situation arises you just go ahead and pay for it?

A: Yeah. And fortunately I have insurance, and the co-pays, even for the non-generics, are not outrageous, but it adds up.

Q: So you've never had to adjust how you take your medicines because of this co-pay issue?

A: No. I'm very fortunate that UNC does have good health care compared to some of the other companies that are out there.

Q: Have you ever had to change how you were taking your vasculitis medica-tions to better meet your needs? You brought up earlier that after talking to your doctor you realized that you weren't supposed to take your medicines within two hours of each other. Has anything like that come up previously where you had to switch timing, or…?

A: Yeah, it has because when I travel, when I go to meetings and stuff, I've occasionally had to change the time that I've taken medicine, but it hasn't been anything drastic. It's more a matter of hours rather than a day or something.

Q: Have you ever had to switch dosages for other medications besides the steroid, where you threw up?

A: Well, yeah. We've had to adjust the CellCept. We've also played with the dose of Rituxan as people come to know more about it. When I first got it in '03, I had six infusions – six or eight. When I had it in '05 I had four infusions, and when I had it in December I had two infusions because Ron has learned more about how it works. They found that maybe once you knock out the B cells that you don't really need to keep knocking out the B cells. If you can do it in two doses instead of four or six, then that's good.

Q: Yeah, why give the extra medication?

A: Yeah.

Q: Which source of medication information do you trust the most, and why?

A: My doctor.

Q: And why do you trust your doctor the most?

A: Because I figure he knows this disease and he has the most information about it, so that's what I'm going to go with.

Q: If you had to come up with a second most trusted source of information, which would that be?

A: Depending on the drug, I guess, I would either look at the insert from the drug store or something on WebMD.

Q: Of all the sources of medication information that you have, which one is the easiest for you to understand?

A: That's a good question. Well, it's always easiest, of course, to talk to my physician. But I guess…easiest, I guess, would be the stuff from the drug store because it's right there; you don't have to find it. It's just right there in front of you and it's pretty user-friendly to read. And then if I want to go more in-depth, then I go online.

Q: And with the inserts that you're talking about from the pharmacy, are those the ones that come within the medication pack, or is this the one that the pharmacy prints out?

A: It's the one that the pharmacy prints out, yeah.

Q: Okay. So overall you've found those pretty useful?

A: Yeah, I have. I keep one on file for each of the medicines that I'm taking just to have.

Q: When you've had these other issues come up before, why hasn't the pharmacist popped into your head as someone that you could go to for information?

A: Because you have to go there, and it's busy. I would rather do something quick that I can do on my own. And on occasion I have talked to pharmacists.

Q: But it's not your first choice?

A: No.

Q: Okay, well, that's it.

A: Oh, okay.

Q: Unless you have any questions for me.

A: No. I think that going forward this will be really useful information because I hope to goodness that we get some new drugs for vasculitis. It will also be interesting…I had a [board of visitors] meeting yesterday, and ____ that individualized therapy [Howard McCloud] did that kind of thing.

And I think some of these issues will be resolved as ____, I hope, are able to test a person upfront, and, oh, well, we shouldn't really start you with CellCept because we can see that's not going to work with you. We need to start you on this [Trexate], or maybe not everybody would necessarily have to have Cytoxan right off the bat. But I think for now this is a very useful survey, and I think it could inform a lot of interactions with physicians and nurses.

Q: Oh, thank you.

[*End of interview.*]

Interview with F2
_____

Q: Studies with cancer and arthritis patients show that people get medication information from different sources like doctors, pharmacists, family, friends and the Internet. Where do you get your information about your vasculitis medicine?

A: Pretty much from my doctor.

Q: Do you ever get information from the pharmacists, like on the inserts that they give you in the medication booklet or from a pharmacy leaflet?

A: No, not so much anymore. I used to, but now, with the Internet, if I have additional questions, I'll go online.

Q: So you go online for additional information?

A: Mm-hmm.

Q: What kinds of information do you get online?

A: I pretty much, honestly, will go into Google and put in the drug name and pull up the PDR or a site that actually gives information on the drug. So specifically, I would be looking for what it does and side effects, etc.

Q: Are you going on the Internet to get information that you might not have gotten

during the doctor's appointment?

A: I would say just to get expanded information. And plus to see it in written format. I would even think, unless they gave me a really good one, even some of the stuff…they rarely hand you out something, unless they give you a trial. So I'll usually almost always follow up with Googling online.

Q: So that's a typical behavior for you?

A: Yeah.

Q: Does anyone ever offer unsolicited information to you, like maybe a spouse or family member or friends, maybe a vasculitis support group member, about medicines?

A: No.

Q: So you don't have discussions about medications with these people?

A: Well, yeah, we might. That's a little different question. What we do is we may talk about what we've taken and the side effects and the way it affects us. Not so much about should you or shouldn't you, but more of a support, like I understand, I take that, too type of thing.

Q: Okay. Have you ever found out something new about your vasculitis medicines on the Internet that you didn't know from your doctor's appointment or medication leaflet?

A: I don't think so.

Q: Some people with other diseases like diabetes have reported receiving conflicting information from different people about their medicines. For example, if they see two doctors, maybe doctors use two names for the same thing or someone tells them to take the medication at a different time of day. Have you ever run into any situations like this where you've gotten conflicting information about your vasculitis medicine?

A: Yeah.

Q: Could you describe one of those for me?

A: Sure. It's just a matter of whether to take something in the morning or take it at night, where one will say it's best to take it in the morning, another will say it's best to take it at night. And what I've really found for me is, unfortunately, with vasculitis, it is a chronic situation, and I've had it since 1982, so I've kind of learned to tell them when I'm going to be…

Q: Do you test out and see which one works best for you?

A: Yeah, I do. Especially if it's a time of day type of thing. Because I'll ask them. If I do get a conflicting thing, I'll say, well, Dr. So-and-so said for me to take it in the morning. And they'll say, well, you can take it in the morning and that's fine. It's not going to affect the way the drug interacts with your body, but it might make you feel hyper or this or that; it might be hard for you to sleep, that type of thing.

Q: So this is usually another doctor that you're…?

A: Yes. Yes, it would always be a doctor.

Q: What kind of doctors?

A: It would be a nephrologists or a rheumatologist.

Q: I'm going to ask you about different situations that you might have run into, and if you've have any of those happen, just go ahead and explain how you handled the situation.

A: Okay.

Q: You experience a side effect that you didn't know was associated with your vasculitis medicine. Have you had that happen?

A: Let me go back in my history here. Let me think. Yes.

Q: Could you describe the side effect and how you handled that?

A: Sure. It was when I was taking oral Cytoxan, and they had told me to drink a lot of fluid and everything to flush out my bladder. And I'd seen the doctor because I was having cramping in my stomach, and the long and short of it, I didn't know that you could get a chemically induced urinary tract infection. I didn't know that. And they hadn't really mentioned that.

Q: Did you go to the doctor with the infection?

A: I did. I actually ended up going to the Emergency Room.

Q: Ooh! Okay. Were you able to bring up with your doctor that you didn't realize that was a side effect, that that hadn't been explained to you?

A: Mm-hmm.

Q: And how did the doctor react?

A: They were fine. The thing is that this was 1982, so a lot has happened and changed since then, luckily enough. At that time I was getting the protocol for a clinical Stage 3 trial for [one of these].

Q: Okay.

A: Yeah, so I don't think they knew exactly everything that would happen.

Q: Okay, that's good to know.

A: Yeah, so it was kind of like a learning experience for all of us.

Q: The second situation…your vasculitis medicine side effects were more severe than you expected. You already knew that there was going to be this medication side effect, but you didn't know it would be that severe. Has that happened?

A: No.

Q: Have you ever had an unexpected drug interaction?

A: With my vasculitis medicine?

Q: Yes.

A: Or other medication?

Q: It could be your vasculitis medicines with your other medications or two vasculitis medications together.

A: Yeah, I have.

Q: Could you describe that?

A: Sure. It was when I was taking Cytoxan…I think it was Cytoxan. But anyway, I ended up getting [nauseous], so they gave me Compazine. And I ended up having a neurological response to the Compazine where I couldn't speak, and I kept sticking my tongue out.

Q: Did you figure out that was a drug interaction on your own?

A: Actually, the thing is that I don't think it was a drug interaction, now that I think about it. One was a cause and effect in the sense that I was nauseous, they gave me the nausea drug, but the nausea drug didn't respond to me because I was

taking Cytoxan. Does that make sense?

Q: Okay, yeah.

A: So I don't think that was…it wasn't a mixture of the two drugs. So I guess the long and short of it is now is, no, I haven't had an unexpected… [*Laughs.*] Soon as I talked it out.

Q: When you did have that event happen, did you go to your doctor right away, or how did you handle that?

A: I was actually already in the hospital when it happened.

Q: Okay. Have you ever had a situation arise where your vasculitis was more or less effective than you expected?

A: No, I don't think so.

Q: Has someone ever suggested that you take your vasculitis medicine differently than your doctor prescribed?

A: No.

Q: Has someone ever suggested that you try a new medicine or treatment? This could be complementary, seeing a nutritionist, acupuncture, holistic or alternative medicine.

A: Yeah.

Q: Could you describe that?

A: I actually do…myself, I do acupressure and therapeutic massage and some energy healing.

Q: How did you hear about these alternative treatments?

A: I actually sought them out myself.

Q: On the Internet, or…?

A: No, I've just been very much a mindful health person. I think it might have started when I was diagnosed and my rheumatologist at the time gave me a book called *Anatomy of an Illness* by Norman Cousins. And I read that and kind of took control of my own life and my own healing and medical care. One of the things he talked about was meditation and laughter, and so I've kind of known about it, so it was really just me.

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Q: Was it difficult for you to find these types of treatment options, or did you just go to the phone book? I'm interested in that process.

A: Well, what I actually did first is I went to see a psychologist, just to start talking about some of the support I thought I needed. And then just talking that out. And then, as I moved to Boston, Massachusetts, it actually was readily available, especially in Cambridge. And I think I actually did go…I want to say that I went to the Yellow Pages at that time. And if we're talking about now, going forward, I would have definitely searched it out online.

Q: Does your physician know that you're doing acupressure, massages and energy healing?

A: Yes.

Q: Are they generally supportive of the alternative…?

A: Sure, yeah.

Q: Very good.

A: Yeah, the one thing I don't do is any supplements or anything like that, just because of the fact that I have kidney involvement.

Q: Did you read somewhere that you shouldn't do supplements, or did your doctor tell you that?

A: No, I mean, it's as you learn about the kidney. It wasn't necessarily my doctor, but it was probably my nutritionist, or…they didn't say don't take supplements, but it was logical to me not to because you're monitoring your potassium and your phosphorous. And so the more you know, you know that if you take too much vitamins or whatever, they're going to be secreted through your kidney anyway, and you're going to pee them out. So I kind of figured that if your kidneys don't work, not such a good idea.

Q: Okay, excellent. Have you ever found out that your vasculitis medicine costs more or less than you expected? Found out insurance wouldn't cover it or a situation like that?

A: When I first started Cytoxan, I was completely shocked how much it cost. Yeah, the Cytoxan specifically.

Q: How did you handle that? Did you go to an insurance company, or…?

A: Well, no, now because I guess I have paid for it, because I was on my parents'

insurance.

Q: Have you had any recent experiences like that with any new drugs?

A: No, not so far. I think pretty much the stuff that I'm on is pretty cheap now.

Q: Have you ever had to change how you were taking your vasculitis medications to better meet your needs?

A: Yeah, the only thing is the way that shift my steroids, because I live on Prednisone, and I can't ever get off it. I started taking it in the evening, believe it or not. I take it right before I go to bed and then I'm fine.

Q: How was it originally prescribed? To take it in the morning, or…?

A: Yeah. And that tended to upset my stomach more.

Q: Okay. So it's because of a side effect that you…?

A: Yes.

Q: Which source of medication information do you trust most, and why?

A: I would say the source that I would trust most is an online, like WebMD or the PDR, Physician's Desk Reference, electronic version.

Q: And why would you trust that source the most?

A: Because it's been around for a really long time and has a reputation of being accurate. And physicians use it, so… [*Laughs.*]

Q: Right. Where would you rank physicians and pharmacists in terms of trustworthy medication information?

A: I would rank the PDR first, physicians second, and pharmacists third.

Q: Okay. Which source of medication information do you think is easiest to understand?

A: Written.

Q: So the PDR again?

A: Uh-huh.

Q: That's all the questions that I have for you today. Is there anything that you'd

like me to know about your medications or a survey about medication information?

A: Yeah, let me think for a second. I'm trying to think back to when I wasn't very knowledgeable on the whole thing. You might have asked this question, I'm not sure, but with the vasculitis, there are many options to treat you, and are those options discussed? Or have they been discussed?

You can take CellCept, you can take Cytoxan, you can take Prednisone. You can do a lot of these different things. And I'm just curious now if, when a patient, like let's just say I'm feeling crappy, I go to the doctor, we have some tests done, it looks as though I have Wegener's or vasculitis, how are the different options to treat it discussed?

Q: Oh, okay.

A: Because there really are, there's different options with different…obviously the doctor can make the best choice, but they all have different side effects, and they all have different ways in which they work within your body. So I'd just be curious if the doctor decides this is what I'm going to do, and then go down that path, or do they say these are our options, let's discuss those options? Input you have.

Q: So basically the involvement and input…

A: Yeah.

Q: …you have as a patient in the decisions for the treatment options?

A: Right, for treatment options, because there are quite a few, especially now. My time there wasn't, and at the time there wasn't even anything. It was clinical trials for Cytoxan and Prednisone, so you had no choice. But now there is a lot more of a choice. I'd just be curious if patients are presented with those options.

Q: Oh, that's good. I can ask people how many options they were initially presented with.

A: Right. And if they understood the difference, because definitely each one has a different side effect.

Q: Yeah, that's great. I think I will include a question like that in the survey.

A: I know if I was going to be diagnosed now, I'd be like, whoa, I don't know.

Q: Right, right. You've got this one with side effect A, and then this one with side

effect B.

A: Right. And then you have the different forms of vasculitis, right? So there's some who have non-ANCA, you know what I mean? I think that under-standing what the ramifications are and trying to think, well, let's do it the less caustic one first, and let's see how that goes. That type of thing. To see how involved they are in that thought process, or how involved they want to be in that thought process. [*Laughs.*]

Q: Right, right.

A: That's the other thing.

Q: Some people just want the physician to make the decision.

A: Exactly.

Q: Others would want to be very involved.

A: Exactly. And it's kind of shocking, because there's some that you would think wouldn't want to be and actually want to be more, and vice versa.

Q: Okay, that's excellent. Any other thoughts about things that are important to include?

A: I don't think so. Did you ask me about did anybody offer you coping mechanisms for dealing? Or is that part of the support group?

Q: I asked you if people offered you information about the medications, but not how to cope. Like coping with side effects, is that what you're…?

A: Right. To me that's what's really missing in the health care team that you have. They can tell you what the side effects are, and say let us know if you experience this, this, and that, but then some of them are inevitable, right, like, they're going to happen.

And so maybe that's where you could go to a support group or whatever, but it would be nice, too, if they said here's a little pamphlet that also shows people…it's different for everybody, but as they lose their hair, they do this, or as they have nausea, they try this. That type of thing. I just don't know if that's even appropriate, but that might yield some information.

Q: No, I think that type of information probably would be perceived as very helpful by people who are in treatments like this.

A: Yeah.

Q: I don't know if there's anything available. I'll have to talk to some of the…

A: Because I know it could be weird, because not everybody…you want to make sure that it's something that's not…what's the word? Like it doesn't…

Q: It doesn't induce fear.

A: It's not invasive. It's kind of like this is the way you can cope with this medication. For instance, if you have to take iron, taking a stool softener with the iron helps you deal with that issue. That type of thing.

Q: Right. Yeah, that would be good. Yeah, that's definitely important information, because if you know there's going to be side effects, just knowing that there's going to be side effects is not the most useful information.

A: Right. It's like, how do you deal with it, how do you live with it?

Q: Right, right.

A: And what makes it better? Because that's some of the things that I've had to learn trial and error. And even with Prednisone that's very true, too. Especially when you first start, you're on a very high dose.

Q: Yes, some of those medications have very extreme side effects.

A: Yeah, so how people have given little coping…to deal with these. It's going to happen, you don't have any choice. However, people have found that if you bla-bla-bla.

Q: And do you get that at your support groups now? Do you go to a support group or an online chat group?

A: I do. I actually was the chair of the North Carolina Vasculitis Support Group here for seven years, and I just handed that over to Elaine.

Q: Oh, okay.

A: I ran that for quite a long time. You do, you can share it with one another. We're starting to get into long-term things now. One of the guys that I'm really good friends with who's had the exact same path of Wegener's that I had, as far as where it went, is now really suffering from pretty bad leukemia from the Cytoxan, [verifications] of that. So he and I talk about that. And you know, when you get the Cytoxan, that's a possibility in the future. But you have to make your decision at that point. Like, uh, die now or die in 20 years from now, that type of thing.

Q: Is it beneficial to you to have those discussions with the support group members?

A: It is. It is if it's in a positive light. The one thing is sometimes ignorance is bliss. And you find out, like, uh…but you know, that's one of the things that they do tell you, that it suppresses your bone marrow, which makes sense. But you have to make the best decision that you can. So what was good, the fact that he's always experienced this, and so I know if it happens, this is what you've got to do. I'm hoping it doesn't, but it could.

Q: And then having some of that information in a written form would be useful?

A: Yeah. I think so. And that could be something that maybe the Vasculitis Foundation could really think about, to assist physicians who actually do treat vasculitis patients to come up with something like that that they could distribute. [That these are] some suggestions; in no way is it medically…we're not advocating any of these things, we're just telling you this could happen and this is how other patients have dealt with it, or something like that.

Q: Right. And then if I could identify on the survey that this is a real need area for vasculitis patients, then you can bring some actual data to the table saying that people want this information.

A: Exactly. That's what I'm thinking, just as far as to help behavior. It would be really helpful to know that. In fact, people do respond to that. And some people would respond…a lot of people do not like support groups. I can be one of them, too. I'm not a huge fan of sitting around having people outdo each other with these horror stories, so we really try to keep it at the, you know, we all have a badge of honor and courage.

We've all been through stuff at all different levels; let's actually talk about coping forward. So we do that a lot. So I think that if you do show that people would respond to that, and I don't know how you would do it because some people just don't want it because of the whole negativity of support groups. But if it did say that it was just like a written coping for new…because there's so much for cancer patients.

Q: Right.

A: When you're diagnosed with cancer, you get anything you could possibly want, right?

Q: Right.

A: So what are the effects of radiation, right? What should you eat? What should

your diet be while you're on radiation? All those types of things that, with vasculitis, even though a lot of what we do is very similar to chemotherapy – it is chemotherapy – we don't necessarily translate those into the same coping skills. Like, what's the best thing you should be eating as you're going through chemo, as you're having Prednisone, as you're having these things? What they are is some more generalized. So if you're on Prednisone, this is what you should do, but not if you're on Prednisone because you have vasculitis, that type of thing.

Q: Right.

A: And I think that would be very helpful. But that's just my own anecdotal thoughts. [*Laughs.*]

Q: I definitely will [gear] this towards what's the next steps we can take after doing this, because I'm not a big fan of just asking a bunch of questions and not doing anything with the [answers]. So that would be very good. You could do interventions. You could have materials and discussion groups around these issues specifically, because it's a need area. Identifying that's a need area first is definitely important.

A: Yeah.

Q: So yeah, that's great. Well, thank you for your time.

A: Thank you for doing this as your dissertation. I really appreciate it.

Q: Oh, no problem. I do have one other way I'd like to thank you. I'd like to send you a [Nuller] season gift card in the mail, if that's okay.

A: I can take that, I think. [*Laughs.*]

Q: All right, and should I send that to the same address that I sent the consent form?

A: Sure, that's fine.

Q: Okay, great. I'll do that.

A: Okay?

Q: All right. Thanks so much for your time.

A: All right. Thanks so much. Take care.

Q: All right.

A: Bye-bye.

Q: Bye.

[*End of interview.*]

Interview F3
_____

Q: All right, we're live! So, my first question is: studies with cancer and arthritis patients show that people get medication information from different sources, like their doctors/pharmacists/family friends/Internet. Where do you get information about your vasculitis medicines?

A: Well, I get information from my doctors. I get information from the package inserts that come with the medicine. I get information from the Internet, information from books, occasionally; information from my own experience.

Q: Can you expand more on the information you get from your own experience? That's the first time I've heard that come up, so I want to know more about that.

A: Well, I've had vasculitis four years now, so I'm accumulating some experience with the different medications. I can kind of judge. The doctor will tell me what the side effects are, but then I have my own experience, and I know how the medicine affects me.

        I think the first time it occurred to me how important my own experience was when I was taking psytoxin, and I started losing my hair. The doctor had said that the hair would thin, and I went back to her and said, "What does 'thin' mean?" She wasn't too sure, and she talked to some other doctors, and they said, oh, it would just thin a bit.

        At that point, I could see that we were talking more than thin, so I went out and bought some scarves and a wig to be prepared. They were talking in terms of the general things that affect a lot of people, but I was seeing it from my own experience.

Q: Mm-hmm. Okay, that's very interesting. Now, with the books -- that's the first time I've heard that answer too. Where are you finding books, and what kind of books are you looking at?

A: Well, the Vasculitis Foundation had recommended a book about prednisone. I can't remember the title of it, but it was a really good book because it was thorough. It involved different things, and experiences with it, and all the different side effects.

Q: Okay. Was it written by vasculitis patients?
A: I'm not sure she was a vasculitis patient, but she was a patient on high doses of

steroids.

Q: Okay. So that translated well to you, in your experience?

A: Yeah, it did.

Q: You said you went on the Internet. What kinds of websites do you go to for information?

A: Oh, there are lots of websites with drug information. There's [Medline], my health insurance company has a drug site, and if you just cruise looking by the drug name, you'll find a lot of websites.

Q: Is that what you usually do? Do you go to a Google or a search engine, and type it in, and pick out a few to look at?

A: Yes. I usually use Google.

Q: Okay. Why do you use those sources that you had just described? Why do you choose those sources?

A: Well, I use my doctor because I trust him. He knows the drugs, he knows me, and he can kind of put the two together. I use the Internet because I tend to get more complete information for all the possibilities – more information about the drug, in more depth, and I can sit down and read it at my speed.

I read the books because they have stories about how people have dealt with it. I guess another source that I didn't mention -- the first answer, Vasculitis Support Group – linked me to other patients about their experiences with the drugs, and how they take them.

Q: So you talk about how you take the medications?

A: Dosage, and timing, and things like that.

Q: During the support groups, do you discuss ways that you've been able to adjust your medications to better suit your needs?

A: Yes. I remember that particularly during CellCept and the different ways people take their dosage – with or without food and all of that.

Q: So you get a general impression that the certain way things are prescribed doesn't work for everybody? Little adjustments need to be made?

A: Right, yes.

Q: Okay. Have you ever found out something new about your vasculitis medicines on the Internet that you didn't know about from your doctor, or some of the other sources that you've looked at?

A: Yes, I have.

Q: Can you describe that for me?

A: With the steroids, I found out about muscle weakness as an issue. I had actually had run into the problem without realizing that was what the problem was. This was after I had just started the IV steroids, and I remember trying to go up a flight of stairs, and I couldn't make it.

I talked to the doctor about it later, and she said, "Well, were you short of breath?" I said, "No, I wasn't short of breath, I just couldn't make it; couldn't get up." She didn't say anything more about it, but I continued to have trouble, and I fell down in a parking lot and couldn't get back up until this guy helped me.

At that point, I started researching it, and saw that it was a side effect of the steroids. My doctor referred me to a rheumatologist, who referred me to a physical therapist who said later, "Yeah, it's the steroids that cause the muscle weakness in the legs."

Q: So you'd found out about it on the Internet, and then it was confirmed by a physical therapist?

A: Right, well I found out about it from my own experience!

Q: Yeah! So with that experience, it caused you to go to the Internet and find out about what was going on?

A: I didn't question the doctor at that point about it. I had told her what was happening, but she hadn't said that it's the reason. I did have a lot going on, so who knows?

Q: Were you able to tell the doctor, maybe at your next appointment, that you...

A: She left the practice, and I didn't see her again.

Q: Oh, okay. Some people with other diseases, like diabetes, have reported receiving conflicting information from different sources about their medicine, so especially if you're seeing more than one doctor... One doctor tells you to take it in the morning, another doctor tells you to take it in the evening, dosing issues, using different names for the same thing. Have you ever received conflicting information about your medicines from different sources?

A: Well, I've not received conflicting information between doctors, but between the doctor and the package insert, or the doctor and the Internet. Then, I've gone back

and asked the doctor about it.

Q: Okay, so when you get that type of information, you go back to the doctor.

A: A package insert might say not to take it with food, but if I take it without food, it makes me sick. I talk to the doctor, and the doctor says, "It's okay to take it with food."

Q: So, if there is an issue, you go to the doctor to find out about what the best way to take it is. Okay. Is that a specific instance that had occurred with you -- like a food versus non-food issue? That actually happened with you?

A: Yes.

Q: Which drug was that?

A: CellCept.

Q: Now, I'm going to list simple situations that may have occurred to you. If you have had this situation occur, please describe how you handled it. I know this first one because of the hair instance, but have you experienced a side effect that you didn't know was associated with your vasculitis medicine?

A: Well, the hair, the muscle weakness. One experience with cyclosporine was kind of like your heart is racing. You get really anxious. That's happened.

Q: With the heart racing, were you able to go back to your doctor and say, "I'm having this problem," and they tell you it's associated with the medicine?

A: Yes.

Q: Okay. Your vasculitis medicine side effects were more severe than you expected. Has that occurred?

A: I wouldn't use the words "more severe." There were things that came up that I didn't expect. Probably, that's why I started working at the Internet: to forewarn myself to get a more complete picture of what might be going on as I got exper-ience. I've been taking the drugs a while, so I know pretty well what they do.

Q: Is there anything that you didn't expect, besides some of the ones we talked about – muscle weakness, heart racing, hair loss...?

A: Well, my fat face!

Q: Did you gain weight?

A: I didn't gain weight -- I actually lost weight, but my face got really, really round, and my stomach got large. I didn't gain weight, though. I actually lost weight while I was on the steroids.

Q: What was that associated with?

A: Steroids. When they started me on the steroids, I was in the hospital. I started with IV steroids, and then went to the daily oral steroids. They had warned me about the side effects, but residents tended to focus on the really severe, unusual side effects: hallucination, psychosis. They didn't warn me about the moon face. They did warn me about the diabetes. They actually stressed more the really severe things, and less the day-to-day kind of things that I ran into.

Q: Okay. Is that what you discuss in the Vasculitis Support Group – these day-to-day instances that come up with the medications, and how to cope with those?

A: We talk more about what medications are people on: are they working, are they controlling the disease, what dosages they are on, and then somewhat about side effects.

Q: Okay. Have you ever had an instance where you had an unexpected drug inter-action? This could be between two vasculitis medications, or a vasculitis medication and some other medication that you were on.

A: No, I haven't.

Q: Okay.

A: I had one where the doctor felt there might be one, and he checked it out. Gosh, what was it? Cyclosporine and a cholesterol-lowering drug.

Q: Okay. My mom was on that one. Why did your doctor think you had a drug interaction?

A: I was having a lot of joint pains.

Q: It turned out not to be from those?

A: It was not from those.

Q: Okay. Have you ever had an instance where your vasculitis medicine was more or less effective than you expected at controlling your symptoms, or controlling vasculitis?

A: Less effective. I had the experience where it was less effective.

Q: Could you describe that?

A: Well, when I switched from the Cytoxan to CellCept, the [centrum] started percolating again over a period of about six months.

Q: How did you handle that? Did you switch back? How did you handle it?

A: The doctor added cyclosporine to the cycle.

Q: How long was this? About six months to get the symptoms to go away?

A: Yeah. I got off of cyclosporine after about a year on it.

Q: Okay.

A: The Cytoxan, I think that was the hardest one. I had the IV Cytoxan for six months, and two weeks after the sixth infusion, I had a major flare, with kidneys involved. I went to oral Cytoxan after that.

Q: Have you ever had an instance where someone suggested that you take your vasculitis medicine differently than prescribed? Maybe a pharmacist or another vasculitis patient who was taking the same medication?

A: Yes.

Q: Dan you describe that?

A: It came up with CellCept on the issue of "With or without food?" But I had talked to my doctor about it, so I knew what I was doing was okay.

Q: So you shared that information with another person that had vasculitis?

A: No, they were sharing with me!

Q: Oh! Okay. Was this at a support group, or was it more informal?

A: Someone I know.

Q: Okay. Has someone ever suggested that you try a new medicine or treatment? This could be something complimentary.

A: Oh, yes, lots. Particularly when I was working! Every time I got a cold, everyone was volunteering cold remedies – zinc, echinacea. Any time my muscles hurt, they would volunteer Advil and all that stuff.

Q: These were coworkers?

A: Coworkers.

Q: Okay. Has anyone suggested you try an alternative treatment, or something like going to a nutritionist or massage? Acupuncture?

A: Massage has been suggested.

Q: Was that from your doctor?

A: No, that was coworkers. Wait, wait, that was people where I exercise. They're the ones who said that. In terms of doctors, they had signed me up for physical therapy.

Q: Okay. Did you ever end up trying massage?

A: No. My joints hurt too much! The thought of somebody pressing on them doesn't sound too good!

Q: Have you ever found out that your vasculitis medicines cost more or less than you expected? So, you were given an idea that it might cost 'x' amount of dollars, and you got to the pharmacy to pick it up and it was different?

A: Yeah, not a lot different, but my insurance changed to really focus on mail order. I have to go through mail order and get a certain amount, and that's the lowest cost.

Q: You're the first person I've talked to that's gone through mail order. Could you maybe describe this experience for me – how it compares to going to a community pharmacy, or a hospital pharmacy?

A: On Avapro, for example, I would pay $90.00 at a regular pharmacy for a three-month supply. If I go through mail order, I pay $26.00. Basically, I get three month's supply for the price of one month, and with a little discount added. So it's a really huge difference.

Q: Do you know why the difference is that big?

A: I'm sure they save money on bulk purchase of the drugs.

Q: Okay.

A: Mail-order service has been great. For medicines like CellCept, they send them air express, and they come pretty quick.

Q: Was it your insurance company that told you about the mail order pharmacy?

A: Yes. They built in these cost incentives.

Q: Have you shared information about mail-order pharmacy with some of the other people that have vasculitis, and have they been able to get the same kind of discounts through their insurance?

A: I don't recall really talking about it, because it's so unique to my plan.

Q: Okay. We've kind of discussed this before, but if you have any other situations you want to bring up...? Have you ever had to change how you were taking your vasculitis medicines to better meet your needs?

A: Well, yeah. With the CellCept, the timing and the dosage. I had one medicine that I tried, and I had a bad reaction to it so I just stopped taking it. I stopped that.

Q: Okay. Which source of medication information do you trust the most, and why? Out of all the ones that you look at, which one is the most trustworthy?

A: I trust my doctor the most, because he knows the medicines. He has a lot of experience with them, and he knows me. I trust myself, too, in that I have my own experience with them now. I know how the steroids affect me.

Q: Okay. Where would the Internet fall in on the scale of most trustworthy to least trustworthy?

A: Below those two.

Q: Okay.

A: The doctor, really, is the only one I can talk to about the medicines, who knows me as well as the medicine.

Q: Right.

A: I can talk to my family and friends about it, but these medicines are all medicines they've never heard of. They have no idea what I'm talking about! There are a lot of barriers talking to a pharmacist. You have to be able to get them to come to the window, it's not private, and they don't know these medicines – at least, the community pharmacists don't know them very well.

Q: Okay, that's important to know, for sure. Just out of curiosity, have you ever had an instance where you're talking about your medications and the side effects to family and friends, and they reacted defensively? Like, "Why do you have to take these?" or "Is there anything you could do to prevent these side effects?" or "We don't like to see this happen to you." Have you ever had an instance like that?

A: Well, I ran into it with the prednisone. They were saying, "Well, gosh, you gained a

lot of weight!" I was saying, "Gosh, I haven't gained any weight, I've lost weight!" Then, when I got off the steroids, and my face got back to my normal face, they said, "Oh, you've lost so much weight!"

And that's kind of...you don't feel great about that. *Or*, they recommended things like "Take Advil" and all of that. I shouldn't be doing that because of my kidneys. For the most part, they've been really supportive. They listen to what I say about the medicines, and respect that.

Q: Okay. Which source of medication information is easiest to understand, out of all the ones you've gone through?

A: The doctor.

Q: The doctor is the easiest to understand, as well? Okay. Something that has come up in other interviews that I'm interested in now is, have you received information about how to cope with the side effects of your medications?

A: Oh, no, not directly. A lot of it I've learned on my own, how to cope. I read the book about the steroids, trying to cope with that. There have been a couple of occasions where I've talked to the doctor about a side effect, and we've talked about how to cope with it.

Q: Would written materials with information about the different types of vasculitis medicines -- side effects and how to cope with side effects -- be useful to you?

A: It would be so useful. Particularly when I was new to all of this, and the steroids, to understand the steroids and what they're doing, and how to cope with that and be prepared. The Cytoxan, the same thing.

You don't want to read so much that you think all these side effects are going to happen, but it's reassuring to know the information, and know what to expect. It does happen. It's much easier to accept and deal with.

Q: That's something that has been coming out of the interviews, and it's something that is starting to evolve as a need area.

A: With the prednisone and the psytoxin, particularly....CellCept too, but only somewhat. They have more across-the-board side effects. They affect so much of your body. I tried azathioprine, and the doctor had warned me about that. I was prepared, and that was fine.

Q: When he warned you, did he also talk to you about different mechanisms you could use to reduce the side effect, or deal with it?

A: Well, what he warned me about is that some people aren't able to process it. I was in

the "not able to process it" group. It wasn't a matter of adjusting.

Q: Okay. I'm finished with my questions. This has been very focused on medica-tions, but if there are other issues that you think are important regarding medica-tions or other sources of information for vasculitis patients, feel free to let me know about it now. I'm developing my questions this way.

A: One thing that's very useful is the doctor's computerized list of medicines. It's very useful when they print that out and give that to you, because when you go to another doctor, you have it to show and share. You can carry it with you.

That's just a small thing, but it really is helpful to know exactly what you're on. It's helpful, too, to know the different names of the medications sometimes. some doctors call CellCept, and some call it adenylate – which I now know!

Q: Right, I learned that while I was writing my literature review!

A: In terms of education, those things are important.

Q: Any other issues that are important?

A: I'm sure there's a balance that everyone has to consider, between telling someone about the effects of the medicine, and scaring them to death! Probably, people have different personalities in what they need to know.

For me, knowing information is very reassuring, and I feel in control – the old "knowledge is power" kind of thing. It's much easier to live with the disease and the medications with that kind of information, instead of kind of stumbling along and happening upon the side effects.

Q: How would you most like to get this kind of information -- from a one-on-one with your doctor or a health professional, or written?

A: One-on-one with a doctor is great, and nothing replaces that. I know a doctor doesn't have time to go over it all, and also, my memory gets faulty. Having it backed up with a written handout would be useful, too.

Q: Okay.

A: A lot of the handouts for patients tend to be so vanilla, so bland, so general – "You may have some side effects. Call your doctor if you do." -- that it's not helpful.

Q: Not helpful, okay.

A: Maybe if it were Tylenol, but here, you're dealing with something that has a lot more potential to give you a problem. So, real information and hard information is better.

It would be really helpful, too, in planning how to cope with the side effects.

I know if I ever go back on the hydrosteroids that I've got to do something about the muscle weakness. I got so weak that it was problematic. If you fall down and you can't get back up unless you can find something to drag yourself up with, you've got a problem!

Q: Right.

A: Knowing it now, I would try to do more exercises and therapy, and whatever it took. Of course, I don't know -- I was sick at the time. I don't know whether I would have done anything had I known.

Q: Okay.

A: Being warned about the psychological side effects of prednisone is really impor-tant, and doctors did a really good job of that.

Q: Just stopping at, "You'll probably experience mood swings from this," isn't good enough. You'll need to know more.

A: Actually, they got very specific -- don't burn your bridges, don't lose your temper. You may feel like it, but don't do it!

Q: Okay, well that's good!

A: The funniest one was when a doctor asked me, "Have you got a gun?" That was very helpful. It was very specific, but then how do you cope with feeling like that? We worked on that.

Q: Okay. All right, well that's everything that I had. If you have anything else for me, or if you come up with something that you think is important, feel free to email me!

A: Okay.

[*End of interview*.]

Interview F4

_____

Q: So it is recording now.

A: Okay.

Q: So studies with cancer and arthritis patients show that people get medication information from different sources like their doctors, pharmacists, family friends,

Internet, for example. Where do you get information about your vasculitis medicines?

A: My primary source is my rheumatologist.

Q: Okay. Are there any other sources that you use?

A: Other patients have been a huge help. For example, people who I know has been on a drug, especially a new drug, for that's invaluable – you know, what doses did you take, how did you feel?

Q: And these other patients – are these people you've met through support groups or some other avenue?

A: Support groups.

Q: Okay.

A: Yeah.

Q: And it's online or in-person support groups?

A: In person.

Q: Okay. Do you ever get any information from your pharmacist?

A: I used to, before we went to a…our insurance went to a mail order pharmacy service.

Q: Okay.

A: And so maybe six years ago, and previous to that, the service was excellent. My pharmacist was full of very helpful information. If a new prescription would come through, she would sit and meet with me.

Q: Oh, okay.

A: But that does not happen anymore.

Q: And how is the mail order?

A: Very challenging, very different.

Q: Do you ever read information from the medicine leaflets or inserts that come with your medication?

A: I do.

Q: Okay.

A: I do, and I save it because you never know what… God, I mean, I've had so many different side effects over the years, it kind of helps when you're experiencing something to be able to go, "Okay. How much is because of these? How much does ___?"

Q: Right, right.

A: Or maybe I'm sick with the flu, you know? It's a little hard to pace it out, so I try and file that information just in case I need it because I have, but rarely have needed it. But once…when you do, you do, you know?

Q: Right, right. Did you ever go on the Internet and research your medications at all?

A: I do not. I've used it for other diseases and things that have come up that I don't know about, but I've had this disease for so many years that I don't use it. I don't need it.

Q: All right. And do other people who don't have vasculitis – maybe like a spouse or partner, a family member, friends – do any of those people ever provide you with information about your vasculitis medicine?

A: I think…

Q: You know, like solicited?

A: My memory is that three years ago when I started to use a new drug, my husband went online and read about it. And he talked some about what he had encountered, but it wasn't anything new to me. But that was a source for him to get information because he's very functional with computers.

Q: Okay. Yeah, that's one of the ___ that I'm interested in is how much do family…

A: Yeah. He went right to the computer for a new drug.

Q: Okay. And was he concerned about the new medication or he just wanted to know more about it?

A: You know what? It was a drug of some concern because the drug had a philatelic shock as a reaction when you first did it.

Q: Okay. Well, my mother has multiple scholerosis, so when she gets put on

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something new, I'm on the Internet.

A: It can be very helpful. It was a valuable… Like, I was diagnosed with a rare form of cancer – I went right to the Internet, you know?

Q: Yeah. Oh, yeah. It's so convenient.

A: It is.

Q: So why do you use the rheumatologist as your primary source?

A: I sort of grew up with her, and the sense of growing up with education and informa-tion about the disease – we came along sort of together. And so I have a huge, deep trust basis with her. And so, to me, she's like gold, you know? I've travelled around the country and seen other doctors she's referred me to, and they adore her.

So everyone I meet sort of builds her credibility. They're like, "Oh, I'd do anything for her," you know? I mean, they literally say that to me, you know. And so my trust is huge from experience and years of dealing with all kinds of drugs and problems and procedures and side effects and symptoms. So she would be my ___ source of information.

Q: Alrighty. And were the other patients – the secondary source…that was the second group of people that you brought up.

A: Yeah.

Q: Now, why do you use them as a secondary source?

A: I have one particular patient I go to who is extremely bright and she always asks a lot of questions and she has a lot of information available to her because of her job. So I know – because I know this gal – how much research she's done and what's available.

And I'm not terribly concerned about risks. I mean, I'm not looking to live forever. I'm just interested in side effects, and she's not…you know, some patients are more motive and reactive about things, and I know she's not. So I know that the informa-tion is pretty distilled. It's just sort of…it's factual if I can get it through a patient, and so that's what I'm looking for.

Q: Okay.

A: You know, did you feel nausea? Were you tired?

Q: All right.

A: [*Voice overlap.*] ____.

Q: Is she usually on the same medications as you? Does she have ___?

A: [*Voice overlap.*] No. Usually not at the same time, but what happens is over the course of the year, eventually, we all seem to take all the drugs, you know? "What? Try this. That one didn't work? Well, try this," you know?

Q: Right.

A: I would be having very different ___ view if I was 30 or 40 instead of 50.

Q: Right.

A: But it's just years of experience with it.

Q: Okay.

A: This is how I deal with it now.

Q: Well, that's good to know.

A: For what it's worth.

Q: No, it's great. I mean, this has been very educational for me so far.

A: I can't imagine trying to tackle someone else's illness.

Q: So I know you said you don't use the Internet much for your vasculitis, but have you ever looked anything up medication-wise about it? Because one of my questions is have you ever found out something new about your vasculitis medicines on the Internet, but if you don't use it, then that's not really applicable.

A: You know, I don't use it, and I can tell you why if you're interested – and you may not be.

Q: I would love to hear that.

A: I have dealt so many years with so many side effects that I've found that it helps to just sort of distill everything down to just sort of yes or no – you're either taking the drug or you're not. And if I had a doctor, I would ___ my doctor, first of all. And I meet a lot of doctors and have traveled a lot before I settled here, so I've been through a lot of different specialists.

And so having spent that much time finding the right doctors who would be a

partner with me in this illness, it's easiest for me just to trust her judgment on it because I've never found her to be wrong in a way that impacts my health negatively. It's a nuance process to have the disease and live with it. No one's going to make the right decisions all the time, doctor or patient, because there just aren't a lot of right deci-sions – it's not that clear-cut. But it makes my life simpler if I just…it gives me more time to live the rest of my life without focusing and obsessing about the illness.

So I'm not that worried about side effects – not that worried about, you know, cancer risks or, you know, my hair's going to turn blue or my nails are going to fall out. I'm just not that concerned, and I don't want to waste my precious rest of my life and energy reading about stuff that doesn't really… You know, I've got the basics. Does that make sense?

Q: Yeah. Is it because…are you not concerned about the side effects because you think the benefits of medication far outweigh any side effects that you might experience or…?

A: That's a very good question. Usually, when I'm using a drug that has significant side effects, it's because not using the drug would have worse problems – I would have kidney damage, lung damage, you know. There would be worse side effects without using the drug. It's always a matter of weighing which is going to cost you more in the long run.

And it's sort of a…well, I want to say crapshoot, but that's not really the right word. It's almost like a juggling game to figure it out, and so you just do the best you can. It's like cancer patients making choices – how much treatment am I going to have with cancer, you know, all three layers of treatment? Surgery, radiation, and chemo or just one or just two, you know?

Q: Right, right.

A: And you don't know if you've made the right call 'til you're dead. You know, you don't know how long you're going to live or what's going to…you know, you just do the best you can with information.

Q: Right. But some people with other diseases like diabetes have reported receiving conflicting information from different people about their medicines.

A: Yeah.

Q: Overall, how consistent is the information you get about your vasculitis medicines from different sources?

A: Well, there are definitely different opinions about treatments of kind of ___ over the past 20 some years. Certain big medical centers have other protocols and

even ways and amounts and dosages to give certain IV drugs or daily medicines. It's that there's a lot out there, and I feel like if I went to another huge medical center – not to say any old medical center, but a great, big one – then I would go with their protocol because that's what their research would show that's what they were used to.

I haven't bought in to the way it's done here so much that I think it's the only way to do it. I just think it's the way to do it in here. I don't have a lot at stake and say, "Hey, this is the only way to do this particular proto, and it has to be done this way – these drugs, this timing, this amount."

But I'm willing to go along with what they're doing here – it's fine with me. I don't have a big problem with it in any way. I'm happy to leave those choices to the people who are researching here and now, but I know that if I went to another big medical center, they would do it differently and it would be just as valid for them until proven otherwise.

Q: So have you ever, like for yourself, gotten conflicting information about time of day to take your medicines, how to take your medicines – maybe from two different physicians?

A: Yes. Yes, I have.

Q: You have had that happened.

A: Mm-hmm.

Q: Could you describe one instance of that for me and how you handled that situation?

A: Sure. I was referred to a big medical center in Bethesda, Maryland, and I went there for a protocol study. And they wanted to use huge amounts of steroids as part of a surgical procedure that was repeated once a month, and I knew that my bone density would go down and my hair would fall out and I would bleed under the surface of my skin. So I pushed back on the ___ on that based on what my experience had told me, and what we had decided based on how I'd respond due to steroids back at my main treatment center. And the surgeon was extremely unhappy with me, almost to the point of being abusive.

It was a very unpleasant experience, and I was disappointed that he couldn't flux at all about something that I thought was actually being slightly destructive to me. It was not just a personal choice – it was something I felt strongly about based on how it was actually going to make me feel.

So I stood my guns. I was treated badly in the OR room, treated badly in recovery, and just never went back. And the surgery didn't actually do me any

good anyway because it created more scar tissue in the airway. So you know, it was definitely conflicting information. It wasn't about the actual procedure – it was about the actual protocol of the way they wanted to do it. So, you know, it happens all the time. It's part of having a rare disease is that there is no hard and fast way to do it ___ a particular medical center or doctor's way to do it.

Q: And in general, are you presented with different treatment options?

A: Yeah.

Q: You are?

A: Oh, sure. Sure. You could do A, B, or, you know, nothing.

Q: Okay. Next, I'm just going to list a series of situations that might have happened to you, and if you have had the situation happen to you, could you please describe how you handled it?

A: Okay.

Q: Okay.

A: Okay. You've experienced a side effect that you didn't know was associated with your vasculitis medicine.

Q: Well…

A: It can be things like hair loss or weight gain or psychological mood swing type issues.

Q: Yeah. I know years ago, we all used to kind of go nuts on the steroid. We were using prednisone instead of Medrol. I went to the first national conference – the one inter-national ___ for the support group, so it's what we call the Wagner support group – the vasculitis support group. And we were all talking and laughing about the side effects from the drug. But we hadn't realized how significant the side effects were.

We thought maybe it was just we weren't coping well with the impact of having the disease and being so young – we were all in our early thirties. And somebody laughed and said, "Yeah. One day I wanna kill myself, and the next day I wanna kill my husband." And it's hard ___ laughter – just kind of, "Oh, okay," you know? It's like I said, I'm not coping well with being a young mother and having no breasts and being on, you know, the drugs. It's sad, it's ___, you know.

And the doctors became very aware of it, and within the next six or seven years, they were prescribing Medrol instead of prednisone. And if you had to go on a

dose that went any higher than – I don't know – 25 or 30 milligrams a day, they actually wanted to hospitalize you 'cause they'd watched so many other patients have bad side effects.

So it was really helpful to watch it over the course of time. So initial frustration over them not understanding to now, you know, they just will tell a new patient: "Watch out for this. You are gonna gain weight, feel weird, you know." It just makes a difference to know that. But initially, years ago – and that was when I first got it – there was nothing said about any of it. They just handed it to you and said, "Take this," you know?

Q: Oh, wow. But you haven't had an experience like that recently?

A: Mm-mm. Because I worked so hard to find better doctors. When you get treated like that, you're like, "Okay. This isn't working for me. We've got to do something different," you know?

Q: So have you ever had a situation which you had an unexpected drug interaction? So one other drug – it doesn't necessarily have to be vasculitis drug, but with one vasculitis medication interacting with something that you didn't expect a drug interaction?

A: I don't know that I've ever had a drug interaction, Lisa. I'm not sure that's happened.

Q: Okay. Great. Have you ever had a situation where your vasculitis medicine was more or less effective than you expected?

A: [*Laughs.*] Almost all the time.

Q: In which way does it tend to swing – towards the more effective or less effective?

A: Oh, I think less effective – you know, I don't get the remission we're hoping for or that kind of thing.

Q: Is there anything that people could do to help you feel more prepared for a situation like that or do you know right from the get-go that this is kind of…?

A: Yeah. The doctor I work with is very clear, which is one of the reasons I like to work with her. She's an information person, so she'll say, "This is the…" Well, she won't say best case, but that's sort of what I take away, you know – "This is what we're hoping for. This is what most patients experience, and this is what the downside is some patients can ___ remission," so that I know that going in.

Q: Okay. Did someone ever suggest that you take your vasculitis medicine differently than prescribed?

A: Yes. We go to Maine in the summer and live there for two or three months, and the drug I was on, they were ___ down there. They were supposed to give it to me in an IV situation in a cancer IV infusion room, but they were really ___ doing that 'cause the amounts were so huge, they were just never… You know, they gave it, like, once every six weeks in about one-quarter the amount I was getting. And I was getting it two weeks apart – big doses, you know. So they were uncomfortable doing that, and the pharmacist – they actually put me on the cancer ward for the day in the hospital.

Q: Oh, wow.

A: Checked me in, put me in a room with a dying patient, which I didn't mind – nothing wrong with that. But I felt bad for the patient who was dying. There I am, sitting there perfectly healthy, you know. And they just ___ the pharmacist came in before they administered the drug and said, "How ___ this? These are the side effects, and you know, ____." But I knew the protocol for the drug, and I knew that they had switched the protocol from what they were doing nationally. So I knew that I had to ___ -- I just sort of reassured them, you know.

Q: And then they didn't measure it according to the protocol nationally?

A: Yeah. They did administer it that way, but I was – like I say – in the cancer ward of a hospital as a patient for the day. ___ didn't just get an IV. We just do it in a rheumatology infusion clinic – the drug. So very different.

Q: Did that cause you some distress in that situation? Did you ever have the thought go through your head that, "Oh, maybe I'm not taking it the best way" or did you feel pretty confident that the way that they had described it was…?

A: I thought I was fine. I was kinda laughin' at it. I just thought it was kind of like, whatever, you know? I had had to meet with a local rheumatologist that had studied under my rheumatologist here in North Carolina, and he had a local practice as a rheumatologist in Maine.

       And he said, "Well, that's an unusual way to do that. We don't give this. In fact, I don't give it at all, but people that do give it ___ start giving it over four different doses, you know, half that amount," you know, those kinds of things. It was the same amount, totally, but they were giving it in four doses instead of two, so I was kind of prepped because the other doctor had given me the information that that was done in that area. But if this is what she wants to do, I totally trust yeah, that's what we're gonna do. So that's how we handled it.

Q: Okay. All right.

A: So I had quite a bit of information going into it, and I find I usually just give

doctors information, you know.

Q: So has someone ever suggested that you try a new medicine or treatment – this could be something like visiting a nutritionist or taking acupuncture or seeing a holistic healer?

A: [*Laughs.*] I wish. Usually we're suggesting that to the doctors. No.

Q: Okay. So no doctor has suggested any treatment like that?

A: No. We're the ones who are going, "How about that?" "Well, if you want. I don't think it'll make a difference, but you know."

Q: So you bring up some of those options at your doctor's visits.

A: Or I used to years ago before we had a firm diagnosis. I would try anything to try and breathe. I did all of that – acupuncture, kinesiology, anything I could think of. ____. Yeah.

Q: Okay. And have you found out that your vasculitis medicine costs more or less than you expected?

A: Well, I had a drug that was supposed to cost $10,000 a dose, and I actually got it free for a time or two, which was thrilling. And it really has never cost me more than a couple thousand a dose, I think, and that was supposed to cost $10,000 a dose. So that's kind of a nice surprise.

Q: Okay. So there's never been, really, an issue where you expected it to be a certain amount, and ended up being a lot more or less that it actually caused you to stress?

A: Well, no, not at this phase in my life. Maybe if I was 20 or 25 and had not __, I'd be panicked, you know. I certainly know enough patients and have counseled them as a support group leader, you know, how to deal with funding trouble with drugs. There's not a lot of options, but you do what you can, you know. It is a consistent problem for folks – the cost of drugs – but it is not a problem for me right now at this point, which is a mercy.

Q: Do you know how most people handle that situation if they run into it? Do they call their insurance companies or do they go to the drug companies or…?

A: Oh, I've seen patients do all kinds of things. Patients can be amazing advocates for themselves. They go and go and go – letters and calls. I've had people contact congressmen – you know, people on the state level – trying to help them with the state health plan, and rarely does it work. Once in a blue moon, you'll get a break, but I mean, they work their butts off trying to get discounts, and

usually they just wind up not taking a drug, which is difficult. I wish we could start a fund that would be available to patients who really needed drugs and couldn't afford 'em 'cause the price of drugs isn't goin' down, is it? [*Laughs.*]

Q: No, unfortunately not.

A: Yeah, yeah.

Q: Well, have you ever had to change how you were taking your vasculitis medicines to better meet your needs?

A: Oh, lord, yeah. Yeah.

Q: In general, how does this process occur? You're prescribed it a certain way, and then take it from there. What usually happens?

A: I've had a lotta trouble as years have progressed tolerating medicines with my intestinal tract. And it was suggested by some specialists that it may just be because there's been so many drugs over the years, you know? I've even had some advice recently, which is one of the reasons it's been hard to schedule time to do this 'cause I'm trying to deal with a stomach involvement. So everything is…just taking the drugs has revolved around that.

I've pushed to get liquid forms of the drugs. I met with a nutritionist and she suggested that liquid forms of the drugs might be easier to digest. And so then I'd go back to the specialist or rheumatologist and they'd go to the pharmaceutical – I think it's all on the Web now. It used to be a big book – and they would go and find a drug that they could use that would be available in a liquid form and I can tolerate that much better.

I've also done shots of drugs instead of trying to run them through my ___ system. And that's been helpful ___, and that will avoid the whole problem. So it's been sort of a nuance because they're trying to get enough drugs in my system and not the vasculitis.

It's been a challenge, and it's a matter of working with dosing. I'm not a really big person, and so sometimes drugs aren't prescribed by weight, and so I, generally, will wind up as I call back and forth with the rheumatologist and her assistant, I wind up taking one-quarter or even one-eighth of what's originally prescribed and I actually tolerate that amount very well. It takes a month or two to sort of work that through with a new drug, and not only do I tolerate it well and can digest that amount without being miserable, but it actually will put me into a remission. So that's fascinating that it doesn't take that much of the drug, which is interesting to me.

Q: And so does your rheumatologist usually react well to that? Does she say, "Okay.

If that's working for you, just keep doing it" or…?

A: Well, usually I'm calling to say, "You know, what do we do now?"

Q: So you ask before you do it.

A: Oh, yeah. I do 'cause I don't know the drug. You know, the ones that I've been ___ was I got ___ -- you know, I know them inside out. But the ones that I haven't, you know, so they start here, call me at this number at work or email me or page me or whatever.

Q: Okay.

A: She's not really busy now, but she was tremendously available for years trying to get me up and running. I can't believe the kind of sacrificial life these guys lead. I mean, truly, I'm not just saying that. It is amazing to me the availability that she has for patients to try and get them better.

Q: That's good that you have a quality physician. I know not everybody does.

A: Well, I just learned. I mean, I couldn't live that way – being dismissed or treated in a way that made me feel like they weren't taking it seriously. It's hard enough to have it without being treated that way.

Q: Well, you've kind of alluded to this a couple of times, but I'll ask the question anyway. Which source of medication or information do you trust the most and why?

A: Yeah. Well, I do trust my doctor that I currently have, and it's because I've had her so many years and have a lot of experience with her judgment. We've tried it on probably 20 different drugs over the years and different procedures she's recommended and things. So it's just the process of trusting by experience, you know.

Q: And which source of information is easiest to understand?

A: I think other patients, to tell you the truth.

Q: Okay.

A: Because most of the times, they have information about daily taking of medicine and living with it that the doctor forgets – like, it has to stay in the fridge, or it's okay to leave a liquid solution that's dispersing water at room temperature, which I would assume you'd have…you know, that kind of thing. And those are just details that are helpful to know.

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Q: Would it be useful if there was a particular forum for you to get this kind of information or make posts like this – information about these little details that sometimes go missed by physicians?

A: Oh, it'd be invaluable for my doctor to be able to say, "We're prescribing this drug and here's a booklet with all the information that we've compiled from patients' experiences and ours so that you've got all the interactions, what to expect." That would be very, very useful. It would save her a lotta time and the nurses and everybody. I would think patient compliance would go up enormously.

Q: This is what I've heard from some of the other interviews __ some of the questions I'll be including in the survey that had originally intended for is to get some kind of material – patient materials – that are about patients' experience about coping with medications' side effects…

A: Yeah.

Q: …and other details that go around it.

A: Yep.

Q: And so I'll be asking questions like that as well as, like, "How would you like this information – in a booklet form, over the Internet, in person, telephone, from your doctor?" So it's good to hear that somebody else actually – without me even probing it said that that would be useful. It kind of confirms that that's an issue for vasculitis patients.

A: It would be very helpful to know if you're taking this drug, these are the side effects. Also, these are the ways the drug is available – injection, pills, liquid, IV – because sometimes the doctors don't think of different delivery systems, but they're really simple to have if you just ask for 'em.

Q: That's a good confirmation.

A: It's made a huge difference to the course of my treatment in the past two or three years to be able to not only inject drugs but to get 'em in a liquid form. It really has.

Q: Well, have you received any information at all about how to cope with the side effects of your medicines?

A: Let me think. I don't know if I have. I'm not sure ___. You're gonna feel like a dog for a couple weeks. I think patients just sort of ___ up and kind of get through it. There's not much, other than the very traumatic steroid problem that we've all experienced, and they're pretty good about saying, "Okay. You're going

to feel ___." I'm not sure anybody's discussed this.

Q: Okay.

A: My impression is that they think it's all very personal from person to person, and they don't wanna suggest something that might be psychosomatic because I've heard that. ___ like, "Why didn't you tell me this?" "Well, I ___ experience with it. We don't want you to ___ a thing because ___ X, Y, Z."

Q: So some information is that some people experience this or that – you think that kind of information would be well-received and useful for people?

A: I think it would be invaluable.

Q: Okay.

A: I've started a support group in the area with another two doctors and a patient, and I've been on the hotline for phone calls from around the country. And so I think the bulk of patients are not well educated about how to advocate for themselves. You know, their doctors are busy and they just say, "Okay." And so if there was a booklet available, maybe they could begin to…

I've heard…you know, I've been to so many ___ and __ people just don't know this stuff. I had a young woman who showed up at a roundtable dinner thing, and she said, "Well, I thought about ___. ____. She was like, 27 years old and newly married, and she had no idea it would make her infertile for life. She was from Michigan, and her doctor hadn't told her, and didn't even know where to look. She was so upset, she was practically hysterical. She went, "Are you kidding?" I mean, she never heard it, and so not every doctor ___ gonna be ___.

But not every doctor gives the kind of information that I think every patient would want if they had the opportunity, and not every patient knows. Most of them don't know how to advocate for themselves. They don't wanna bother the doctor, they wanna be compliant, they wanna be perceived as a good patient versus a bad patient, being demanding, you know, so it's a challenge.

Q: Well, thank you for that. Is there any other issues you think are important that I should be probing in the survey while I have the chance?

A: Your focus really is information about drugs and treatment for vasculitis. It'd be neat if there was some sort of a timeline-type chart that wasn't really timeline, but the various side effects – permanent side effects – 'cause some of the drugs, the older drugs, carry such huge cancer risks and not every patient knows that – like ___ and it's so toxic. I guess drugs like [Cytoxan] are not, relatively speaking. They all have some toxicities in side effects, but it would be nice to put 'em on a medically approved doctor ___ timeline – a graph of least toxic to… Toxic's not

quite the right word. You know what I'm sayin'?

Q: Yeah.

A: Because I run into patients who don't have a clue. They don't know what to ask their doctors, they don't know whether treatments are available, and they might not be able to advocate for themselves even with the information, but they could sure show it and point to it and say, "Talk to me about this or can we move down a level on this chart."

Q: Right. Yeah, that does sound like it would be a useful way, especially in graph form.

A: You know, I mean, even in our ones in the fall, the support group meeting has ___ last weekend, but the support group meetings we broke into those discussion groups. And one of the women were saying – an older woman, maybe seventyish – was saying she's been on X months, two years worth or something on Cytoxan. And the rest of the women were like, "Oh, man! ____." ___ somewhere, and her doctors just don't know. That's a 70-year-old ___. Times have changed. But if the patient cared enough to find out ____, we could hand this out in other support groups and the national group could hand it, then at least it would be available to them.

Q: Right.

A: ___ chose to act on it.

Q: So is it your impression that some doctor education about vasculitis medications is also needed, especially in rural areas?

A: It would be invaluable if there was a book – if there was a way to get them to read it. There would have to be some benefit to them…

Q: Right.

A: …for taking the time to read it…

Q: Right.

A: …to educate themselves. But it would make a huge difference 'cause so many of us patients are not at UNC ____ Clinic where they can really get some help.

Q: Right.

A: So ___, I'm fully aware that across the country, these big medical centers do not agree on protocols, but they all do agree on toxicity levels. We've had patients die

of lymphoma 20 years of surviving with vasculitis because of the side effects of the original treatment.

Q: Yeah. It would definitely ___ some people across centers to get together and create materials that would be considered approved.

A: It would, and it may be futile, but that is actually sort of where the rubber meets the road – what I see over and over. It's the rural that's not as capable of advocating for themselves that I see is the weak link in terms of their own health care. Whether they could actually take information that contradicted their doctor and apply it and advocate, I don't know.

I don't know if that would be enough to make a difference for them, but that's where I had the greatest difficulty as an advocate, trying to get…it's hard to get that across. If ___ at the patient and you're trying to be so careful not to upset anybody, you know? That's not the point. But you do know that there's information out there and that they could have a less toxic treatment that would probably be as effective.

Q: All right. Is there anything else you'd like to share with me?

A: I don't know, except I'm very grateful that you're trying to get the funding and that you're doing this. I think it's thrilling.

Q: Yeah. These interviews…well, they were suggested by my dissertation committee. I was just going to go ahead and pop right into the survey, but I'm really glad that they suggested that I do some of these interviews first. And so it's given the opportunity to ___ because I've been reading patient stories online and stuff to try to get patients' perspective.

A: Oh, yeah.

Q: [*Voice overlap.*] It's definitely been a lot more insightful as to, you know, what's going on with medications and…because I'm not necessarily a big…even though I'm doing a study about medications and cures, I don't always believe the doctor is the correct person to know what's best for the patient. And, you know, the patient knows what's best for the patient.

A: Right.

Q: So…

A: Right.

Q: …even though it's about ___ it's not necessarily my viewpoint. But, you know, having this kind of information will be really useful. Over here, I've got a pre-

doctoral fellowship over at the kidney center with [Dr. Fall], [Dr. Knockman] and other people, and so I can talk to them about this information and then…

A:　　That's great.

Q:　　…___ to suggest putting in for some money to try to address this issue, just based off of the four interviews that I've done because when you do interviews – like, what you hear independently from a certain number of people ___ the issue.

A:　　Well, yeah. If you've got Diane, Sean, ____, and you've got the best ___ people that advocate for ___, and you know.

[*End of interview.*]

APPENDIX C:
BASELINE QUESTIONNAIRE

FACT SHEET FOR THE ASSIST STUDY

IRB Study # 06-0408 **Date:** April 23, 2008
Title of Study: ASSIST – Accessing Social Support in Symptom Treatment Study
Principal Investigator: Delesha Miller Carpenter, MSPH
UNC-Chapel Hill Department: UNC Kidney Center
Advisor: Robert F. DeVellis, PhD
3300 Thurston Bowles Building, CB#7280
Chapel Hill, NC 27599
919-966-0557
Study Contact telephone number: 919-966-2561 x 302
Study Contact email: dlmiller@email.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 stop participating at any time, for any reason, without penalty.

The information you share by completing these surveys will help us to better understand how support from loved ones helps individuals cope with vasculitis. There 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 ask the researchers named above if you have any questions about this study.

What is the purpose of this study?

The purpose of the ASSIST Study is to understand where you get information about your vasculitis medications. Additionally, this study seeks to understand how support and interactions in close relationships (e.g. spouse/partner, family member, friend, doctor) affect your ability to cope with and effectively manage vasculitis. This is one of the first studies to investigate the effects of different supportive relationships for vasculitis patients.

How many people will take part in this study?

We plan to enroll a total of 300 vasculitis patients in this research study.

How long will it take to complete the survey?

There are two study surveys. The first survey should take no longer than 1 hour to complete, while the second survey should take approximately 30 minutes to complete. You can end your participation in the study at any time.

What will happen if you take part in the study

If you decide to participate in this study, you will need to contact Delesha Carpenter (919-966-2561 x 302, dlmiller@email.unc.edu) to receive a participant ID number. This ID# will be used in place of your name on the study surveys. A document with your name and ID# will be kept on file; however, we will never link your name with your survey responses. You will use this ID number to log into the surveys. The surveys are confidential and will contain questions about how different people in your life (spouse/partner, family member, friend, doctor) interact with you to help you manage your vasculitis.

Specifically, you will be asked about the kinds of vasculitis information and support these people provide to you. You will also be asked about your vasculitis treatment regimen and how confident you are in managing your illness. You do not have to answer any questions that you do not wish to answer.

What are the possible benefits from being in this study?

Research is designed to benefit society by gaining new knowledge. Your participation is important because it helps us understand how support received in close relationships helps you to manage and effectively cope with vasculitis. You may not benefit personally from being in this research study.

What are the possible risks or discomforts involved from being in this study?

We do not think you will experience any discomfort or risk while completing these surveys. We encourage you to leave questions that make you feel uncomfortable blank.

How will your privacy be protected?

These surveys are confidential, so your name and contact information will never be associated with your survey answers. Your name will not be used in the presentation of this research to others, so no one will know how you responded.

Will you receive anything for being in this study?

After you complete the second survey, you will be mailed a $10 gift card to thank you for your time.

Will it cost you anything to be in this study?

There are no costs for being in the study.

<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, or concerns, you should contact Delesha Carpenter at 919-966-2561 x 302 or email dlmiller@email.unc.edu. You can also contact Dr. Robert DeVellis at 919-966-0557 or by emailing bob_devellis@unc.edu.

<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 you may contact, anonymously if you wish, the Institutional Review Board at 919-966-3113 or by email to IRB_subjects@unc.edu.

I have read and understood the information contained in this fact sheet.

☐ Yes ☐ No

Please enter your **3-digit login number**. If you do not know your login number, please call Delesha Carpenter at 919-608-4938. To enter your login number, click on the blank box below and type the three numbers.

-SECTION ONE-

General Information

Please enter today's date.
Example: 12/31/2008

How old were you on your last birthday?

What is your gender?
☐ Male
☐ Female

What is your race? *(Check all that apply)*
☐ African American
☐ American Indian
☐ Asian
☐ Hispanic/Latino
☐ White
☐ Other

What is the highest grade or year of school you have completed? Please enter 16 if you have completed a Bachelor's degree, 18 if you have completed a Master's degree, and 22 if you have completed a doctoral degree.

What is your current health insurance status?
☐ Insured
☐ Not Insured

Does your insurance company currently cover the majority (greater than 80%) of your vasculitis medication costs?
☐ Yes
☐ No
☐ Don't know

In what year did you receive a medical diagnosis of vasculitis? For example, if you were diagnosed in 2002, please enter 2002.

What form of vasculitis has your doctor diagnosed you with? *(Check all that apply)*
☐ Wegener's granulomatosis

☐ Microscopic polyangiitis
☐ Churg-Strauss syndrome
☐ ANCA disease
☐ Don't know
☐ Other (Please specify):

During the **past week**, have you experienced **any** vasculitis symptoms?
☐ Yes
☐ No
☐ Don't know

When was the last time you experienced a flare-up or relapse of your vasculitis?
☐ I am currently experiencing a flare-up or relapse
☐ Less than 1 year ago
☐ More than 1 year ago
☐ I have never experienced a flare-up or relapse

Based on how you have been feeling during the **PAST WEEK**, please select the one number that best represents how <u>severe</u> you consider your vasculitis to be.

Not at all severe	2	3	4	Moderately severe	6	7	8	Extremely severe

Have you ever had a kidney transplant?
☐ Yes
☐ No

When did you receive the kidney transplant? Example: 02/2004
Month/year

Have you **ever** been on dialysis?
☐ Yes
☐ No

Are you **currently** on dialysis?
☐ Yes
☐ No

Do you have any major medical conditions other than vasculitis?
☐ Yes
☐ No

Please list the other major medical conditions you have.

(Items from Section Two and Three were not used in this dissertation)

-SECTION FOUR-

This section asks about where you get information about your vasculitis medicines.

This section asks about sources of vasculitis medicine information. In the **PAST YEAR**, please indicate **HOW OFTEN you have gotten vasculitis medicine information** from the sources listed below. Please choose the **ONE** answer that best represents how you get information.

	Never	Rarely	Sometimes	Often	Always
Doctors	☐	☐	☐	☐	☐
Pharmacists	☐	☐	☐	☐	☐
Nurses	☐	☐	☐	☐	☐
Brochures & pamphlets	☐	☐	☐	☐	☐
Medicine package insert	☐	☐	☐	☐	☐
Articles & books	☐	☐	☐	☐	☐
Internet (information websites)	☐	☐	☐	☐	☐
Support groups (on the Internet or in-person)	☐	☐	☐	☐	☐
Spouse/partner	☐	☐	☐	☐	☐
Family members (other than spouse)	☐	☐	☐	☐	☐
Friends	☐	☐	☐	☐	☐
Newsletters	☐	☐	☐	☐	☐
Other	☐	☐	☐	☐	☐

If you have ever gotten information about your medicines from the Internet, which websites did you get information from <u>most often</u> (Vasculitis Foundation, WebMD, pharmaceutical companies)? If you do not get information about your vasculitis medicines from the Internet, please leave this question blank.

-SECTION FIVE-

This section is about your vasculitis medicines.

The following questions are about whether you have ever received conflicting information about your vasculitis medicines from two different sources. These sources could be two different doctors, a doctor and the pharmacist, a doctor and the Internet, the Internet and the medicine information insert, etc. **Please indicate whether you have EVER received conflicting information about the following.**

	Have received conflicting information	Have not received conflicting information	Don't remember
What time of day to take your vasculitis medicines	☐	☐	☐
How to take your vasculitis medicines (with or without food, for example)	☐	☐	☐
How much (dose) of your vasculitis medicines to take	☐	☐	☐
How long to take your vasculitis medicines (5 months vs. 6 months, for example)	☐	☐	☐
The side effects associated with your vasculitis medicines	☐	☐	☐
The severity of your vasculitis medicines' side effects	☐	☐	☐

-SECTION SIX-

This section asks about your doctor.

Do you have a doctor that you see for your vasculitis?
☐ Yes
☐ No

What kind of doctor do you see for your vasculitis? (Please refer to your "<u>main</u>" vasculitis doctor.)
☐ Rheumatologist
☐ Nephrologist
☐ Internist
☐ General practitioner (GP)
☐ Other (Please specify):

How long have you been seeing your "main" vasculitis doctor?
☐ Less than 1 year
☐ 1-3 years
☐ More than 3 years

The following questions are about the **doctor who prescribes your vasculitis medicines**. Please answer how often you **DISCUSS** different aspects of your vasculitis medicines with your doctor. Please do not refer to medicines you are taking for reasons other than vasculitis.

	We never discuss	We hardly ever discuss	We discuss a modest amount	We discuss a lot
Your medicines	○	○	○	○
How to take your medicines (with meals, with water, in the morning)	○	○	○	○
Your medicine's side effects	○	○	○	○
How your medicines interact with other medicines you are taking	○	○	○	○
Alternative/complementary/holistic medicines or therapies	○	○	○	○
New medical trials or research studies	○	○	○	○
The financial costs of your medicines	○	○	○	○
How effective your medicines are at treating your symptoms	○	○	○	○

The following questions ask about how supportive your doctor is when it comes to managing your vasculitis medicines. Please REFER ONLY TO YOUR **VASCULITIS MEDICINES** when answering these questions.Please choose the **ONE** answer that best represents **how often your DOCTOR has been supportive** in each of the following areas.

	N/A	Does not do this	Does this a little	Does this a fair amount	Does this a lot
Support you in taking your vasculitis medicines	☐	☐	☐	☐	☐
Provide helpful hints about how to remember your vasculitis medicines	☐	☐	☐	☐	☐
Make it easy to get your vasculitis medicine refills	☐	☐	☐	☐	☐
Encourage you to take your vasculitis medicines when you are not feeling well or experiencing side effects	☐	☐	☐	☐	☐
Share new information about vasculitis medicines with you	☐	☐	☐	☐	☐
Provide helpful hints about how to deal with your vasculitis medicine's side effects	☐	☐	☐	☐	☐
Take your needs into account when making recommendations about which vasculitis medicines to take	☐	☐	☐	☐	☐
Give you enough support when it comes to taking your vasculitis medicines as prescribed	☐	☐	☐	☐	☐

For this next group of questions, use your mouse arrow to move the gray bar (on the right of the red number scale) up and down.

On a scale from 1 to 9, with 1 being "not at all knowledgeable" and 9 being "very knowledgeable", how knowledgeable is your doctor about vasculitis medicines?
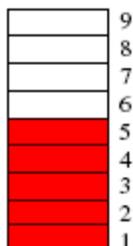
On a scale from 1 to 9, with 1 being "not at all expert" and 9 being "very expert", how expert is your doctor about vasculitis medicines?

	9
	8
	7
	6
	5
	4
	3
	2
	1

-SECTION SEVEN-

This section asks about your spouse or partner.

You are halfway done with the survey now!

Are you currently married or in a committed/serious relationship with a romantic partner?
☐ Yes
☐ No

Have you been in a relationship with your spouse or partner for longer than 1 year?
☐ Yes
☐ No

How many years have you been in a relationship with your current spouse/partner?

The following questions are about your spouse/partner. Please answer **how often you DISCUSS different aspects of your vasculitis medicines with your spouse/partner**.
Please do not refer to medicines you are taking for reasons other than vasculitis.

	We never discuss	We hardly ever discuss	We discuss a modest amount	We discuss a lot
Your medicines	○	○	○	○
How to take your medicines (with meals, with water, in the morning)	○	○	○	○
Your medicine's side effects	○	○	○	○
How your medicines interact with other medicines you are taking	○	○	○	○
Alternative/complementary/holistic medicines or therapies	○	○	○	○
New medical trials or research studies	○	○	○	○
The financial costs of your medicines	○	○	○	○
How effective your medicines are at treating your symptoms	○	○	○	○

The following questions ask about how supportive your spouse/partner is when it comes to managing your vasculitis medicines. Please refer only to your VASCULITIS MEDICINES when answering these questions. Please choose the **ONE** answer that best represents **how often your SPOUSE/PARTNER does each of the following**.

	N/A	Does not do this	Does this a little	Does this a fair amount	Does this a lot
Support you in taking your vasculitis medicines	◌	◌	◌	◌	◌
Encourage you to take your medicines exactly as your doctor prescribed	◌	◌	◌	◌	◌
Help you to remember to take your vasculitis medicines	◌	◌	◌	◌	◌
Help you to get your vasculitis medicine refills	◌	◌	◌	◌	◌
Encourage you to call your doctor when you are not feeling well or experiencing side effects	◌	◌	◌	◌	◌
Share new information about vasculitis medicines with you	◌	◌	◌	◌	◌
Provide helpful hints about how to deal with your vasculitis medicine's side effects	◌	◌	◌	◌	◌
Encourage you to ask your health care provider questions about your vasculitis medicines	◌	◌	◌	◌	◌
Give you enough support when it comes to taking your vasculitis medicines as prescribed	◌	◌	◌	◌	◌

For this next group of questions, use your mouse arrow to move the gray bar (on the right of the red number scale) up and down.

On a scale from 1 to 9, with 1 being "not at all knowledgeable" and 9 being "very knowledgeable", how knowledgeable is your spouse/partner about vasculitis medicines?

```
9
8
7
6
5
4
3
2
1
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On a scale from 1 to 9, with 1 being "not at all expert" and 9 being "very expert", how expert is your spouse/partner about vasculitis medicines?

```
9
8
7
6
5
4
3
2
1
```

Is your spouse/partner a medical professional (doctor, nurse, or other health care provider)?
☐ Yes
☐ No

Were you in a relationship with your current spouse/partner when you were diagnosed with vasculitis?
☐ Yes
☐ No

How, if at all, has your relationship with your spouse/partner changed since you were diagnosed with vasculitis? Please briefly describe any positive or negative changes that you have noticed.

Has a spouse/partner ever left you (divorced, separated, broken up) because of your vasculitis?
☐ Yes
☐ No

-SECTION EIGHT-

This section asks about a family member (other than a spouse) or close friend who is most involved with your vasculitis.

Please think of a FAMILY MEMBER (**other than your spouse**) or CLOSE FRIEND who is **MOST INVOLVED** when it comes to your vasculitis. The family member could be anyone in your family, including a child, sibling, cousin, or parent.

Please choose the answer that best represents this person's relationship to you.
☐ Child
☐ Sibling (brother or sister)
☐ Cousin
☐ Parent
☐ Close friend
☐ Other (Please specify):
☐ No one

Is this family member or friend over 18 years of age?
☐ Yes
☐ No

What is the gender of this family member or friend?
☐ Male
☐ Female

The following questions are about the **family member or friend you just described.** Please answer **how often you DISCUSS** different aspects of your vasculitis medicines with this person. Please do not refer to medicines you are taking for reasons other than vasculitis.

	We never discuss	We hardly ever discuss	We discuss a modest amount	We discuss a lot
Your medicines	⊙	⊙	⊙	⊙
How to take your medicines (with meals, with water, in the morning)	⊙	⊙	⊙	⊙
Your medicine's side effects	⊙	⊙	⊙	⊙
How your medicines interact with other medicines you are taking	⊙	⊙	⊙	⊙
Alternative/complementary/holistic medicines or therapies	⊙	⊙	⊙	⊙
New medical trials or research studies	⊙	⊙	⊙	⊙
The financial costs of your medicines	⊙	⊙	⊙	⊙
How effective your medicines are at treating your symptoms	⊙	⊙	⊙	⊙

The following questions ask about how supportive your family member or friend is when it comes to managing your vasculitis medicines. Please refer only to your VASCULITIS MEDICINES when answering these questions. Please choose the **ONE** answer that best represents **how often your FAMILY MEMBER or FRIEND does** each of the following.

	N/A	Does not do this	Does this a little	Does this a fair amount	Does this a lot
Support you in taking your vasculitis medicines	○	○	○	○	○
Encourage you to take your medicines exactly as your doctor prescribed	○	○	○	○	○
Help you to remember to take your vasculitis medicines	○	○	○	○	○
Help you to get your vasculitis medicine refills	○	○	○	○	○
Encourage you to call your doctor when you are not feeling well or experiencing side effects	○	○	○	○	○
Share new information about vasculitis medicines with you	○	○	○	○	○
Provide helpful hints about how to deal with your vasculitis medicine's side effects	○	○	○	○	○
Encourage you to ask your health care provider questions about your vasculitis medicines	○	○	○	○	○
Give you enough support when it comes to taking your vasculitis medicines as prescribed	○	○	○	○	○

For this next group of questions, use your mouse arrow to move the gray bar (on the right of the red number scale) up and down.

On a scale from 1 to 9, with 1 being "not at all knowledgeable" and 9 being "very knowledgeable", how knowledgeable is your family member of friend about vasculitis medicines?

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9
8
7
6
5
4
3
2
1
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On a scale from 1 to 9, with 1 being "not at all expert" and 9 being "very expert", how expert is your family member or friend about vasculitis medicines?

```
9
8
7
6
5
4
3
2
1
```
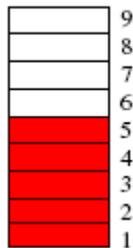
Is your family member or friend a medical professional (doctor, nurse, or other health care provider)?

☐ Yes
☐ No

How, if at all, has your relationship with your **family** changed since you were diagnosed with vasculitis? Please briefly describe any positive or negative changes that you have noticed.

How, if at all, has your relationship with your **friends** changed since you were diagnosed with vasculitis? Please briefly describe any positive or negative changes that you have noticed.

-SECTION NINE-

This section asks about your pharmacy and your pharmacist.

Where do you get your vasculitis prescriptions filled most often?
☐ Community pharmacy (Eckerds, CVS, Walgreens)
☐ Hospital pharmacy
☐ Mail-order pharmacy
☐ Internet pharmacy
☐ Other (Please specify):

Does your pharmacy give you information about your vasculitis medicines?
☐ Yes
☐ No

Do you and your pharmacist ever discuss your vasculitis medicines?
☐ Yes
☐ No

The following questions are about your **pharmacist.** Please answer **how often you DISCUSS** different aspects of your vasculitis medicines with your pharmacist. Please do not refer to medicines you are taking for reasons other than vasculitis.

	We never discuss	We hardly ever discuss	We discuss a modest amount	We discuss a lot
Your medicines	☐	☐	☐	☐
How to take your medicines (with meals, with water, in the morning)	☐	☐	☐	☐
Your medicine's side effects	☐	☐	☐	☐
How your medicines interact with other medicines you are taking	☐	☐	☐	☐
Alternative/complementary/holistic medicines or therapies	☐	☐	☐	☐
New medical trials or research studies	☐	☐	☐	☐
The financial costs of your medicines	☐	☐	☐	☐
How effective your medicines are at treating your symptoms	☐	☐	☐	☐

The following questions ask about how supportive your pharmacist is when it comes to managing your vasculitis medicines. Please refer only to your VASCULITIS MEDICINES when answering these questions. Please choose the **ONE** answer that best represents **how often your PHARMACIST does** each of the following.

	N/A	Does not do this	Does this a little	Does this a fair amount	Does this a lot
Support you in taking your vasculitis medicines	⊙	⊙	⊙	⊙	⊙
Encourage you to take your medicines exactly as your doctor prescribed	⊙	⊙	⊙	⊙	⊙
Provide helpful hints about how to remember your medicines	⊙	⊙	⊙	⊙	⊙
Make it easy to get your vasculitis medicine refills	⊙	⊙	⊙	⊙	⊙
Encourage you to call your doctor when you are not feeling well or experiencing side effects	⊙	⊙	⊙	⊙	⊙
Share new information about vasculitis medicines with you	⊙	⊙	⊙	⊙	⊙
Provide helpful hints about how to deal with your vasculitis medicine's side effects	⊙	⊙	⊙	⊙	⊙
Give you enough support when it comes to taking your vasculitis medicines as prescribed	⊙	⊙	⊙	⊙	⊙

For this next group of questions, use your mouse arrow to move the gray bar (on the right of the red number scale) up and down.

On a scale from 1 to 9, with 1 being "not at all knowledgeable" and 9 being "very knowledgeable", how knowledgeable is your pharmacist about vasculitis medicines?
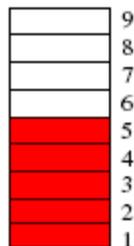
On a scale from 1 to 9, with 1 being "not at all expert" and 9 being "very expert", how expert is your pharmacist about vasculitis medicines?

-SECTION TEN-

This section asks about someone else that you may know who is living with vasculitis.

Do you know someone else who has vasculitis? This could include someone from a vasculitis support group, your neighborhood, church, or clinic. This could also include someone with vasculitis that you met on the Internet or on an online chat group.

☐Yes
☐No

The following questions are about another person you know that is living with vasculitis. **If you know multiple people living with vasculitis, ANSWER THESE QUESTIONS ABOUT THE PERSON WITH WHOM YOU ARE CLOSEST**. Please answer how often you discuss different aspects of your vasculitis medicines with this person. Please do not refer to medicines you are taking for reasons other than vasculitis.

	We never discuss	We hardly ever discuss	We discuss a modest amount	We discuss a lot
Your medicines	○	○	○	○
How to take your medicines (with meals, with water, in the morning)	○	○	○	○
Your medicine's side effects	○	○	○	○
How your medicines interact with other medicines you are taking	○	○	○	○
Alternative/complementary/holistic medicines or therapies	○	○	○	○
New medical trials or research studies	○	○	○	○
The financial costs of your medicines	○	▓	○	○
How effective your medicines are at treating your symptoms	○	○	○	○

Thinking of the person living with vasculitis that you referred to early, please answer how supportive this person is when it comes to managing your vasculitis medicines. Please refer only to your VASCULITIS MEDICINES when answering these questions. Please choose the **ONE** answer that best represents **how often the PERSON LIVING WITH VASCULITIS does** each of the following.

	N/A	Does not do this	Does this a little	Does this a fair amount	Does this a lot
Support you in taking your vasculitis medicines	⊙	⊙	⊙	⊙	⊙
Encourage you to take your medicines exactly as your doctor prescribed	⊙	⊙	⊙	⊙	⊙
Help you to remember to take your vasculitis medicines	⊙	⊙	⊙	⊙	⊙
Help you to get your vasculitis medicine refills	⊙	⊙	⊙	⊙	⊙
Encourage you to call your doctor when you are not feeling well or experiencing side effects	⊙	⊙	⊙	⊙	⊙
Share new information about vasculitis medicines with you	⊙	⊙	⊙	⊙	⊙
Provide helpful hints about how to deal with your vasculitis medicine's side effects	⊙	⊙	⊙	⊙	⊙
Encourage you to ask your health care provider questions about your vasculitis medicines	⊙	⊙	⊙	⊙	⊙
Give you enough support when it comes to taking your vasculitis medicines as prescribed	⊙	⊙	⊙	⊙	⊙

For this next group of questions, use your mouse arrow to move the gray bar (on the right of the red number scale) up and down.

On a scale from 1 to 9, with 1 being "not at all knowledgeable" and 9 being "very knowledgeable", how knowledgeable is this person about vasculitis medicines?

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9
8
7
6
5
4
3
2
1
```

On a scale from 1 to 9, with 1 being "not at all expert" and 9 being "very expert", how expert is this person about vasculitis medicines?

```
9
8
7
6
5
4
3
2
1
```
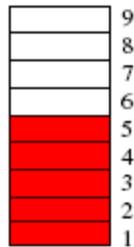
Is this person a medical professional (doctor, nurse, or other health care provider)?
☐ Yes
☐ No

-SECTION ELEVEN-

This section asks about your Internet use.
You are almost done with the survey now!

How often do you use the Internet?
- ☐ Rarely or never
- ☐ Occasionally
- ☐ Frequently

Do you ever use the Internet to find out more information about vasculitis?
- ☐ Yes
- ☐ No

The following questions are about the **Internet**. Please answer **how often you have looked up** different types of information about your VASCULITIS MEDICINES. **Please do not refer to medicines you are taking for reasons other than vasculitis.**

	Never look up	Hardly ever look up	Look up a modest amount	Look up a lot
Your medicines	⊙	⊙	⊙	⊙
How to take your medicines (with meals, with water, in the morning)	⊙	⊙	⊙	⊙
Your medicine's side effects	⊙	⊙	⊙	⊙
How your medicines interact with other medicines you are taking	⊙	⊙	⊙	⊙
Alternative/complementary/holistic medicines or therapies	⊙	⊙	⊙	⊙
New medical trials or research studies	⊙	⊙	⊙	⊙
The financial costs of your medicines	⊙	⊙	⊙	⊙
How effective your medicines are at treating your symptoms	⊙	⊙	⊙	⊙

How long have you been using the Internet?
- ☐ Less than 1 year
- ☐ 1-3 years
- ☐ More than 3 years

For this next group of questions, use your mouse arrow to move the gray bar (on the right of the red number scale) up and down.

On a scale from 1 to 9, with 1 being "not at all knowledgeable" and 9 being "very knowledgeable", how knowledgeable are Internet sources about vasculitis medicines?

	9
	8
	7
	6
	5
	4
	3
	2
	1
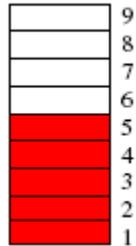
On a scale from 1 to 9, with 1 being "not at all expert" and 9 being "very expert", how expert are Internet sources about vasculitis medicines?

	9
	8
	7
	6
	5
	4
	3
	2
	1
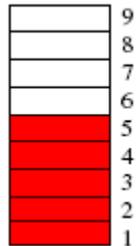
-SECTION TWELVE-

This section asks about the different vasculitis medicines you take and how you take them.

This is the last section of the survey!

Please indicate if you are currently taking any of the following medicines to manage your vasculitis, its complications, or its treatment side effects.

Start with the first drop down box next to Cytoxan. Use your mouse to press the black arrow that is next to the blank box and select the correct answer. If you do not have a prescription for this medicine, then choose the "N/A" option and move down to the next medicine. After you answer how often you take the medicine, **move to the second column** in the same row and select how you take your medicine. Then **move to the third column** and select 'Yes' or 'No' to indicate whether you have experienced any side effects.

PLEASE REPEAT THIS PROCEDURE FOR EACH MEDICINE.

	How many times a day are you supposed to take this medicine?	How do you take this medicine?	Have you ever experienced any side effects related to this medicine?
Cyclophosphamide (Cytoxan)	☐N/A- I do not have a prescription for this medicine ☐Less than once a day ☐Once a day ☐Twice a day ☐3 times a day ☐More than 3 times a day ☐As needed	☐By mouth ☐Injected ☐Inhaled ☐Ointment, cream ☐Other	☐Yes ☐No
Steroids (Prednisone, Methylprednisolone)			
Co-trimoxazole (Bactrim)			
Azathioprine (Imuran)			
Cyclosporin			
Methotrexate (Trexall, Rheumatrex)			
Mycophenolate mofetil (Cellcept)			
Rituximab (Rituxan)			
Other #1			
Other #2			

CONGRATULATIONS!
You have finished the survey!

Thank you for taking the time to complete this survey. The project director will send you an email in about 3 months asking you to complete the second survey, which is much shorter.

If you would like to learn more about vasculitis, the Vasculitis Foundation is a wonderful resource.

Vasculitis Foundation
www.vasculitisfoundation.org
(800) 277-9474

APPENDIX D:
FOLLOW-UP QUESTIONNAIRE

Would you like to read the study fact sheet? This is the same fact sheet that was at the beginning of the survey you took three months ago.

☐ Yes
☐ No

Please enter your **3-digit login number**. If you do not know your login number, please call Delesha Carpenter at 919-608-4938. To enter your login number, click on the blank box below and type the three numbers.

-SECTION ONE-

General Information

Please enter today's date.
Example: 12/31/2008

How old were you on your last birthday?

What is your gender?
☐ Male
☐ Female

In what year did you first begin taking medicines to treat your vasculitis? For example, if you began taking vasculitis medicines in 2002, please enter 2002.

Based on how you have been feeling during the **PAST WEEK**, please select the one number that best represents how <u>severe</u> you consider your vasculitis to be.

Not at all severe	2	3	4	Moderately severe	6	7	8	Extremely severe

(Items from Section Two were not used in this dissertation)

-SECTION THREE-

This section asks about your vasculitis medicines.

Please indicate if any of the following changes in your medicine regimen have occurred in the <u>past three months</u>? (Check all that apply)

Please indicate if you are currently taking any of the following medicines to manage your vasculitis, its complications, or its treatment side effects.

☐ Started taking a new vasculitis medicine
☐ Stopped taking a vasculitis medicine
☐ Changed how you were taking a vasculitis medicine (time of day, dose, etc)
☐ There have not been any changes to my vasculitis medicine regimen

Please answer the following questions about your medicines.

According to your current treatment plan, how many different medicines are you supposed to be taking for your vasculitis? This includes medicines used to treat vasculitis, its complications (like blood pressure medicines), and treatment side effects.

How many different medicines are you supposed to be taking for reasons UNRELATED to your vasculitis?

Please answer the following question about your <u>current</u> vasculitis medicine regimen, which includes medicines used to treat vasculitis, its complications, and its treatment side effects.

In your opinion, how complicated is your current vasculitis medicine regimen?

Not at all complex	2	3	4	Moderately complex	6	7	8	Extremely complex

The following questions refer to all of the health-professional recommended medicines you <u>take on your own</u> (all medicines taken by yourself or administered in your home by someone else) for vasculitis or its complications. When answering these questions, please do NOT consider medicines that are administered in a doctor's office or clinic by a health professional.

During the past 4 weeks, what percentage of your recommended medicine(s) did you take exactly as directed? 100% would mean you took every single dose exactly as prescribed and 50% would mean you took half your doses exactly as prescribed.

☐ 0-24%
☐ 25-49%
☐ 50-74%
☐ 75-99%
☐ 100%

Please refer to the **PAST FOUR WEEKS** when answering these questions. Select the one answer that best represents your medicine-taking behavior.

	None of the time	A little of the time	Some of the time	Most of the time	All of the time
I skipped a dose of my medicine.	◉	◉	◉	◉	◉
I did not follow specific instructions for taking my medicines (for example, taking medicine with meals, drinking a certain amount of water, timing of doses).	◉	◉	◉	◉	◉
I could have done a better job following my health professionals' recommendations for taking my medicine.	◉	◉	◉	◉	◉
During the past 4 weeks, how often did you FAIL to take all of your recommended medicine(s) EXACTLY as directed?	◉	◉	◉	◉	◉
During the past 4 weeks, how often did you have a hard time taking your medicine(s) exactly as prescribed?	◉	◉	◉	◉	◉
During the past 4 weeks, how often did you find it easy to take your medicine(s) exactly as directed?	◉	◉	◉	◉	◉
During the past 4 weeks, how often did you miss a dose of your medicine because it was too expensive?	◉	◉	◉	◉	◉
During the past 4 weeks, how often did you not get a prescription filled/refilled because it was too expensive?	◉	◉	◉	◉	◉

Start with the first drop down box next to Cytoxan. Use your mouse to press the black arrow that is next to the blank box and select the correct answer. If you do not have a prescription for this medicine, then choose the "N/A" option and move down to the next medicine. After you answer how often you take the medicine, **move to the second column** in the same row and select how you take your medicine. Then **move to the third column** and select 'Yes' or 'No' to indicate whether you have experienced any side effects.

PLEASE REPEAT THIS PROCEDURE FOR EACH MEDICINE.

	How many times a day are you supposed to take this medicine?	How do you take this medicine?	Have you ever experienced any side effects related to this medicine?
Cyclophosphamide (Cytoxan)	☐N/A- I do not have a prescription for this medicine ☐Less than once a day ☐Once a day ☐Twice a day ☐3 times a day ☐More than 3 times a day ☐As needed	☐By mouth ☐Injected ☐Inhaled ☐Ointment, cream ☐Other	☐Yes ☐No
Steroids (Prednisone, Methylprednisolone)			
Co-trimoxazole (Bactrim)			
Azathioprine (Imuran)			
Cyclosporin			
Methotrexate (Trexall, Rheumatrex)			
Mycophenolate mofetil (Cellcept)			
Rituximab (Rituxan)			
Other #1			
Other #2			

(Items from Section Four were not used in this dissertation)

-SECTION FIVE-

This section is about your medication beliefs.

The following statements are about your vasculitis medicine beliefs. For each statement, please choose the **ONE** answer that best represents what you believe.

	Strongly disagree	Somewhat disagree	Neither agree or disagree	Somewhat agree	Strongly agree
My health, at present, depends on my medicines.	◯	◯	◯	◯	◯
My life would be impossible without my medicines.	◯	◯	◯	◯	◯
Without my medicines, I would be very ill.	◯	◯	◯	◯	◯
My health in the future will depend on my medicines.	◯	◯	◯	◯	◯
My medicines protect me from being worse.	◯	◯	◯	◯	◯

-SECTION SIX-

This section asks about how confident you are in performing medicine-related tasks.

For each question below, please select **ONE** answer that best represents your response.

How *confident* are you that you can take your VASCULITIS medicines correctly...

	Not at all confident		Somewhat confident		Very confident
When you take several different medicines each day?	☐	☐	☐	☐	☐
When you have a busy day planned?	☐	☐	☐	☐	☐
When you are away from home?	☐	☐	☐	☐	☐
When no one reminds you to take the medicine?	☐	☐	☐	☐	☐
When you take medicines more than once a day?	☐	☐	☐	☐	☐
When your normal routine gets messed up?	☐	☐	☐	☐	☐
When the schedule to take the medicines is not convenient?	☐	☐	☐	☐	☐

Thinking about the vasculitis medicines prescribed to you by your doctor(s), please answer the following questions.

	True	False
Do you ever forget to take your medicine?	☐	☐
Are you ever careless at times about taking your medicine?	☐	☐
When you feel better do you sometimes stop taking your medicine?	☐	☐
Sometimes, if you feel worse when you take the medicine, do you stop taking it?	☐	☐

-SECTION SEVEN-

Your opinions

Please use the space below to comment on anything related to vasculitis and its treatment regimen that you think is important but was not addressed in this survey.

CONGRATULATIONS!
You have finished the survey!

Please press the **NEXT** button to make sure your survey answers are recorded.

Thank you so much for taking the time to complete the survey. The project director will put your gift card in the mail soon.

If you would like to learn more about vasculitis, the Vasculitis Foundation is a wonderful resource.

Vasculitis Foundation
www.vasculitisfoundation.org
(800) 277-9474

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