

PATIENT PERSPECTIVES ON BARRIERS TO HEPATITIS C TREATMENT:
QUALITATIVE ANALYSIS OF PATIENT FOCUS GROUPS

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DEDICATION

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PATIENT PERSPECTIVES ON BARRIERS TO HEPATITS C TREATMENT:
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by

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Abstract

Much of the research to date on barriers to treatment for patients with hepatitis C (HCV) has approached the problem from either the perspective of either the medical provider or healthcare system. To better understand these barriers from the patients' perspectives, exploratory focus groups were conducted with both mono-infected HCV and coinfecting HCV/HIV patients. Nine focus groups with a total of 48 patients were conducted in 2008 and 2009. Transcribed focus group passages were categorized using qualitative analysis software. The category with the most passages was treatment knowledge (24%), which contained patients' expressions of their personal understanding as well as requests for additional information. The category with the fewest passages was desire for treatment (6%). The treatment barriers category included frustration with medical provider communication and difficulty with physician-patient relationships as well as social stigma and lack of accurate disease knowledge. These areas of concern expressed by patients in focus groups have highlighted underexplored areas that may warrant future investigation as potential opportunities for development of intervention.

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CHAPTER ONE

Introduction

Statement of the Problem

The hepatitis C virus (HCV) represents a significant public health concern as approximately 2.2 percent of the world's population, 130 million individuals as of 2007, is currently infected with the disease (Te and Jensen, 2010). Based on data available from 2009, within the United States alone approximately 2.7-3.9 million individuals are currently infected, with an additional estimated 16,000 new cases each year (Centers for Disease Control and Prevention [CDC], 2009). In the United States, the CDC (2009) estimates 12,000 chronic liver disease deaths related to viral hepatitis in 2009. However, there are some who estimate a much higher prevalence of infection. According to Edlin (2005), estimates of HCV infection in the United States may be low by as many as one million individuals due to exclusions of critical populations such as incarcerated persons, homeless persons, and those currently hospitalized.

The disease process of HCV is often asymptomatic and slow moving. Many patients have few or no symptoms, sometimes for decades, while their liver is slowly being overrun with disease. The current treatment regimen for HCV involves up to 12 months of daily pills and injections, which have a variety of negative side effects. This combination of asymptomatic disease and a difficult treatment side effect profile, along with many other individual, relational, and

systemic factors, can interfere with patients obtaining and completing treatment. End-stage liver disease, past the point of benefitting from standard HCV treatment, requires liver transplantation, which is very costly and unobtainable for most patients without substantial contribution, such as an insurance plan.

Although figures vary, an estimated 16-33 percent of patients diagnosed with HIV are also infected with HCV (Sherman, Rouster, Chung, & Rajicic, 2002; Soriano et al. 2002). This large subpopulation of coinfecting HCV/HIV patients may experience their diseases differently than mono-infected patients and are important to consider when conducting research on HCV populations.

Despite continued improvement in treatment efficacy (Poordad, F. et al., 2011) the vast majority of HCV patients never achieve a sustained virologic response (SVR) (Murray et al., 2011). There are several major hurdles for patients to clear between acquiring the disease and achieving SVR. Due to the asymptomatic course of HCV over many years, patients may not even be aware of their infection status. As such, many do not receive a diagnosis, and thus treatment, until it is too late to receive treatment. Upon diagnosis, patients may be denied a referral for treatment by their physician due to a variety of potential factors that would negatively impact their likelihood of completing treatment and achieving SVR. For those patients who are referred, some do not begin treatment either through explicit choice or due to circumstances beyond their control. Of the patients who are fortunate enough to begin HCV treatment, a significant

proportion fail to complete the required number of weeks or months to maximally benefit from the medication. Finally, patients who move from diagnosis through completed treatment may or may not achieve SVR because of less than 100% drug efficacy. Each step in the journey from beginning to end has barriers that prevent patients from moving forward.

Much of the work of identifying barriers to treatment has focused on broad-based approaches that encompass several types of barriers including factors related to the patient, the physician, treatment eligibility, and/or the healthcare delivery system. Specifically, much of the research to date has worked to identify barriers to treatment from the perspective of the physician or healthcare delivery system. It is unclear at this time whether patients would identify the same or different barriers as the doctors or health clinics that provide treatment. Factors such as perceived social stigma (Moore, Hawley, & Bradley, 2009), unrealistic, inaccurate and/or unmet expectations regarding the effects of illness and treatment (Proeschold-Bell et al., 2010), and difficult communication with physicians (Cousin, Schmid Mast, Roter, & Hall, 2012), have all been identified as important to medical outcomes and patient treatment decisions.

This study explored HCV patients' thoughts and feelings about HCV and its treatment to identify barriers most salient and important to them by conducting content analysis of transcribed conversations obtained in a focus group setting. This analysis shed light not only on the experience of HCV among patients, but

also provides a window into their most pressing concerns in seeking and obtaining treatment. This early work utilizes an emergent theory approach, allowing the data to provide clarity for categorizing the content of the text.

CHAPTER TWO

Review of the Literature

Overview of Hepatitis C

The hepatitis C virus (HCV) was first cloned and named in April 1989 (Choo et al, 1989). Prior to that time, it was known only as Non-A/Non-B hepatitis. HCV is a virus transmitted primarily parenterally, especially through repeated or prolonged exposure to blood products. Prior to discovery of the virus, transmission also occurred in infected organ transplantation and blood transfusion. IV drug use has also been a primary transmission mode for the last three decades. HCV can also be transmitted sexually, but this occurs far less efficiently (Centers for Disease Control and Prevention, 1998). Although vaccines exist for other forms of hepatitis, the high mutability and unclear immune response to infection have prevented development of a vaccine for HCV to date (World Health Organization, 2011). Despite decades of research and treatment development, hepatitis infection has lagged behind other infectious diseases, namely HIV/AIDS, in public awareness. It was only in 2011 that the WHO dedicated the first official World Hepatitis Day on July 28.

According to the CDC (2011), there are at least six known HCV genotypes and more than 50 subtypes. This genetic variation in the virus is important to identify in patients as it affects the efficacy of treatment and can aid in determination of the necessary treatment length. The most common genotype in

the United States is genotype 1 (CDC, 2011). Even when treated with higher doses of medication over 48 weeks instead of 24, HCV genotype 1 has a low SVR rate, only between 40-50%, compared to genotypes 2 and 3, which have rates of 70-80% in clinical trials (Rosen, 2011). Thus, HCV patients, particularly in the United States, may not achieve SVR despite clearing each of the potential barriers mentioned throughout this discussion.

Prevalence and Incidence

The World Health Organization (WHO, 2011) estimates between 130 and 170 million people worldwide are currently infected with the virus. It is also estimated that three to four million new cases arise each year. The countries with the highest HCV prevalence are Egypt (22%), Pakistan (5%), and China (3%). The death toll from HCV is estimated at 350,000 each year across the globe (WHO, 2011).

The United States Centers for Disease Control and Prevention (CDC) estimated in a 2009 report (most recent available) that between 2.7 and 3.9 million Americans are currently living with HCV. This includes approximately 2,600 estimated new acute clinical cases and 16,000 new infections annually (CDC, 2009). Although HCV is a major contributor to the global disease burden, longitudinal data indicate that the rate of new infections has decreased dramatically from its zenith in the 1980s when an estimated 380,000 new infections occurred annually (Armstrong, Alter, McQuillan, & Margolis, 2000).

Because of the often long delay between infection and symptom presentation, the burden on the healthcare system at large may continue to increase as more infected persons move past the two-decade point from infection.

Although the majority of HIV patients are not coinfecting with HCV-HIV, coinfection prevalence increases significantly when considering only HIV patients with recognized risk for contracting HCV such as injection drug users or hemophiliacs (Sherman, Rouster, Chung, & Rajicic, 2002).

Treatment Recommendations

Although there is currently no vaccine against HCV infection, pharmacological treatments are available and can offer many patients an SVR, defined as undetectable HCV RNA in the patient's blood 24 weeks after the end of treatment. According to the CDC (2011), the current standard treatment of HCV is a combination of pegylated interferon and ribavirin, with SVR rates varying between 40% and 80%, depending on a number of factors, including the specific genotype of the HCV. Treatment duration for HCV is typically between 6 and 12 months (Weiland, 1999).

The relatively long duration of the treatment for HCV and the difficulty tolerating the side effects of interferon and ribavirin are important factors for patients deciding whether or not to pursue treatment. Some of the most common adverse effects from standard HCV treatment are headache, fever, muscle pain and stiffness, nausea, loss of appetite, weight loss, diarrhea, hair loss, fatigue,

depressed mood, anhedonia, insomnia, and irritability (Manns, Wedermeyer, and Cornberg, 2006). The psychiatric side effects of standard treatment are of particular importance for patients and providers. The overlap of psychiatric illness and behaviors that increase risk of HCV infection results in patients presenting for treatment evaluation with preexisting psychiatric comorbidity. As such, providers may be reticent to prescribe a treatment regimen that is known to have psychiatric side effects, as it could exacerbate patients' symptoms. Additionally, some providers may hold the belief that patients with psychiatric illness are less likely to be adherent to medical treatment plans. Because of the necessity of high adherence in HCV treatment for the best chance of eradicating the infection and the serious nature of the psychiatric side effects of treatment, the patient's psychiatric history is typically taken into consideration in treatment decisions.

Health Consequences of Untreated Disease

Although chronic HCV infection is asymptomatic for many years, if left untreated, the illness will eventually result in cirrhosis, and sometimes liver failure or hepatocellular carcinoma (Thein, Yi, Dore, & Krahn, 2008). Researchers have yet to come to a clear agreement about the magnitude of the likelihood of progression to serious liver problems as well as the speed of this progression. One meta-analysis reported studies ranging from 2-3% of patients developing cirrhosis after 20 years up to 51% of cirrhotic patients after 22 years (Thein, Yi, Dore, & Krahn, 2008).

Although reported rates of cirrhosis vary, it is clear that untreated infection can be a silent killer, causing significant morbidity and mortality after more than two decades with no signs or symptoms. When HCV patients reach end-stage liver disease, they are no longer eligible for standard treatment and many are left with only the option of liver transplantation, which does not cure the disease as the new liver will also become infected. However, the cost for such a procedure, including immediate and lifetime medical costs, can be upwards of \$500,000 (Bentley & Hanson, 2011).

Additionally, many of the risk factors for HCV infection such as chronic drug or alcohol use, among other psychosocial factors, are considered contraindications for liver transplantation (Kemmer, Alsina, & Neff, 2011). Thus, the opportunities for this last-resort medical intervention are few and far between for most HCV patients.

Medical Implications of HCV-HIV Coinfection

HIV not only presents a well-established set of medical risks, but it also exacerbates the disease progression of HCV. As anti-retroviral treatments (ART) for HIV have improved over the last several decades, coinfecting patients are now living long enough to experience HCV-related complications, and many patients are now dying of liver-related complications of HCV sooner than from AIDS-related complications (Sulkowski, 2008). Liver disease was the second leading cause of death in the 23,441 patients followed during the Data Collection on

Adverse Events of Anti-HIV Drugs (D:A:D) study (Weber et al., 2006). In addition to the exacerbation of liver-related problems, coinfecting patients may have serious adverse effects from ART, which may induce drug-related hepatotoxicity (Sulkowski, Thomas, Chaisson, & Moore, 2000). However, HCV infection does not seem to have any direct adverse effects on HIV-1 disease progression or immunologic response to ART (Rockstroh et al., 2005).

Conclusions

HCV, both alone and comorbid with HIV, represents a serious disease that leads to potentially life-threatening complications, costly medical treatment, and significant personal burden. As such, it is of critical importance to better understand how and why patients fail to receive the appropriate medical treatment. As more information becomes available to define and understand the barriers that prevent patients from achieving SVR, better interventions can be developed to aid patients in overcoming those obstacles.

Identified Barriers to Treatment of HCV

Many studies have highlighted a wide variety of potential barriers that prevent patients from initiating and completing the recommended treatment for HCV. Some of the barriers mentioned below are common to many chronic illnesses; others are specific to HCV. For any individual patient, his or her combination of specific barriers may prove so overwhelming that even follow-up with a physician after initial diagnosis seems insurmountable. The following

sections provide an overview of the literature on identified treatment barriers for both HCV mono-infected and HCV-HIV coinfecting patients.

Patient Barriers

Many identified barriers to HCV treatment are understood at the individual patient level and are impacted by both factors external to the patient, such as SES, and those internal to the patient, such as beliefs about the efficacy of the medication. These primarily influence a patient's decision to refuse treatment or to prematurely discontinue treatment, often observed as failure to follow up with medical appointments. This difficulty with adherence is seen not only in both mono-infected and coinfecting HCV patients, but also in other chronic illness populations. Long-term illness requiring significant lifestyle changes creates an insurmountable burden for many patients.

Among many patients with Type 2 diabetes, poor adherence to regular medication and dietary changes is a reality and can lead to problems in relationships with medical providers (Grant et al., 2007). One review of studies aimed at improvement in Type 2 diabetes treatment adherence concluded that despite efforts in many domains, little has been done to significantly change adherence (Vermeire, Wens, Van Royen, Biot, Hearnshaw & Lindenmeyer, 2005). In cancer patients, even the development of effective oral medications, which patients prefer, has not had the same improvement to adherence in clinical practice as seen in clinical trials (Hohneker, Shah-Mehta, & Brandt, 2011).

Mono-infected HCV patients share many of these same barriers as other chronic illness populations. Some HCV patients refuse to be treated or even have their disease managed by a physician. Studies have found that approximately 10% of HCV patients refuse physician disease management (Doab, Treloar, & Dore, 2005; Delwaide, El Saouda, Gerard, & Belaiche, 2005; Morrill, Shrestha, & Grant, 2005). Other patients opt out of treatment for fear of adverse side effects. Rates of treatment refusal due to fear of side effects have been reported as 2-18% (Bini et al., 2005; Doab, Treloar, & Dore, 2005). A final major category of patient-related barrier is poor treatment adherence. Some estimates put the number of HCV patients with adherence difficulties above 25% (Falck-Ytter, Kale, Mullen, Sarbah, Sorescu, & McCullough, 2002).

Studies of coinfecting HCV-HIV patients have demonstrated similar issues with refusal, fear of side effects, and poor adherence. One study of homeless and urban poor HCV-HIV coinfecting patients in San Francisco reported that nearly 50% of those interviewed refused medical treatment of their disease (Thompson, Ragland, Hall, Morgan, & Bangsberg, 2005). In that same study, providers familiar with the patients indicated that half of all patients reviewed would be ineligible for treatment due to medication adherence issues. In a larger study by Cacoub, Rosenthal, Halfon, Sene, Perronne, & Pol (2006), 16% of 205 treatment-naïve patients refused treatment for HCV. Of this group refusing treatment, 52% refused to undergo a liver biopsy. However, neither of these studies collected

information on why patients refused. Prior to Thompson et al. (2005), The Research and Access to Care for the Homeless (REACH) program reported a lower rate (3%) of HCV treatment refusal among a similar urban poor and/or homeless sample. When asked about reasons for refusing treatment, some coinfecting patients have also expressed concerns about side effects. Fleming, Craven, Thornton, Tumilty, and Nunes (2003) reported 6% of coinfecting patients refusing treatment due to side effect fears. Although there has been significant work in the area of HCV treatment barriers, one of the complications within this line of study is the difficulty obtaining consistency for describing and categorizing barriers such as patient refusal (Lekas, Siegel, & Leider, 2012).

Aside from treatment refusal, many coinfecting patients have histories of poor treatment adherence. This also represents a significant barrier to successful care. In some instances (Thompson et al., 2005), providers defer or deny treatment to patients due to beliefs that the patients will be unable to adhere to the long, difficult treatment regimen for HCV. Cacoub et al. (2006) reported that 30% of patients were considered to be likely noncompliant with anti-HCV treatment. One of the difficulties in identifying factors associated with non-adherence is parceling the relative contributions of patient and physician factors influencing treatment decisions.

It is clear that a significant portion of patients are choosing to remain untreated or to terminate treatment prior to completion, either actively through refusal or passively through histories of medical non-adherence.

Ineligibility Barriers

Although some patients may be interested in treatment, it is often the case that their preexisting conditions or other health-related problems lead physicians to deem them ineligible. Many patients fall into this category and are thus never offered treatment.

A study of 107 HCV-HIV coinfecting patients by Rauch, Egger, Reichen, Furrer, et al. (2005) reported that 77% were determined ineligible for treatment based on standard exclusion criteria of CD4 cell count <250 cells/mm³, anemia, cytopenia, liver diseases other than hepatitis C, decompensated liver disease, significant comorbidities (e.g., psychiatric disorders, seizures, cardiopulmonary disease, immunologically mediated diseases), uncontrolled addiction (illicit drug abuse or alcohol consumption >40 g/d), poor adherence to prescribed drugs (based on treating physician report), and pregnancy. This list comprises the most common exclusion criteria reported in the literature. Of these, substance use, psychiatric disorders, and comorbid medical conditions are the most prevalent (Nunes, Saitz, Libman, Cheng, Vidaver, & Samet, 2006; Thompson et al., 2005, Bini et al., 2005).

Active substance use, often injection drugs or alcohol, represents one of the most significant exclusion criteria for both mono-infected and coinfecting patients. Because the most common shared transmission route for both HIV and HCV is blood-to-blood contact through shared needles, it is understandable that a large proportion of coinfecting patients are either active or prior injection drug users. Sulkowski and Thomas (2003) reported that 85% of HIV patients who self-reported IV drug use were also infected with HCV, although only 14% of patients who contracted HIV through heterosexual contact were coinfecting. In a study of more than 4,000 HCV-infected U.S. veterans, 20% were listed as ineligible for treatment because of substance use (Bini et al., 2005).

Because of the possibility of significant psychiatric side effects from standard HCV treatment (Manns, Wedermeyer, and Cornberg, 2006), the presence of preexisting severe mental illness often precludes patients from treatment. Muir and Provenale (2002) defined severe mental illness as schizophrenia, bipolar disorder, schizoaffective disorder, major depressive disorder, and post-traumatic stress disorder. It was noted that symptoms of these diseases are concerning for treating physicians as HCV treatment can lead to new onset or exacerbation of psychiatric problems. Psychiatric comorbidity is among the top reasons given by physicians for not referring HCV patients to treatment (Cacoub et al, 2006; Cawthorne et al., 2002; Fleming, Tumilty, Murray, and Nunes, 2005; Thompson et al., 2005).

A final consideration for patients being evaluated for HCV treatment is the physical toll taken by the medications. Other serious medical conditions, mentioned previously, can disqualify a patient from treatment due to concerns their body will not be able to tolerate the medication over the 6 to 12 months of treatment. Rauch et al (2005) reported that 57% of 107 coinfecting patients were considered treatment ineligible due to medical comorbidities. Bini et al. (2005) reported again that 20% of veterans in a large HCV study were ineligible for HCV treatment due to serious medical comorbidities.

Healthcare System Barriers

Many patients infected with HCV not only experience one or more of the above barriers to treatment, but substandard insurance coverage and medical cost also impede those who would otherwise seek treatment. The cost of medications for treatment of HCV can run well into the tens of thousands over the course of the illness, which is out of reach for many uninsured or underinsured patients (Federico, 2012). That does not take into account the financial cost of missing work due to appointments and adverse side effects. Thus, patients may find themselves without the ability to receive treatment even if they express a desire to do so.

Conclusion

Through extensive literature, it has been made abundantly clear that many HCV and HCV-HIV patients have an insurmountable task of preparing for,

initiating, and completing HCV treatment. Although there are clear indications for some patients to defer treatment, many who could potentially benefit from treatment refuse it, continue behaviors that increase the likelihood of ineligibility such as drug use or poor management of other medical problems, fail to follow up with appointments, or start and fail to complete treatment. Understanding how HCV patients experience living with the disease and how they encounter barriers in their daily life may be helpful in increasing the body of extant knowledge about why such a gap exists between clinical trial treatment results and real-world outcomes in clinical practice.

Existing Theories of Illness Perception

Researchers have been describing and modeling patient illness perceptions and health-related decision-making since the mid-20th century (Rosenstock, 1966). Currently, one of the prevailing conceptual models for understanding and assessing patient illness perceptions is the Common Sense Model of illness perception (CSM), originally developed by Levanthal et al. (1997). This model categorizes a patient's illness perception into five main components: cause, identity, length of illness (acute/chronic), controllability, and disease consequences (severity). This model has been used to characterize patient perception and predict health behaviors across a variety of chronic medical conditions including asthma, diabetes, cancer, HCV, and HIV (Broadbent, Petrie, Main, & Weinman, 2006; Cameron, 2008; Fraenkel, McGraw, Wongcharatrawee,

& Garcia-Tsao, 2005; Reynolds et al., 2009). Although this model has important patient-focused material to contribute to the current discussion on barriers to HCV treatment (Fraenkel, McGraw, Wongcharatrawee, & Garcia-Tsao, 2005), its focus specifically on patient illness perceptions is too narrow to encompass the full scope of potential barriers. Use of existing models as a framework to conduct this study may inadvertently overlook the general sense of patient perspective.

Approaching the data inductively with no a priori theoretical approach allows for the development of a new theory structure based on patient experience, potentially addressing the shortfalls in working from a limited existing theoretical perspective.

Common Qualitative Approaches

There are many approaches to conducting qualitative research. However, several basic ones provide a foundation for qualitative research in both psychological and social sciences. Some of these are relevant to conducting focus groups and utilizing content analysis. They include grounded theory, narrative, and phenomenological approaches. Listed below are brief overviews of these approaches.

Grounded theory approaches to qualitative research have become very popular over the last 10-15 years (McKibbin & Gadd, 2004; Padgett, 2008). The goal of grounded theory is to refine and revisit a developing theory of a phenomenon such that the theory accounts for all the variance among the

collected data. As such, conducting a research project within a grounded theory approach might require months or years of repeated data collection and/or analysis to adequately develop and refine a theory of treatment barriers among HCV patients. The protracted, iterative nature of this approach and its requirement for repeated data collection and analysis is beyond the scope of this project since the data collection phase for this work has already passed. The results contained herein do not comprise enough data or repetition to satisfy the requisite saturation of a theory, but could potentially be used as a starting point for future investigation on a grounded theory. This could potentially be structured as new focus groups with more targeted discussion topics, based on results from this study. Alternatively, the original participants could be contacted to complete follow-up interviews or additional focus groups with the same targeted discussion goals. This project's focus is on phenomenological understanding and preliminary theory conceptualization and development. It will attempt to offer explanation for the larger components of the phenomenon (McKibbin & Gadd, 2004; Padgett, 2008).

Narrative approaches involve not only examination of the content of conversation between two or more people, but also attend to the manner and context in which it is said (Riessman & Quinney, 2005). Narrative approaches are often conducted in a more personalized manner with focus on a deeper understanding of each individual's experience. An individual narrative approach

would not allow for participants to build on each other's thoughts and feelings. This focus on verbal process as well as content is not ideally suited to aid in answering the question(s) posited in this study. Additionally, the lack of potential interaction between participants in a narrative approach may fail to address or elucidate important features of living with HCV and the associated barriers to treatment.

Finally, phenomenological approaches to qualitative research offer one of the broadest perspectives on understanding the experiences of a group or population of individuals. The primary aim in a phenomenological approach is to create for the investigator, and eventually manuscript reader, the experiential world of the participant as if to "walk a mile in their shoes" (Padgett, 2008). The aims of this project were most suited to the phenomenological approach, allowing the participant data to guide thematic development and analysis, creating a structure to better describe the full picture of treatment barriers that patients experience.

Qualitative Methodology

Focus Groups

A focus group is a particular type of group interview, used often in research as well as other fields, that explores topic(s) of interest through discussion among the participants (Basch, 1987). This technique can elicit opinions, ideas, and perceptions from participants and can generate qualitative

data for research in education and healthcare (Eisenman, Glik, Maranon, Gonzales, & Asch, 2009; North et al., 2005). Typically, participants in focus groups are people who are believed to possess important perspectives, insights, or expertise pertinent to the question or topic posed by the facilitator. These individuals may be expert workers, supervisors, subordinates, patients, or customers.

Kitzinger (1995) described several advantages of conducting health research in a focus group setting. Inclusion of patients who may be illiterate, patients who would otherwise be reticent to share their thoughts and feelings in an individual setting, and patients who may initially feel unimportant, but who contribute to discussion generated by other participants, represent one such advantage to a focus group over an individual-interview approach (Kitzinger, 1995). Additionally, the group setting can utilize broader forms of communication such as anecdotes, jokes, or arguing among members that do not traditionally exist in a research interview (Kitzinger, 1995). Hearing other participants' thoughts or feelings on a topic may also help clarify an individual's own beliefs (Kitzinger, 1995). These benefits may help participants to better elaborate their opinions, feelings, and beliefs about HCV treatment and its barriers that may not be described elsewhere in the extant literature.

When compared to an individual or narrative approach, focus groups allow investigators to better record and understand the commonalties between participants and not the individualized experience of one person.

Content Analysis and Thematic Coding

Although used interchangeably in some instances, there are important differences between content analysis and thematic coding when conducting qualitative research. Content analysis was originally developed as a quantitative method in communications research and involves quantifying the frequency of a phenomenon in either written or spoken works (Padgett, 2008, p. 142). Thematic coding, although similar to content analysis, is interested in capturing more than the number of times a specific word or phrase is used, but also the essence of what is being said (Padgett, 2008).

CHAPTER THREE

Rationale, Study Aims, and Propositions

RATIONALE

Despite improvements in treatment for hepatitis C, many patients remain either untreated or unsuccessfully treated. Although much research exploring barriers to treatment and possible interventions has been conducted to date, the standard methodologies approach the problem from the perspective of either the treatment provider or the healthcare delivery system. Little has been done to engage members of the HCV community in describing and addressing their own perceived barriers. It may be the case that HCV patients have very different explanations and beliefs about why they are not receiving treatment or why they struggle to complete the treatment regimen. By integrating patient perspectives into the extant literature on barriers to HCV treatment, a more complete picture of the problem can be developed. As part of the larger body of research on treatment barriers, patient perspectives could augment existing or newly developing interventions by addressing patients' previously unrecognized barriers. These may include barriers such as lack of trust in the healthcare system, frustrating and chaotic lives, or scarcity of accurate information about the treatment process and outcomes and ultimately improve treatment outcomes.

STUDY AIMS

1. Develop a qualitative thematic coding system from both mono-infected HCV and coinfecting HIV/HCV patient focus group transcripts.
2. Utilize the developed coding system to better understand what it is like from the patient's perspective to live with HCV or HCV-HIV coinfection.
3. Identify barriers to treatment from the perspective of patients living with HCV and with coinfection (HCV-HIV). Compare these barriers to barriers found in existing literature for possible differences.

PROPOSITIONS

Proposition One

It is expected that patient perspectives will highlight external or systemic components of treatment barriers, such as difficulty navigating the healthcare system, supplementing potential income loss from missed work, or social stigma of a HCV diagnosis. This will contrast with the existing literature, which places significant emphasis on patient choice or behaviors, such as drug use or non-adherence to medical appointments and medication regimens.

CHAPTER FOUR

Methodology

Study Design

This study utilized a phenomenological approach and hybrid methodology to conduct a secondary thematic coding/content analysis of the focus group transcript data. This method allowed for the benefits of a broader view of the data while augmenting the work with quantifiable results using frequencies of responses within thematic categories. The data set consists of transcriptions of focus groups held separately with mono-infected HCV and coinfecting HCV/HIV patients conducted in 2008 and 2009. Participants were recruited from clinics affiliated with the Parkland Health and Hospital System (PHHS). The Parkland system is the only safety-net healthcare network in Dallas County and consists of one hospital and 11 adult clinics providing care to predominantly uninsured and low-income residents. Dallas County is one of the most populous counties in the United States, with approximately 2.4 million residents, of whom 38% are Hispanic, 33% are White, and 22% are African-American (U.S. Census Bureau, accessed 2012). An estimated 19% of Dallas County residents live at or below the poverty line (U.S. Census Bureau, accessed 2012), and the number of medically uninsured persons in Dallas County in 2011 was estimated at more than 800,000 (Cantrell District 2, accessed 2012).

The hybrid analysis methodology described above is the method of choice for this lab group and has been used in several published manuscripts on topics as broad as terrorism, emergency preparedness, and trauma exposure (North et al., 2005). The intent of the original study and data collection was to obtain a broad base of information from HCV and HCV/HIV patients regarding their experience with the disease, with the road to treatment, and barriers to receiving care. This analysis focused specifically on identifying barriers to treatment contained within the text.

Participant Recruitment and Procedures

After obtaining approval from the Institutional Review Board of the University of Texas Southwestern Medical Center 48 participants were referred to the study through their treating physician or other community providers or were self-referred in response to flyers posted in local clinics. Inclusion criteria for participation were intentionally broad, only requiring either a diagnosis of HCV without HIV or dual diagnosis of HCV and HIV and no history of prior or ongoing HCV treatment. Four focus groups (N=20 mono-infected HCV participants in all) were conducted with mono-infected HCV patients. Five groups were conducted with coinfecting HCV-HIV patients (N=28 coinfecting HIV-HCV participants in all). The number of participants within each of the nine groups conducted ranged from two to seven. During each of the focus groups, facilitators introduced themselves and instructed the participants to discuss amongst

themselves their experiences living with HCV, barriers to treatment, and strategies for coping with their illness. They informed the groups that the facilitator would remain as inconspicuous as possible, only interfering to redirect the conversation if it becomes too far off topic. However, in several groups, participants asked direct questions of the facilitator/s regarding specific medical information, which were answered briefly as not to alter the course of the discussion.

Demographic Data

Participants were invited to complete a demographics form, but eight did not turn in a demographics form. A breakdown across race and gender among the 40 participants who provided demographic information is listed in Table 1. The mean age of the 32 patients who reported their age was 50.15 years with a standard deviation of 7.16 years.

Data Analysis

Content categories were designed by an investigator familiar with the project, but not involved in group facilitation or content analysis. This investigator read all the passages in each of the transcripts and designated the overarching themes of discussion. Throughout this text, the term “category” will be used to describe the specific content area into which passages are coded. The term “theme” will be used to describe larger, broader conceptual grouping of one or more categories. A passage was defined as the text representing a set of words

spoken by one participant; passages are demarcated by a change to a different speaker. A set of coding rules for assignment of content of the passages to each of the categories was created to aid in the achievement of inter-rater reliability across the content categories. The text of the nine focus groups was reviewed for these themes, and content nodes were created for identified categories. Qualitative analysis was conducted using NVivo (QSR International) software to organize and data from transcriptions by labeling passages of text with codes identifying specified categories. Two independent raters who were not involved in group facilitation or category development reviewed the passages, coding them with all applicable categories. Thus, some passages received multiple codes. Cohen's kappa coefficient was calculated to measure inter-rater reliability on items included in each of the categories to ensure consistency of coding across all transcripts. Passages identified by both raters as having no data relevant to any category were not included in the inter-rater reliability analysis. All inter-rater differences in ratings were discussed by the raters and resolved by agreement. The mean kappa coefficient across all categories was 0.82. The range of kappa values for individual categories was 0.66-1.00. These values fall in the good to excellent reliability range. The number of items coded into each category was tabulated using NVivo, allowing determination of relative frequencies of responses by category.

Because each focus group contained either only mono-infected or only coinfecting patients, a comparison of category frequencies between combined mono-infected and combined coinfecting groups was conducted using a chi-square test (Preacher, 2001).

CHAPTER FIVE

Results

Response frequencies were coded in 11 categories identified in the focus group transcripts. However, three of the categories (Prognosis, Symptoms, and Changes in Daily Routine) were each representative of less than 3% of the total text and were thus not included in further analysis. The frequency percentages of the remaining eight categories are illustrated in Figure 1.

Table 2 lists the criteria used to define each content category for the purpose of establishing inter-rater reliability. As coding disagreements were resolved, the category definitions were expanded to represent the agreed-upon consensus.

A passage for analysis was defined in each transcript as a change of speaker. All passages from the facilitators were removed from analysis. This yielded 1,849 participant passages. However, many of the passages contained insufficient material (e.g., “Mhmmm” or “Uh-uh”) to warrant coding. Participant passages that did not contain any coded data were then removed from further analysis. The remaining passages yielded 936 total codes.

The percentages of total passages classified within each category analyzed range from 7-24% with passages about treatment knowledge representing the single largest category. When combined, the three categories representing

treatment-related issues (treatment knowledge, barriers to treatment, desire for treatment, i.e., bars labeled A, C, and H in Figure 1) comprise 43% of the total analyzed text. Additionally, categories related to information about HCV or HIV (i.e., bars labeled D, F, and G in Figure 1) combine to represent 36% of the text. These two sets of categories were clustered into overarching themes, treatment and information about HCV or HIV. Together, they clearly dominated the focus groups' discussions representing 79% of the total analyzed passages. The third largest single category was social aspects and represented 15% of the analyzed text. Patient discussion of methods of coping with HCV or HCV/HIV represented 7% of the analyzed text.

Treatment Knowledge

The single largest category, representing 24% of the analyzed text, was treatment knowledge. This category was defined as patients discussing their thoughts, feelings, and understanding about the treatment process. This category excluded passages with content regarding a patient's desire for treatment or reported barriers to treatment as these were coded into their respective categories. Many of the passages in this category were related to patients' questions about treatment and its side effects.

Yeah, well, yeah there was a lady that claimed she went through the treatment and she is still on it. She told me about it. She tells me she takes so many pills a day and a shot.

Okay, like they say they'll give it to you for three months, six months and if they see then it's not doing anything then they'll stop. Well, what if you don't want them to stop? Do you have a choice?

The problem I have with the discussion on this is I've had it for quite a while but nobody seems to be clear about what's going to happen once you get on the treatments, you know. They don't talk about how it's going to affect your job, how it's going to affect your social life, what arrangements you need to make, you know, if there's anything you need to change...

It was clear that some patients, despite reporting regular contact with a physician, felt poorly informed about the overall treatment process. Many reported receiving treatment-related information from non-medical sources such as friends or neighbors.

Secondhand Information about HIV/HCV

This category included passages discussing what patients had heard about HCV or HIV from others, both professional and non-professional. It represented 17% of the analyzed text. This category was differentiated from the other two categories regarding information by noting that these passages were not necessarily the beliefs of the patient, just what information they had encountered in a variety of settings.

They said my sodas, everything have to have no caffeine in it. I can't drink caffeine.

I know people that have got it and got jaundice, real sick and it was hard to keep anything down.

Additionally, patients reiterated their frustration with the gap in knowledge despite contact with medical professionals and what appears to be an interest in obtaining more information.

One thing that would help people like us is give us more information. There are many, many things that can make you have hepatitis and stuff. I'm pretty much in the dark. You know, I talk to Dr. S about stuff, but he tells me so much and then he tells me to talk to you.

So anything, shouldn't we have had this class when I first found out about it? So people, when they first find out, so they won't be so rebellious. They're like I'm never going back there. They lie.

Social Factors

One of the largest categories, representing 15% of the analyzed text, was discussion of the social factors of HCV or HCV/HIV infection. Participants shared details of the challenge of deciding to whom they should disclose their infection status. Some mentioned that HCV now carries more stigma than HIV. Others were concerned about retaining employment if their supervisor found out about their infection.

My wife is real iffy about telling people at her job that I have it because she works for a blood donation company. She's afraid they're going to say, oh, you can't work here because he's a carrier and you could possibly transfer. I tell her, you know, if they're going to fire you for that, let them. Go somewhere else.

Feelings of isolation from friends and family were another social concern raised in nearly all groups. Participants felt that their HCV status made them contagious, leading to less contact with children, parents, or other loved ones.

Their and their families' incomplete understanding of disease communicability created more isolation than would be reasonably necessary to prevent infection.

And he says, well I had a hep C test. And my feelings were a little bit hurt because I had shared with him...that I had hep C, that somehow he felt it necessary for him to have a hep C test. And so if he jumps to that conclusion, what other friends or family members who are not very informed about hep C would have that same anxiety, fear and issues like that.

And he said he claimed he didn't know about the hep C and ran for the hills. Well that is also one of the primary reasons why in the last three and one-half years I have not been dating or been in a relationship whatsoever in that form because it's kind of like, people find out I have hep C and they run.

Okay, like, Thanksgiving I went over there. She gave me a paper plate. Everybody else got pretty china, you know. I got a paper plate...

Social factors surrounding HCV appear important to patients and seem to play a role in how they navigate their personal and professional lives. Feelings of stigma were apparent in anecdotes shared with the group.

Need for Information about HCV/HIV

The second information-related category about HCV/HIV comprised 13% of the analyzed text. This category was unique from the others in that it specifically targeted patients' questions about HCV or HIV. It became clear that many patients had a strong desire to learn more about their condition and its effect on their everyday lives.

I would like to know what hepatitis C is?

What does nonreactive mean as far as that test?

Is hepatitis C in any way connected to the HIV virus or are they just two separate viruses?

Is there anything we could do to help the hep C progress?

What does sero-converted mean?

Someone was telling me the liver is one of the organs that can heal itself. Is that a fact?

Does that pass through, I mean like me interacting with my grandkids?

Is there any interaction between hep C and the kidney and maybe filtering out of some of the uric acid?

Is it contagious? Can we have a big family come over?

Questions ranged from broad, general information to specifics about food choices, physical contact and transmission, and other daily activities that may be impacted by HCV or HIV.

Treatment Barriers

The category directly addressing patient-reported treatment barriers represented 11% of the analyzed text and contained many different views on barriers to treatment. A poor relationship with medical staff or the system as a whole was reported as a major problem for patients. Feelings of mistreatment or misunderstanding contributed to some patients changing their minds about pursuing treatment. A total of 11 passages referring to doctor-patient communication and/or relationship were noted and represent 10% of this category.

And I had a doctor in the interim too who wasn't a doctor, was a physician's assistant who was quite nasty to me and said, because you didn't make an appointment, why do you want me to treat you differently...

And if all that doctor is going to do is talk to me, I'm not even going to bother to go back. That's like I have invested six or seven months in this and I ain't seen...it just seems like I'm just running over there, talking to them. I mean they're not doing nothing for me... if they don't do a biopsy or lab work or stuff, talk to me about what? If they don't do nothing for me and try to reschedule, then I'm going to tell them don't even worry about it. I've been living with it this long...

He [*physician*] say you don't know what you did to yourself. You just messed your life up. What can I do for you? I'm here for treatment. Ain't nothing I can do. How did you get it? I got shot. You all gave it to me. He said what do you expect me to do? I just walked back but my doctor wasn't there. I told them you don't have to worry about me coming back.

Another major concern for patients is both financial and logistical. The complicated system of insurance and reimbursements from either federal or other programs represents a major barrier to patients receiving care. The cost of treatment was unknown or a moving target as these patients moved in and out of jobs and insurance coverage.

But when I go back to work, it's over. I won't be able to get insured. The thing that really burns me up, none of my doctors did this, but they did tell me, "don't worry about it. We need to get this done and we'll take care of you for the rest of your life." See, that's not true. Because just until I get to working again, so right now it's beneficial for me not to work.

The complicated balance of working enough to survive and earning too much to lose government health insurance creates a "lose-lose" scenario for some patients.

“If I want to keep up a quality lifestyle I have to work. But if [I] worked I can’t keep quality health.”

A friend of mine had medical insurance and he was on the same treatment. The treatment was so devastating to him... he would miss work....He kept missing so much work they fired him. Well, when they fired him, he lost his medical coverage. There went his medicine. We found him New Year’s. He’s not with us anymore.

A final cluster of treatment barriers reported by patients is lack of symptoms and no assurance of a cure. Patients were concerned that treatment would make them ill even though they felt healthy at the moment and may not result in a cure.

...what would be the disadvantage of not doing treatment if I’m not having any problems and potentially there could be no problem. I’m hearing that it could go 20 years I could pass away from something else, cancer, and perhaps never become an issue for me. So what would be the advantage, obviously, why should I have treatment for hep C if it’s not a problem and potentially could not become a problem?

Desire for Treatment

Patients’ express statements about wanting to receive treatment represented 7% of the analyzed text. Although many barriers were shared, as reported above, a large number of group participants indicated their willingness to initiate HCV treatment.

I’m 24 and I got life to live, a lot of life. I don’t want to miss out on church no more.

Yeah, I’m willing to try it. The side effects may not affect me the same way.

And I'm the type of person, if I feel like it's going to help me, then, yeah...come on with it. Quit prolonging it. Then after they keep prolonging and prolonging, then I get mad.

Well the treatment will be a beginning and it will ease my mind that I am getting treatment and there's a possibility that it could help me. I always took care of my family really good and my children. Single parent. But I can't help them if I'm not here. The only way to stay here is to get the treatments you need and not drink.

Some participants expressed frustration with experiencing a delay in starting treatment even though they desired to begin immediately.

Patient Knowledge of HCV/HIV

This category represented 7% of the analyzed text and was defined as patients reporting what they believe or understand to be true about HCV or HIV.

One of the striking findings from this category is the misinformation about the disease process.

This lady who works with me, her husband has hepatitis C. He was taking his treatment and everything. And then all of a sudden he stopped because somebody told him to take olive oil or something. If your husband takes it, it will go away. I'm like, no, that's not true. It won't just go away. Right now he's got this big knot on his side or something. But he won't go back to the doctor. He keep drinking the olive oil or whatever.

Another finding was the concern about disease transmission and contact with other people. Transmission was discussed in several groups as a serious concern.

...that you can even get it from using a comb or a brush. If there was a little blood or whatever. That's why I have my own comb and my own brushes and everything.

Because if I do fall and split my head open, I don't want somebody to just run over there with unprotected hands and start taking care of me because of the concerns I have for other people

...hey, you know, if I cut myself don't grab me. I'll take care of it. So those people need to know that the mode of transmission for hep C is the same as HIV.

Now remember that in addition to an additional support playing it safe whenever you do have sex is not only that you don't want to be exposed to a different strand of HIV, which may complicate your treatment, you don't want to be exposed to hep C and the exposure goes hand in hand with safe sex.

Coping Methods

Despite the tremendous challenges represented by HCV or HCV/HIV infection, patients showed surprising resilience. Faith in God and support from family were central for participants in dealing with the burden of HCV illness.

Passages coded with this category label represent 7% of the analyzed text.

It's like I'm mature enough to understand, okay, you got to do this for your health. When it came to my mind I was like, okay, do what you can. Make sure you can live. Make sure you beat this.

That's how I get through the worst case scenario is you pick up, brush yourself off and you laugh about it because when you're told already you have a disease that will obviously take your life eventually, or cause it to not be a...you're going to have some problems.

I started treating the HIV virus years ago was some words my mother said to me. She said to me, well, you know there's nothing we can do about it but pray...She said those words to me and that's how I've lived this long with the HIV virus. Now once I found out about the hepatitis I started treating that as I treated the HIV.

Chi-square tests for independence were conducted to compare content category passage frequencies between mono-infected groups and coinfecting groups. Significant differences were noted in three categories. Mono-infected patient focus groups had significantly more passages in the secondhand information category ($p < .01$). Coinfecting groups had significantly more passages in the treatment barriers ($p < .05$) and need for information about HCV/HIV categories ($p < .01$).

CHAPTER SIX

Discussion

Discussions of the focus groups analyzed in this study addressed HCV and HCV-HIV patient issues including treatment-related concerns, social support and stigma, coping methods, sharing of HCV information with each other, and a need for more information from their medical providers about the disease and treatment processes. Four primary themes were derived from the analysis. In order of descending relative frequency they are: treatment, information, social factors, and coping methods. Figure 2 displays the proportion of analyzed passages represented by each theme. The treatment theme represents the largest portion of passages (43%), across all focus groups. This finding highlights the importance of treatment to these participants and is not unexpected for patients seeking medical care. However, it may be difficult to generalize this finding to the broader HCV population because individuals with HCV not selected from treatment settings may have much less interest in learning about and/or obtaining treatment. It might be expected that the barriers encountered by patients who have not yet made contact with a medical provider or clinic would be at least equal to or even more challenging than the barriers encountered by this study's participants.

Within the treatment theme, patients shared four major areas of barriers to treatment: doctor/patient relationship and communication, financial/logistical

concerns, fear of treatment side effects, and lack of guaranteed treatment outcome. The financial/logistical concerns, fear of side effects, and concern about outcome have been well documented in the literature and are often expected by medical providers and systems. However, issues related to doctor/patient relationship and communication have received much less attention in the HCV literature.

The extant literature provides examples of communication issues between patients and physicians regarding health-related information in other medical illness populations (Haskard Zolnieriek & DiMatteo, 2009; Nelson, Gay, Berman, Powell, Salazar-Schicchi, & Wisnivesky, 2011). The patients in this study shared their frustrations over the communication process as well as over their relationships with doctors and medical staff. They provided examples of personal experiences of being ignored, mistreated, or misinformed about the purpose of a medical visit or the treatment process. For some of these patients, a negative experience in a clinic was the deciding factor in discontinuing follow-up medical care.

There are several possible factors contributing to the relationship quality between patients and treatment providers in general medical settings. Physicians may communicate using a style that is incongruent with patients' expectations about how they would prefer their physician to interact with them (Cousin, Schmid Mast, Roter, & Hall, 2012). Physicians working with patients with low

health literacy sometimes use medical jargon that patients cannot readily understand without additional explanation (Castro, Wilson, Wang, & Schillinger, 2007). The amount of time spent with a patient could also be a factor in facilitating poor communication and negative patient experiences in medical settings. Shorter medical visit times have been associated with lower levels of patient satisfaction as well as lower levels of physician satisfaction (Dugdale, Epstein, & Pantilat, 1999). Additionally, Kaplan, Greenfield, Gandek, Rogers, and Ware (1996) reported that fewer physicians in high-volume practices (a proxy for shorter visit times) utilized a participatory decision-making style, which is associated with greater patient satisfaction and better retention. It was clear in the present study's focus groups that some patients were dissatisfied with their patient-physician relationship, which they reported as a deciding factor in their decreased willingness to continue HCV care. Poor patient-physician communication occurs in many settings and across medical specialties. Schwartzberg, Cowett, VanGeest, and Wolf (2007) found that, although many medical providers report using simple techniques for better communication with low literacy patients (e.g., speaking slowly or avoiding jargon), far fewer utilize more advanced techniques recommended by health experts (e.g., checking for understanding or showing/drawing pictures) on a regular basis.

The only barrier identified in the information theme parallels one of the barriers found in the treatment theme: lack of accurate knowledge. The frequency

of questions posed about HCV and the many inaccuracies regarding the illness disclosed by the patients despite their reports of conversations with their doctors again suggests a breakdown in the communication process. Proeschold-Bell et al. (2010) identified coinfecting HCV-HIV patients as lacking in critical knowledge of HCV transmission, prevention, and treatment. If patients in this study, who are at least minimally connected to the healthcare system, are expressing confusion and frustration regarding health-related information, it is likely that patients with no substantial connection to the medical system are more confused and potentially more frustrated regarding knowledge about their disease. Specifically, when compared to other knowledge areas, a general lack of knowledge about how HCV is transmitted seemed to affect patients' social experiences as well. Patients in this study reported that family members and others avoided them as a means of preventing transmission of HCV. The stigma identified in this theme is resonant with stigma in the social factors theme. Patients or those in their social circles who do not accurately understand HCV transmission routes may reduce social interaction in circumstances where social connection may be most important for facilitating motivation for treatment. Swan, Long, Carr, Flanagan, Irish, Keating, ... & Cullen (2010) identified strong emotional ties to family/children as promoting care and treatment for injection drug users infected with HCV.

The social factors theme consisted of two general topics: support and stigma. Research in HCV and other chronic medical illnesses has addressed the

importance of stigma for patients (Else-Quest, LoConte, Schiller, & Hyded, 2009; Zickmund, Hillis, Barnett, Ippolito, & LaBrecque, 2004). However, stigma as an HCV treatment barrier is a less-developed area of research (Butt, Paterson, & McGuinness, 2008; Moore, Hawley & Bradley, 2009; Swan, et al., 2010). Treloar and Rhodes (2009) posited that interaction with the healthcare system could actually increase stigma associated with injection drug use and HCV, leading to greater distancing of patients from the healthcare system and potentially life-saving treatment. The frustration expressed by the patients in the comments coded in the treatment and information themes in this present study seems to support Treloar and Rhodes' conclusions. The stigmatization reported by patients in this study seemed to have two sources: self and others. The negative beliefs about HCV infection held by patients themselves may be just as significant to their social and psychological functioning as those held by members of a patient's social network. For example, Waller (2004) reported that a significant number of patients experienced a diminished self-esteem upon receiving a diagnosis of HCV. Patients who contracted HCV through injection drug use may begin to accept the cultural belief of having an "immoral" disease, which furthers their own negative self-image (Sandelowski, Lambe, & Barroso, 2004; Zickmund, Ho, Masuda, Ippolito, & LaBrecque, 2003). This leads persons living with HCV to expect others to hold negative opinions of them that they themselves believe are justifiable (Joachim & Acorn, 2000).

Despite the difficulties of living with HCV (e.g., stigma, financial burdens, and difficult physician relationships) described by the patients in this study, the coping methods theme contained comments describing personal resilience and determination. Patients spoke frequently about positive coping methods such as faith and perseverance as ways they manage their illness and keep pressing onward. Better coping methods have been associated with improved medical outcomes across the extant literature. For example, the power of faith as a coping method in improving treatment adherence and other medical milestones has been well documented across many medical and psychological studies (Narayanasamy, 2002; Peterman, Fitchett, Brady, Hernandez, & Cella, 2002; Swan et al., 2010).

Although not conclusive, the differences in category frequencies between mono-infected and coinfecting focus groups suggest there may be features unique to these subpopulations. Coinfecting patients may be experiencing more intense treatment barriers, different barriers or simply be more keenly aware of barriers than mono-infected patients. Additionally, they are seemingly more interested in obtaining disease-related information than mono-infected patients. Further study is needed to clarify these potential differences.

The patients' emphasis on their desires to obtain more information about HCV treatment may also represent their attempts to better formulate their illness conceptualization. Many of their questions and concerns can be linked to the five

illness perception components of the CSM (Levanthal, 1997). Using the CSM as a qualitative analysis framework with focus groups, Fraenkel et al. (2005) identified the way in which patients conceptualize their HCV illness as a factor in the treatment-related decision-making process of patients. Absent from the CSM is a prerequisite discussion of basic patient illness knowledge seemingly necessary for illness conceptualization. Our finding that many patients describe an ill-informed understanding of their illness and treatments that may or may not be available to them suggests that their treatment-related decisions may be negatively affected by their lack of knowledge. Furthermore, the importance of relational and social factors described by patients is not captured within the CSM and, thus, necessitates an expanded model for HCV treatment barriers. This more complete model would need to incorporate patients' social network, including family, friends, and medical providers, in addition to their beliefs and understanding of their illness and its components.

Strengths and Limitations

One of the main strengths of this study is the open-ended nature of the discussions among patients in the focus groups conducted. With little direction for desired content from the facilitators, focus group members with HCV were able to provide a rich narrative on their most salient concerns regarding their HCV. Thus, the groups were able to capture a broad array of patients' thoughts, feelings, and frustrations about living with HCV. This inductive method of inquiry allows the

data to identify where patient perspectives are consistent or inconsistent with the existing literature from the health provider or system perspective.

A measure of the success of this study is in its achievement of high inter-rater reliability and themes with good face validity. High reliability reflects methodological rigor. The strong face validity suggests the areas discussed here are important focus points for future research and clinical applications.

The design of the project with separate HCV and HCV/HIV groups allowed for comparison of possible differences between these subpopulations and represents a clear strength because potentially important differences were uncovered. The group differences found in this study suggest that further exploration might yield information needed to guide intervention development for these subpopulations.

A notable limitation of this study is the potential bias inherent in this study's participant selection. Because the sample was recruited primarily from infectious disease clinics, the sample may not represent the general HCV population that also includes a large proportion of individuals not connected with treatment. Additionally, the small sample size and circumscribed area of geographic recruitment, limited to the Dallas area, reduce the generalizability even among the treatment-seeking subpopulation. However, the use of the PHHS as a recruitment source allows for better generalization to the uninsured, underinsured, or otherwise indigent subpopulation of HCV patients. Patients

whose options for clinical care are limited to the social safety-net system comprise a significant portion of all HCV patients (Stepanova, Kanwal, El-Serag, & Younossi, 2011). Although full characterization of the sample was limited by the amount of demographic data collected, it is presumed that participants in this study are members of the HCV subpopulation with either inadequate or nonexistent medical insurance. These patients are important to include in the growing body of research on HCV treatment and its barriers as they often encounter a multitude of these barriers as part of their daily experience and can be very difficult to treat.

The terminal nature of the data collection in this study limits its future applicability to a grounded theory approach as the original study design did not include follow-up groups with the participants or additional groups on which to further refine an emergent theory.

Although the minimal direction provided by group facilitators is a methodological strength, reliance on the spontaneous thoughts and comments of participants was a potential limitation as it could inadvertently overlook important areas of discussion. In studies with larger sample sizes this limitation may be diminished.

Clinical Implications and Future Research

Participants in this study reported frustration about communicating and building relationships with their medical providers. These messages may improve

general physician awareness of potential problems and allow for a more open dialogue between them and their patients. Further study is needed to investigate the effect of physician communication skills and expression of empathy on treatment motivation and whether intervention in this area could translate into more patients obtaining and completing treatment.

Mental health professionals working in medical clinics or hospitals may serve as liaison and communication coaches for providers and patients to both prevent and to repair relationship disruptions (Brown et al., 2002). As many of the barriers described by patients in this study were related to patient-physician and patient-family relationships, psychologists can provide expertise to strengthen connections among patients, families, and providers. This could be accomplished through several avenues. Psychologists could offer training for physicians on skills in better communicating their empathy toward patients. Additionally, psychologists could work with individual providers and patients who have expressed conflict or frustration regarding treatment planning. Psychologists could also work with families of patients to provide supportive interventions for caregivers and offer solutions for improved coping and disease/treatment management.

Because many HCV patients acquired the disease through injection drug use, a culturally and legally unacceptable behavior in Western society, the stigma associated with drug use may overflow to HCV status. Treolar and Rhodes (2009)

point out that even printed materials written for HCV health promotion can unintentionally emphasize personal responsibility and blame. Providers may inadvertently further patient stigmatization through indirect communication of blame. For example, concentrating on the biomarkers or physical signs of HCV instead of the patient's own personal experience can be perceived by the patient as devaluing and even dehumanizing (Treloar & Rhodes, 2009).

Findings from this study support the proposition that HCV and HCV/HIV patients seeking treatment identify many barriers, some of which differ from those generally described in the existing literature. Future research is needed to identify those barriers that differentiate patients who successfully obtain HCV treatment from those who have unsuccessfully sought treatment and from those who are not seeking treatment at all. Such studies may suggest interventions to be developed and tested, targeting each group specifically with the intent of moving them to the next logical stage in the process of receiving treatment toward the goal of SVR. As mentioned previously, further exploration of potential group differences between mono-infected HCV and coinfecting HCV/HIV patients is needed.

A potentially valuable area of future research suggested by the findings in this study is the potential for intervention in provider communication of empathy and disease/treatment-related information. As Swan et al. (2010) described, patient motivation for treatment is facilitated by encouraging and supportive medical providers. If patients are not retaining the most relevant pieces of

information or are not feeling emotionally supported during visits due in part to physician communication style, additional training programs specific for HCV providers could be created to improve congruence between physician style and patient need. It has been generally recognized that application of physician skills in this area help providers maximize the time spent in each visit with patients and better overall medical outcomes (Schwartzberg, Cowett, VanGeest, and Wolf, 2007).

The needs of both patients and their families have insufficient study. Research is needed to develop and evaluate support or education groups for both patients and their families/friends. Groups offering opportunities for patients to meet other patients and find accurate answers to their questions would likely be of great benefit. Groups with a support and/or education focus could address a number of identified barriers in a single location through dissemination of accurate information, facilitation of social support, and reduction of stigma. Research to develop these kinds of groups is currently underway. Such program development is currently underway within this research group (North, 2006).

Identifying and overcoming treatment barriers for HCV patients carry tremendous potential to shed light on the experiences and struggles of a largely marginalized population. When interventions based on these identified barriers are ultimately developed, tested, and implemented, physicians and patients will be

maximally equipped to restore their lives to health, improving the lives of the millions connected to them.

APPENDIX A

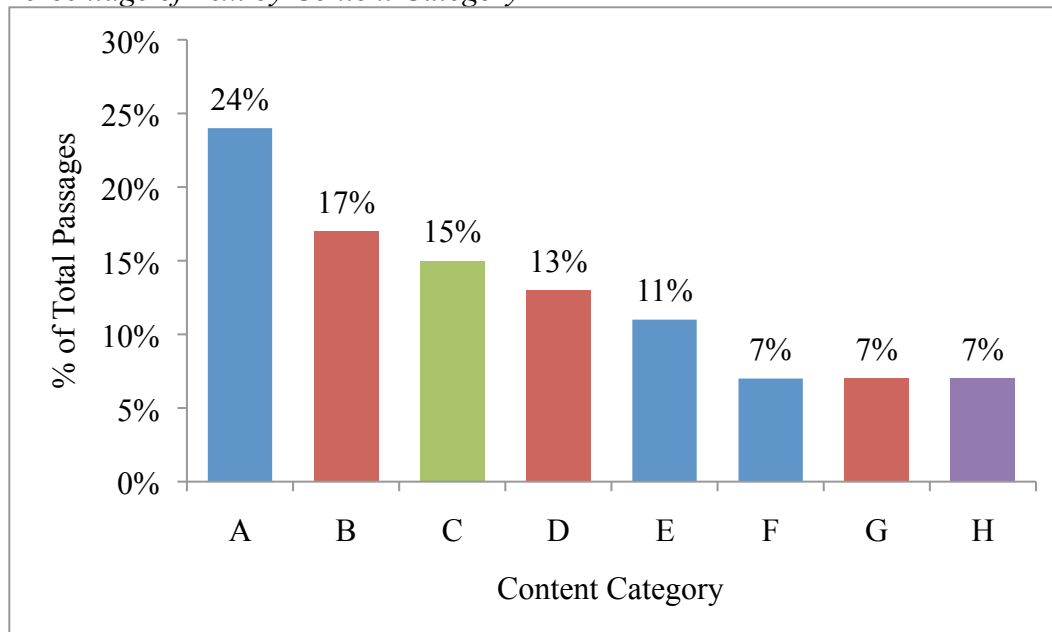
Tables and Figures

Table 1

Focus Group Demographics

	<i>Black</i>	<i>Hispanic</i>	<i>White</i>	<i>Other/ Unknown Race</i>	<i>Total</i>
Female	9	0	4	1	14
Male	13	2	5	5	25
Unknown Gender	0	0	1	8	9
Total	22	2	10	14	48

Figure 1
Percentage of Text by Content Category



A.	Treatment knowledge (n= 223 passages)
B.	Secondhand information about HCV/HIV (n=156 passages)
C.	Social factors (n= 139 passages)
D.	Need for information about HIV/HCV (n=120 passages)
E.	Treatment barriers (n=107 passages)
F.	Desire for treatment (n= 68 passages)
G.	Patient fund of knowledge about HIV/HCV (n=62 passages)
H.	Coping methods (n=61 passages)

Figure 2

Themes with Associated Categories (excluding non-analyzed categories)

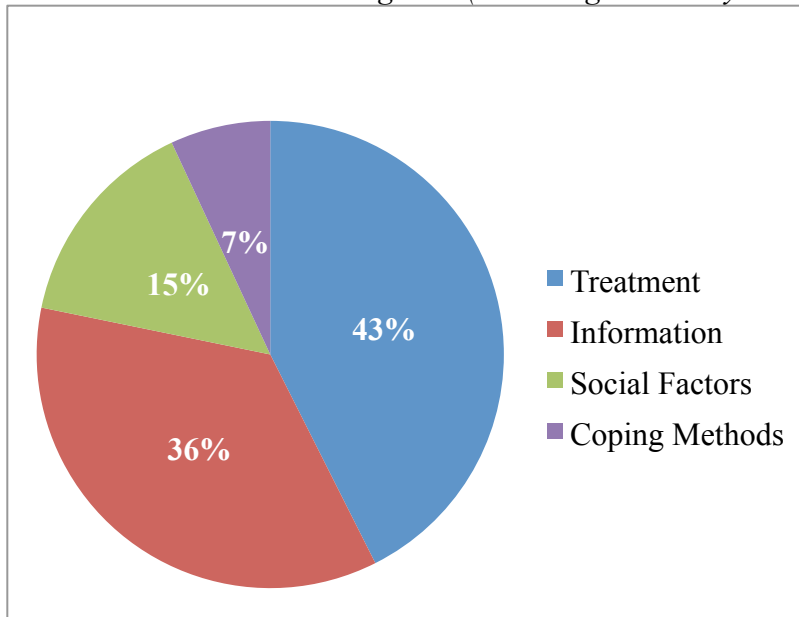


Table 2
Categories and Definitions

Category	Description	Examples
Treatment Knowledge	<p>Participant knowledge regarding the components of HCV treatment acquired from any source, both professional and non-professional. Knowledge of the specific medication regimen, length of treatment, and possible side effects.</p> <p>Knowledge of the treatment efficacy and potential effects of side effects on overall health and well-being including ability to work or complete other obligations to family/friends.</p> <p>Includes questions from the participant to the facilitator about specific treatment-related information.</p> <p>Excludes statements of participant desire for treatment or participant-identified barriers to obtaining/completing treatment (these are coded in the Desire for Treatment category).</p>	<p>Now, I'm coming over here through Parkland Healthcare Plus. You're talking about this is six months.</p> <p>The side effects are mostly nausea, sickness and...hair loss.</p> <p>Are there any other medications besides Interferon?</p> <p>So how long does the treatment last?</p> <p>They wouldn't give us a liver transplant anyway because we have HIV.</p>
Secondhand Information about HCV/HIV	<p>Statements about sources and types of disease-related information that the participant does not necessarily identify as a personal belief. Includes information provided from professionals, family/friends, other infected persons, or media resources such as books.</p> <p>Includes hearsay anecdotes about other infected persons' experiences with HCV or HCV/HIV</p>	<p>they said you have hepatitis non-A, non-B, which would be C, but they never called it C.</p> <p>It was told to us it was not contagious.</p> <p>I don't know anybody who's ever died of hepatitis C. I know several people who have died of HIV. So that's what I'm more concerned about.</p> <p>They said my sodas, everything have to have no caffeine in it. I can't drink caffeine.</p>

		I'm not a library person but I had girlfriends that would go and check out books and bring them back and read them.
Social Factors	<p>Includes statements about experienced or perceived stigma related to infection status. Can be from any source including family, friends, community, strangers, or health professionals.</p> <p>Includes statements about disclosure or non-disclosure of infection status to others.</p> <p>Includes statements of social support such as encouragement from family/friends or other infected persons.</p> <p>Includes being treated differently or changing social contact with others due to infection status.</p> <p>Includes both participant changing behaviors and others changing behaviors.</p>	<p>I refrain from kissing my children.</p> <p>I got a great support group outside of it. I got support at every stage. I can pick up the phone and call people.</p> <p>When I cross somebody like that I don't talk to them. I just let them go about their business.</p> <p>Whether they know or not some people are just ignorant to the fact where they don't care. They got their minds stuck on, okay, you're contagious. No matter if you educate it because some people are going to take heed to it and some people are just going to overlook it.</p>
Need for Information	<p>Questions posed by the participants to either the facilitator or other group members. Questions can range from basic disease process to more advanced inquiries about transmission, jargon clarification, long term medical issues of HCV or HCV/HIV coinfection.</p> <p>Also includes basic statements about needing/wanting more HCV-related information.</p>	<p>So the chance of our liver is just going to get worse and worse?</p> <p>I was here to get information.</p> <p>My main concern, I recently, what is it? Four stages? Is that how much you say?</p>
Treatment Barriers	Reasons for participant to feel less capable of or less willing to obtain/complete treatment including financial, logistical, relational/social, medical, or	<p>That's what scared me. Because she was taking the shot. And watching her get ill and lose her hair...</p>

	<p>behavioral factors. Can be directly or indirectly identified as a barrier by participants.</p> <p>Barriers identified as social/relational in nature may also be coded as “Social Factors” where appropriate.</p> <p>Excluded are statements containing only participant-acknowledged level of motivation/desire to obtain treatment (These are coded in the Desire for Treatment category).</p>	<p>You won’t be able to get on the insurance.</p> <p>...why should I have treatment for hep C if it’s not a problem and potentially could not become a problem?</p> <p>I didn’t come last time because nobody bothered to let me know the time before.</p>
Desire for Treatment	<p>Expressions of positive motivation to obtain HCV treatment. Includes indirect statements of treatment motivation through general desire to “get well”.</p> <p>Statements of reasons for wanting to get better or receive treatment.</p> <p>Can be coded as both Desire and Barrier if a conditional statement about receiving treatment “if” is given.</p>	<p>No, I want to get better.</p> <p>Single parent. But I can’t help them if I’m not here.</p> <p>Yeah. I feel like the sooner the better.</p> <p>I would be willing to do it if that length of time was shorter.</p>
Patient Fund of Knowledge	<p>Knowledge, both accurate and inaccurate, about HCV or HCV/HIV. Includes statements of pre-treatment monitoring procedures (e.g., biopsy), transmission routes, expected symptoms, and outcomes of untreated disease. Also includes statements about how long a participant has been diagnosed with HCV or HIV.</p>	<p>I understand it’s there [HCV in my system], but some people don’t know it’s there.</p> <p>Your eyes yellow.</p> <p>You start losing weight.</p> <p>Yeah. No Tylenol. Don’t take Tylenol.</p> <p>Until HIV came out and they did more study, then they said you could catch it [HCV]by using a fingernail clipper or something like that.</p>

		...you don't want to be exposed to hep C and the exposure goes hand in hand with safe sex.
Coping Methods	<p>Positive thoughts, feelings, or actions used to maintain mental or physical health in light of diagnosis. These can be directly identified by participants as ways of coping or indirectly. Includes general health behaviors (e.g., exercise), specific liver-related behaviors (e.g., reduction in alcohol use), utilization of support networks, and all internal methods such as faith/prayer or resilience/willpower</p> <p>Includes methods that the patient believes are helpful even if there is little connection between the method and improved health outcomes.</p>	<p>Exercise and all that stuff will help me.</p> <p>I know I have it, but I don't look at it as I have it. I just keep on working.</p> <p>I put it in the Lord's hands.</p> <p>You just have to do it. It's just like no more alcohol. You cannot drink.</p>

References

- Armstrong, G.L., Alter, M.J., McQuillan, G.M., Margolis, H.S. (2000). The past incidence of hepatitis C virus infection: Implications for the future burden of chronic liver disease in the United States. *Hepatology*, 31(3), 777-782.
- Basch C.E. (1987). Focus group interview: an underutilized research technique for improving theory and practice in health education. *Health Education Quarterly*, 14, 411-448.
- Bentley, T.S. and Hanson, S.G. (2011). 2011 U.S. organ and tissue transplant cost estimates and discussion. Milliman Research Report. Retrieved from <http://publications.milliman.com/research/health-rr/pdfs/2011-us-organ-tissue.pdf>. Accessed February 1, 2012.
- Bini, E.J., Brau, N., Currie, S., Shen, H., Anand, B.S., Hu, K... & Wright, T.L. (2005). Prospective multicenter study of eligibility for antiviral therapy among 4,084 U.S. veterans with chronic hepatitis C virus infection. *American Journal of Gastroenterology*, 100, 1772-1779.
- Broadbent, E., Petrie, K.J., Main, J., Weinman, J. (2006). The brief illness perception questionnaire. *Journal of Psychosomatic Research* 60(6), 631-637.
- Brown, R.T., Freeman, W.S., Brown, R.A., Belar, C., Hersch, L., Hornyak, L.M., ... and Reed, G. (2002). The role of psychology in health care delivery. *Professional Psychology: Research and Practice*, 33(6), 536-545.
- Butt, G., Paterson, B.L., and McGuinness, L.K. (2008). Living with the stigma of hepatitis c. *Western Journal of Nursing Research*, 30(2), 204-221.
- Cacoub P., Rosenthal E., Halfon P., Sene D., Perronne C., & Pol S. (2006). Treatment of

- hepatitis C virus and human immunodeficiency virus coinfection: from large trials to real life. *Journal of Viral Hepatitis*, 13, 678-682.
- Cameron, L.D. (2008). Illness risk representations and motivations to engage in protective behavior: The case of skin cancer risk. *Psychology & Health* 23(1), 91-112.
- Cantrell, M. County Commissioner District 2. Health and Human Services. Retrieved from <http://www.dallascounty.org/department/comcrtdistrict2/faq.html>. Accessed June 14, 2012.
- Castro, C.M., Wilson, C., Wang, F., and Schillinger, D. (2007). Babel babble: Physicians' use of unclarified medical jargon with patients. *American Journal of Health Behavior*, 31 (Supplement 1), S85-S95.
- Cawthorne, C.H., Rudat, K.R., Burton, M.S., Brown, K.E., Luxon, B.A., Janney, C.G., & Fimmel, C.J. (2002). Limited success of HCV antiviral therapy in United States veterans. *American Journal of Gastroenterology*, 97, 149-155.
- Centers for Disease Control and Prevention. (1998). Recommendations for prevention and control of hepatitis C virus (HCV) infection and HCV-related chronic disease. MMWR 47(No. RR-19):[1-39].
- Centers for Disease Control and Prevention. (2009). Estimates of disease burden from viral hepatitis. Atlanta, GA: US Department of Health and Human Services, CDC. Retrieved from http://www.cdc.gov/hepatitis/PDFs/disease_burden.pdf. Accessed December 1, 2011.
- Centers for Disease Control and Prevention. (2011). HCV FAQ's for Health Professionals. Atlanta, GA: US Department of Health and Human Services, CDC. Retrieved from <http://cdc.gov/hepatitis/HCV/HCVfaq.htm>. Accessed January 3, 2012.

- Choo Q.L, Kuo G., Weiner A.J., Overby L.R., Bradley D.W., Houghton, M. (1989). Isolation of a cDNA clone derived from a blood-borne non-A, non-B viral hepatitis genome. *Science*, 244 (4902), 359–362.
- Cousin, G., Schmid Mast, M., Roter, D.L., and Hall, J.A. (2012). Concordance between physician communication style and patient attitudes predicts patient satisfaction. *Patient Education and Counseling*, 87(2), 193-197.
- Cresswell, J.W. (2007). *Qualitative inquiry and research design* (2nd. Ed.). Thousand Oaks, CA: Sage.
- Delwaide J., El Saouda R., Gerard C., and Belaiche J. (2005). Hepatitis C infection: eligibility for antiviral therapies. *European Journal of Gastroenterology and Hepatology*, 17, 1185-1189.
- Doab A, Treloar C, and Dore G.J. (2005). Knowledge and attitudes about treatment for hepatitis C virus infection and barriers to treatment among current injection drug users in Australia. *Clinical Infectious Diseases*, 40 Supplement 5, S313-S320.
- Dugdale, D. C., Epstein, R. and Pantilat, S. Z. (1999). Time and the patient–physician relationship. *Journal of General Internal Medicine*, 14, 34-40.
- Edlin, B. (2005, November). *Five million Americans infected with the hepatitis C virus: A corrected estimate*. Presented at the American Association for the Study of Liver Diseases. Retrieved from http://www.natap.org/2005/AASLD/aasld_49.htm on February 2, 2012.
- Eisenman D.P., Glik D., Maranon R., Gonzales L., and Asch, S. (2009). Developing a disaster preparedness campaign targeting low-income Latino immigrants: Focus group results for project PREP. *Journal of Health Care for the Poor and Underserved*, 20(2), 330-345.

- Else-Quest, N.M., LoConte, N.K., Schiller, J.H. and Hyded, J.S. (2009). Perceived stigma, self-blame, and adjustment among lung, breast and prostate cancer patients. *Psychology and Health*, 24(8), 949-964.
- Falck-Ytter Y., Kale H., Mullen K.D., Sarbah S.A., Sorescu L., & McCullough, A.J. (2002). Surprisingly small effect of antiviral treatment in patients with hepatitis C. *Annals of Internal Medicine*, 136, 288-292.
- Farnell, B. and Graham, L.R. (2000). Discourse-centered methods. In H.R. Bernard (Ed.), *Handbook of methods in cultural anthropology* (pp. 411-454). Walnut Creek, CA: Altamira Press.
- Federico, C. A., Hsu, P. C., Krajden, M., Yoshida, E. M., Bremner, K. E., Weiss, A. A., ... and Krahn, M. D. (2012), Patient time costs and out-of-pocket costs in hepatitis C. *Liver International*. doi: 10.1111/j.1478-3231.2011.02722.x
- Fleming, C.A., Craven, D.E., Thornton, D., Tumilty, S., & Nunes, D. (2003). Hepatitis C virus and human immunodeficiency virus coinfection in an urban population: low eligibility for interferon treatment. *Clinical Infectious Diseases*, 36, 97-100.
- Fleming, C.A., Tumilty, S., Murray, J.E., & Nunes D. (2005). Challenges in the treatment of patients coinfecting with HIV and hepatitis C virus: need for team care. *Clinical Infectious Diseases*, 40(Suppl 5), S349-S354.
- Fraenkel, L., McGraw, S., Wongcharatrawee, S., and Garcia-Tsao, G. (2005). What do patients consider when making decisions about treatment for hepatitis C?. *The American Journal of Medicine*, 118, 1387-1391.

- Grant, R., Adams, A., Trinacty, C.M., Zhang, F., Soumerai, S.B., ... and Ross-Degnan, D. (2007). Relationship between patient medication adherence and subsequent clinical inertia in type 2 diabetes glycemic management. *Diabetes Care*, 30(4), 807-812.
- Hall C.S., Charlebois E.D., Hahn J.A., Moss A.R., & Bangsberg D.R. (2004). Hepatitis C virus infection in San Francisco's HIV-infected urban poor. *Journal of General Internal Medicine*, 19, 357-365.
- Haskard Zolnieriek, K.B. and DiMatteo, M.R. (2009). Physician communication and patient adherence to treatment: A meta-analysis. *Med Care*, 47(8), 826–834.
- Hohneker, J., Shah-Mehta, S., and Brandt, P.S. (2011). Perspectives on adherence and persistence with oral medications for cancer treatment. *Journal of Oncology Practice*, 7(1), 65-67.
- Kaplan, S.H., Greenfield, S., Gandek, B., Rogers, W.H., Ware Jr., J.E. (1996). Characteristics of physicians with participatory decision-making styles. *Annals of Internal Medicine*, 124, 497-504.
- Kemmer, N., Alsina, A., & Neff, G.W. (2011). Social determinants of orthotopic liver transplantation candidacy: Role of patient-related factors. *Transplantation Proceedings*, 43(10), 3769-3772.
- Kitzinger, J. (1995). Introducing focus groups. *British Medical Journal*, 311, 299-302.
- Lekas, H., Siegel, K., Leider, J. (2012). Challenges facing providers caring for HIV/HCV-coinfected patients. *Qualitative Health Research*, 22(1), 54-66.
- Levanthal, H., Benyamini, Y., Brownlee, S., Diefenbach, M., Levanthal, E.A., Patrick-Miller, L.,

- and Robitaille, C. (1997). Illness Representations: Theoretical Foundations. In K.J. Petrie and J.A. Weinman (Eds.), *Perceptions of health and illness: Current research and applications* (pp. 19-45). East Sussex, UK: Psychology Press.
- Manns MP., Wedemeyer, H., Cornberg, M. (2006). Recent advances in clinical practice: Treating viral hepatitis C: efficacy, side effects, and complications. *Gut* 55(9), 1350-1359.
- McKibbin, K.A. and Gadd, C.S. (2004). A quantitative analysis of qualitative studies in clinical journals for the 2000 publishing year. *BMC Medical Informatics and Decision Making*, 4, 11-18.
- McNally S., Temple-Smith M., Sievert W., & Pitts M.K. (2006). Now, later or never? Challenges associated with hepatitis C treatment. *Australian and New Zealand Journal of Public Health*, 30, 422-427.
- Moore, G. A., Hawley, D. A., and Bradley, P. (2009). Hepatitis C: Experiencing stigma. *Gastroenterology Nursing*, 32(2), 94-104.
- Morrill J.A., Shrestha M., & Grant R.W. (2005). Barriers to the treatment of hepatitis C. Patient, provider, and system factors. *Journal of General Internal Medicine*, 20, 754-758.
- Muir A.J., & Provenza D. (2002) A descriptive evaluation of eligibility for therapy among veterans with chronic hepatitis C virus infection. *Journal of Clinical Gastroenterology*, 34, 268-271.
- Murray, M.C.M., Barrios, R., Zhang, W., Hull, M., Montessori, V., Hogg, R.S., & Montaner, J.S.G. (2011). Hepatitis C virus treatment rates and outcomes in HIV/ hepatitis C virus coinfecting individuals at an urban HIV clinic. *European Journal of Gastroenterology & Hepatology*, 23, 45–50.

- Narayanasamy, A. (2002). Spiritual coping mechanisms in chronically ill patients. *British Journal of Nursing*, 11(22), 1461-1470.
- Nelson, J. E., Gay, E. B., Berman, A. R., Powell, C. A., Salazar-Schicchi, J. and Wisnivesky, J. P. (2011). Patients rate physician communication about lung cancer. *Cancer*, 117(22), 5212–5220
- North, C.S. (2006). Psychoeducation for HCV and alcohol behaviors. R01 AA15201. National Institute of Alcohol Abuse and Alcoholism.
- North C.S., Pollio D.E., Pfefferbaum B., Megivern, D., Vythilingam, M., Westerhaus, E.T... and Hong, B.A. (2005). Concerns of Capitol Hill staff workers after bioterrorism: Focus group discussions of authorities' response. *Journal of Nervous and Mental Disease*, 193(8), 523-527.
- Nunes D., Saitz R., Libman H., Cheng D.M., Vidaver J., & Samet J.H. (2006). Barriers to treatment of hepatitis C in HIV/HCV-coinfected adults with alcohol problems. *Alcoholism: Clinical and Experimental Research*, 30, 1520-1526.
- Padgett, D.K. (2008). *Qualitative methods in social work research* (2nd Ed.). Thousand Oaks, CA: Sage.
- Peterman, A.H., Fitchett, G., Brady, M.J., Hernandez, L., and Cella, D. (2002). Measuring spiritual well-being in people with cancer: The functional assessment of chronic illness therapy – spiritual well-being scale (FACIT-Sp). *Annals of Behavioral Medicine*, 24(1), 49-58.
- Preacher, K. J. (2001, April). Calculation for the chi-square test: An interactive calculation tool for chi-square tests of goodness of fit and independence [Computer software]. Available from <http://quantpsy.org>.

Poordad, F., McCone Jr., J., Bacon, B.R., Bruno, S., Manns, M.P., Sulkowski, M.S., ...

Jacobson, I.M. (2011). Boceprevir for Untreated Chronic HCV Genotype 1 Infection. *The New England Journal of Medicine* 364(13), 1195-1206.

Proeschold-Bell, R.J., Blouin, R., Reif, S., Amana, A., Rowland, B.J., Lombard, F., ...

and Muir, A.J. (2010). Hepatitis c transmission, prevention, and treatment knowledge among patients with HIV. *Southern Medical Journal*, 103(7), 635-641.

Rauch, A., Egger, M., Reichen, J., Furrer, H., & the Swiss HIV Cohort Study. (2005). Chronic hepatitis c in HIV-infected patients: Low eligibility and applicability of therapy with pegylated interferon-a plus ribavirin. *Journal of Acquired Immune Deficiency Syndromes*. 38(2), 238-240.

Reynolds, N.R., Sanzero Eller, L., Nicholas, P.K., Corless, I.B., Kirksey, K., Hamilton,

J., ... and Holzemer, W.L. (2009). HIV illness representation as a predictor of self-care management and health outcomes: A multi-site, cross-cultural study. *AIDS and Behavior* 13(2), 258-267.

Riessman, C.K. and Quinney, L. (2005). Narrative in social work: A critical review. *Qualitative Social Work*, 4(4), 391-412.

Rockstroh, J.K., Mocroft, A., Soriano, V., Tural, C., Losso, M.H., Horban, A., ... & Lundgren, J.

(2005). Influence of hepatitis c virus infection on HIV-1 disease progression and response to highly active antiretroviral therapy. *The Journal of Infectious Diseases*, 192, 992-1002.

Rosen, H.R. (2011). Chronic hepatitis C infection. *The New England Journal of Medicine*, 364(25), 2429-2438.

Rosenstock, I.M. (1966). Why people use health services. *Milbank Memorial Fund*

Quarterly 44 (3), 94–127

- Sandelowski, M., Lambe, C., and Barroso, J. (2004). Stigma in HIV-positive women. *Journal of Nursing Scholarship, 36(2)*, 122-128.
- Schwartzberg, J.G., Cowett, A., VanGeest, J., and Wolf, M.S. (2007). Communication techniques for patients with low health literacy: A survey of physicians, nurses, and pharmacists. *American Journal of Health Behavior, 31 (Supplement 1)*, S96-S104.
- Sherman K.E., Rouster S.D., Chung R.T., Rajicic N. (2002). Hepatitis C virus prevalence among patients infected with human immunodeficiency virus: a cross-sectional analysis of the US adult AIDS clinical trials group. *Clinical Infectious Diseases, 34(6)*, 831–837.
- Soriano, V., Sulkowski, M., Bergin, C., Hatzakis, A., Cacoub, P., Katlama, C., ... & Rockstroh, J. (2002). Care of patients with chronic hepatitis C and HIV-coinfection: recommendations from the HIV-HCV international panel. *AIDS, 16(6)*, 813–828.
- Stepanova, M., Kanwal, F., El-Serag, H.B., and Younossi, Z.M. (2011). Hepatitis C patients: Analysis of population-based data from the United States. *Hepatology, 53(3)*, 737-745.
- Sulkowski, M.S. (2008). Viral hepatitis and HIV coinfection. *Journal of Hepatology, 48*, 353-367.
- Sulkowski M.S. & Thomas, D.L. (2003). Hepatitis C in the HIV-infected person. *Annals of Internal Medicine. 138(3)*, 197-207.
- Sulkowski M.S., Thomas D.L., Chaisson R.E., & Moore R.D. (2000). Hepatotoxicity associated with antiretroviral therapy in adults infected with human immunodeficiency virus and the role of hepatitis C or B virus infection. *Journal of the American Medical Association. 283*, 74–80.
- Swan, D., Long, J., Carr, O., Flanagan, J., Irish, H., Keating, S,... and Cullen, W. (2010).

- Barriers to and facilitators of hepatitis c testing, management, and treatment among current and former injecting drug users: A qualitative exploration. *AIDS Patient Care and STDs*. 24(12), 753-762.
- Te, H. S. and Jensen, D.M. (2010). Epidemiology of hepatitis B and C viruses: A global overview. *Clinics in Liver Disease*, 14(1), 1-21.
- Thein, H., Yi, Q., Dore, G.J., Krahn, M.D. (2008). Estimation of stage-specific fibrosis progression rates in chronic hepatitis C virus infection: A meta-analysis and meta-regression. *Hepatology*, 48(2), 418-431.
- Thompson V.V., Ragland K.E., Hall C.S., Morgan M., & Bangsberg D.R. (2005). Provider assessment of eligibility for hepatitis C treatment in HIV-infected homeless and marginally housed persons. *AIDS*, 19 Suppl 3, S208-S214.
- Treloar, C. and Rhodes, T. (2009). The lived experience of hepatitis C and its treatment among injecting drug users: Qualitative synthesis. *Qualitative Health Research*, 19(9), 1321-1334.
- U.S. Census State and County QuickFacts: Dallas County, TX. Available at:
<http://quickfacts.census.gov/qfd/states/48/48113.html> [accessed 13.06.12].
- U.S. Census Small Area Income and Poverty Estimates: Dallas County, TX. Available at:
<http://www.census.gov/cgi-bin/saipe/saipe.cgi> [accessed 14.06.12].
- Vermeire EIJJ, Wens J, Van Royen P, Biot Y, Hearnshaw H, Lindenmeyer A. (2005). Interventions for improving adherence to treatment recommendations in people with type 2 diabetes mellitus. *Cochrane Database of Systematic Reviews*, Issue 2.
- Waller, L. (2004). Living with hepatitis C: From self-loathing to advocacy. *The Medical Journal of Australia*, 180(6), 293-294.

- Weber R., Sabin C.A., Friis-Moller N., Reiss P., El Sadr W.M., Kirk O., ... & Lundgren, J.D. (2006). Liver-related deaths in persons infected with the human immunodeficiency virus: the D:A:D study. *Archives of Internal Medicine*, 166(15), 1632–1641.
- Weiland, O. (1999). Treatment of naive patients with chronic hepatitis C. *Journal of Hepatology*, 31(Supplement 1), 168-173.
- Williams, M.V., Davis, T., Parker, R.M., & Weiss, B.D. (2002). The role of health literacy in patient-physician communication. *Family Medicine*, 34(5), 383-389.
- World Health Organization. Hepatitis C, WHO fact sheet no. 164, revised June 2011. Available at: <http://www.who.int/mediacentre/factsheets/fs164/en/>. Accessed December 1, 2011.
- Zickmund S., Hillis S.L., Barnett M.J., Ippolito L., and LaBrecque D.R. (2004). Hepatitis C virus-infected patients report communication problems with physicians. *Hepatology*, 39, 999-1007.
- Zickmund, S., Ho, E. Y., Masuda, M., Ippolito, L., & LaBrecque, D. R. (2003). “They treated me like a leper.” Stigmatization and the quality of life of patients with hepatitis C. *Journal of General Internal Medicine*, 18(10), 835-844.