

Substance Use Experiences and Hepatitis C Treatment Decision-Making Among
HIV/HCV Co-infected Adults

A Dissertation Presented

by

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Dedication

This dissertation is dedicated in the memory of my mother and my inspiration
Kathleen Marie Rush Fink (1948-2002). Mother, your love and spirit is with me always.

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Abstract

Substance Use Experiences and Hepatitis C Treatment Decision-Making Among HIV/HCV Co-infected Adults

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Hepatitis C virus (HCV) infection affects between 150,000 to 300,000 human immunodeficiency (HIV) positive adults in the US (Alter et al., 1999; Sherman, Rouster, Chung, & Rajicic, 2002). The majority of co-infected adults (50%-90%) have acquired HCV through substance abuse (Centers for Disease Control [CDC], 1998; CDC, 2006b). A patient's decision to begin HCV treatment is not straightforward. HCV evaluation and treatment involves a significant amount of time, energy, effort, and compliance on the part of the patient. There is limited information on how adults with HCV mono-infection make decisions about HCV evaluation and treatment (Fraenkel, McGraw, Wongcharatraee, & Garcia-Tsao, 2005). Even less is known about how adults with HIV/HCV co-infection with a history of substance abuse make treatment decisions. The purpose of this study was to describe substance abuse experiences and to explore how these related to patient decision-making about HCV treatment in HIV/HCV co-infected adults. Qualitative descriptive design and secondary data analysis were used to study these phenomena. Data were managed by using NVivo software and analyzed by secondary data analysis and qualitative content analysis.

Five major themes with sub-themes emerged during the data analysis. They were: (1) The Evolution of Substance Abuse (with sub-themes: substance abuse initiation, escalation, polysubstance abuse, normalcy: a family of addicts, the enemy within, and transmission and disclosure), (2) Revolving Door: Going Back Out (with sub-themes: specific events as a trigger, emotions as a trigger, alcohol as a trigger, and destructive relationships as a trigger), and (3) Reconstructing Life (with sub-themes: defining moments in substance abuse addiction and maintaining sobriety), (4) HCV Infection Treatment Issues (with sub-themes: HCV treatment: not a priority, fear, and misinformation, and desire to use stimulated during HCV treatment), and (5) Get Clean and Try It.

The participants spoke about how their substance abuse evolved from inception to sobriety, and for some it remained a problem. Relapse and recovery were fragile in nature especially in these adults with HIV/HCV co-infection. The decision-making process is influenced by substance abuse experiences, however more research is needed to uncover specific factors influencing these decisions.

Chapter I

State of the Science

Introduction

Hepatitis C virus (HCV) infection affects between 150,000 to 300,000 human immunodeficiency (HIV) positive adults in the US (Alter et al., 1999; Sherman, Rouster, Chung, & Rajicic, 2002). The majority of co-infected adults (50%-90%) have acquired HCV through substance abuse (Centers for Disease Control [CDC], 1998; CDC, 2006b). Research has been conducted to understand substance abuse within the context of HIV infection (Buchanan et al., 2006; Doherty, Garfein, Monterroso, Brown, & Vlahov, 2000; Galai, Safaeian, Vlahov, Bolotin, & Celentano, 2003; Irwin et al, 1996; Mehta et al., 2006; Nelson, Vlahov, Solomon, Cohn, & Munoz, 1995) and in HCV and HIV/HCV co-infection (Fleming, Craven, Thornton, Tumilty, & Nunes, 2003; Nunes et al., 2006; Tracy Swan Treatment Action Group, 2006). Treatment decision-making can be difficult and complex for patients (Woolf et al., 2005) and these decisions can be influenced by a variety of factors such as health status, misinformation, emotions, and past experiences (Benbassat, Pilpel, & Tidhar, 1998; Redelmeier, Rozin, & Kahneman, 1993; Wills & Holmes-Rovner, 2006). Furthermore, not everyone wants the same level of involvement in the decision-making process (Levinson, Audiey, Kuby, & Thisted, 2004). In addition, much of the current research focuses on treatment decisions made by providers rather than the patient (Fultz et al., 2003; Patil et al., 2001; Sylvestre, 2005). Some research investigations have sought to understand treatment decisions made by HIV-infected and HCV-infected patients (Fraenkel, McGraw, Wongcharatraee, & Garcia-Tsao, 2005; Laws, Wilson, Bowser, & Kerr, 2000; Misener & Sowell, 1998). Current HCV treatment

guidelines suggest patients take a more active role in HCV treatment decision-making (National Institutes Of Health [NIH] Consensus Development Program, 2002). However, little is known about the substance abuse issues that may influence HCV treatment decisions among co-infected adults from their perspective (Fraenkel et al., 2005). Wagner and Ryan (2005) have suggested that research is needed to assess co-infected patients' attitudes, beliefs, and readiness for HCV treatment along with factors influencing treatment decision-making.

The purpose of this chapter is to describe substance abuse experiences among HIV/HCV co-infected adults and decision-making regarding HCV treatment. Also, this chapter will focus on studies, reviews, and treatment guidelines from the US due to the differences in cultural, legal, health care systems, and treatment options between countries.

Prevalence of HIV and HCV and Co-infection

HIV Prevalence

An estimated 1 to 1.2 million persons are living with HIV/AIDS in the US (CDC, 2006c; CDC, 2006d; Glynn & Rhodes, 2005). While sexual contact remains the leading risk associated with HIV infection, injection drug use is a significant source of new HIV infection in both men and women in the US (CDC, 2006a). For men, male-to-male sexual contact remains the primary mode of HIV transmission, followed by injection drug use and then heterosexual contact (CDC, 2006a; CDC, 2006b; CDC, 2006d). Black males are the largest group to be infected with HIV (CDC, 2006a; CDC, 2006c; CDC, 2006d). For women, heterosexual contact with HIV-infected males is the leading cause of infection, followed by sexual contact with male injection drug users, then sexual contact with

bisexual males. The overall number of women with newly diagnosed HIV infection has risen from 8% in 1985 to 27% in 2004 (CDC, 2006d). Black women outnumber white non-Hispanic women three-to-one in HIV/AIDS infections in the US (CDC, 2006a). There is no known cure for HIV however, advances in HIV care, treatment, and the introduction of combination antiretroviral therapy (ART) in 1996 have decreased mortality in HIV-infected adults as well as slowed HIV disease progression (Michaels, Clark, & Kissinger, 1998; Palella et al., 1998).

HCV Prevalence

Approximately 3.9 million individuals are living with HCV infection in the US and nearly twice as many men than women are infected (Alter et al., 1999; Alter, 2006; Butterfield et al., 2003; CDC, 2006b; Lauer & Walker, 2001). In the National Health and Nutrition Survey ($N = 10,612$), the prevalence of HCV in males was 3.4% (2.6-4.4 at 95% Confidence Interval [CI]) and 1.5% in females (1.1-2.0 at 95% CI) (Kruszon-Moran & McQuillan, 2005). It has been suggested up to five million Americans have been infected with HCV (Edlin, 2005). Historically, HCV was acquired through exposure to blood products or blood transfusions (CDC, 2006b; CDC, 1998). Currently, injection drug use is the primary source of newly diagnosed HCV infection in the US (CDC, 2006a; CDC, 2006b; Edlin et al., 2005). Prevalence studies show HCV infection rates in injection drug users to be 67% (Piccolo et al., 2002), 76.9% (Garfein, Vlahov, Noya, Doherty, & Nelson, 1996), 89% (Thiede, Hagan, & Murrill, 2000), and 80% to 100% (Murrill et al., 2002).

HCV is an enveloped ribonucleic acid (RNA) blood-borne virus of the Flaviviridae family and is categorized into six genotypes. Approximately 75% of adults

in the US are infected with genotype 1, 16% with genotype 2, and 8% with genotype 3 (Nainan et al., 2006). Patients can also be infected with genotypes 4 to 6, but patients with these genotypes are less common in the US (Nainan et al., 2006).

HCV is emerging as a major source of morbidity and mortality in the US. About 30,000 new cases of HCV are diagnosed each year and approximately 85% of those will go on to develop chronic HCV infection (CDC, 2006d, Leung, 2002, CDC, 1998; Nainan et al., 2006; Sasadeusz, 2001). Approximately 8,000 to 10,000 people die each year from complications of liver disease and failure caused by HCV (CDC, 2006e; CDC, 1998). Currently, HCV infection accounts for one-third of hepatocellular carcinoma (HCC) cases in the US (NIH, 2002) and it has been estimated the number of persons with HCV induced liver failure will increase four-fold by the year 2018 (Lawrence, 2000).

HIV/HCV Co-infection Prevalence

HCV infection affects between 150,000 to 300,000 HIV positive adults in the US (Alter et al., 1999; Sherman et al., 2002). The overall prevalence rates of HIV/HCV co-infection are difficult to determine (CDC, 2006e; Sherman, 2002). This is due to variation and delays in testing and reporting between state agencies and the cost of large population based studies (CDC, 2006e; Shepard, Finelli, & Alter, 2005). In addition, no national US database exists to track HIV/HCV co-infection rates. Reported co-infection rates range from 1.6% to 72.7 % (McCoy et al., 2004; Sherman et al., 2002; Tedaldi et al., 2003).

In adults with HIV/HCV co-infection, mortality due to end-stage liver disease and liver failure is on the rise due to HCV infection (Bica et al., 2001). In a meta-analysis, Graham and colleagues (2001) concluded that co-infected patients had a six-fold greater

risk of liver decompensation (adjusted relative risk of 2.92 (95% CI, 1.70-5.01). HIV infection appears to increase HCV RNA levels (Sherman et al., 1993) and progression of HCV-related liver disease (Monga et al., 2001; Thomas et al., 2000). Merriman and colleagues (2006) found that HCV/HIV co-infection was associated with higher frequency of liver function abnormalities (37% vs 20%; $p < 0.0003$) and greater mortality (17% HCV/HIV vs 6% HCV vs 9% HIV $p < 0.000$) compared with mono-infected subjects.

Also, HCV was found to increase the rate of HIV progression (Anderson, Guest, Rimland, 2004; De Luca et al., 2002; Piroth et al., 1998). In other studies, HCV was not associated with the progression of HIV or death due to AIDS (Staples, Rimland, & Dudas, 1999; Hershow et al., 2005; Sulkowski, Moore, Mehta, Chaisson, & Thomas, 2002; Sullivan, Hanson, Teshal, Whotring, & Brooks, 2006). In a prospective trial ($N = 1955$) no significant differences were found in the progression to AIDS, death, or responding to highly active antiretroviral therapy (HAART) between HCV-infected and HCV uninfected group (Sulkowski et al., 2002). The authors found an increased risk of death in a subgroup ($n = 429$) of HCV-infected patients with a baseline CD4 cell count of 50/microL to 200/microL (relative hazard [RH], 1.51; 95% CI, 1.01-2.27). However, after adjusting for exposure to HAART in a multivariate Cox regression analysis, death was not independently associated with HCV infection in this subgroup (RH, 1.01; 95% CI, 0.65-1.56) (Sulkowski et al., 2002).

Substance Abuse Issues

HIV and Injection Drug Abuse

There has been considerable work done to understand substance abuse within the context of HIV infection (Doherty, Garfein, Monterroso, Brown, & Vlahov, 2000; Galai, Safaeian, Vlahov, Bolotin, & Celentano, 2003; Irwin et al, 1996; Mehta et al., 2006; Nelson et al., 1995). Injection drug use (IDU) is the second leading risk factor associated with new HIV infections in the US (CDC, 2006a). Studies show a multitude of risk factors exist in the transmission of HIV in injection drug users.

Reported risk factors for HIV in injection drug users include:

- Injecting heroin to mediate the effects of crack cocaine smoking (Irwin, 1996),
- Moving from snorting heroin to injecting heroin to improve the high (Doherty et al., 2000; Irwin et al., 1996),
- Injecting heroin or cocaine out of curiosity or for fun (Doherty et al., 2000),
- Poly-substance abuse (using a variety of drugs and alcohol to get a high) (Doherty et al., 2000; Irwin et al., 1996),
- Injecting a speedball (the mixing of heroin and cocaine in the same syringe) (Doherty et al., 2000),
- Having a sexual partner who injects or trades sex for drugs and money (Galai et al., 2003; Irwin et al., 1996),
- Sharing needles with one or more persons in a shooting gallery (Doherty, et al., 2000; Galai et al., 2003; Mehta et al., 2006), with a sexual partner

who provides emotional support (Unger et al., 2006), and with an injection partner if HIV status has been discussed (Unger et al., 2006),

- Indirect sharing of drug preparation equipment (cotton, straws, rinse water, cookers) (Koester, Glanz, & Baron, 2005; Thorpe et al., 2002; Tortu, McMahon, Hamid, & Neaigus, 2003).

Injection drug abuse continues to be a major source of HIV infection in the US. Greater numbers of adults are living with HIV infection than ever before due to the improvements in treatment (CDC, 2006c). HIV prevention efforts should be directed toward individuals who have a history of injection drug use and other high risk behaviors (Edlin et al., 1994; Nelson et al., 2002). Drug detoxification and rehabilitation remains a priority for injection drug users (Institute of Medicine [IOM], 2007). Several studies have shown that those in methadone treatment programs have lower rates of HIV seroconversion (Metzger et al., 1993; Moss et al., 1994). In a review of the literature, Gibson, Flynn, and McCarthy (1999) concluded that methadone treatment programs are effective in preventing HIV disease among injection drug users.

HIV and Alcohol Abuse

Injection drug users frequently abuse alcohol which can influence high risk decision-making behaviors (Stein et al., 2000; Stein et al., 2002). Alcohol ingestion is known to reduce inhibition and judgment skills (Abroms, Fillmore, & Marczinski, 2003; Marczinski & Fillmore, 2005). The use of alcohol has been reported as an independent risk factor for needle sharing among injection drug users (Stein et al., 2000). In addition, it has been shown that when drinking, injection drug users are more likely to visit shooting galleries compared to days when they did not drink ($p < .001$) (Stein et al.,

2002). Thus, alcohol abuse can increase the risk of HIV in injection drug users (Doherty et al., 2000; Galai et al., 2003; Mehta et al., 2006).

HCV and Injection Drug Abuse

There are a number of studies that address HCV infection and substance abuse issues (Garfein et al., 1996; Hagan et al., 2005; Klinkenberg et al., 2003; Osher et al., 2003; Thorpe et al., 2002; Tortu, McMahon, Pouget, & Hamid, 2004). Transmission of HCV can occur rapidly after initiating IDU. Garfein and colleagues found that 65% of injection drug users in their sample were infected with HCV within the first year of IDU (Garfein et al., 1996). Hagan, Thiede, and Des Jarlais (2005) found that 134 of 484 (28%) of HCV antibody negative injection drug users seroconverted to HCV positive within a weighted average time of 3.4 years. Additionally, the risk of HCV infection increases with the duration of IDU; close to 100% of injection drug users are infected by year eight of IDU (Kwiatkowski, Fortuin-Corsi, & Booth, 2002; Murrill et al., 2002). Reported risk factors for HCV infection in the injection drug user include:

- Sharing used needles (Hagan et al., 2005),
- Sharing injection drug preparation paraphernalia (cotton, cooker, rinse water) (Hagan, Thiede, Weiss, Duchin, & Alexander, 2001; Kwiatkowski et al., 2002).
- Sharing non-injection drug paraphernalia (intranasal and oral drug implements) (Tortu et al., 2004).

IDU practices place individuals at risk for HCV infection (Hagan et al., 2005; Sherman et al., 2002). Targeted prevention programs such as needle exchange programs, sterile syringe prescriptions, and risk-reduction programs designed specifically for the

prevention of HIV and HCV transmission are needed (Hagan et al., 2005; NIH, 2002).

Encouraging patients to participate in prevention programs along with drug detoxification and rehabilitation, especially early in injection drug use initiation, may help reduce the transmission of HCV infection (Hagan et al., 2005).

HCV and Alcohol Abuse

Alcohol abuse can co-occur with HCV infection and can worsen the course of the HCV disease (Campbell et al., 2006; Nunes et al., 2006; Peters & Terrault, 2002). Studies have shown a high prevalence of HCV infection in patients who abuse alcohol (Anand et al., 2006; Campbell et al., 2006). In the longitudinal Study to Reduce Intravenous Exposures (STRIVE), 37% of the sample ($n = 598$) were problem drinkers based on the 10-item Alcohol Use Disorder Identification Test (AUDIT) (Campbell et al., 2006). In the final multivariate model within this study, problem drinking was associated with male gender (adjusted odds ratio [AOR] = 2.5, 95% CI = 1.5-4.3), homelessness (AOR = 1.6, 95% CI = 1.1-2.5), prior alcohol treatment (AOR = 3.7, 95% CI = 2.4-5.7), injection drug use within the past three months (AOR = 2.0, 95% CI = 1.3-3.1), and depression (AOR = 1.7, 95% CI = 1.1-2.6) (Campbell et al., 2006).

Alcohol use can increase the risk of developing liver fibrosis in persons infected with HCV (Peters & Terrault, 2002; Schiavini et al., 2006; Thomas et al., 2000). In an integrative review, these authors concluded that heavy alcohol ingestion (more than 50 grams/day) may worsen liver fibrosis in adults with HCV infection (Peters & Terrault, 2002). Other studies have shown that patients with HCV infection and concurrent alcohol use have a more rapid progression of liver disease (Di Martino et al., 2001; Poynard, Bedossa, & Opolon, 1997). Westin and colleagues (2002) found that moderate alcohol

intake (4.8 grams/day, interquartile range 1.1-11.6 grams/day) increased fibrosis progression in adults with HCV infection. The authors suggested that patients with HCV infection should abstain from alcohol consumption (Westin et al., 2002). The National Institutes of Health Consensus guidelines suggest alcohol ingestion is not an absolute contraindication to HCV treatment, however safe levels of consumption have not been established and patients should be encouraged to abstain before and during treatment (NIH, 2002).

HIV/HCV Co-infected Adults and Injection Drug Abuse

According to recent statistics, the majority of new HIV/HCV co-infected adults (60% to 90%) acquired HCV through injection drug abuse (CDC, 1998; Thomas et al., 1995; Thomas, 2002; Shepard et al., 2005). Many of the same risk factors associated with HIV or HCV mono-infection places the injection drug user at risk for HIV/HCV co-infection. Reported risk factors for HIV/HCV co-infection in injection drug users include:

- Direct contact of blood through sharing needles and syringes (Hsu, 2002; Novelli et al., 2005),
- Sharing drug preparation equipment such as cotton, cookers, straws, and rinse water (Koester, Glanz & Baron, 2005; Thorpe et al., 2002; Tortu, McMahon, Hamid, & Neaigus, 2003),
- Sharing used needles and syringes with sexual partners, having unprotected sex or trading sex for money or drugs, or having sex with someone who injects drugs (Miller, & Neaigus, 2001).

HIV-infected patients and anyone with a history of IDU should be screened for HCV infection in order to identify those who may need HCV treatment (Alter, 2005;

CDC, 1998; NIH, 2002; Sherman, 2002a; Sherman, 2002b; Strader, Wright, Thomas, & Seeff, 2004). With treatment, HCV-related liver failure may be reduced in HIV/HCV-infected patient (Sherman, 2005b).

HIV/HCV Co-infection and Alcohol Abuse

Alcohol abuse is common in HIV/HCV co-infected patients (Nunes et al., 2006). Alcohol consumption has been shown to increase HCV RNA, aspartate aminotransferase (AST), and gamma-glutamyl transpeptidase (GGT), and alanine transaminase (ALT), and progression of liver disease in patients with HIV/HCV co-infection (Cooper & Cameron, 2005; Conigliaro et al., 2003; Nunes et al., 2006; Pol et al., 1998). In addition, alcohol consumption can increase hepatotoxicity in those patients who are taking HIV antiretroviral medications (Hernandez et al., 2001; Soriano et al., 2002).

Persistence of Substance Abuse

Despite the number of inpatient and outpatient drug and alcohol treatment programs in the US, relapse and persistent substance abuse remains a major problem for those who abuse drugs and alcohol (IOM, 2006). Persistent IDU places the individual at a greater risk for contracting HIV/HCV infections (Galai, Safaeian, Vlahov, Bolotin & Celentano, 2003; Lucas et al., 2006; Mehta et al., 2006). Substance abuse tends to emerge gradually and persists on a continuum (Miller & Carroll, 2006). For example, an individual who smokes cocaine may need to move to injecting heroin to mitigate the withdrawal effects of cocaine (Irwin, 1996). Or, drug escalation may occur to improve the high (Doherty, Garfein, Monterroso, Latkin, & Vlahov, 2000). Addictive behaviors tend to be self-perpetuating and reinforced as part of other psychological, social, and physical problems such as mood/psychiatric disorders, homelessness, violence, poverty,

and neglect (Mehta et al., 2005; Miller & Carroll, 2006). As tolerance increases, dependence sets in, causing repetitive drug use (Hyman & Malenka, 2001). This pattern of tolerance and dependency can be persistent and reinforced due to compulsive psychological mechanisms, as well as neurochemical changes in the cells (Hyman & Malenka, 2001; Hyman, Malenka, & Nestler, 2006). In addition, there is some evidence that structural deficiencies within the grey matter of the brain exist associated with decision-making behavioral inhibition and emotions in persons who abuse cocaine (Childress, 2006; Franklin et al., 2002). Thus, with exposures to cues and reinforcement, persistent drug abuse can be a life-long behavior (Childress, 2006; Volkow et al., 2006; White, 1989).

Patients with persistent IDU are at risk for HIV and HCV infections and have a higher mortality rate than in those with HIV/HCV co-infection who do not inject drugs (Galai et al., 2003). The AIDS Link to Intravenous Experience (ALIVE) study revealed only 19.6% of the total participants ($N = 1,339$) were able to abstain from substance abuse during the 12-year study period (Galai et al., 2003). In addition, persistent injection drug users (29.2%) and those who had multiple relapses (36.9%) had the highest rates of mortality due to AIDS, with deaths at 21% and 20.2% respectively. Greater efforts need to be placed on detoxification and treatment of active substance abuse before beginning HCV treatment (Soriano et al., 2002).

Treatment of HCV in HIV/HCV Co-infected Adults

Treatment of HCV in Adults

The primary purpose of treatment of HCV in an HCV mono-infected or HIV/HCV co-infected adult is to either eradicate HCV or reduce the likelihood of HCV-

related liver disease including cirrhosis and liver cancer. The main goal of HCV treatment is to achieve a sustained viral response (SVR). An SVR is defined as the absence of a detectable HCV-RNA six months after the completion of treatment (Ballesteros et al., 2004; Hughes & Shafran, 2006; Manns et al., 2001; Strader et al., 2004). HCV-RNA is the direct serological measure of the HCV virus. Several drug combinations have been approved by the Federal Drug Administration (FDA) for the treatment of HCV in the mono-infected adult (Stader, Wright, Thomas, & Seeff, 2004). The approved combination therapies include:

- Peginterferon alfa-2a (Pegasys, Hoffmann-La Roche, NJ) and ribavirin,
- Peginterferon alfa-2b (Peg-Intron, Shering-Plough, NJ) and ribavirin,
- Interferon alfa-2a (Roferon-A, Hoffmann-La Roche, NJ) and ribavirin,
and
- Interferon alfa-2b (Intron-A, Shering-Plough, NJ) and ribavirin.

However, alfa interferons and the recombinant forms (alfa-2a, alfa-2b, and consensus interferon) are being replaced with pegylated interferons (peginterferons) (NIH, 2002). This is because pegylated interferons have a longer half-life than alfa interferons and can be given once a week rather than multiple times a week (National Digestive Disease Information Clearinghouse [NDDIC], 2006). The once-a-week dosing of peginterferons make it easier for patients to adhere to treatment since they are only receiving one injection per week versus three. Pegylated alfa-2a is a standard dose (180 micrograms/subcutaneous injection/once weekly in combination with ribavirin) and pegylated alfa-2b is based on an individual's weight (1.5 microgram/kilogram body weight/subcutaneous injection/once weekly in combination with ribavirin). Treatment is

recommended for a duration of 24 or 48 weeks in HCV mono-infected adults depending on HCV genotype (Strader et al., 2004). A full 48-week course of HCV treatment peginterferon plus ribavirin costs approximately \$20,000 (Raymond, 2004; Solomon, Weinstein, Hammitt, & Goldie, 2003).

Treatment of HCV in HIV/HCV Co-infected Adults

Interferon alfa-2a and interferon alfa-2b are FDA approved for use in HIV/HCV co-infected adults (Thomas, 2006). Pegylated interferon alfa-2a or interferon alfa-2b plus ribavirin are the current treatment choices for chronic HCV in HIV co-infected adults and are prescribed for 48 weeks (Carrat et al., 2004; Voigt et al., 2006). Guidelines suggest that an HCV-RNA test should be performed at week 12 of therapy to assess for early viral response (EVR) (Strader et al., 2004). EVR is defined as an undetectable HCV-RNA or a reduction in the HCV-RNA level by 2 log or more which happens at approximately 12 weeks of therapy and can be indicative of SVR (Torriani et al., 2004). In three randomized clinical trials, EVR predicted 97.5% to 100% of non-responders of HCV treatment (Chung et al., 2004; Fuster et al., 2006; Torriani et al., 2004). If an EVR is not achieved, treatment can be discontinued in an effort to mitigate the medication side effects and the cost of treatment. Fuster and colleagues (2006) found that there was no benefit to extending interferon alfa-2a plus ribavirin past 12 weeks in HIV/HCV co-infected patients if EVR was not achieved at 12 weeks.

There are modifiable physiological and psychological contraindications to HCV treatment in the HIV/HCV co-infected adult. Before HCV treatment begins, the patient should undergo stabilization of HIV infection with HAART, stabilization of active psychiatric disease, and management of active substance abuse (Edlin et al., 2005).

Management of active substance abuse can include the use of buprenorphine or opioid agonists such as methadone alone or in combination with psychotherapy. Treatment of alcohol abuse is also part of the initial pretreatment phase. Patients should be encouraged to enroll in an alcohol treatment program before beginning HCV treatment; however this should not prevent the individual from being assessed for treatment (NIH, 2002).

Treatment of HCV infection is not recommended in HIV/HCV co-infected adults who have advanced cirrhosis, comorbidities with a limited life expectancy, renal failure, malignancies, uncontrolled autoimmune disorders, pregnancy or potential pregnancy (among those refusing to use birth control measures), and in those with heart, lung, or kidney transplantations (CDC, 2006e; Yee, Currie, Darling, & Wright, 2006; CDC, 1998). In patients who have contraindications for HCV treatment, management of drug and alcohol use, may slow progression of liver fibrosis (Adeyemi, 2007).

Since the progression to cirrhosis is faster and the mortality related to liver failure in HIV/HCV co-infected adults is increasing, efforts to move patients toward HCV treatment is warranted (Eldin et al., 2005; DiMartino et al., 2001). Brau (2005) suggests all patients with HIV/HCV co-infection should be evaluated for treatment.

Treatment Response Rates in HIV/HCV Co-infected Adults

The rates of SVR in HCV mono-infected adults ranges from approximately 40% to 80% depending on HCV genotype (Fried et al., 2002; Manns et al., 2001). In adults with HIV/HCV co-infection, SVR is generally lower than in HCV mono-infected adults (Sherman, 2003; Shire, Welge, & Sherman, 2007). Two randomized controlled trials have examined HCV treatment in HIV/HCV co-infected adults with standard interferon alfa-2b (INF-2b) and ribavirin (Brau et al., 2004; Sulkowski et al., 2004). The SVR was

11% and 9%, respectively. Peginterferon alfa-2a plus ribavirin and pegylated interferon alfa-2b plus ribavirin have been shown to be more effective than standard interferon alfa-2a or standard interferon alfa-2b and ribavirin (Chung et al., 2004; Carrat et al., 2004) in randomized clinical trials. In the AIDS Pegasys Ribavirin International Co-infection Trial (APRICOT), peginterferon alfa-2a plus ribavirin was shown to be more effective than either peginterferon alfa-2a as monotherapy, or standard interferon alfa-2a plus ribavirin (Torriani et al., 2004).

SVR rates vary in adults with HIV/HCV co-infection. Reported SVR rates in randomized trials examining peginterferon alfa-2b plus ribavirin versus standard interferon alfa-2b plus ribavirin include:

- In the International Hepatitis Interventional Therapy Group: 54% ($n = 274/511$) in peginterferon alfa-2b plus ribavirin compared to two different arms: 1) 47% in standard interferon alfa-2b plus ribavirin ($n = 235/505$) or 2) 47% in lower dose peginterferon alfa-2b ($n = 244/514$) ($p = .01$ for both comparisons) (Manns et al., 2001).
- 44% in peginterferon alfa-2b plus ribavirin arm ($n = 52$) compared to 7% in standard interferon alfa-2b plus ribavirin arm ($n = 43$) ($p = .007$) (Laguno et al., 2004).
- 27% in peginterferon alfa-2b arm ($n = 205$) compared to 20% in standard interferon alfa-2a plus ribavirin arm ($n = 207$) ($p = .047$) (Carrat et al., 2004).

Reported SVR rates in peginterferon alfa-2a plus ribavirin versus standard interferon alfa-2a plus ribavirin include:

- The APRICOT Trial: 40% in peginterferon alfa-2a plus ribavirin arm ($n = 224$) compared to 12% in standard interferon alfa-2a plus ribavirin arm ($n = 178$) ($p = .001$) (Torriani et al., 2004),
- The Adult AIDS Clinical Trial Group (ACTG): 27% in peginterferon alfa-2a plus ribavirin ($n = 6$) compared to 12% ($n = 67$) in standard interferon alfa-2a plus ribavirin arm ($p = .03$) (Chung et al., 2004).

In each study, the peginterferon alfa arm was the most effective (Carrat et al., 2004; Chung et al., 2004; Laguno et al., 2004; Manns et al., 2001; Torriani et al., 2004). Currently, ribavirin plus either peginterferon alfa-2a or peginterferon alfa-2b is the standard of care for treatment of HCV in HIV/HCV co-infected adults in the US (Thomas, 2006).

Research has demonstrated a wide variation in HCV treatment response rates in the various genotypes. Patients with genotype 1 have the lowest treatment response rate (Simmonds, 1999; Nainan et al., 2006; Shire, Welge, & Sherman, 2007). Treatment response rates in patients with genotype 1 treated with peginterferon alfa-2a plus ribavirin range from 14% to 29% (Chung et al., 2004; Torriani et al., 2004). In those treated with peginterferon alfa-2b plus ribavirin, SVR rates range from 10% to 38% (Cargnel et al., 2005; Carrat et al., 2004; Laguno et al., 2004). Some early research results indicate that a higher dose of ribavirin at 1000 mg to 1200 mg versus 800 mg, may play a more critical role in achieving SVR, especially in patients with HCV genotype 1 and in those with HIV/HCV co-infection (Ramos et al., 2007).

Only a few observational studies have included active substance abusers in HCV evaluation studies (Backmund, Meyer, von Zeilonka, & Eichenlaub, 2001; Schaefer et al., 2003; Sylvestre, 2002; Sylvestre, Litwin, Clements, & Gourevitch, 2005). Sylvestre and colleagues (2005) examined a group of individuals infected with HCV ($N = 76$) in a methadone maintenance program and treated with interferon alfa-2b and ribavirin. The authors found those who used substances (heroin, cocaine, methamphetamines) regularly during HCV treatment ($n = 8$) did not achieve SVR. These findings did not reach statistical significance ($p = .09$). However, a progressive decrease in SVR was seen among those treated as substance abuse increased.

HCV Treatment Rates in HIV/HCV Co-infected Adults

The numbers of HIV/HCV co-infected patients treated for HCV infection are low (approximately 15%) (Taylor, Costello, Alt, Yates, & Tashima, 2002). Furthermore, co-infected substance abusers have lower HCV treatment rates than non-substance abusers (Fultz et al., 2003; Taylor et al., 2002). Reported HCV treatment rates in co-infected adults range from 0.2% ($N = 881$) in a group of military veterans (Fultz et al., 2003) to 15% ($N = 104$) in an urban setting in New York (Restrepo et al., 2005).

There have been numerous studies examining medical treatment of HCV in the adult with HIV/HCV co-infection (Chung et al., 2004; Fleming et al., 2003; Laguno et al., 2004; Nunes et al., 2006; Taylor, 2005; Torriani et al., 2004). The findings suggest there are many barriers to HCV treatment.

Barriers to HCV Treatment in HIV/HCV Co-infected Adults

Treatment rates for HCV infection in adults co-infected with HIV/HCV remain low (Clanon, Mueller, & Harank, 2005; Mehta et al., 2005). HCV treatment can be

challenging and complex in the co-infected substance abuser. Therefore, HCV treatment decisions should be based on a collaborative process between provider and the patient (Fleming, Tumilty, Murray, & Nunes, 2005; Mehta et al., 2005). Due to low HCV infection treatment rates in adults with HIV/HCV co-infection, a greater understanding of the factors contributing to treatment decisions from the patient and provider perspective are needed (Wagner & Ryan, 2005). Low HCV treatment rates in HIV/HCV co-infected adults can be due to a variety of structural, personal, and social barriers.

Structural Barriers to HCV Treatment

Structural barriers are obstacles that are generally not controlled by the patient. Structural barriers to HCV treatment include issues such as treatment guidelines, provider decision-making about treatment eligibility or ineligibility, limited access to care, limited appointments with HCV treatment specialists, and difficulty accessing HCV treatment programs (Edlin, 2002; Edlin et al., 2001; Edlin et al., 2005; Mehta et al., 2005; Thompson, Ragland, Hall, Morgan, & Bangsberg, 2005).

Individual health care systems have guidelines to assist providers in delivering care to adults requiring treatment of HCV infection (National Institutes of Health [NIH], 1997, NIH, 2002; Thompson et al., 2005; Yee et al., 2006). Historically, treatment guidelines excluded persons from HCV treatment who were drinking alcohol and injecting illegal drugs until a six-month period of sobriety had been established (CDC, 1998; NIH, 1997). Changes in HCV treatment guidelines now allow providers to assess the risks and benefits of treatment in active substance abusers (NIH, 2002). Active alcohol and active substance abuse are considered relative contraindications to HCV treatment and the patient should be encouraged to enroll in a drug or alcohol treatment

program before beginning HCV treatment (Adeyemi, 2007; NIH, 2002; Nunes et al., 2006; Soriano et al., 2002; Sulkowski & Thomas, 2005a). Despite these changes to treatment guidelines, active alcohol and injection drug abuse remains a significant barrier for the treatment of HCV in HIV/HCV co-infected adults (Fleming et. al. 2003; Fultz et al., 2003; Nunes et al., 2006; Thompson et al., 2005; Walley, White, Kushel, Song, & Tulskey, 2005; Sylvestre, 2005). Nunes and colleagues (2006) found that active alcohol abuse was the largest barrier to HCV treatment in HIV/HCV co-infected adults. These researchers found that 54 of 200 patients (27%) were ineligible for HCV treatment due to current heavy alcohol abuse (defined as more than 14 standard drinks per week or more than four drinks per day for men, more than seven drinks per week or more than three drinks per day in women). In this same study, 17 of the 200 (8.5%) patients were ineligible for HCV treatment due to active IDU (Nunes et al., 2006). In a prospective study from The US Department of Veterans Affairs (VA) to assess HCV treatment candidacy and adherence and outcomes, 80% of the sample (584/726) had a history of alcohol use and 27% (194/726) had used alcohol regularly in the past year (Anand et al., 2006). These authors found that alcohol consumption was associated with increased HCV treatment discontinuation (40% vs. 26%; $p = < .0002$), but not SVR ($p = .06$).

Sylvestre and colleagues (2005) suggest that arbitrary abstinence times should not be used as a criterion for beginning HCV treatment; rather, individual assessment should take place in order to determine HCV treatment options. Furthermore, it has been suggested that withholding HCV treatment in active substance abusers is unwarranted and unethical (Geppert & Arora, 2005). Withholding treatment can delay access to necessary health care and can pose a threat to public health by allowing the virus to go

untreated (Edlin et al., 2001; Geppert & Arora, 2005). Edlin (2002) suggests allowing patients to attempt HCV treatment if they want to try. Conversely, others have suggested medical efforts be placed on detoxification and treatment of active substance abuse before HCV treatment is initiated (Soriano et al., 2002).

Additionally, healthcare providers make decisions about HCV treatment eligibility or ineligibility (Thompson et al., 2005). There may be a lack of referral for treatment due to provider decision-making. In a study investigating eligibility, providers ($N = 52$) classified 70% (94/133) of HIV/HCV co-infected individuals as ineligible for HCV infection treatment (Thompson et al., 2005). In addition, the providers in this sample concluded that patients would be ineligible for HCV treatment because of poor medication adherence, lack of interest in treatment, active depression, and active IDU. The authors went on to assess HCV treatment rates in the patients. They found that out of the total sample ($N = 133$) 13.8% (4/133) started HCV treatment, two of the four patients completed HCV treatment and one achieved SVR. A major consideration in this patient population was that most were homeless or marginally housed. In another study, the authors found that injection drug users would be motivated to undergo HCV evaluation and treatment. However in this study, treatment rates were not assessed (Stein, Maksad, & Clarke, 2001).

Limited access to HCV treatment specialists and treatment programs exist from a structural perspective (Edlin et al., 2005; Litwin, Soloway, & Gourevitch, 2005). There may be a limited number of appointments and therefore, long wait times to be evaluated by a gastroenterology (GI) specialist due to a finite number of specialists in a given geographical location (Edlin et al., 2005; Clanon et al., 2005; Fishbein, Lo, Reinus,

Gourevitch, & Klein, 2004; Thompson et al., 2005). The wait to see a GI specialist can be up to six months (Thompson et al., 2005).

To help alleviate access to HCV treatment, alternative programs are being developed to provide comprehensive care to those with HCV infection or HIV/HCV co-infection. For example, the VA has the National Hepatitis C Program and the National HIV/AIDS Program and has specific treatment guidelines for HCV and HIV/HCV co-infected veterans (Tien & Wright, 2005; Yee et al., 2006). The VA system estimates approximately 5% to 10% of veterans who receive care through the VA system are infected with HCV and 40% of those are co-infected with HIV (Tien & Wright, 2005; United States Veterans Affairs, 2005; Yee et al., 2006). Despite having one of the largest treatment programs in the US for HCV and HCV/HIV co-infected patients (Backus, Boothroyd, & Deyton, 2005; Philips, Mole, Backus, Halloran, & Chang, 2003), there are reported barriers to HCV evaluation and treatment and low HCV treatment rates in the VA medical system (Fultz et al., 2003). In a study to evaluate characteristics of HIV/HCV co-infected patients who received a pretreatment workup, the authors found that adults with HIV/HCV co-infection had higher rates of HCV pretreatment laboratory tests compared to those with HCV mono-infection (Backus, Boothroyd, Phillips, & Mole, 2006). These researchers suggest that these findings may be due to frequent clinic visits for HIV disease management rather than for a specific HCV workup. Approximately 11% (377/4135) of the sample started HCV treatment. Positive predictors of treatment initiation included a higher CD4 count ($p = .001$), non-Hispanic white race ($p = .001$), receiving ART ($p = .001$), and having an undetectable HIV viral load ($p = .001$). Negative predictors of HCV treatment in this sample included chronic mental illness ($p <$

.05) and a history of hard drug abuse ($p = .001$) (Backus et al., 2006). In this study, hard drug abuse was defined as the documented use of opiates, cocaine, or amphetamines within the past year.

Other programs have been developed to deliver HCV treatment outside traditional gastroenterology clinics. For example, HCV treatment is being delivered in methadone maintenance programs (Litwin, Soloway, & Gourevitch, 2005; Sylvestre et al., 2005), a community HIV clinic (Clanon et al., 2005), and a comprehensive HIV clinic associated with large medical center (Adeyemi et al., 2004). These clinics have provided access to HCV evaluation for approximately 300 adults with HCV mono-infection or HIV/HCV co-infection. Substance abuse treatment programs, primary care providers, infectious disease clinics, and addiction specialty clinics may also be able to provide the infrastructure for points of entry for HCV evaluation and treatment (Edlin et al., 2005; Kresina, Bruce, Cargill, & Cheever, 2005; Mehta et al., 2005; Walley et al., 2005). These alternative programs may help expand the access to HCV evaluation and treatment in populations that may have difficulty accessing GI specialists.

Personal Barriers to HCV Treatment

Personal barriers can impede evaluation and treatment of HCV in adults with HIV/HCV co-infection (Edlin et al., 2005). These barriers can include limited knowledge of HCV treatment, fear of treatment and treatment side effects, or lack of follow-up with appointments or referrals (Clanon et al., 2005; Fishbein et al., 2004; Restrepo et al., 2005; Taylor, 2005; Walley, White, Kushel, Song, & Tulskey, 2005). However, many personal barriers such as fear and lack of knowledge can be modified with education and support by the healthcare team (Fleming et al., 2003; Taylor, 2005).

Limited knowledge or information about HCV treatment options can prevent a patient's ability to make an informed decision about treatment (Walley et al., 2005). The lack of knowledge about HCV infection can start with not knowing his/her HCV infection status. Providers should offer HCV testing to all patients with HIV infection and to anyone with a history of percutaneous blood exposure (Edlin, 2005; Kontorinis, Agarwal, & Dieterich, 2005). Providers should work to educate patients about HCV infection, transmission risks, treatment options, and risks and benefits of HCV treatment (Struss, Astone, Hagan, & Des Jarlais, 2004).

Also, patients can be reluctant to start HCV treatment due to fear (Fleming et al., 2003; Fleming et al., 2005). Fear can be associated with medication side effects, liver biopsy, and the act of self-injecting interferon which might trigger relapse of injection drug use (Fishbein et al., 2004).

Other reported personal barriers to HCV evaluation and treatment include lack of follow-up on referrals, appointments, and evaluation workups (Fishbein et al., 2004; Oluwatoyin et al., 2004; Thompson et al., 2005). Even when patients are referred for HCV treatment, few patients with substance abuse disorders take advantage of the referral and even fewer receive treatment (Fishbein et al., 2004). Fishbein and colleagues (2004) found that active alcohol and drug abusers were less likely to accept referral for HCV evaluation (odds ratio adjusted [OR adj], 0.51, 95% CI 0.30-0.88). However, having HIV/HCV co-infection was associated with accepting a referral for HCV evaluation for treatment (OR adj, 0.51, 95% CI, 0.30-0.88). In the patients with HIV/HCV co-infection, having a history of IDU was associated with accepting a referral for HCV evaluation (OR adj, 3.60, 95% CI, 1.08-11.96). Despite patients' willingness to

accept the referral, only one-third ($n = 21$) kept their appointment; of this group, five underwent a liver biopsy, and only one person started HCV treatment (Fishbein et al., 2004). Notably, patients with HIV infection were more likely ($p < .001$) to keep their appointment for the HCV evaluation process than those with HCV mono-infection (Oluwatoyin et al., 2004).

Social Barriers to HCV Treatment

Social barriers related to HCV treatment ranges from individual to community level issues (Edlin et al., 2005) and can include homelessness, joblessness, lack of transportation, lack of family support, and other family issues (Clanon et al., 2005; Fleming et al., 2005; Mehta et al., 2005). Difficulty in accessing HCV treatment programs is a problem for marginalized or disadvantaged populations (Strader, 2002; Thompson et al., 2005). Research is beginning to address social issues related to treatment access in HIV/HCV co-infected adults in the inner-city, the urban poor, and recovering injection drug users (Fleming et al., 2003; Fleming et al., 2005; Sylvestre et al., 2005). Many patients rely on public health systems for evaluation and treatment of HCV infection and delays in evaluation can be lengthy for these individuals (Thompson et al., 2005). Hall and colleagues (2004) examined a sample of HIV positive homeless and marginally housed urban adults and found that non-white individuals (OR, 0.26, 95% CI. -0.11 to 0.62, $p < .01$) and injection drug users were less likely to receive HCV testing (OR, 0.14, 95% CI, -0.19- to 0.92, $p < .05$). These authors also found that only 38/249 (21%) of the HCV positive individuals in the study reported receiving a referral to a GI specialist for HCV treatment and only 7/249 (3.8%) reported receiving HCV treatment. The individual barriers were not assessed in this study. However, the study

illustrates the need for research to assess the barriers to HCV treatment in disadvantaged populations.

Patient Treatment Decision-Making Process

Historically, research on medical decision-making has focused on understanding how healthcare providers make treatment decisions and the development of tools to assist in the decision-making process (e.g., decision aides, treatment guidelines, and computer assisted-technologies) (Kaplan, Ganiats, & Frosch, 2004; Patel, Kaufman, & Arocha, 2002). Decision-making research evaluates decision-making characteristics based on hypothetical treatment scenarios (Patel et al., 2002). However, there is a shift towards understanding patient treatment decision-making through naturalistic inquiry and in diverse settings (Patel et al., 2002; Wills & Homes-Rovner, 2006).

Decisions regarding healthcare have moved from a paternalistic model to a collaborative or shared approach between the healthcare provide and the patient (Deegan & Drake, 2006; Thomasma, 1983; Quill & Brody, 1996). The National Institute of Mental Health (NIMH, 1999) and the Committee on Quality Health Care in America Institute of Medicine (IOM) (2001) suggest healthcare providers enlist the patient's active participation in decisions about care. The inclusion of patient autonomy and values should be an integral part of the treatment decision-making process (Committee on Quality Health Care in America Institute of Medicine, 2001). Healthcare providers are faced with providing the necessary support and education to the patient in order for them to be more involved with treatment decision-making (Woolf et al., 2005). However, research is needed to understand the patient's perspective and understanding of the decision-making processes (Deegan & Drake, 2006; Straus, 2002).

Patients are routinely asked to participate in decisions about their health care (Pierce & Hicks, 2001). Current research reveals that patients prefer shared decision-making with their healthcare providers. Patients also want to be informed about their treatment choices, possible side effects, and preferences for health care (Bruera, Willey, Palmer, & Rosales, 2001; Levinson, Kao, Kuby, & Thisted, 2005; Murray, Pollack, White & Lo, 2006; Stiggelbout & Kiebert, 1997). In an integrative review of patient preferences and decision-making, Benbassat and colleagues (1998) concluded patients wanted to be informed about their illness (92% of the time) but there was variability among individuals in preferences about their participation in decision-making. Levinson and colleagues (2004) conducted a population-based study ($N = 2,765$) and concluded that 96% of the participants wanted to be offered treatment options.

Patient decision-making is considered a process (Hicks & Holm, 2003; Pierce & Hicks, 2001; Theroux & Taylor, 2003; Wills & Holmes-Rovner, 2006). Decision-making processes are influenced by multidimensional activities that can include cognitive, perceptual, and affective, factors and are defined as “the interactions of patient and contextual factors that are set in motion by the unique features of the decision problem” (Pierce & Hicks, 2001, p. 270). Patient decision-making can be influenced by a variety of factors such as health status, misinformation, emotions, and past experiences (Benbassat et al., 1998; Redelmeier, Rozin, Kahneman, 1993; Wills & Holmes-Rovner, 2006). The patient goes through a decision-making process to come up with a solution to a particular problem. Decision problems are the “representations of relevant information that must be considered in selecting a preferred alternative” (Pierce & Hicks, 2001, p. 270).

Patient Treatment Decision-Making in Substance Abuse

Current substance abuse research suggests that individuals make an initial choice, or decision, about substance abuse behaviors. Over time, substance abuse behaviors become self-perpetuating and share similar patterns with other addictive behaviors such as gambling, sexual compulsions, and overeating (Miller & Carroll, 2006). Drug abuse has been described as a biological disorder that can range from impulsivity to compulsiveness, and the behaviors associated with drug abuse (such as self-injecting) can cause rewards such as pleasure, gratification, and relief of anxiety or stress (Koob, 2006). As the individual moves to addiction and with persistent drug abuse, he/she can lose decision-making control from an imbalance in the neurochemical center of the brain (Bechara, 2005; Bechara & Damasio, 2001). Researchers continue to investigate what triggers initial and ongoing decision-making choices surrounding substance abuse (Bechara, Dolan, & Hindes, 2002). In addition, how decisions are made to use illicit substances and turn to injection drug use is an area of active research in neurobiology (Bechara, 2005; Bechara & Damasio, 2001; Bechara et al., 2002; Di Chiara & North, 1992), psychology (Compton, Conway, Stinson, Colliver, & Grant, 2005), sociology (Diaz et al., 2001; Hall, Charlesbois, Hahn, Moss, & Bangsberg, 2004; Inciardi, Surratt, & Kurtz, 2006) and behavioral medicine (Friedman et al., 1999; Lane & Cherek, 2000; Lane, Cherek, Pietras, & Tcheremissine, 2004; Lynch, Roth, & Carroll, 2002; Lane, Yechiam, & Busemeyer, 2006). Findings from substance abuse and decision-making literature demonstrate that substance abusers have poor decision-making capabilities and tend to make self-destructive decisions (Grant, Contoreggi, & London, 2000; Jeste & Saks, 2006; McNeil, 1987). There are continued debates in the healthcare industry about

the decision-making capabilities of individuals with substance abuse disorders (Jeste & Saks, 2006). In addition, little is known about the substance abuse issues that may influence HCV treatment decisions among co-infected infected adults from their perspective (Fraenkel et al., 2005).

Patient Treatment Decision-Making in HIV Mono-infected Adults

While little is known about how substance abuse affects decisions in HCV treatment choices, there have been several studies (see Table 1) examining patient decision-making in the context of HIV treatment from the patient's perspective (Kremer, Ironson, Schneiderman, & Hautzinger, 2006; Laws et al., 2000; Marelich, Johnson Roberts, Murphy, & Callari, 2002; Misener & Sowell, 1998). For example, a positive or negative relationship with the healthcare provider can influence treatment decisions (Laws et al., 2000; Misener & Sowell, 1998). For patients deciding not to take HAART, they noted that their providers did include them in the decision-making process (Misener & Sowell, 1998). However, many also reported a lack of trust in their provider and stated that, because of this distrust, they were not truthful with their provider about their adherence to the medication regimen (Laws et al., 2000; Misener & Sowell, 1998). Fear of side effects from HIV medications was another factor in patients' decisions not to begin ART (Kremer et al., 2006; Misener & Sowell, 1998). In one study, patients also admitted that their active substance abuse caused them to miss or skip taking their antiretroviral medications because they were instead focused on acquiring and using cocaine or heroin (Laws et al., 2000).

For patients with HIV infection who choose to take HAART, findings indicate that patients wanted to work as part of a team in joint decision-making; however they

also took an assertive role by telling the healthcare provider which medications they wanted to take (Marelich, Johnson Roberts, Murphy, & Callari, 2002). Patients considering ART also actively seek out information from other healthcare providers, journals, and the Internet to supplement their knowledge about the treatment. These findings suggest that some patients with HIV infection take an assertive role and desire more control over their healthcare decisions (Kremer et al., 2006; Marelich et al., 2002). Understanding a patient's thought process in decision-making may assist healthcare providers in guiding patients through treatment decisions.

Patient Treatment Decision-Making in HCV Mono-infected Adults

Because only one study was found on HCV patient treatment decision-making (see Table 2), (Fraenkel et al., 2005), there is limited information about how adults with HCV mono-infection make HCV treatment decisions. These investigators used focus groups to examine factors that influence patient decisions about HCV treatment. The sample ($N = 40$) consisted of mostly white (82%), employed (55%), men (80%) from two sites in Connecticut with a mean age of 51.5 (range 40-60). Separate focus groups were conducted with those who had a diagnosis of mental illness, and/or substance abuse, and those who did not have either comorbidity. The authors did not report the different outcomes between the two groups. However, the results offered six themes including treatment risks, benefits and tradeoffs, protected values, heuristics, conceptualization of illness, social issues, and physician recommendations. The patients wanted to know what their choices were, expected response rates, treatment side effects, the possibility of regretting treatment if the treatment failed, how sick they may be or become, how the therapy would affect work and family, and finally, what the physician recommended. The

authors concluded that healthcare providers should help facilitate patient decision-making through education. Also, healthcare providers should understand that the decision-making process may be influenced by their recommendations. This study offers some preliminary understanding of decision-making processes within a fairly specific group of individuals with HCV infection. Additionally, more work is needed to understand HCV treatment decision-making within various populations.

Patient Treatment Decision-Making in HIV/HCV Co-infected Adults

A patient's decision to begin HCV treatment is not straightforward. HCV evaluation and treatment involves a significant amount of time, energy, effort, and compliance on the part of the patient. There is limited information on how adults with HCV mono-infection make decisions about HCV evaluation and treatment (Fraenkel et al., 2005). Even less is known about how adults with HIV/HCV co-infection with a history of substance abuse make treatment decisions. No research studies have focused on HCV treatment decision-making in adults co-infected with HIV/HCV and who have a substance abuse history. This gap in the literature prevents healthcare providers from understanding the influence of substance abuses on decision-making in the HIV/HCV co-infected adult.

Chapter Summary

HCV infection affects between 150,000 to 300,000 HIV positive adults in the US (Alter et al., 1999; Sherman et al., 2002). Unfortunately, HCV treatment rates remain low in HIV/HCV co-infected patients. There is some evidence that patients face a variety of structural, personal, and social barriers when faced with the possibility of needing HCV treatment. However, there is limited knowledge about how these barriers affect decision-

making in adults with HIV/HCV co-infection. In addition, there is little information about the influence of substance abuse on HCV treatment decision-making. Therefore, this study examined substance abuse experiences in adults with HIV/HCV co-infection and explored the experience of substance abuse as it relates to patient decision-making about HCV treatment.

Chapter II

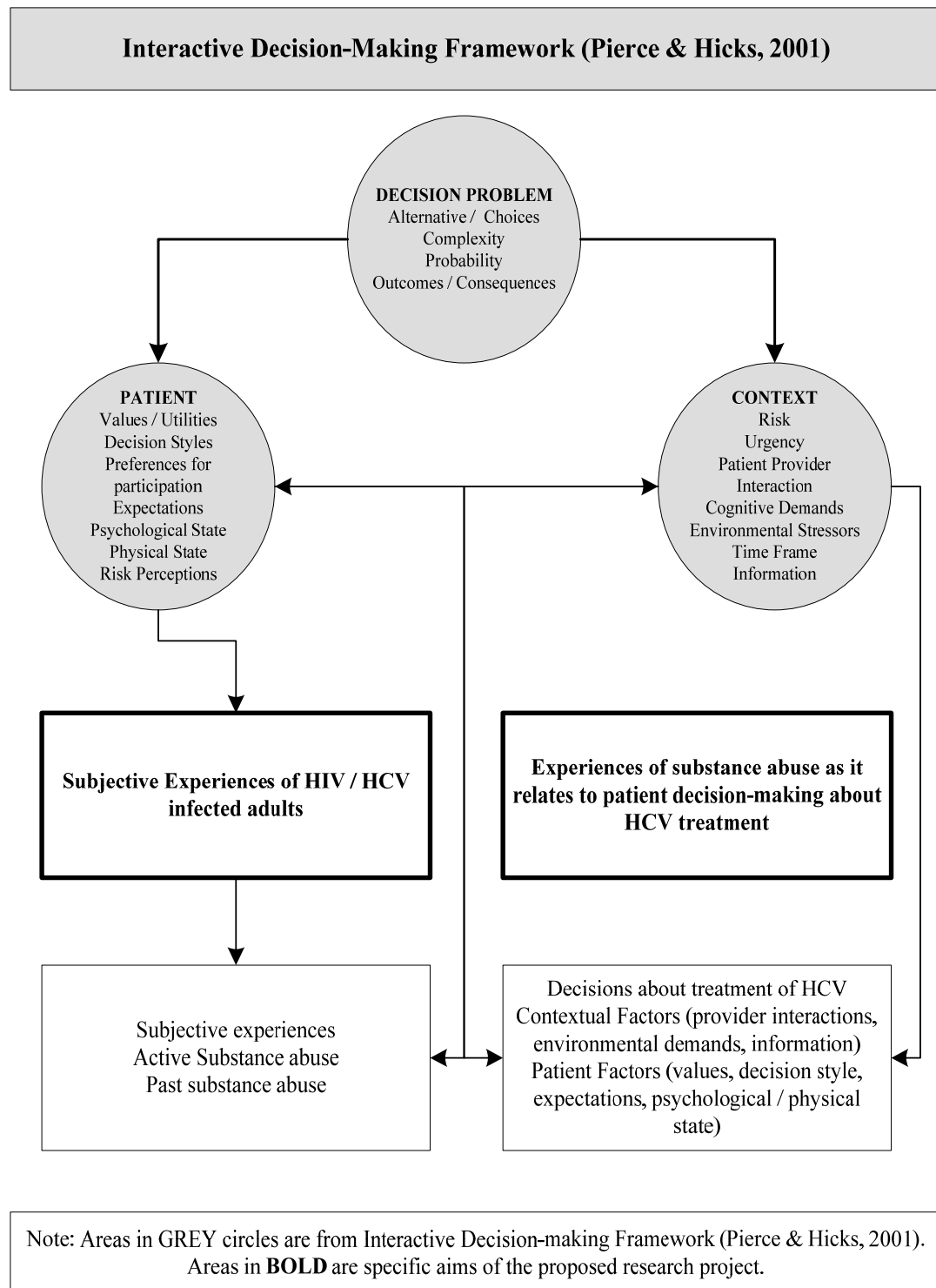
Organizing Framework

Introduction

The Interactive Decision-Making Framework by Pierce and Hicks (2001) was used to guide the data analysis section of the proposed study (See Figure 1). An organizing framework provides a foundation and guidance for a qualitative research study (Patton, 2002). This framework served as a general guide to organize the data analysis. However, the researcher was open to additional ideas or emerging themes outside any a priori beliefs or the organizing framework (Lincoln & Guba, 1985). Miles and Huberman (1994) suggest a framework should be used to structure the qualitative research study to provide a foundation for collecting and evaluating data. The structured qualitative project provides the researcher the opportunity to assess for patterns across the data set related to key concepts rather than just developing random thematic codes (Miles & Huberman, 1994). Also, some structure helps to prevent data overload which is caused by collecting large amounts of data with little organization and then not having the ability to sort out the important findings (Miles & Huberman, 1994). However, being open and observant to themes and codes outside the framework is an important skill for a qualitative researcher (Miles & Huberman, 1994). The purpose of the proposed qualitative descriptive study was to describe the substance abuse experiences in adults co-infected with HIV and HCV. In addition, the experiences of substance abuse as it relates to patient decision-making about HCV treatment were explored. A secondary aim of this study was to explore whether substance abuse experiences fit best with patient or

contextual factors within the framework. This chapter focuses on understanding the Interactive Decision-Making Framework (Pierce & Hicks, 2001).

Figure 1. Organizing Framework for the Influence of Substance Abuse on Hepatitis C
Treatment Decision-Making among HIV/HCV Co-infected Adults



Interactive Decision-Making Framework

Patients are routinely asked to make decisions about their health care (Pierce & Hicks, 2001) and many of these decisions involve understanding complex therapies and treatments which can lead to stress and anxiety (Pierce, 1996). The decision-making process may be easy for some and difficult for others (Pierce, 1996). Researchers are beginning to explore decision-making processes and factors that influence patient choices (Fraenkel et al., 2005; Manias, Botti, & Buchnall, 2006; Pierce, 1993; Pierce, 1996; Redelmeirer, Rozin, & Kahneman, 1993). Moreover, there is limited research examining the decision-making process in patients faced with complex and stressful decisions (Pierce & Hicks, 2001).

Defining Characteristics of the Framework

Pierce and Hicks (2001) outline a decision-making framework to guide researchers investigating patient decision-making processes. The decision-making framework is deductive in nature and has three central concepts (See Figure 1). These concepts include the decision problem (alternative/choices, complexity, probability, outcomes), the patient (values/utilities, decision styles, preferences for participation, expectations, psychological state, physical state, and risk perceptions), and contextual factors (risk, urgency, patient-provider interaction, cognitive demands, environmental stressors, time frame, information).

Decision Processes and Problems

Patient decision-making is considered a process (Hicks & Holm, 2003; Noone, 2002; Pierce & Hicks, 2001; Theroux & Taylor, 2003; Wills & Holmes-Rovner, 2006). Decision-making processes are complex cognitive, perceptual, and affective

multidimensional activities and are “the interactions of patient and contextual factors that are set in motion by the unique features of the decision problem” (Pierce & Hicks, 2001, p. 270). The patient goes through a decision-making process to come up with a solution to a particular problem. Decision problems are the “representations of relevant information that must be considered in selecting a preferred alternative” (Pierce & Hicks, 2001, p. 270). The decision problem has four basic elements: initial options (alternatives or choices), values (worth, utility, or attractiveness), uncertainties (probabilities) and possible consequences (outcomes). The decision-making process is influenced by the interactions between patient factors and the contextual factors. There is a codependent relationship between the patient and the contextual factors and the relationship between these factors are constantly evolving depending on the decision problem. For example, as the patient gains more experience with the illness or disease process the stress of the decision may be diminished (Pierce & Hicks, 2001).

Patient Factors

There are a variety of patient factors that influence the decision-making process. The decision-making processes can be influenced by personal characteristics such as values, decisions styles, preferences, expectations, physical and psychological health, and perception of risk (Pierce & Hicks, 2001). Patient’s decision-making behaviors can evolve or adapt depending on the context of the patient’s personal experiences (Pierce & Hicks, 2001). For example a patient may be hesitant and fearful about hemodialysis treatment due to personal and cultural beliefs but, may be forced to accept treatment or face death (Lin et al., 2005).

Contextual Factors

Contextual factors may influence the decision-making processes include: risk, urgency of the problem, patient-provider interaction, cognitive demands, environmental stressors, time frame, and information (Pierce & Hicks, 2001). For example, the decision can be influenced by the urgency of the problem or by how much information the patient has to make the decision (contextual factors).

The decision-making process is influenced by the codependent relationship between the patient and contextual factors. For example a patient may have made specific decisions (patient factors) about their health care and those preferences change because they were not supported in their choice or they lacked information to make an informed decision (contextual factors) (Carlton, Callister, & Stoneman, 2005).

Use of the Framework in Research

The interactive decision-making framework has been used to study patients' decision-making processes regarding hemodialysis treatment among (1) Taiwanese adults (Lin et al., 2005), (2) in women during labor (Carlton et al., 2005), and (3) women with breast cancer (Budden, Pierce, Hayes, & Buettner, (2003). The interactive decision-making framework has also been used to guide the development of a heart failure self-management tool (Hicks & Holmes, 2003).

Decision-making styles vary among patients and personal values influence decisions (Budden et al., 2003; Carlton et al., 2005; Lin et al., 2005). Patients also want to have a choice and be in control of their health care decisions (Budden et al., 2003; Carlton et al., 2005). As part of maintaining a sense of control, many patients seek out information from family, friends, internet resources, and other healthcare providers

before making decisions (Budden et al., 2003; Hicks & Holm, 2003; Lin et al., 2005). Patients can be fearful of treatments which can delay important decisions about their health care (Lin et al., 2005).

Carlton and colleagues (2005) found women went into labor with certain planned preferences. However, their decisions changed because of contextual factors such as lack of support by nurses or healthcare providers, lack of alternative strategies for pain management, lack of education on birthing strategies, or because of emotions such as guilt. Hick and Holms (2003) found patients tended to make fewer decisions as their disease advanced.

Currently, a decision-making theory or empirical model has not been generated from this framework. There are no published studies using this framework examining patient decision-making behaviors surrounding substance abuse or HCV treatment.

Chapter Summary

Patients with HIV/HCV co-infection must make decisions about HCV treatment in which they may experience significant side effects, and a relatively high likelihood of treatment failure. Limited knowledge exists on how patients make decisions about HCV treatment. In addition, it is unclear how patients with substance abuse disorders and co-infection make decisions about HCV treatment. Finally, it is unclear where substance abuse fits in the interactive decision-making framework. A secondary aim of this study was to uncover the “best fit” for substance abuse within the framework. It is possible that substance abuse may fit in either category (patient or contextual), however there may be an unknown intermediary category to the framework that is not yet known. The

researcher was open to any emerging possibilities and report the findings. Specifically this framework was used to address the following questions:

- What are the substance abuse experiences in adults co-infected with HIV and HCV infections? and,
- How does the experience of substance abuse influence patient decision-making about HCV treatment?

The answers to these questions may improve our understanding about substance abuse experiences in individuals with HIV/HCV co-infection and add to our knowledge about how these experiences influence HCV treatment decisions. Knowledge gained may lead to the development of interventions to support HIV/HCV co-infected patients with substance abuse problems during the HCV treatment decision-making process.

Definitions and Specific Aims

For the purpose of this study the following definitions were used:

- Substance abuse is defined as problematic use (self-identified by study participants) of alcohol and drugs (prescription or street drugs).
- Decision-making processes are the interactions of patient and contextual factors that are set in motion by the unique features of the decision problem (Pierce & Hicks, 2001).

The specific aims of this study were to:

- Describe substance abuse experiences in adults co-infected with HIV and HCV and,
- Explore the experience of substance abuse as it relates to patient decision-making (including the decision problem, patient, and contextual factors) about HCV treatment.

A secondary aim of this study was to:

- Explore whether substance abuse experiences fit best with patient or contextual factors within the Interactive Decision-Making Framework (Pierce & Hicks, 2001).

Chapter III

Methods

Introduction

The proposed study used qualitative description and secondary data analysis to describe substance abuse experiences of adults with HIV/HCV co-infection. In addition, how these experiences were related to patient decision-making about HCV treatment was examined. A secondary aim was to explore whether substance abuse experiences fit with patient or contextual factors within the framework Interactive Decision-Making Framework (Pierce & Hicks, 2001). The Interactive Decision-Making Framework (Pierce & Hicks, 2001) was used to guide the secondary data analysis and summary of findings (see organizing framework, Figure 1). The pre-existing data set was collected as part of a longitudinal multi-method study (NIH #1R15 NR0834) aimed at describing the experiences of HCV treatment among HIV seropositive adults.

The purpose of this chapter is to describe the methods used in this study. Qualitative descriptive methodology and rationale, epistemological, ontological and theoretical underpinnings, the process of secondary data analysis, and description of the parent study will be delineated. The sample, procedures for data collection and management, data analysis, trustworthiness, ethical considerations, human subject considerations, and limitations are described for the research study.

Qualitative Descriptive Methodology and Rationale

Qualitative descriptive design was chosen as the method of inquiry for the proposed study to describe substance abuse experiences. In addition, how these experiences impact patient decision-making regarding HCV treatment in adults with HIV

and HCV co-infection were explored. The qualitative methodology allowed the researcher to gain insight into the phenomenon of interest by exploring the day-to-day experiences of the participants, develop a rapport with the participants, and to stay close to the data without an in-depth deconstruction and reconstruction of the findings (Gallo & Dumas, & Shurpin, 1996; Knafl & Howard, 1984; Miles & Huberman, 1994; Sullivan-Bolyai, Bova, & Harper, 2005). Qualitative description is a method that allows the researcher to describe the phenomenon of interest with minimal interpretation of data (Sandelowski, 2000). A key benefit of the methodology is the ability to obtain an in-depth subjective view into HIV/HCV co-infected participants' experiences. Qualitative description was used to provide a preliminary understanding of this scarcely researched phenomenon (Sandelowski, 1999).

Epistemological/Ontological/Theoretical Underpinnings

Epistemologically, the naturalistic paradigm fits well to explore subjective substance abuse experiences in adults with HIV and HCV infection. The researcher becomes a research instrument who can interact with the subject of inquiry (Lincoln & Guba, 1985). The researcher for the proposed study was the research assistant for the parent study. This involvement afforded the researcher a working knowledge of the parent study. However, the researcher is aware that all inquiry is value-laden, to some extent. Personal views and a priori assumptions of the subject matter were bracketed (Marshall & Rossman, 1999). A reflexive journal was maintained throughout the analysis process to document the research process. Ideas, assumptions, and a priori beliefs were documented (Ahern, 1999). In addition, for this study, the researcher bracketed

preconceived ideas about the personal biographies of the participants. Further, the journal was available to the dissertation committee throughout the study.

Ontologically, reality and the meaning of the experience come from the subjective perspective; this can only come from the individual living the experience. The meaning was derived and presented by using quotes and developing themes based on the stories of the participants (Creswell, 1998).

Theoretically, the Interactive Decision-Making Framework (Pierce & Hicks, 2001) was used to guide secondary data analysis. The framework provided the initial structure for the data analysis; however, it did not limit the findings. The researcher was open to themes that emerged outside of the framework as they related to the research questions. Major themes and sub-themes were identified and are described in the findings.

Process of Secondary Data Analysis

The study used secondary data analysis (SDA) to investigate the pre-existing data set. SDA is a research technique used to “generate new knowledge from existing data” (Magee, Lee, Giulano, & Munro, 2006). SDA is a research technique used to examine pre-existing data based on a new set of questions; it can also be used for a more focused analysis of the parent study (Castle, 2003; Heaton, 1998; Heaton, 2004; Hinds, Vogel, & Clarke-Steffen, 1997; Szabo & Strang, 1997). Quantitative data has typically been used for SDA, however the use of pre-existing qualitative data sets is growing (Heaton, 2004).

There are several advantages to SDA, including a shorter time in answering research questions. Using pre-existing data also saves the expense of primary data collection (Heaton, 1998; Heaton, 2004; Rew, Koniak-Griffin, Lewis, Miles, O’Sullivan,

2000; Shepard et al., 1999). SDA provides the researcher the opportunity to access difficult populations or those who may be over-sampled due to the uniqueness of their condition (Kiecolt & Nathan, 1985). Moreover, burden to study participants is reduced, especially in vulnerable or hard-to-reach persons by using an existing data set (Heaton, 1998). This was an important consideration in this research study. The participants of the parent study are co-infected with HIV and HCV and may be suffering from a variety of disease symptoms and side effects of medications and treatments. Participating in an additional study may have placed an added burden on them. Furthermore, SDA can be used to explore information which was not part of the original question (Hinds, Vogel, & Clark-Steffen, 1997). Many of the participants in the parent study disclosed information about their substance abuse history that went beyond the scope of the initial investigation. These data emerged spontaneously and the participants were allowed to freely express their substance abuse experiences. The principal investigator (PI) of the parent study decided that these data should be analyzed and reported. It was important to represent and respect the participants of the original study by reporting the additional findings. The information provided by participants may serve others in their quest for additional understanding of substance abuse experiences and HCV treatment decision-making in adults with HIV and HCV co-infection.

Moreover, the researcher using secondary data analysis may provide objectivity and neutrality (Heaton, 2004). At the time of the parent study, the researcher of the proposed study was not working with this patient population, thus allowing for objectivity and neutrality during the interviews. In addition, this strength can transfer to

the data analysis. The data set was analyzed objectively without preconceived biases about individuals with HIV/HCV co-infection and substance abuse problems.

Disadvantages of SDA include the fact that the parent study may be grounded from a different philosophical or theoretical perspective (Rew et al., 2000); there may be missing data without the possibility of further data collection; lack of face-to-face contact with participants; and there may be issues with sensitivity (Hinds et al., 1997). For the context of the research study, each of these issues will be addressed in the following paragraphs.

From a philosophical and theoretical perspective, the researcher of the parent study sought to reveal the subjective experiences in adults with HIV and HCV co-infection. The organizing framework of the parent study was based on health related quality of life, symptom/side effects, treatment adherence, mental health issues, and substance abuse issues. In the proposed study, the Interactive Decision-Making Framework (Pierce & Hicks, 2001) was used to guide the secondary data analysis. The framework is multifaceted and deductive in nature. The purpose of the framework was to provide insight into the phenomenon of interest through the literature and to assist in the organizing and representation of the data (Sandelowski, 1993). The framework allowed the researcher to explore subjective experiences of HCV treatment without limiting the participants' responses. The researcher used the framework to guide the analysis and gain control over the volume of data, however, the framework did not limit the findings. Alternative findings were explored within the data set and reported in the discussion.

Lack of face-to-face contact with participants has been identified as a disadvantage to SDA (Heaton, 1998; Hinds et al., 1997). The secondary researcher does

not have the opportunity to “be there” to be immersed within the data collection.

However, the secondary researcher can become immersed within the data without the risk of biases and preconceived beliefs in order to develop new knowledge (Thorne, 1994).

The researcher of the study listened to the tone, emotions, and inflections of the participants by listening to the audiotapes. The transcripts, field notes, and memos were read to become immersed within the data set which was done to enhance sensitivity.

Sensitivity refers to how immersed or close the researcher can become in the data set in qualitative research (Hinds et al., 1997). This may be challenging in SDA of qualitative data since the researcher is considered an instrument of the investigation and immersed in the research process but was not there during data collection (Heaton, 1998; Hinds et al., 1997). The researcher of the study was involved in the data collection in the parent study and developed a rapport with the participants. In addition, the researcher was involved in meetings and discussions and dissemination of results of a pilot study and original study data at the Eastern Nursing Research Society Meeting in 2004. By being involved in the parent study is different from that of someone looking at the data for the first time (Thorne, 1994).

Description of Parent Study

The parent study was an NIH funded (1R15 NR0834) longitudinal multi-method study to describe the experiences of HCV treatment among HIV seropositive adults conducted by Dr. Carol Bova from the University of Massachusetts, Worcester. The setting for the parent study took place at three HIV specialty clinics. Approval for the parent study was obtained from the Institutional Review Board (IRB) of University of Massachusetts, Worcester Medical School. IRB approved recruitment flyers were

distributed at the approved clinical sites. The participants were instructed to call a designated phone number and leave contact information if they were interested in participating in the research study. The PI or the research assistant (RA) called the prospective participant back to discuss the objectives of the study, answer questions, and set up an interview. The participants were told their involvement in the study was voluntary, they could withdraw from the study at any time, and participation or lack of participation would not influence their care in any way. Informed written consent and HIPAA authorization was obtained prior to the interview. The participants received \$25.00 for their participation in the parent study. A signed original copy of the consent was given to the participant and a copy was retained in the study files. The participants were assigned a study number to protect anonymity and confidentiality. The study number is on each data form, audiotape, and transcription to keep the data organized. The participant's name was not used on any data form, audiotape, or transcription. The PI maintained the list of participants and their assigned study numbers.

Description of Parent Study Data Collection and Measures

The data were collected by the PI or the RA by face-to-face semi-structured interviews. The researchers used the Parent Study Interview Guide (Appendix A) to conduct the qualitative interview. The interviews were audiotaped, and then transcribed verbatim by a professional transcriptionist. Additional data collected during the parent study included the Parent Study Demographic Data and Clinical Cofactor Sheet (Appendix B), the Parent Study Alcohol and Drug Dependency Questionnaire (Appendix C), and the Parent Study Mental Health Questionnaire (Appendix D).

The Parent Study Qualitative Interview Guide (Appendix A) was used to provide a general direction to the in-depth baseline interview to explore patient experiences of living with HIV/HCV co-infection. The interview guide was used to direct the open-ended questions about symptoms of HCV, problems with mental health, drugs and alcohol problems, and how the health care provider could help the patient manage HCV before beginning treatment. Probes were structured to illicit more specific information about their personal reactions to their diagnosis, emotional feelings about living with HCV, current and past problems with substance abuse, and the usefulness of the information that was given to them by their healthcare provider.

The Parent Study HIV/HCV Co-infection Baseline Demographic and Clinical Cofactor Sheet (Appendix B) was a self-report measure that included the participant's age, gender, race, ethnicity, education, work status, marital/partner status, housing status, length of time with HIV, substance abuse history. Clinical cofactors were collected by medical record review via the clinical database that included the patient's HIV illness stage, current HAART treatment, HIV RNA, HCV RNA, HCV subtype, and liver biopsy results.

The Parent Study Alcohol and Drug Dependency Baseline Questionnaire (Appendix C) was a self-report measure that was used to ascertain the participant's current and past substance abuse, which substances they used, the last time they used substances, and what was their most problematic substance.

The Parent Study Mental Health Questionnaire (Appendix D) was a self-report measure that was used to determine the participant's current and past mental health

problems, hospitalizations to treat depression/mood problems, current medication to treat mental health/mood problems, and any history of suicide attempts.

Description of Parent Study Participants

The participants in the parent study were recruited by purposive and theoretical sampling techniques. The sample size was determined by theoretical saturation which is the point when no new properties or dimensions emerge from the data and the analysis accounts for as much variation as possible (Stauss & Corbin, 1998). The sample included 39 HIV/HCV co-infected adults (16 in the treated cohort and 23 in the non-treated cohort), 48% were female, 52 % were male, 54% were racial or ethnic minorities, 33% AIDS, 73% had HCV genotype 1 and 95% had a history of substance abuse. The mean age was 44.7 years. Inclusion criteria for the parent study were: (1) age 18 years of age or older, (2) HIV/HCV co-infected (detectable HCV viral load and HIV positive antibody test or viral load documented in medical records), (3) not yet on HCV treatment, and (4) able to speak English. Forty participants were initially recruited into the study. However, one participant was excluded from the analysis because she was later found not to be HIV positive.

Proposed Research Study

Sample for Proposed Study

Sampling in secondary data analysis in a qualitative study has been considered sorting of data (Heaton, 2004). The researcher sorts through the parent study to determine the sub-sample for the secondary data analysis (Heaton, 2004). Through sorting, the parent sample should be assessed to determine if there will be a sufficient sample size available to answer the new research questions (Heaton, 2004; Thorne, 1994). The PI of

the parent study determined there would be adequate information available for the secondary data analysis as she completed her examination of the data set. Sandelowski (1995) has suggested that different qualitative approaches require different sample sizes. Sample size depends on the purpose of the qualitative study and what the researcher wants to know which may be more important than an actual number of participants (Patton, 2002; Sandelowski, 1995). Morse (1994) suggests at least six participants are needed in studies directed toward discerning the essence of experiences. Quality versus quantity may be more important when establishing a sample in a qualitative study (Patton, 2002). The interviews should contain specific in-depth information pertaining to substance abuse experiences and HCV treatment decision-making and only the interviews that contain this information were used for the analysis. It was estimated that approximately 25 (64%) of the 39 interviews would be used for the secondary data analysis (Morse, 1994). The researcher used the Secondary Data Inclusion/Exclusion Extraction Criteria Tool (Appendix F) to review each interview. Inclusion criteria for the proposed study: (1) only baseline interviews from the longitudinal data set; (2) current or past injection drug abuse and/or alcohol substance abuse; and (3) interviews containing rich descriptive information about substance abuse experiences and decision-making information.

The researcher evaluated the quality of the interview to determine if it contained enough information to be considered part of the sample. If the interview contained the required information, it was included into the analysis. If the individual interview did not contain enough information to answer the research questions, the researcher consulted with the dissertation chairperson. A meeting was scheduled to assess each interview that

did not meet the inclusion criteria. The dissertation chairperson member read through the interviews in questions to determine if it met the inclusion criteria (Appendix F). Notes were compared by the team members and a collaborative decision was made about the inclusion or exclusion of the transcript. All notes about the excluded interviews were documented in the journal for the audit trail. The final interviews and sample size was verified by the dissertation chairperson. The final sample included 31 interviews.

A total of eight interviews (six men and two women) were excluded from the secondary data analysis. Interviews were excluded for the following reasons: the participant spoke mostly Spanish and did not understand the questions presented ($n = 1$), no history of substance abuse ($n = 2$), the interview tape was blank ($n = 1$), blaming dentist for HIV/HCV co-infection rather than injection drug abuse ($n = 1$), and responses contained only yes/no answers ($n = 3$).

Procedures for Proposed Study

Data Collection and Management for Proposed Study

The researcher obtained the data set from the PI of the parent study after the proposal was approved by the dissertation committee members. The PI transferred the electronic version of the transcripts onto a password protected universal serial bus (USB) thumb drive. The data were checked to ensure all of the components were accounted for (Appendix E).

The interviews have been transcribed previously and were available in individual coded electronic Microsoft Word documents. After receiving the data set, the researcher listened to audiotapes and read the transcripts to ensure accuracy (Sandelowski, 1995). The plan was to note the discrepancies between the audiotape and transcripts and discuss

these findings with the PI however, there were no discrepancies to discuss. The demographic data were checked by comparing the hard copy of each participant with the transcription. Missing data from the qualitative and demographic measures were assessed. Again the plan was to note any patterns in missing data and discuss these patterns with the PI. There were a few missing data points, however, no patterns existed in the data set.

The data set was stored in a locked file cabinet in the researcher's office throughout the data analysis. In addition, the electronic data were stored on a password protected USB thumb drive and computer hard drive. All of the electronic data were deleted from the thumb drive and computer hard drive and the entire data set was returned to the PI at the conclusion of the study. All of the printed interviews were mechanically shredded at the end of the study.

Data Analysis

Data Analysis Plan

The researcher used qualitative content analysis to examine the data. Qualitative content analysis uses a systematic format to develop codes, or labels, to describe data from careful reading of the interview transcripts (Knafl & Webster, 1988; Morgan, 1993).

NVivo software was used to manage and organize the qualitative data (QRS International, 2007). Initially, the researcher transferred the Microsoft word transcripts from the USB thumb drive into the NVivo software program. Then, the transcripts were printed. The researcher then read through the transcripts and listened to the audiotapes to ensure the accuracy of the transcripts. Initial impressions of the interview were noted in the reflexive journal. A codebook was created to list, organize, and arrange codes and

data according to predetermined criteria. The purpose of coding is to cluster large pieces of data into a smaller number of focused descriptive themes (Miles & Huberman, 1994; Morgan, 1993). Codes were consolidated where possible, and ongoing attempts were made to compare and contrast patterns within and across data (Creswell, 2003). Some of the codes referred back to the organizing framework; others emerged spontaneously during analysis (Sandelowski, 2000).

Responses related to the specific research questions and the framework were identified and coded during the first pass analysis. Initial codes were documented in the reflexive journal and discussed with the dissertation chairperson. The codes were cut and pasted into a Microsoft Word document data display (Glaser & Strauss, 1967; Miles & Huberman, 1994; Webb, 1999). The data display listed each participant and the raw data pertaining to each research question according to the Secondary Data Extraction Tool (Appendix G) (Miles & Huberman, 1994; Williamson, 2005). The same process took place for each transcription. The frequencies of the responses were counted and were used as part of the description of the patterns within the data (Sandelowski, 2000). Codes were consolidated when possible, and ongoing attempts were made to compare and contrast patterns within and across data (Creswell, 2003). The purpose of qualitative content analysis was not to develop exclusive categories, but to develop salient points from the data (Marshall & Rossman, 1999; Sandelowski, 2000). Minimal interpretation allowed the experience to be portrayed as it was described by participants.

Data Re-Presentation

Finally, the categories and themes were reconstructed into a meaningful description of the experiences of the participants (Knafl & Howard, 1984; Sandelowski,

2000). Descriptive statistics in SPSS for Windows 14.0 were computed for all demographic and clinical cofactors to describe the sample characteristics. The results, sample demographics and clinical cofactors were displayed in written format as well as in tables.

Trustworthiness

Establishing rigor or trustworthiness in qualitative research is based on four components: transferability, dependability, credibility, and confirmability (Lincoln & Guba, 1985). Transferability or fittingness is a form of external validity that is constructed in qualitative research projects (Morse & Singleton, 2001; Rolfe, 2006). Ensuring the phenomenon of interest fits with the research questions and methods is an element of validity construction (Morse & Singleton, 2001; Whittemore, Chase, & Mandle, 2001). Fittingness was accomplished by constructing descriptions of the experiences of the participants and summarizing the overall observations of the data. Fit has occurred if the researcher can describe how the clusters of data are part of the whole (Morse & Singleton, 2001). The reconstructed themes can be traced back to the original data by the use of direct quotes from the participants. The dissertation chairperson reviewed the themes and codes as they emerged from the data set to ensure transferability and fit. Dependability refers to the consistency and authenticity of the research process (Koch, 1994; Lincoln & Guba, 1985). A reflexive journal was maintained by the researcher and included personal reflections, biases, field notes, bracketing notes, methodological issues, and any decisions made during the research process (Ahern, 1999). The researcher retained a copy of all written or electronic correspondence that pertained to the research project. The journal was made available to the dissertation

committee throughout the research process. These tasks served as the audit trail and dependability was verified by an audit of the research process. Credibility refers to the overall quality of the research and accurate representation of the data and internal validity (Lincoln & Guba, 1985; Whitemore et al., 2001; Creswell, 1998). Developing credibility took place by maintaining a personal journal, and peer debriefing. Peer debriefing took place by constant contact with the dissertation committee. Peer debriefing was accomplished through phone, email, and face-to-face meetings throughout the entire study.

Confirmability refers to the degree in which the results can be corroborated by others through documentation or audit trail. The dissertation committee audited the study process. The audit process was also used to ensure biases were not introduced into the findings.

Human Subjects Considerations

IRB approval was obtained for the parent study from the University of Massachusetts, Worcester Medical School and continued re-approval was obtained to extend the study timeline which is maintained by the PI of the parent study. There were no anticipated psychological or physical risks to the participants as the data have been previously collected. A major concern was that the data were analyzed and made available, as the participants freely spoke about their substance abuse history and personal life stories. The consent from the parent study allows the researcher to contact participants every three months for up to two years after the completion of the parent study which will be in June of 2007. Two participants from the parent study will be

contacted for member checks. The researcher of this study did not have access to names, addresses, or contact information of the participants.

Ethical Considerations for Proposed Study

After the data set was obtained from the principal investigator, it was stored in a locked file cabinet in the investigator's office. Any electronic data were stored on a password protected USB thumb drive and computer hard drive. All of the electronic data were deleted off of the USB thumb drive and computer hard drive and the entire data set was returned to the PI at the conclusion of this study. Any printed material was mechanically shredded at the conclusion of the study.

The participants were assigned a study number to protect confidentiality in the parent study and the same number was used in this study. The list of names was not transferred to the researcher of this study. The researcher of this study did not have access to names, addresses, or contact information of the participants.

Limitations

A limitation of this study was the use of secondary data analysis. The data set contained a finite amount of information. The researcher of this study did not ask the participants to provide additional information. Secondly, it was anticipated that the sample size may not be adequate to reach saturation due to the number of participants in the parent study. However, the PI found that many of the interviews contained rich descriptive content pertaining to substance abuse experiences and HCV treatment decision-making issues. It was estimated that approximately 25 of the interviews could be included in the proposed study. Thirty-one interviews were included in the final sample for the secondary data analysis. Lastly, the participants of the parent sample were

recruited through purposive and theoretical sampling techniques limiting the sample to those with HIV/HCV co-infection. It is unknown if the individuals who volunteered for the parent study would have similar experiences as those who did not participate.

Chapter Summary

This study used a qualitative descriptive design and secondary data analysis to describe substance abuse experiences and explore the experiences of substance abuse as it related to patient decision-making about HCV treatment in HIV/HCV co-infected adults. The Interactive Decision-Making Framework (Pierce & Hicks, 2001) was used to guide secondary data analysis and summary of findings. Through secondary data analysis and qualitative content analysis, the researcher organized, summarized, and reported common themes related to the phenomena of interest. The results of this study will enhance the knowledge about substance abuse experiences in adults with HIV/HCV co-infection. Moreover, the findings of this study may help researchers and clinicians design and study strategies that address substance abuse issues related to HCV treatment decision-making. Finally, the information gleaned from this study may aid healthcare providers in assisting the patient in their decisions about HCV evaluation and treatment.

Chapter IV

Results

Introduction

Qualitative description and secondary data analysis were used to describe the substance abuse experiences of adults with HIV/HCV co-infection. Additionally, how these experiences were related to patient decision-making about HCV treatment was examined. A secondary aim explored whether substance abuse experiences fit with patient or contextual factors within the Interactive Decision-Making Framework (Pierce & Hicks, 2001). The data were analyzed across and within subjects and the results were organized by each study aim. Next, qualitative content analysis was completed on 31 interviews. NVivo 7 (QRS International, 2007) software was used to help manage the data during the coding process. SPSS was used to manage the demographic and clinical characteristic data. Some themes emerged spontaneously during the analysis while others were extracted based upon the research questions and the Interactive Decision-Making Framework (Pierce & Hicks, 2001). Information was removed from some quotes (indicated by brackets) to protect the anonymity of the individual participants.

Five major themes with sub-themes emerged during the data analysis. They were: (1) *Substance Abuse Evolution (with sub-themes: substance abuse initiation, escalation, polysubstance abuse, normalcy: a family of addicts, the enemy within, and transmission and disclosure)*, (2) *Revolving Door: Going Back Out (with sub-themes: specific events as a trigger, emotions as a trigger, alcohol as a trigger, and destructive relationships as a trigger)*, (3) *Reconstructing Life (with sub-themes: defining moments in substance abuse addiction and maintaining sobriety)*, (4) *HCV Infection Treatment Issues (with*

sub-themes: HCV treatment: not a priority, fear, and misinformation, desire to use stimulated during HCV treatment), and (5) Get Clean and Try It. A detailed description of the findings major themes, sub-themes, and a description of the secondary aim follow. The results are organized by each study aim.

Participants

Based on the Inclusion/Exclusion Criteria Form (Appendix F), 31 participants were selected from the parent study sample. This sample included 16 men (52%) and 15 women (48%) with a mean age of 44.7 (range = 34-58). The majority of the participants were educated at the high school or GED level (71%), were not currently employed (68%), were single (52%), and were living in a rented apartment (55%). The racial breakdown for this sample was 58.% White, 26% Hispanic, 13% African American, and 3% American Indian. In comparing men to women, men ($M = 47$) were older than women ($M = 42$) ($\chi^2 = 2.962$, $df = 27$, $p < .05$). More women ($n = 4$) were marginally housed (homeless, shelter, or half-way house) compared to men ($n = 0$) ($\chi^2 = 4.9$, $df = 1$, $p < .05$). See Table 3 for the demographic characteristics of the sample.

The participants had been living with HIV infection an average of 13.7 years (range = 2-20 years). Their CD4 cell counts ranged from 104 to 1056 ($M = 468.5$), 36% had AIDS, and 81% were on antiretroviral therapy to treat their HIV infection. There was no difference by gender in participants with a diagnosis of AIDS ($p = .12$).

The HCV/RNA ranged from 550 to 18,900,000. Ten percent of the participants had an undetectable HCV/RNA, and a majority (61%) had undergone a diagnostic liver biopsy. More men ($n = 13$) had a liver biopsy when compared to women ($n = 6$) ($\chi^2 = 5.5$, $df = 1$, $p < .05$). Ten (32%) of the participants had a history of previous HCV

treatment or were currently undergoing HCV treatment. The majority of the participants (76%) were infected with HCV genotype 1. See Table 4 for the complete clinical characteristics of the sample.

All of the participants had a history of substance abuse with 87% identifying heroin as a frequently abused drug; cocaine followed with 84% reporting abuse, and then alcohol (77%). Twenty-nine (94%) of the participants reported problems with poly-substance abuse (use of two or more substances in various combinations).

During the interviews, the participants self-identified one to nine problematic substances. The largest group included nine participants who identified the same six problematic substances. These six substances were alcohol, heroin, cocaine, speedball, crack, and marijuana. See Tables 5, 6, and 7 for more information about the substance abuse characteristics of the sample.

A majority (87%) of the participants reported having a diagnosis of mental illness at some point in their lives, with depression (67%) being the most frequent condition. Of those with mental illness, 65% were taking medications for their illness. Over a third of the participants (39%) reported prior suicide attempts, and 29% had been hospitalized to treat their mental illness. See Table 8 for the mental health characteristics of the sample.

Four participants (13%)—one man and three women—voluntarily disclosed they had been in prison for possession of drugs, intent to distribute drugs, or distribution of drugs.

Aim 1: Substance Abuse Experiences

The participants spoke openly about their substance abuse experiences. However, it was difficult for them to separate their substance abuse experiences from HIV- or

HCV-related experiences. Therefore, when asked to describe what it was like living with HCV infection, nearly half (45%) of the participants began speaking about their substance abuse experiences instead.

Three major themes with sub-themes emerged during the data analysis associated with substance abuse experiences. They were: (1) *Substance Abuse Evolution (with sub-themes: substance abuse initiation, escalation, polysubstance abuse, normalcy: a family of addicts, the enemy within, and transmission and disclosure)*, (2) *Revolving Door: Going Back Out (with sub-themes: specific events as a trigger, emotions as a trigger, alcohol as a trigger, and destructive relationships as a trigger)*, and (3) *Reconstructing Life (with sub-themes: defining moments in substance abuse addiction and maintaining sobriety)*. Data supporting each theme and sub-theme are presented below.

Substance Abuse Evolution

The evolution of substance abuse was the first major theme to emerge in data analysis. All of the participants had a history of substance abuse and there was a wide variety of responses describing how their substance abuse evolved. For example, some participants described how their substance abuse began, how their substance abuse escalated, and how they then abused multiple substances. For some, drugs and alcohol abuse in the home was a normal part of growing up and for others, there was something within themselves telling them it was okay to abuse drugs and alcohol. The participants discussed how their lifestyles and substance abuse led to HIV/HCV co-infection. Finally, some disclosed they were still struggling with substance abuse at the time of the interview.

Substance Abuse Initiation

Fourteen (45%) participants said they were children or teenagers when they started drinking alcohol and/or abusing drugs. For example:

- “I can remember I started injecting heroin at a very early age, age 13,”
- “I started drinking alcohol as a teenager,”
- “I started drinking around age eight or nine.”

Another participant described feeling nervous as a young child saying “I always had anxiety attacks even when I was young. I started using heroin and stuff, it made me feel a lot better.”

Nine of the 14 participants said they started drinking alcohol as children because it was available to them and from there they moved on to hard drugs. One woman said “My father was an alcoholic. I drank in school when I was a teenager. I then used [heroin] everyday when I got out of jail [for distribution of drugs].” One participant told the story of how he became involved with drugs and alcohol as a child:

I started with alcohol at eight or nine because alcohol was always in the home.

From alcohol, I graduated to marijuana. From marijuana, it was a mixture of anything you could get your hands on, acid to hallucinogenics. At 14, I picked up heroin and injected it. Nobody sniffed heroin back then. We used to inject it....

Then after that it led to the cocaine and to drinking and all kinds of other pills.

Two women and one man disclosed they had been sexually, physically or emotionally abused as children by family members and turned to drugs and alcohol to cope. One of the women said:

I came from a very abusive family, sexually, emotionally and physically. I ran away at 16—got married at 17—had my first baby two months before I turned 18. My first husband was a user. There is not a drug addict that I know that doesn't want the other one they're with not to be like them. Somebody always wants to pull you down. I got pulled down, started using.

The second female participant recalled being physically and sexually abused by a male relative at around age 11 and as a result started hating herself. Then, she became involved with a man that introduced her to drugs by using and selling them. She said “I became involved in drugs around the age of 16 and I loved how the drugs made me feel.” She was in jail several times for using and distributing heroin. She is now taking her recovery and her return to health “one day at a time.”

The male participant described the severe physical and sexual abuse and neglect he suffered as child. He turned to living on the streets and started using and selling drugs in shelters and in shooting gardens (abandoned buildings used for squatting and drug use) to earn money to live.

Escalation

Sixteen (52%) participants described how their substance abuse escalated. For some, their drug and alcohol consumption escalated over a period of years; for others it was very rapid. One participant said this about her substance abuse: “At first it was recreational and then as a profession.” Another participant said this about how substance abuse controlled her life:

I was going through so much and never told anyone how I felt, just numbed it all away with drugs. I was high 24/7. I used to stay up for days, days. It was a terrible

way to live. My whole life was about heroin and cocaine and where I could get it and who had the best...I thought I had it going on. I went to jail many times.

One man described how his substance abuse escalated from drinking alcohol in high school with his friends to snorting cocaine as a young adult. A decision to inject cocaine one time at a party changed this participant's life forever:

[It started] in high school. I think all guys start drinking in high school and it's kind of one of those things. At first it was a fun thing, and I thought it was something I could control. You go out to a club on the weekend, and get drunk. First it was one night, then two to three times a weekend, then it was every day... So it wasn't a party anymore, it became an issue. Margaritas and lines of cocaine. It started out as a recreational line, then doing two or three at work. I was at someone's house, we had all been doing cocaine, and someone mentioned a needle. We didn't know about the needle-sharing thing. When you are under the weather like that, your judgment is way off. Somebody had suggested trying this. They were doing the thing with the needle and cotton ball and injecting it. At first I said no, I don't do needles, I don't like that kind of stuff, I never have... As far as recreational, I never had access to it. That is the one and only time it ever happened to me. That is why I am here today.

Being around others who injected drugs was another reason for substance abuse escalation. One participant said:

I used everyday for a while and I use to be a sniffer although all my friends used to shoot up. One time I tried it for a month. I don't consider myself an IV user. I guess since I tried it, I am.

Another participant said “I started doing heroin at the age of 32. I got HIV from sharing a cocaine needle.” She went on to say “I should have just kept snorting it.” She also said she was getting “high” with the person she was buying the heroin and cocaine from and she knew this person was infected with HIV. She said “I kept sharing [the needles] anyway.” Another person said “drinking alcohol leads to smoking pot” then on to “smoking dope.”

One participant appeared to be impaired on drugs during the interview. He admitted to injecting heroin on top of his daily methadone dose. He said he just wants to get high because “I have no life, no career, no family, and no friends.” He said he used to inject heroin with friends when he was younger, but he said “now I just do it by myself.” He knows the use of heroin is illegal and it is harming his health, however he said there is “not much else to do.” A second person admitted to injecting heroin in addition to his daily methadone dose. However he said “I am high on methadone and I can’t really feel [the heroin]. The high lasts about five minutes, so I don’t even bother.”

The participants who were children when they started abusing drugs and alcohol also described an escalation pattern to their substance abuse. One participant said:

I started drinking real early, probably about eight or nine. I’d steal beers out of the refrigerator, and the parents would get a little loaded and then they wouldn’t miss them. When I was about 12 years old, I started smoking a lot of pot and doing LSD and that went on for a number of years...I was about 33 when I started shooting heroin and drinking [in combination].

Nine (29%) participants described how if they drank alcohol it stimulated the desire to abuse other drugs such as marijuana, heroin, or cocaine. One participant said “it

started with the alcohol and then I went out there and got high. I know where to go [to purchase crack and heroin].” Others said once they start drinking they consumed harder drugs:

- “When I drink I want to do other drugs, marijuana or dope”
- “Alcohol and marijuana equals heroin,”
- “When I drink beer or Bacardi I want the crack,”
- “I start drinking I start shooting heroin, not a pretty combination.”

Polysubstance Abuse

Twenty-nine (94%) participants self-identified substance abuse problems with two or more substances. The most problematic substance was heroin, followed by cocaine and alcohol respectively. Participants described their abuse of multiple substances:

- “I was shooting heroin and drinking,”
- “Drinking heavily and smoking pot, and then it was drinking and heroin,”
- “I used lots of drugs and alcohol. I was using cocaine for about 20 years, then it was the mixture of cocaine and heroin, the speedball in addition to alcohol,”
- “It was acid, hallucinogenics, heroin, a mixture of anything I could get my hands on.”

Normalcy: A Family of Addicts

Six (19%) participants said that alcohol and drug abuse were a normal part of growing up. They spoke about how parents or family members were abusing drugs and alcohol and it was not unusual to be exposed at an early age. For example, one man said

he abused drugs and alcohol because it was accepted in the community where he was raised. He said “I thought this was how everyone lived.” He also stated: “I thought everyone did something—alcohol, drugs, or smoking—to take the edge off.” In addition, substance abuse was multigenerational for some participants. They said their parent(s) and they themselves were substance abusers. In addition, two had children who were substance abusers. One participant had a child in jail on drug-related charges. One man described how two of his close family members were dying from liver failure due to their HCV infection and “they had been serious alcoholics all their lives.”

The Enemy Within

Some of the participants spoke about their substance abuse as something within themselves that they could not control. For example, one woman said this about her drug addiction: “My disease is telling me I can get high and don’t have to worry.” Another said: “Drugs were my whole life; I would do anything or steal anything just to get drugs.” Another person said he knew he was an alcoholic and he needed to “control” something within himself. He said, “I am a binge drinker...I lied to my physician about my drinking.” A fourth person said:

I don’t know what’s wrong with me. What is really going on? I guess the disease is telling me to get up and go. That is all I have been doing, just running from my problems. I have been doing drugs all my life.

Transmission and Disclosure

Twenty (65%) of the participants said they knew they contracted the HIV/HCV co-infection from injecting drugs. Four (13%) thought they could have been infected with HIV/HCV co-infection through unprotected sexual contact. One participant said: “I could

have been infected with both from my husband since I was injecting drugs and having unprotected sex with him.” Another woman said: “My boyfriend told me he was HIV positive right after we had unprotected sex.” She said she thinks she was infected with both the HIV and the HCV infections at the same time. She also said she was injecting heroin. Another woman said “my boyfriend deliberately infected me” with both HIV and HCV infections; however she did not elaborate further. One man said he was relieved to know that he probably contracted both infections because of his injection drug abuse rather than sex. He said “I would be frustrated in knowing that sex may have been the cause.” Another participant described how he would “go out drinking and drugging in the bars” and then “I would pick anyone up, I would take them home [for sex]. I was doing both, sharing needles and having [unprotected] sex.”

Despite knowing their HIV infection and HCV infection status, many ($n = 29$) continued to abuse drugs and alcohol after their diagnosis. One participant said he was “shooting dope like mad” when he was diagnosed with HIV 19 years ago and had a physician tell him “You need to stop [doing drugs] or you are going to die.” He admitted he was still injecting drugs at the time of the interview.

Five (16%) of the participants disclosed they were active substance abusers at the time of the interview. Of these participants, three were women and two were men. All five were single and unemployed. Four were abusing alcohol. Two were injecting heroin and one was smoking it. The two participants injecting heroin said they were not sharing needles; they made these comments about their injection practices: “I haven’t shared needles in years,” and “I just do it by myself.” One participant was drinking alcohol and smoking crack cocaine. Two of the participants actively using a combination of drugs and

alcohol drugs were in a residential treatment facility; the other three were living on their own. Both participants in the residential treatment had recently entered the program. One participant was moving into the residential treatment facility the day of the interview and the second had been admitted for two months. All five of the participants were on HIV medications and two had AIDS. Only one of the five participants with active substance abuse problems had undergone a liver biopsy and none had started HCV treatment.

All five of the participants with active substance abuse problems had been diagnosed with depression. However, only one of the five (20%) was taking medications to treat the depression, compared to 20 (65%) who were not active substance abusers. All five current substance abusers described their current mood and emotions as “anger,” “frustration,” “bitterness,” “loneliness,” and “depression.” They also said:

- “I know I need help, but I am always running from my problems,”
- “I am frustrated, angry, and bitter,”
- “I blame my family for my problems,”
- “I feel like I am always getting bad news,”
- “I don’t trust anyone.”

One participant said “I am always starting over” [with rehabilitation] and “I am still standing in the same place as I have always been in.” They described how they responded to negative emotions or events by turning to drugs and alcohol. All five of the participants seemed to be tired of their substance abuse problems; however they did not have the necessary skills to overcome them. Two participants spoke about their belief in “God” or “a Higher Power.” Both were asking God or their Higher Power for help and strength to get through their personal problems and substance abuse issues.

Revolving Door: Going Back Out

Revolving Door: Going Back Out was the second major theme to emerge from the data analysis. One participant described relapse as “going back out” into the drug and alcohol scene. Twenty (65%) of the participants spoke about how they would go through substance abuse recovery, either on their own or through a treatment facility, and then relapse back to substance abuse. Some participants shared the number of times they have been through substance abuse rehabilitation. For example:

- “I have been here [inpatient treatment facility] a couple of times before,”
- “It took me three detoxes to get all the heroin out of my system,”
- “I have been in and out of recovery many times. Three months here, a year and half there,”
- “I have been in this program three times. I gave up my freedom to come back here.”

One participant currently in a residential treatment facility said “I don’t understand. I am the one always going out and relapsing.” Several said they felt “ashamed” of their relapse into substance abuse.

It was also interesting to note that the definition of relapse was different among the participants. One participant said she would “stay clean and sober all week” and then she would relapse on the weekends. Another woman said she was “always going out and relapsing” rather than realizing she was in a pattern of continual drug abuse. Another woman said: “I am looking for an easy way out into addiction.” This participant admitted she used any excuse to abuse injection drugs.

The participants also described the triggers that caused them to return to substance abuse, such as stressful life events, emotions, alcohol, or their destructive relationships with others.

Stressful Life Events as a Trigger

Seven (23%) participants described specific events in their lives that triggered substance abuse relapse. For example, one participant said the death of her young child caused her “to lose it” and she started injecting heroin again because she did not care about anything anymore. Other events that triggered relapse in the participants included the death of a brother, a husband, and the suicide of a brother. Another participant described how she “wound up going back out” after receiving the HCV diagnosis. Another woman said she would relapse once she was off probation because she was no longer required to provide urine samples for her probation monitoring. One participant was in a car accident and started using heroin again to control the pain she suffered from her injuries. She said this about the use of heroin to control the pain: “I had other choices, it’s just I wanted to use [heroin]. I loved the way it made me feel.”

Emotions as a Trigger

Nine (29%) participants said their emotions such anger, low self-esteem, boredom, pain, or fear were triggers for substance abuse relapse. Seven (78%) of the nine individuals with an emotional trigger were women. Two men said they used drugs or alcohol to manage their anger or anxiety.

Anger was a common trigger for relapsing. One woman described how she felt “everyone was always picking on me” and it made her angry and frustrated causing her to use drugs and to drink alcohol. For another woman, both anger and drinking alcohol were

triggers for her to inject heroin. She said: “When I become angry or frustrated I want to drink and then I want to go out and find something to smoke.” One woman said her mother was her trigger. She said she will speak to her mother on the phone, however she knows that if she visits her she knows they will wind up fighting, which will trigger the desire to use drugs. She said “she aggravates me so therefore I go out and use.”

Three (10%) people said their low self-esteem was a trigger for substance abuse relapse. One participant discussed how she has a very low self-esteem and does not have any friends. She said “I am very focused on my children and grandchildren, but I feel I need to get a life of my own. I am always trying to take care of everyone else except myself.” However, she did say this about her substance abuse recovery: “All the people I used to associate with are in the past and I am not going back.” A second participant spoke about how his compulsive behavior led to the risks he took while he was abusing drugs and alcohol. He said: “Through my compulsive behavior in the midst of my drug use, I took all kinds of chances. I wasn’t even concerned about myself or my life. I did not respect others.” The third person described depression as her trigger for heroin use. She said “I was so depressed. If I sit too long in my own head I’m going to resort to old behavior.” In response to this statement she reflected: “I now ask for help [through her sponsor at the rehabilitation center].”

One woman said pain was her trigger: “Pain is a big trigger for me. Physical pain I can’t deal with. That is what makes me relapse 80% of the time.” She said she received a prescription for Oxycodone to help manage her pain, but she relapsed after taking them, so she said: “I just deal with the pain, I guess.”

Alcohol as a Trigger

Thirteen (42%) participants described alcohol as a trigger for substance abuse and 11 (85%) of the 13 participants said their substance abuse escalated once they started drinking. For example: Another participant said: “I thought I was missing something [by not drinking] so I started drinking again. I like the taste of beer. I know I can’t handle it.” One woman said she knows she is going to relapse when she starts drinking and smoking marijuana. This caused her to move onto harder substances, especially heroin. Another person said when he started drinking alcohol “it just leads to more heavy drinking and smoking pot and then onto injecting heroin.”

Destructive Relationships as a Trigger

Eight (26%) participants, seven women and one man, felt that their substance abuse was connected with their romantic relationships. The women said they became involved in drugs because they were “young,” “uneducated,” or “controlled” by the men with whom they had relationships. Furthermore many described dysfunctional relationships with their spouses or their partners as major contributors to their substance abuse problems. One woman said: “Usually it [substance abuse] had to do with my relationships. I was meeting the wrong kind of guys. Going nowhere, same kind of people. I couldn’t get out of that cycle.” A second women said she was in an “unhealthy relationship” with a man for nine years that included alcohol and drug use. She said she also was “distributing drugs” and “was out on the streets selling myself to pay off his drug debts.” Another woman said she “felt like I was never good enough for them [the men]. I was always in an abusive relationship.” Another woman called her relationship with her husband an “insane marriage, all dysfunctional. It was one big mess.” She also

said, “He had magical powers over me and he was like a god.” She said her mission in life was to take care of her husband by providing the drugs and alcohol for the relationship. She said she “would steal or do anything in order to get the drugs and alcohol. I got very selfish, the criminal behavior started coming out in me. I did things I would never do today.” Another woman admitted she was currently drinking alcohol in place of doing heroin. She said when her boyfriend left her four years ago “I started drinking when he left me” and “he really did screw up my life.” She said she drinks because she is bored, lonely, and depressed. All of the women confided they were no longer in these relationships.

The one man that said his relationship with a woman was part of his substance abuse problem said this woman enabled him by providing him with anything he needed, especially money. He said, “Once I broke off the relationship with her, I was able to start working on my sobriety.” None of the other men elaborated on their past relationships with significant others or how these relationships may have impacted their substance abuse habits.

One man did mention he was now married to a woman who was not infected with either HIV or HCV and he was surprised that she was willing to be with him since he had both diseases. Another man said, “I am now married and I have a child since I gave up drinking and injecting drugs.”

Reconstructing Life

Reconstructed Life was the third major theme to emerge from the data analysis. Sub-themes that came out were defining moments, maintaining sobriety, and setting priorities. Twenty-six (84%) of the participants were in various stages of recovery

ranging from a few months to 17 years. They were learning to accept themselves without substance abuse to relieve the emotions that they typically concealed or treated by using. This learning process was especially apparent in those who were new to recovery or in those who had relapsed and were returning to a life of sobriety. The participants spoke about defining moments that helped move them toward sobriety in order to reconstruct their lives. They also described how they were maintaining sobriety and setting priorities, even if it meant doing so one day at a time.

Defining Moments

Eight (26%) participants described experiencing a defining moment that helped to propel the participants towards sobriety. One participant described in detail a defining moment that he considered a turning point in his life:

Through my compulsive behavior, while being in the midst of my drug use, I took all kinds of chances. I wasn't even concerned about my life...[I] became more self-destructive. I actually had a spiritual experience that really turned my life around. It was a cold, misty morning in Boston, I hopped on a bus and I had this flash. It must have lasted a tenth of a second. I was going through the tunnel and I had somebody's hand. But I had a sense of comfort, peace, security.

He went on to describe how he faced his addictions and a dysfunctional relationship with a woman who was enabling him to use drugs by providing him money and housing. He went through rehabilitation and "got his act together."

Two participants said that receiving the diagnosis of HIV infection saved their lives. One man said he stopped injecting heroin and drinking alcohol after his diagnosis. He said: "Once I stopped using heroin, everything was a piece of cake. And that's how I

made myself believe that really it [HIV] saved my life. I probably be dead by now if I didn't." Another participant said that being diagnosed with both HIV and HCV four years ago saved his life too because he made major life changes after his diagnosis, including becoming clean and sober.

One woman said she stopped using drugs when her child tried to commit suicide, scaring her into sobriety. Another participant said by nearly becoming homeless he made a commitment to himself about his sobriety that changed his life:

I was close to being homeless when the love of my life tossed me out. Nobody wanted me. I moved into a sobriety house. I did not know if I could do it [get clean and sober]. I don't want to let people down [by relapsing]. A lot of good things have happened in my life in the past five years that I wouldn't want to give up for anything.

Finally, realizing that help was available and asking for it were defining moments for some participants. One person described how she asked for help before she relapsed again. She said: "I have never asked for help or support so this was a milestone for me." She said she finally admitted she was an addict and said she needed help. She said she wanted her children to be proud of her. She also said: "Nobody can say she went out and got high in the end." Another participant realized she was not ready for sobriety and her attitude was holding her back in her recovery: "I did not want it. Now I want it! I don't want to relapse. I love myself, I don't want to get sick with full blown AIDS!"

Maintaining Sobriety

Twenty-six (84%) of the participants had experienced sobriety—ranging from a few months to 17 years—and staying clean and sober was a priority for many of them.

They managed their substance abuse recovery “day-by-day,” by “keeping busy,” and by “dealing with emotions and stress.” Others said they are “giving the day to God” to manage their recovery. Support groups have been helpful for a number of the participants. Still others have gotten out of destructive relationships that enabled their substance abuse. The importance of maintaining sobriety was especially apparent for six individuals in a residential treatment facility. Major goals for these residents included staying substance abuse free, being united with family and minor children, and obtaining and maintaining their own home. The residents of the facility as a whole felt they wasted much of their lives abusing drugs and alcohol. One participant said: “I realized I don’t have to drink or do drugs to have fun,” and “This is the first time my mother has seen me sober in 13 years.” Another participant said she was taking advantage of everything she lost when she was “using and abusing.” Being tired of the consequences of substance abuse was cited by one participant as a reason for her sobriety. She said, “I’ve always been using drugs. I never thought I’d be able to stay clean. Just last year it got to the point where I was sick of the consequences.” One of the women said she was sober because “I don’t want my grandchildren to remember their grandmother as some loser, some drug addict.”

Nine (29%) participants felt their belief in God or a Higher Power was an important part of their sobriety and recovery. These statements they gave were similar to the terminology used in 12-Step recovery programs. For example:

- “I give God the day and my goal. I try to if I can [stay clean],”
- “I give my day to God. Yesterday is gone. I am working [on my sobriety] one day at a time,”

- “God is a beautiful God and he has given me strength every day to restore my sanity.”

Others said they believed God had a plan for them. For example: “I believe God is not going to let me suffer if I [do] the full work. Stay clean” and “God had something important for me to do and I am not done living.” Another felt God was in charge of his life and he said “If it wasn’t for God, I wouldn’t be here.”

In order to maintain their sobriety, three (10%) participants said they were involved in Alcoholics Anonymous or Narcotics Anonymous support groups. Eleven (35%) others said they were involved in rehabilitation or support groups, but did not identify the programs. The participants in recovery spoke about how they maintained their sobriety by “surrounding myself with people who don’t consume alcohol or drugs,” “going to support groups,” or “talking to others” (i.e., friends, family, psychiatrists, healthcare providers) about their problems. One man said he maintains his home as a “drug and alcohol free zone” in order to stay sober. He said anyone who comes to his home knows they are not allowed to be drunk or high on drugs.

Four (13%) participants said they did not belong to a substance abuse recovery support group because they felt they were not helpful. One person said “they [support groups] are not for me.” Another said the meeting irritated her so she would not go back.

Eight (26%) of the participants (both women and men) mentioned how getting out of destructive and abusive relationships with their partners helped them to obtain and maintain sobriety. In addition, they also worked to stay away from family members or others who put their sobriety in jeopardy. One woman said she realized anytime she went

to Boston to visit certain people, she knew she was in danger of using drugs so she stayed away from them. Another participant had this to say about her sobriety:

There is nobody, including my children that I would put my recovery in jeopardy for. Don't get me wrong; I'd die for my kids. I love them all. But if they are going to jeopardize my sobriety, I can't be around them. I won't be around them.

The participants also said keeping busy helped in managing their sobriety. Two men went fishing frequently, one hiked and skied, and another played golf as often as he could. Women said they walked, read books, volunteered, and practiced yoga to manage their sobriety. Sobriety was fragile for some. For example, one woman said "I keep busy so I don't sit in my head for too long." She added, "If I have too much idle time, I will resort to my old ways."

Four (13%) participants spoke about how they managed stressful or emotional situations to maintain their sobriety. Instead of using heroin to cope with stressful life events one woman said, "I am learning how to deal with stressful situations." Similarly, another woman discussed her ability to assess stressful situations and consider the consequences if she used drugs. She said "I am not willing to give up what I have worked so hard for [by using drugs]." Another said: "I have learned how to be independent. I have learned that I don't have to do drugs to deal with my feelings." Likewise, one man said: "I don't have to sedate myself to deal with my problems now."

Aim 1 Summary

Participants in this study described their substance abuse experiences in detail. All of the participants had past or present substance abuse issues. Many ($n = 20$) knew they had HIV/HCV co-infection because of their injection drug abuse. Three major themes

with sub-themes emerged during the data analysis, including: (1) *Substance Abuse Evolution* (with sub-themes: *substance abuse initiation, escalation, polysubstance abuse, normalcy: a family of addicts, the enemy within, and transmission and disclosure*), (2) *Revolving Door: Going Back Out* (with sub-themes: *specific events as a trigger, emotions as a trigger, alcohol as a trigger, and destructive relationships as a trigger*), and (3) *Reconstructing Life* (with sub-themes: *defining moments in substance abuse addiction and maintaining sobriety*).

Aim 2: Impact of Substance Abuse on HCV Treatment Decision-Making

All of the participants in the study knew they were infected with both HIV and HCV infection. Some of the participants received the HCV infection diagnosis at the same time as the HIV infection diagnosis. Others did not find out about their HCV infection until many years after their HIV infection diagnosis. Twenty (65%) of the participants said they knew they contracted both HIV and HCV infections from injection drug use, though when some received the diagnosis they were unsure of how they contracted the disease until it was explained to them.

Upon receiving the diagnosis of HCV infection, the participants said they felt scared ($n = 4$), embarrassed ($n = 2$), shocked ($n = 2$), confused ($n = 1$), surprised ($n = 2$), devastated ($n = 2$), or angry ($n = 1$). Others never gave the HCV diagnosis much thought ($n = 12$) or blocked the diagnosis out of their minds ($n = 2$). One participant said this about the HCV infection diagnosis: “it’s just another day and one more disease to add to the list.” Nearly half of the participants ($n = 13$) disclosed they were injecting drugs at the time of their HCV infection diagnosis. One participant, who was embarrassed and was worried about telling his friends he was infected with both HIV and HCV said “when I

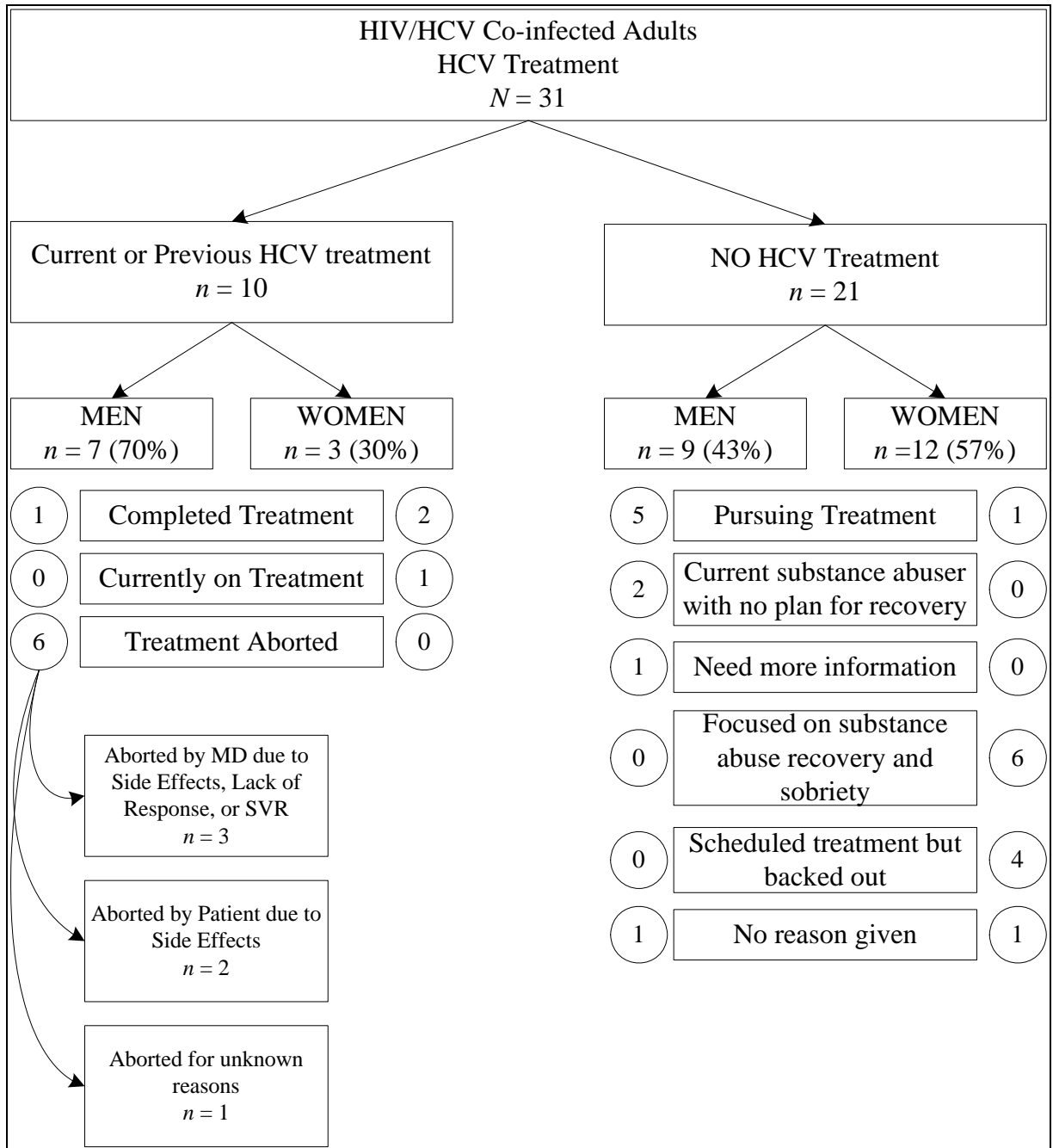
was out there using, it was harder telling them [my friends] not to use my syringes.” One patient relapsed and started injecting heroin again when she received the HCV infection diagnosis. She said: “So, I wound up going back out. I had two years clean and I wound up going to use and said if I’m going, I’m going hard. But then I realized I was still OK.” One participant was selling her blood through transfusion donations to obtain funds to purchase heroin. She said: “I was angry and could not believe the [HCV infection] diagnosis. I asked for the test [HCV] to be repeated.”

Themes and sub-themes emerged regarding HCV treatment decision-making from the data analysis: (1) *HCV Infection Treatment Issues (HCV treatment: not a priority, fear, misinformation)*; (2) *Get Clean and Try It (desires to use stimulated during HCV treatment)*.

HCV Infection Treatment Issues

HCV Treatment Issues was the first major theme concerning the impact of substance abuse on patient HCV treatment decision-making. There were two distinct groups with respect to decision-making information related to HCV treatment. The first group consisted of ten participants (32%) who were currently receiving or had completed HCV treatment at the time of the interview. The second group consisted of 21 (68%) participants who had not received HCV treatment. Figure 2 below outlines HCV treatment outcomes in this sample.

Figure 2. Current or Previous HCV Treatment or No HCV Treatment Flowchart



Of those participants who had not received HCV treatment, there were two sub-groups. The first sub-group ($n = 6$) consisted of five men and one woman who were pursuing HCV treatment. These participants were moving towards treatment by starting the pretreatment evaluation, but they had not started treatment at the time of the interview. They also were making arrangements for dependent children, arranging time off from work, and asking for assistance from family and friends.

The second sub-group ($n = 15$) consisted of participants who had not undergone HCV treatment for a variety of reasons. Six women were focused on substance abuse recovery and sobriety. Four women were scheduled to start treatment, but backed out for unknown reasons. Two men were active substance abusers and thus ineligible for treatment. One man said he would consider treatment if he had more information. And finally, two participants, one man and one woman, gave no reason for not pursuing treatment.

HCV Treatment: Not a Priority

For some of the participants, HCV treatment was not a priority. For example, some of the participants said they had not thought that far ahead, but would consider HCV treatment if they needed it. One person was awaiting results from a recent biopsy and feared she had cancer and HCV treatment was not a priority for her at this time. One group ($n = 6$) was focused on substance abuse recovery and staying clean and sober and treatment of their HIV infection. For this group, treatment of their HCV infection was not a priority at this time.

Some were afraid that they were going to die from their HCV infection before they died from complications of their HIV infection while others did not give their HCV

infection or treatment much thought. One participant was scheduled for a liver biopsy but felt she was healthy and did not need HCV treatment. She said, “I am unsure if I will keep that appointment.” Others were actively abusing drugs and HCV treatment was not a priority. For example, one participant said, “I was so high I never noticed.”

Fear: Substance Abuse Issues and HCV Treatment

Some participants were fearful that the HCV treatment would cause them to relapse back into substance abuse for one of two reasons: (1) if they were in possession of the syringes used for the interferon injections, their desire to use injection drugs would be stimulated, or (2) the desire to use drugs would be stimulated while they were drawing up the interferon for the injection. One woman said, “For my own sanity and safety I prefer to come in and have the injections. I prefer to have the [interferon] injections at the clinic for my own sobriety.”

In addition, two women were fearful their toddlers would somehow manage to pick up used interferon needles and get stuck, thus becoming co-infected. One of these women said: “I have a baby, and if for some reason I got sick and I dropped one [of the needles] and he picked it up...he’s not HIV or HCV positive. He is a miracle.”

To keep from having needles accessible, some participants decided to let their healthcare provider give the weekly interferon injection. They felt this was a way to control their fear and the possibility that the needles could trigger a relapse. They knew if they were in possession of the needles used for the interferon injections, the desire to use injection drugs would be stimulated. One man took the first few interferon injections at the healthcare facility and then decided he was able to give himself the injections after he felt strong enough to handle having syringes in his home. One man who was fearful that

the desire to use drugs would be stimulated while he was drawing up the interferon for his injection devised a technique to get himself through the treatments. He explained, “I forced myself to think that I was not putting drugs into the needle in order to get through the treatment. That’s how I did it.” And this technique worked for him—he was able to stay clean and sober throughout his HCV treatment. One participant was unable to give herself the interferon injection because she developed an extreme fear of needles. She said “touching the needle makes me physically sick since I stopped using heroin ten months ago.” She arranged for the nurse at the clinic to inject the interferon.

Misinformation: Substance Abuse Issues and HCV Treatment

Misinformation about HCV treatment and the impact of substance abuse among the participants was varied. For example, one participant misunderstood how consuming alcohol could impact her hepatic function and health. She was under the impression that she could resume drinking after she completed HCV treatment. She said “I can stop drinking alcohol [while on HCV treatment] and I will know in about three months if the treatment is going to work.” She said: “I can go back to drinking [alcohol]” after completing the HCV treatment. She added: “I drink alcohol in place of injecting heroin.” This participant’s physician and family were encouraging her to go into rehabilitation for her alcoholism before she attempted HCV treatment.

Two participants were unclear of the risks associated with HCV infection on their long-term health outcomes. They thought if they stayed clean and sober they would remain healthy and their HCV infection would remain stable. One participant in particular said, “I don’t need to be on interferon, my liver is fine. As long as I don’t pick up and drink and drug, I will be fine.” Another participant said he was not addressing the

need to treat his HCV infection because “long as I keep busy and I eat healthy and I don’t drink and drug and I seek out advice and I take my medications accordingly, then everything will be all right.”

Desires to Use Were Stimulated During HCV Treatment

While going through HCV treatment, some participants experienced sensations similar to their substance abuse. The participants described feeling these sensations, however none admitted to acting upon these urges. They were able to use techniques or strategies to maintain sobriety during HCV treatment. Three participants said that taking interferon made them feel like they were “detoxing” or “kicking it” from heroin. One man said he had “the psychological sense of injecting” while he was undergoing HCV treatment. He said his lips were “smacking” and “salivating” similar to when he was injecting cocaine. He went on to say, “I had to sit back and process, think about and figure out exactly what was happening.” Another one of these participants said that HCV treatment “makes you want to commit suicide. If it is not the suicide, it’s going to the drugs and you going to hit the streets.” The participant suggested that anyone undergoing HCV treatment with a history of substance abuse “get counseling and fight the urges” the [HCV] treatment induces.

Get Clean and Try It

The participants who had already undergone HCV treatment had advice for others who were considering treatment for their HCV infection: be clean and sober and get the treatment. One man commented: “If there is any chance, even 10% of cure, do it. Try it.” In addition, the participants who had undergone HCV treatment added, “Get counseling

and join support groups,” and “Get all the help you can with your substance abuse recovery.” One participant had this to say about sobriety and HCV treatment:

Probably, out of everything I say, the biggest thing I have done to help myself with this treatment is not using drugs and alcohol, because I’m an alcoholic and drug addict. I would have waited at least a couple of years before [HCV treatment], you need some kind of support system.

Another participant felt it would be important for those considering HCV treatment be sober for at least two months. She also felt it would be misuse of medical resources if someone was still using drugs and was trying to make a decision to start HCV treatment. She had this to say about importance of sobriety before starting HCV treatment:

I think it’s important to be clean and sober. At least a few months, because if you are using, you are defeating the whole purpose of doing the medication. If you are really sincere about getting clean and taking care of yourself, I do believe you should be clean though. Medication is very expensive, so if you’re using drugs or alcohol while you are doing the treatment, it’s kind of a waste of money and energy and time.

Another participant had the same thoughts: “A person considering HCV treatment should be stable in their recovery before beginning the treatment.” He added, “When someone is considering HCV treatment they should be having regular counseling sessions or be involved in a support group since the [HCV] treatment can stimulate the desire to abuse drugs and alcohol.”

Another participant recommend that those going through HCV treatment should smoke marijuana to ease the side effects of interferon. He said: “The treatment [interferon] causes flu like symptoms which is so similar to [narcotic] withdrawals that it makes you want it [narcotics] more than the treatment.” He said he smoked marijuana throughout his HCV treatment to eliminate the nausea and that he preferred to smoke marijuana rather than relapse back to using heroin.

Aim 2 Summary

Substance abuse experiences related to HCV treatment decision-making were threaded throughout the interviews. Preliminary descriptive data were present that suggested possible links between substance abuse and HCV treatment decision-making; however information redundancy was not reached for this second aim. Therefore, the data presented below represents an initial description that will require greater exploration in future studies.

Participants described how they felt when they were diagnosed with HCV infection and their fear of HCV treatment. There were some misconceptions about substance abuse and HCV treatment. In addition, participants who were currently undergoing or had completed HCV treatment, had advice for those contemplating treatment. Participants described how the desire to abuse drugs or alcohol occurred and how they managed these feelings during HCV treatment. Detail about these linkages will be detailed according to patient and contextual factors below.

*Secondary Aim: Exploration of Substance Abuse Experiences within Interactive
Decision-Making Framework*

Rich descriptions of substance abuse experiences were threaded throughout the interviews. These descriptions were evaluated to ascertain whether they fit best with patient or contextual factors within the Interactive Decision-Making Framework (Pierce & Hicks, 2001). Based on the available data, it is unclear whether substance abuse experiences fit with patient or contextual factors. The substance abuse experiences in this sample included both patient and contextual factors.

Patient Factors

In this study, substance abuse experiences could fit within patient factors since many of the participants had a history of long-term substance abuse problems. Participants also said they had choices when it came to substance abuse relapse. For example, one participant said she chose heroin to control her pain after an accident: “I had other choices, it’s just I wanted to use [heroin]. I loved the way it made me feel.” Still others chose not to accept prescriptions for narcotics after a medical procedure such as a liver biopsy. One man said “It [the liver biopsy] hurt afterwards. I refused it [pain medication]. I just didn’t want to start taking anything.” This comment indicated he was unwilling to put himself at risk for a relapse.

In addition, according to the framework, decision values are associated with the patient’s perception of experiences and momentary states of pleasure and pain. Data from this study linked decision-making to these momentary states. For example, participants explained that their substance abuse made them “feel good.” Another participant said “I

just want to get high.” Participants described how they used drugs to “calm,” “numb,” or “control anxiety.”

Patient Factor: Decision Styles

There was a range of decision-making styles across the sample. Some patients expressed their abilities to take charge of their HCV infection by doing whatever it takes to treat their HCV infection, including staying free from drugs and alcohol. They felt the need to make the decision to have HCV treatment to stay alive, be around for their children. None of the participants who were moving toward HCV treatment were actively abusing drugs or alcohol nor were they in the residential treatment facility.

One participant said he had made the decision to move forward with HCV treatment and felt ready. He said he has been clean and sober for nine months. However, he said his healthcare provider wanted him to have more time with his sobriety. In contrast, another participant who was currently undergoing HCV treatment said “I did heroin 10 months ago and I decided to become sober.” She was currently undergoing HCV treatment and having the nurse at the clinic give her the interferon injections because she was fearful of having the needles in the house.

Conversely, some participants said they had trouble making commitments and they knew the treatment would require a long-term obligation on their part. Some participants ($n = 6$) were focused on their substance abuse recovery and HCV treatment was not a priority for them. One participant said this: “It is serious treatment. It is nothing to play around with. It is very expensive. You really have to want it because it is a commitment.” She went on to say: “If you are using drugs you are wasting your time and the doctor’s time and it is a waste of medication.” She felt that making a serious

commitment to HCV treatment meant that someone was serious in their commitment to their sobriety.

Patient Factor: Preferences for Participation

Some participants were actively involved in the HCV treatment decision-making process. Some participants made the decision to wait for the right time to begin HCV treatment. One participant had this to say about the decision to start HCV treatment: “The biggest concern that I had was I waited until the golf season was done, then we waited for the holidays to go because we thought all these things could happen...I was like, what was I waiting for?”

Another participant decided it was a good time to treat her HCV infection based on the stability of her HIV infection. A second woman also said she decided to go forward with HCV treatment based on the stability of her HIV infection in addition to a feeling she had. She said: “My HIV is stable, the decision just feels right, and I want to live!”

Four (13%) participants preferred to take more passive role in the decision-making process. One participant said, “I take all the medications that they [doctors] want me to take,” and another said “I will leave the decision [for HCV treatment] up to my doctor.” Two others said they would leave the final decision for HCV treatment up to their healthcare providers. They said they trusted their healthcare providers to make the right decisions for them.

Contextual Factors

Substance abuse decisions may also fit within the contextual factors of the framework because substance abuse occurred within the context of the individual's environment demands.

Contextual Factors: Patient-Provider Interaction

Across the sample, the participants said their healthcare providers gave them “advice,” “education,” and support.” They also felt their healthcare providers were candid and realistic about their health care issues. Participants were told by their healthcare providers that their substance abuse could worsen their HIV infection or HCV infection. For example, one participant said: “They said it was because of my heavy drinking. They [healthcare providers] said you better make up your mind and quit drinking.” Some participants who have not made the decision to undergo HCV treatment said they needed more education regarding substance abuse issues. Several participants were fearful that the desire to abuse drugs or alcohol would be stimulated during HCV treatment.

Across the sample, the participants said they had positive relationships with their healthcare providers and they made statements such as, “They work with you as a team,” and “We try to work together—which is a good thing.” Participants said they had trust and faith in their healthcare providers and the decisions they made together. One participant said “They [healthcare providers] have always been there for me.” Two participants said that God gave their healthcare providers the necessary knowledge needed to do their jobs. One participant said she was inspired by her healthcare provider to take HCV treatment. She said, “She [my healthcare provider] is like the Mother I never had.”

Only one participant expressed a problem with his healthcare provider. He said his healthcare provider treated him like a drug abuser even though this participant assured the provider he was not. He said he stopped taking his HAART and HCV treatment due to “personality problems” and the way the provider treated him like a drug addict. He was willing to speak to the providers again about HIV and HCV treatment; however he wanted to be very clear he was not abusing drugs or alcohol.

Secondary Aim Summary

Based on this analysis, substance abuse experiences fall into both patient and contextual factors within the Interactive Decision-Making Framework (Pierce & Hicks, 2001). While most of the participants expressed a collaborative relationship with their healthcare providers, there was a need for further education regarding substance abuse issues and HCV treatment. Being clean and sober was an important factor in the decision-making process for the individuals who had undergone or were currently undergoing HCV treatment.

Chapter Summary

In summary, results of this study identified five major themes with sub-themes after analysis of the participants descriptive summaries. They were: (1) *Substance Abuse Evolution (with sub-themes: substance abuse initiation, escalation, polysubstance abuse, normalcy: a family of addicts, the enemy within, and transmission and disclosure)*, (2) *Revolving Door: Going Back Out (with sub-themes: specific events as a trigger, emotions as a trigger, alcohol as a trigger, and destructive relationships as a trigger)*, and (3) *Reconstructing Life (with sub-themes: defining moments in substance abuse addiction and maintaining sobriety)*, (4) *HCV Infection Treatment Issues (with sub-themes: HCV*

treatment: not a priority, fear, and misinformation, desire to use stimulated during HCV treatment), and (5) Get Clean and Try It.

Nearly half of the participants started abusing drugs and alcohol as children or adolescents. For some, substance abuse escalation evolved over time, for others it progressed rapidly. Polysubstance abuse was a major problem for most all of the participants of this study. In addition, they had been abusing drugs and alcohol for much of their lives and knew they had been infected with HIV/HCV co-infection from injection drug abuse. The participants described triggers and stressful life events that caused them to relapse. There was a wide variety of triggers for the participants in this study, in particular, the death of a loved one and emotions such as anger and low self-esteem, and relationships with others were all mentioned. The use of alcohol also was a trigger for many of the participants. Once some of the participants started drinking alcohol, they began using other drugs. Many of the participants had been in substance abuse rehabilitation at some point during their lives and the 12-Step program terminology was threaded through the interviews. They also spoke about how they were maintaining their sobriety with a variety of techniques such as taking it one day at a time, attending meetings, spending times with family and friends, and participating in hobbies or activities.

Most were receiving HIV treatment, but a majority had not undergone HCV treatment for a variety of reasons. However, over half of those who had not undergone HCV treatment were active substance abusers or were in substance abuse treatment. For some, HCV treatment was not a priority for them at the time of the interview. Some of the participants were fearful the HCV treatment would stimulate the desire to use drugs

or alcohol. Some were unclear on how HCV infection could impact their long-term health.

Being clean and sober was an important recommendation from those who were undergoing or had completed HCV treatment. These participants also wanted others to know that their substance abuse could be stimulated by HCV treatment and suggested that anyone going through treatment get all the help that one can to overcome the urge to relapse. Further work is needed to explore how substance abuse experiences impact the patient decision-making process.

Chapter V

Discussion and Implications

Introduction

The purpose of this study was to describe the substance abuse experiences in adults with an HIV/HCV co-infection and to explore how these experiences may relate to HCV treatment decision-making. A secondary aim was to investigate where substance abuse experiences fit within the Interactive Decision-Making Framework (Pierce & Hicks, 2001). The following discussion reviews the major study findings according to substance abuse experiences, which includes substance abuse evolution; relapse, triggers, and recovery; the 12-Step language; and alcohol abuse in HCV infection. The limited data related to substance abuse experience and HCV treatment decision-making is summarized as is the lack of a clear fit of substance abuse within the decision-making framework. Finally, implications for the nursing field and recommendations for further research are outlined.

Substance Abuse Experiences

Substance Abuse Evolution

For the participants of this study, substance abuse was an evolutionary process that proceeded from initiation to escalation, and included polysubstance abuse. Nearly half became substance abusers as children or adolescents and the reasons for substance abuse varied. For example, some started using drugs or alcohol socially with friends (D'Amico & McCarthy, 2006), while others abused substances to calm their mood or reduce anxiety. Another set of the participants experienced drugs and alcohol abuse as part of their family home life (Hops, Tildesley, Lichtenstein, Ary, & Sherman, 1990;

Kandel, Griesler, Lee, Davies, & Schaffran, 2001; Lieb et al., 2002). Others attributed their substance abuse problems to the sexual, physical, or emotional abuse they suffered as children (Hyman, Garcia, & Sinha, 2006; Leenerts, 1999; McCauley et al., 1997; Widom, Marmorstein, & White, 2006; Widom, Weiler, & Cottler, 1999).

The participants of this study spoke about the escalation of their substance abuse. For some, the escalation occurred over a period of years, but for others it was very rapid acceleration. Many revealed alcohol was a starting point that later escalated to abuse of harder substances. They described how they only snorted or smoked cocaine or heroin, but then progressed to injecting the drugs. This finding in the study supports other studies that concluded it is necessary to move on to injecting a drug because the high can no longer be obtained by snorting or smoking it (Doherty et al., 2000). In addition, some said they began to use other drugs when they were under the influence of alcohol (Doherty et al., 2000). The results of this study are consistent with others who have found substance abuse progressed over time (Andrews, Tildesley, Hops, Duncan, & Severson, 2003; Duncan, Duncan, & Hops, 1998). In addition, other studies have concluded substance abuse continued and even escalated after receiving the diagnosis of HIV infection (Von Unger & Collins, 2005).

Polysubstance abuse was a major problem for the participants in this study, affecting 94% of the sample. In many instances, drugs are used in combination to reduce the side effects of one drug (e.g., use of cocaine to reduce withdrawal effects of heroin), to enhance the high, or to obtain a different high (Leri, Bruneau, & Stewart, 2003). The National Survey on Drug Use and Health (2005) showed that 3.3 million out of the 22.2 million persons 12 years or older with substance abuse disorders were dependent on a

combination of alcohol and illicit drugs. Polysubstance abuse poses a significant problem for individuals in substance abuse treatment and recovery. Grella and Joshi (1999) found those entering substance abuse rehabilitation were more likely to be dependent on multiple substances rather than alcohol alone. Further, polysubstance abuse is a reason for dropout in substance abuse rehabilitation or failed outpatient treatment (Chatham, Rowan-Szal, Joe, & Simpson, 1997; Mammo & Weinbaum, 1993; Shah et al., 2006).

Substance Abuse Relapse, Triggers, and Recovery

In this study, five participants were actively abusing alcohol or a combination of drugs and alcohol and 26 were in various stages of recovery ranging from two months to 17 years. The participants of this study said they had been in substance abuse treatment programs multiple times. The findings from this study show the high rates of substance abuse recidivism and the fragile nature of recovery. Other research also shows that many with substance abuse problems spend years in a pattern of relapse, treatment, and recovery (Scott, Foss, & Dennis, 2005). Approximately 1.9 million people entered substance abuse treatment programs in the US in 2005 (Office of Applied Studies, 2006). Of those admitted, 62% entered an outpatient treatment program, 21% entered a detoxification program, and 17% entered a residential treatment program. Of those admitted to a substance abuse treatment program, approximately 44% completed treatment (Office of Applied Studies, 2006). Many relapse to substance abuse soon after treatment (Gossop, Stewart, Browne, & Marsden, 2002). In most instances, those who attend substance abuse rehabilitation return to the same environment in which they came from prior to the treatment. By returning to the same social network after substance abuse rehabilitation, the individual is at risk for returning to injection drug use (Costenbader,

Astone, & Latkin, 2006; Latkin, Knowlton, Hoover, & Mandell, 1999; Latkin et al., 1995; Sun, 2007). Sun (2007) found that when women return to the same environment in which they came from before substance abuse treatment, they were likely to relapse without resources such as employment, family support, and housing security. The Drug Abuse Treatment Outcome Study (DATOS) (Grella, Hser, & Hsieh, 2003), which followed a cohort of cocaine abusers ($N = 347$) for five years, found that 44% of the study participants required substance abuse treatment again on average 2.6 years following discharge from treatment. Instead of viewing relapse as a failure, it can be viewed as part of the recovery process (Sun, 2007). The relapse can be used as a time for education in order to understand the events leading up to the relapse. Therapies for relapse recovery can include increasing the individual's involvement with positive social networks, teaching or practicing behavioral modification skills, and strengthening coping strategies (Carroll & Rounsaville, 2006). It has been suggested that a post rehabilitation discharge monitoring program should include quarterly checkups to shorten the time between relapse and the return to a rehabilitation program (Scott, Dennis, & Foss, 2005; Scott, Foss, & Dennis, 2005). Furthermore, long-term follow-up is needed to address the chronic nature of substance abuse disorders (Grella et al., 2003).

Many of the participants in this study could identify the triggers that stimulated the desire to abuse drugs and/or alcohol. In particular, stressful life events (especially the death of a loved one) and the use of alcohol were mentioned by participants in this study. In two qualitative studies (Von Unger & Collins, 2005; Sun, 2007), women revealed that stressful life events, including the death of a loved one, caused them to relapse.

Several participants, nearly all women, acknowledged their partners influenced their substance abuse practices. In many instances, these negative relationships were triggers for some women to relapse. The women in this study said they were controlled by their male partner and would do anything to maintain the relationship, including distributing drugs, stealing, and participating in prostitution. Others have confirmed that those with substance abuse issues have a tendency to have social and familiar networks that have similar characteristics and tend to perpetuate substance abuse behaviors (McCrady, 2006; Sherman, Latkin, & Gielen, 2001). Also, research is beginning to identify substance abuse similarities in concordant adult couples (Cavacuiti, 2004). It has also been found that individuals tend to partner with others with similar substance abuse disorders (Low, Cui, & Merikangas, 2007). Still other researchers have found that women tend to emulate their male partner's substance abuse patterns (Amaro & Hardy-Fanta, 1995; Daniulaityte, Carlson, & Siegal, 2007; Sherman, Latkin, & Gielen, 2001). Furthermore, women are likely to share injection equipment if their injection partner is: (1) their significant other ($p < .05$), (2) a family member, friend, or acquaintance ($p < .05$), or (3) someone they have shared injection equipment with before ($p < .001$) (Tortu et al., 2003). Women share drug injection equipment within a larger social network that includes both men and women rather than just with their significant other (Doherty et al., 2000; Sherman, Latkin, & Gielen, 2001). On the other hand, a woman who injects drugs with her partner can be isolated, especially if that partner injects drugs and controls the relationship (Rhodes & Quirk, 1998). Moreover, some evidence shows that women use drugs to relieve negative emotions associated with destructive relationships with men (Leenerts, 1999; Miller, 1999; Sun, 2007). In a qualitative study

by Sun (2007), women said they lacked a personal identity and their self-worth was tied to the success or failure in their relationships with men. In addition, the women reported they relapsed for a variety of reasons such as feeling abandoned by their partner, having low self-esteem, or a perceived lack of support from authoritative systems (i.e., child welfare, drug treatment centers, probation monitoring systems). In comparison to the current study, the women in the study by Sun (2007) were younger ($M = 34$) and were addicted to methamphetamines where in the current study the women were older ($M = 42$) and addicted to heroin, alcohol, and cocaine respectively. Similarly, Sun (2007) found many (49%) of the women abused multiple illicit substances, primarily methamphetamines, heroin, cocaine, and alcohol. Despite the differences in the age and drug of choice between the samples, there were several similarities with the present study. The women in both studies reported interpersonal relationships with significant others, negative emotions (especially low self-esteem), and stressful life events (especially the death of a loved one) were all triggers for relapse.

The majority of the participants had experienced periods of sobriety. Some said they wanted to make others proud they were sober; while others spoke about the skills and techniques they used to stay sober. For the few participants who had accomplished long-term sobriety, self-acceptance was essential. They also said it was important that they took control of their sobriety and maintained that sobriety for themselves. Many used support groups in order to help maintain their sobriety. Other techniques included surrounding themselves with others who did not have substance abuse problems, being reunited with family and friends, staying out of destructive relationships, and keeping busy with enjoyable activities. These findings are similar to Flynn and colleagues' (2003)

assertion that those who achieved long-term recovery (five years or more) are significantly more likely to be in a long-term recovery support program ($p < .0001$), have support from family ($p < .05$), have a sense of responsibility to self ($p < .0001$), and viewed self as a productive member of society ($p < .0001$). In addition, those in long-term recovery had higher levels of spirituality than those who were still struggling with substance abuse ($p < .01$) (Flynn et al., 2003). In the current study, many of the participants felt their faith and spirituality helped them to stay clean and sober.

Twelve-Step Language

Many of the participants of this study used language and terms from 12-Step programs such as Alcoholics Anonymous or Narcotics Anonymous. These 12-Step programs are based on a fundamental belief that the person is powerless over drugs or alcohol and that there is a God or a Higher Power that can restore sanity. Faith-based substance abuse programs have been in existence for over a hundred years in the US. In the early 1900s, the Universal Prayer was recited for 15 days in anti-opium and anti-alcoholic meetings as part of protection against the “evils” of opium and alcohol consumption (Crafts, Crafts, Leitch, & Leitch, 1909, p. 12). In today’s 12-Step programs, a person manages their sobriety one day at a time and asks God, or their Higher Power, to give them strength to overcome substance abuse (Alcoholics Anonymous, 2007; Narcotics Anonymous, 2007). Some have found that faith and spirituality are important components of substance abuse treatment (Arnold, Avants, Margolin, & Marcotte, 2002). Pardini and colleagues (2000) found that patients with high levels of spirituality could expect higher levels of social support, more resilience to stress, and a lower level of anxiety.

Some of the participants also spoke about how their substance abuse is telling them it is okay to use and they are powerless over the drugs and alcohol. The language threaded throughout the interviews suggested that many rely on others such as God or a Higher Power as part of their motivation for their substance abuse recovery. Despite having gone through rehabilitation, five participants were active substance abusers and six were in a residential treatment facility at the time of the interview. These data suggest that many participants in this sample continue to struggle with substance abuse issues.

Alcohol as a Major Problem in HIV/HCV Co-Infection

Many of the participants identified alcohol as a problematic substance. One participant admitted he lied to his healthcare provider about his alcohol consumption during and after HCV treatment. He drank alcohol during the treatment and continued drinking heavily after treatment. He, therefore, did not achieve SVR and treatment was aborted at 12 weeks. Active alcohol abuse has been identified as a major barrier to receiving HCV treatment (Adeyemi et al., 2004; Nunes et al., 2006). Alcohol consumption (more than 30 grams/day) has been associated with failure to respond to pegylated interferon and ribavirin in patients with HCV mono-infection (Chang et al., 2005). On the other hand, some studies suggest that alcohol consumption is not an absolute contraindication to HCV treatment, but no safe levels of consumption have been established (NIH, 2002). Treatment of alcohol abuse is recommended prior to HCV treatment, but it should not impede a pre-treatment evaluation (NIH, 2002).

In the US in 2005, 45% of those with an alcohol disorder had a secondary drug abuse disorder (Office of Applied Studies, 2006). In this sample, five out of the six individuals in a residential treatment facility said they had a problem with alcohol.

Because of their substance abuse, none of the individuals in the residential treatment facility were considering HCV treatment at the time of the interview. Unfortunately, limited data exists that describes the experiences of patients with active alcohol abuse and with HIV/HCV co-infection (Nunes et al., 2006; Sherman, 2003; Sherman, 2007). In addition, there is limited information on how active alcohol abuse affects patient decision-making regarding HCV treatment (Fraenkel et al., 2005). Therefore, moving patients with HIV/HCV co-infection towards HCV treatment requires a greater understanding of the interplay between alcohol consumption and the decision-making process (Nunes et al., 2006; Sherman, 2003; Sherman, 2007).

HCV Treatment Decision-Making

The second goal of this study was to gain a preliminary understanding of how substance abuse experiences can affect HCV treatment decision-making. Twenty-one participants in this study sample had not undergone HCV treatment, although over half had undergone a pre-treatment evaluation that included a liver biopsy. In this sample, ten participants (7 men and 3 women) had previously undergone HCV treatment. It is not clear why, in this sample, greater numbers of men had been evaluated and treated for HCV infection. A partial explanation may be that more women were in a residential treatment facility and were marginally housed compared to men. In addition, four women in this study (compared to no men) were scheduled to begin HCV treatment, but backed out for unknown reasons. Because of these obvious gender-related differences, further research is needed to explore the reasons gender plays a role in HCV evaluation and treatment.

The participants described fears regarding substance abuse and HCV treatment. That finding in this study supports others who found fear as a significant barrier to HCV treatment (Fleming et al., 2003; Fleming et al., 2005). Several participants said their initial fear was of handling the needles used to inject interferon. These findings support others who found fear can be associated with the act of self-injecting interferon - which might trigger relapse of injection drug use (Fishbein et al., 2004). Because of this fear, some participants considering HCV treatment knew that having access to needles in their home, or handling the needles, put their sobriety at risk. By recognizing this fear and identifying the risk the needles pose to their sobriety, the participants were able to control triggers associated with relapse. Identifying and acknowledging triggers in relapse prevention is an important aspect in substance abuse recovery (Hoffman, Jones, Caudill, Mayo, & Mack, 2003).

While most of the participants of this study said they had a good relationship with their healthcare provider and felt well prepared for HCV treatment, some suggested a support group would be helpful during the decision-making process and while they were going through HCV treatment. Similarly, Fraenkel and colleagues (2006) found the participants in their study felt it would be helpful to have had the opportunity to attend a support group that included family members when they were preparing for HCV treatment.

Some participants in this study chose to take an active role in the decision-making process, others did not. This is an indication that healthcare providers need to be proactive to ensure HIV/HCV co-infected patients be evaluated for HCV treatment. The decision to move forward with HCV treatment is complex process for those with

substance abuse issues and an HIV/HCV co-infection. Some evidence shows more individuals with an HIV/HCV co-infection are receiving referrals for an evaluation for HCV infection (Mehta et al., 2006). Despite the referrals for an evaluation, there are still low reported HCV treatment rates in this population (Mehta et al., 2006). Consequently, due to low HCV treatment rates in HIV/HCV co-infected patients, a greater understanding of the factors contributing to patient treatment decision-making is still needed (Wagner & Ryan, 2005).

Substance Abuse Experiences within Interactive Decision-Making Framework

This is the first study to use the Interactive Decision-Making Framework (Pierce & Hicks, 2001) to ascertain whether they fit best with patient or contextual factors. The interactive decision-making framework has been used to study patients' decision-making processes regarding hemodialysis treatment among (1) Taiwanese adults (Lin et al., 2005), (2) in women during labor (Carlton et al., 2005), and (3) women with breast cancer (Budden et al., 2003). No study has been identified within the literature documenting the use of this framework to examine substance abuse experiences in HIV/HCV co-infected patients.

In the present study a variety of both patient and contextual factors emerged during the analysis. The patient factors included substance abuse choice, decision values, and preferences for participation in healthcare choices. Several participants recognized they had a choice when it came to their substance abuse habits. Some said they chose to abuse drugs or alcohol because it made them feel better, despite knowing the health risks involved with substance abuse. Others chose sobriety over substance abuse. This was especially important in those who were undergoing or had completed HCV infection

treatment. The participants who were currently undergoing or had completed HCV infection treatment believed being clean and sober was an important decision to make before committing to HCV infection treatment. The contextual factors included patient – provider interactions. Most of the participants felt supported by their healthcare provider. In addition, many relied on their treatment decisions to be made by the providers.

Based on the available data, it is unclear whether substance abuse experiences fit best within patient or contextual factors. In addition, it is unclear if this framework is ideal for examining the decision-making processes in patients with HIV/HCV co-infection face with HCV treatment decisions. Further work is needed to understand substance abuse and decision-making behaviors.

Study Limitations

This study was limited by several factors related to research using secondary data. First, the data were not collected for the purpose of answering these specific research questions, limiting the researcher’s ability to fully explore some of the themes and sub-themes. Second, the researcher was unable to conduct follow-up interviews with the participants. By meeting with the participants in a follow-up, face-to-face interview, information redundancy could have been pursued to more fully define the link between substance abuse and HCV treatment decision-making. In spite of this limitation, the data did reveal rich descriptions of the substance abuse experiences and some preliminary data on how these experiences impacted patient treatment decision-making.

Furthermore, the secondary aim to determine if substance abuse fits best with patient or contextual factors within the framework was not uncovered. A partial explanation may be likely due to the differences in the parent study organizing

framework and the organizing framework used in this study. A study designed to incorporate the Interactive Decision-Making Framework (Pierce & Hicks, 2001) may uncover where substance abuse experiences fit within the framework.

Finally, all of the participants in this study had a history of substance abuse so the results should be interpreted with caution in those with HIV/HCV co-infection without a history of substance abuse.

Implications and Recommendations for Future Research

Findings from this study will be useful to develop knowledge related to substance abuse in HIV/HCV co-infected adults. Implications for future research with HIV/HCV co-infected individuals emerged from these data. The results suggest:

1. There is a need to understand factors associated with substance abuse initiation in children, adolescents, and young adults. Nearly half of the participants of the current study started abusing drugs or alcohol as children or adolescents. In addition, a greater understanding of the decision-making processes regarding drug abuse initiation in children, adolescents, and young adults is needed. Research is needed to develop or enhance targeted interventions to help mitigate risk-taking behaviors associated with substance abuse in children, adolescents, and young adults.
2. Further research is needed to understand issues surrounding substance abuse triggers and relapse in individuals with an HIV/HCV co-infection. In the current study, multiple factors influenced substance abuse relapse. Both men and women in this study had a high rate of substance abuse recidivism. It is important to study why so many individuals fail substance abuse rehabilitation, including

understanding the factors surrounding substance abuse relapse such as social networks, gender issues, and cultural differences.

3. Further research is needed to understand the issues that women face during substance abuse and the recovery process. In the current study women were particularly vulnerable to being in a destructive relationship with a partner and many placed a significant amount of emphasis on their personal well being on the success or failure of that relationship. A greater understanding of how emotions, social networks, and personal relationships affect substance abuse in women is of particular importance.
4. Additional work is needed to understand polysubstance abuse issues in individuals with HIV/HCV co-infection. While it was a major problem for nearly all of the participants in the present study, it was not fully uncovered. A study designed specifically to understand the experiences and factors associated with polysubstance abuse in HIV/HCV co-infected adults is needed.
5. Further work is needed to understand patient decision-making related to HCV treatment in those with an HIV/HCV co-infection. In the current study, some of the patient and contextual factors emerged during analysis, however not enough to reach information redundancy regarding how substance abuse affects HCV treatment decisions. A study designed using the Interactive Decision-Making Framework (Pierce & Hicks, 2001) may uncover patient and contextual factors related to substance abuse and HCV treatment decision-making. Data from this study also showed gender differences in those who had undergone HCV

treatment. It will be important to understand the differences between men and women regarding the factors influencing HCV treatment decisions.

Finally, some practical findings that emerged from the study data that could be applied to research and practice include the following:

1. Early identification and treatment of substance abuse in children, adolescents, and young adults is crucial to prevent the spread of HIV/HCV co-infection.
2. Aggressive substance abuse treatment of HIV/HCV co-infected individuals is essential to improve outcomes.
3. Substance abuse recovery is a long-term process and requires monitoring for potential relapse. Therefore, patients should be assessed frequently for stressful life events (especially the death of a loved one) and alcohol consumption that could trigger relapse.
4. Provider evaluation for possible fear and misconceptions about substance abuse and HCV treatment during clinical visits and throughout HCV treatment in order to alleviate possible barriers for evaluation and treatment.
5. Patients with HIV/HCV co-infection should be encouraged to undergo HCV evaluation according to clinical treatment guidelines (i.e., liver biopsy, laboratory work, HCV genotyping) in order to move patients towards HCV treatment if it is needed.

Study Conclusion

Results of this study provided a rich description of the substance abuse experiences of HIV/HCV co-infected adults. Five major themes emerged describing substance abuse evolution, substance abuse relapse, reconstructing life after substance

abuse, HCV treatment issues, and getting clean. The linkage between substance abuse and HCV treatment decision-making was explored and included patient and contextual factors that linked decision-making to substance abuse issues. Further work is needed to fully understand this linkage. This study adds to the knowledge of substance abuse experiences in HIV/HCV co-infected adults. In addition, this study offers a preliminary examination of how substance abuse experiences influence HCV treatment decision-making. These findings will also be helpful to healthcare providers and to those who develop HCV treatment guidelines for individuals with substance abuse disorders and HIV/HCV co-infection. Further work is needed to understand substance abuse issues in children, adolescents, and young adults to reduce the transmission risks of HIV/HCV co-infection. Relapse and recovery are fragile in nature especially in HIV/HCV co-infected adults. The decision-making process is influenced by substance abuse experiences, however more research is needed to uncover specific factors influencing these decisions.

Tables and Figures

Table 1. Decision-Making Qualitative Literature (HIV Focus)

Study Specifics	Findings / Outcomes	Implications	What is Not Known
<p>Author / Year: *Kremer / 2006</p> <p>Sample: <i>N</i> = 79 Location: Florida Mean age: 42.03 Gender: 35.4% Female Ethnicity: AA: 41.8% Latino: 27.8% White: 24.1% Other: 6.3% Drug use past month: Marijuana: 26% Cocaine: 16.3% Other drugs: 16.6%</p> <p>Method: Cross Sectional Qualitative Sub-study Qualitative Content Analysis Convenience sample</p> <p>Purpose of study: How persons living with AIDS make treatment decisions</p>	<p>Ten Themes:</p> <ol style="list-style-type: none"> 1. Surrogate Markers 2. Better Qualitative of life 3. Resistance Beliefs 4. Mind Body Beliefs 5. Drug Side Effect 6. Easy to Take 7. Spirituality/World View 8. Resistance Testing 9. HIV/AIDS symptoms 10. Preference for Alternative Medicine <p>Patients not taking antiretroviral therapy (ART) preferred complementary/alternative medicine ($r = .43, p = .001$)</p> <p>Perceived a better QOL without ART ($r = .32, p < .040$)</p> <p>Weighted Avoidance of adverse effects of ART more heavily ($r = .24, p = .030$) than patients taking ART</p>	<p>Decisions not to take ART was dependent on not having a partner, having health insurance, individual beliefs about ART, complementary/alternative medicine, spirituality, mind-body connection</p> <p>HIV positive patient placed more weight on alternative medicine, avoiding adverse effects of ART and perceived a better QOL by not taking ART.</p>	<p>How strongly the necessity of taking ART was stressed by the HCP</p> <p>How substance abuse, mental health issues, AIDS diagnosis would effect decisions to take or not to take ART in this sample</p>

Table 1. Decision-Making Qualitative Literature (HIV Focus) (continued)

Study Specifics	Findings / Outcomes	Implications	What is Not Known
<p>Author / Year: Misener & Sowell, 1998</p> <p>Sample: <i>N</i> = 22 Location: Rural Southeastern U.S. Mean age: 31.5 Age Range: 20 - 43 Gender: Women Ethnicity: AA: <i>n</i> = 18 White: <i>n</i> = 4</p> <p>Method: Two Focus Groups Convenience sample</p>	<p>Four Themes:</p> <p>1. Influence of HCP</p> <ul style="list-style-type: none"> - Most of those on AZT reported most had a good relationship with HCP and they felt included in their health care decisions - Many of the women lacked trust in their HCP and felt they were “guinea pigs” and felt the HCP had to 	<p>Decision about AZT were influenced by HCP, lacked trust was the most significant finding around the acceptance of and adherence to treatment. Continued efforts to educate and provide clear information about medication. Many did not believe in taking medications</p>	<p>Not discussed</p>

Table 1. Decision-Making Qualitative Literature (HIV Focus) (continued)

Study Specifics	Findings / Outcomes	Implications	What is Not Known
<p>Purpose of study: To explore factors that influence decisions about ART in HIV-infected women</p>	<p>prescribe the AZT to keep their license, felt they were part of some experiment such as Tuskegee.</p> <ul style="list-style-type: none"> - Feared losing their HC services or being placed in jail if they refused AZT if they became pregnant - were not honest about adherence to medications <p>2. Beliefs about ART</p> <ul style="list-style-type: none"> - desire to avoid drugs due to beliefs about not taking medication - felt the treatment was not helpful or effective and possibly dangerous - some women believed that AZT helped them have HIV negative babies <p>3. Side effects -</p> <ul style="list-style-type: none"> - negative side effects impacted their decisions to take AZT <p>4. Peer & Family</p> <ul style="list-style-type: none"> - influenced by information received from peers and family - were more likely to trust a women, especially their mothers 	<p>and had significant fear about side effects. It is important to support and educate patients throughout the medication ART</p>	
<p>Author / Year: *Marelich / 2002</p>	<p>Four Themes: 1. Joint decision-</p>	<p>Various levels of</p>	<p>It is not</p>

Study Specifics	Findings / Outcomes	Implications	What is Not Known
<p>Sample: N = 39 Location: California HIV clinic Mean age: 40.9 Age range: 33-54 Gender: Female: 21% Male: 69% Ethnicity: AA: 44% White: 39% Latino / other: 12%</p>	<p>making - work with HCP as part of a team</p> <p>2. Patients taking control and making up their own minds - takes an assertive approach - decides treatments based on recommendations</p> <p>3. Initial passivity then involvement - as the patient learned about HIV they were more involved in decisions</p> <p>4. Patients as knowledge gatherers - gathered knowledge about HIV from many sources (peers, other professionals, family, media, other HIV positive individuals)</p>	<p>involvement in health care decisions and had good working relationships with their providers and changed HCP if they felt they were not receiving optimal care</p> <p>Patients were passive initially and as the patients become more knowledgeable, they began to make own treatment decisions and take a more assertive approach to what they wanted</p>	<p>known how the nature of the sample impacted the findings (i.e., strong and empowered). How would those with more advanced HIV/AIDS disease be involved in decision-making?</p>
<p>Method: Four Focus Groups Qualitative Convenience sample</p>			
<p>Purpose of study: To assess Hiv-infected adult patients involvement in ART decision with HCP</p>			

Table 1. Decision-Making Qualitative Literature (HIV Focus) (continued)

Study Specifics	Findings / Outcomes	Implications	What is Not Known
<p>Author / Year: *Laws / 2000</p> <p>Sample: <i>N</i> = 61 <i>n</i> = 25 Sub Analysis Location: Massachusetts Language: English: <i>n</i> = 46 Spanish: <i>n</i> = 15 Mean age: 39.3 Age Range: 24-57 Gender: Female: 25% Male: 75% Ethnicity: AA: <i>n</i> = 7 White: <i>n</i> = 24 Latina: <i>n</i> = 29 Portuguese: <i>n</i> = 1</p> <p>-----</p> <p>Sub-Analysis Group <i>n</i> = 25 Gender: Female: 32% Males: 68% Ethnicity: AA: <i>n</i> = 3 White: <i>n</i> = 9 Latina: <i>n</i> = 12 Portuguese: <i>n</i> = 1</p> <p>Method: Qualitative Convenience Sample Focus group (<i>n</i> = 8) to develop interview tool Random Selection to be in Sub-Analysis group (<i>n</i> = 25)</p>	<p>Three Themes:</p> <ol style="list-style-type: none"> 1. Beliefs about viral resistance and skipping doses (some knew that missing or skipping doses of ART had negative consequences, some believed that the resistance was changes in their body rather than the virus) 2. Patterns of Non-adherence - Several patients initially stated they did not miss medications but later in the interview admitted missing doses frequently, patients stopped treatment without telling their HCP, failed to have prescriptions filled, took “drug holidays” to cleanse the body, not taking medications during sleep/nap periods, sets own schedule for taking medications, substance abuse (caused respondents to forget about HIV and medications and focus was on 	<p>Only 4 of 25 were adherent with medications.</p> <p>Many factors about decisions to take or not take medications due to a variety of factors (forgetting, stopping, drug holidays, sleep patterns, side effects, drug addiction).</p> <p>Complex behavior surrounding decisions about taking ART.</p>	<p>What the HCP told the patient about adherence, medications, assessment of adherence to medication regimens.</p>

Table 1. Decision-Making Qualitative Literature (HIV Focus) (continued)

Study Specifics	Findings / Outcomes	Implications	What is Not Known
Purpose of study: To describe how people with HIV understand the experience the problem of adhering to ART regimens using the Sub-Analysis Group	obtaining drugs and did not want the HIV medications to interfere with high) 3. Relying heavily on HCP advice when deciding about ART		
Author / Year: *Moser / 2001	Five Themes: 1. AIDS as a life altering event 2. Spirituality 3. Mental health issues 4. Barriers to HC services 5. Environmental influences	Coexisting substance abuse and HIV is complex comorbidities for these women	How substance abuse impacts treatment decision-making and how providers impact treatment decision-making in HIV-infected women
Sample: N = 25 Location: Southern US Mean age: 38 Age Range: 22-57 Gender: Women Ethnicity: AA: <i>n</i> = 24 White: <i>n</i> = 1			
Method: Qualitative Four Focus Groups			
Purpose of study: To identify and discuss their concerns and needs related to their HIV / AIDS and substance abuse			

Note 1: * First Author Listed

Note 2: Abbreviations: HCV = hepatitis C virus, HCP = healthcare provider, ART = antiretroviral therapy, QOL = Quality of life, AA = African American, DPH = Department of Public Health, HC = health care

Table 2. Decision-Making Qualitative Literature (HCV Focus)

Study Specifics	Findings / Outcomes	Implications	What is Not Known
<p>Author / Year: *Fraenkel / 2005</p> <p>Sample: N = 40 Location: Connecticut Mean age: 51.5 Age Range 40-60 Gender: 20% Female Ethnicity: 82% White Education: 59% had greater than HS education Employment: 55% employed</p> <p>Method: Eight focus groups Eligible to participate if had a liver biopsy and had HCV treatment undergoing treatment, or had been offered treatment but refused Separate groups for those with substance abuse, mental illness and those who did not have either comorbidities</p> <p>Purpose of study: To ascertain patients perspective about the factors that influence decisions as they consider HCV treatment</p>	<p>Six Themes:</p> <ol style="list-style-type: none"> 1. Consideration of risk benefit tradeoffs (how the risks/tradeoffs of HCV treatment influenced decisions) 2. Protected Values (Strong personal preferences one way or the other) 3. Heuristics (following decision to avoid regret) 4. Conceptualization of illness (how the patient sees the illness either being cured or living with it) 5. Social Issues (family, work, responsibilities) 6. Physician's recommendations (this was very important in either decision to take or not to take HCV treatment) 	<p>Decisions are based on many factors besides risks and tradeoff values of HCV medications / treatment</p> <p>HCP should help facilitate decision-making through education (understanding treatment, side effects, potential outcomes)</p> <p>Respect patient values and decisions</p> <p>Know that treatment decisions may be strongly influenced on HCP recommendations</p>	<p>Unable to infer importance of the factors via quantitative measurement</p>

Note 3: * First Author Listed

Note 4: Abbreviations: HCV = hepatitis C virus, HCP = healthcare provider, ART = antiretroviral therapy, QOL = Quality of life, AA = African American

Table 3. Demographic Characteristics of the Sample

Characteristic	Value	Frequency	Percentage
Gender	Male	16	51.6
	Female	15	48.4
Race	White	18	58.1
	Hispanic	8	25.8
	African American	4	12.9
	American Indian	1	3.2
Marital Status	Single	16	51.6
	Living with partner	5	16.1
	Divorced	5	16.1
	Married	3	9.7
	Separated	1	3.2
	Other	1	3.2
Education	HS/GED	22	71
	No HS/GED	9	29
Housing Situation	Apartment	17	54.8
	Own Home	7	22.6
	Homeless	4	12.9
	Other	3	9.7
Work Status	Not Working	21	67.7
	Work Part Time	3	9.7
	Work Full Time	3	9.7
	Volunteer	3	9.7
	Other	1	3.2

Table 4. Clinical Characteristics of the Sample

Characteristic	Value	Frequency (<i>n</i>)	Percentage
HCV Genotype	1	19	76
	2	1	4
	3	3	12
	4	2	8
	Missing genotype information	6	19
Most Recent HCV/RNA	Range: 550-18,900,000	25	80.6
	Missing HCV/RNA	6	19.4
HIV Status	Asymptomatic	12	38.7
	Symptomatic	8	25.8
	AIDS	11	35.5
Length of Time with HIV diagnosis in Years	Mean, range:13.7, 2-20	31	100
HIV Medications	On HIV Treatment	25	80.6
	Not on HIV Treatment	6	19.4
Most Recent CD4	Mean, range: 468.5, 104-1056	28	90.4
	Missing CD4	3	9.6
Undetectable HIV RNA	<75	6	19.3
HIV/RNA	Mean, range: 8400, 50-69,307	26	83.9
	Missing HIV/RNA	5	16.1

Table 5. Self Reported Problematic Use of Specific Substances

Substance	Frequency (<i>n</i>)	Percentage
Heroin	27	87.1
Cocaine	26	83.9
Alcohol	24	77.4
Speedball	21	67.7
Marijuana	20	64.5
Crack	15	48.4
Tranquilizers	9	29.0
Other Drugs (not identified by participant)	9	29.0
Street Methadone	4	16.1
Oxycontin	3	9.7
Amphetamines	4	12.9
Street Morphine	2	6.5
Ecstasy	2	6.5

Table 6. Self Reported Most Problematic Use of Specific Substances

Most Problematic Substance	Frequency (<i>n</i>)	Percentage
Heroin	15	48.4
Alcohol	6	19.2
Heroin and cocaine	3	9.6
Cocaine	2	6.5
Heroin and alcohol	1	3.2
Speedball	1	3.2
All of the Substances	1	3.2
Missing Data	2	6.5

Table 7. Self-Reported Frequency of Problematic Substances

Self-Reported Numbers of Problematic Substances	Frequency (<i>n</i>)	Percentage
9 Substances	2	6.4%
8 Substances	3	9.6%
7 Substances	2	6.4%
6 Substances	9	29%
5 Substances	5	16.1%
4 Substances	3	9.6%
3 Substances	3	9.6%
2 Substances	3	9.6%
1 Substance	2	6.4%

Table 8. Mental Illness Related to Diagnoses, Hospitalizations, Medications, and
Suicide Attempts

Diagnosis	Frequency (<i>n</i>)	Percentage
Any Mental Illness Diagnosis	27	87.1
Depression	21	67.7
Anxiety	18	58.1
Bipolar Disorder (manic/depressive illness)	7	22.6
Obsessive Compulsive Disorder	7	22.6
Panic Disorder	6	19.4
Post Traumatic Stress Disorder (PTSD)	5	16.1
Personality Disorder	1	3.2
Other (schizoid type)	1	3.2
Schizophrenia	0	0
Hospitalization to treat mood or Mental Illness	9	29.0
Currently taking medications to treat mood or mental illness	20	64.5
Prior suicide attempts	12	38.7

Appendix A

Parent Study Interview Guide

Questions	Probes
What has the experience of having Hepatitis C infection been like for you?	Probes: How did you find out? What information were you given? Was it helpful? What was your initial reaction versus current feelings? What supports do you have?
How has the quality of your life been since you found out that you had Hepatitis C?	Probes: How was the quality of your life before you found out you had HCV? Has it changed? In what way?
What symptoms do you have that you believe are related to Hepatitis C?	Probes: What are these symptoms? How severe are they? Why do you think they are related to HCV? How do you manage these now? How do these affect your ability to live day to day?
Have you had any problems with your mental health?	Probes: Any problems feeling down or depressed? How do these symptoms compare to last week, last month, last year? Have you been anxious or uptight recently? How do these symptoms compare to last week, last month, last year? What helps you to manage these symptoms?
Have you had any problems with drug or alcohol use?	Probes: How do these problems compare to your experiences in the past? What is the most problematic substance for you? What helps you to manage?
How could your doctor or nurse help you manage this experience better?	Probes: Has your healthcare provider given you enough information about HCV? What information would you like? How has he/she been helpful? Not helpful?

Appendix B

Parent Study HCV/HIV Co-infection Baseline Demographic and Clinical Cofactor Sheet

Study ID # ____ ____ ____

Age in Years _____

Gender (☐) Male = 0
 (☐) Female = 1
 (☐) Transgender = 3

Ethnicity (☐) Hispanic/Latino = 1
 (☐) non-Hispanic/Latino = 0

Race (☐) American Indian = 1
 (☐) Asian = 2
 (☐) Black/African American = 3
 (☐) Native Hawaiian/PI = 4
 (☐) White = 5
 (☐) Other: _____ = 6

Years of Education _____ months

HS/GED (☐) no = 0
 (☐) yes = 1

Work status (☐) don't work = 0
 (☐) part time = 1
 (☐) full time = 2
 (☐) volunteer = 3
 (☐) other: _____ = 4

Marital/partner status (☐) single = 0
 (☐) living with partner = 1
 (☐) married = 2
 (☐) separated = 3
 (☐) divorces = 4
 (☐) other _____ = 5

Housing situation (☐) homeless = 0
 (☐) shelter = 1
 (☐) half way = 2
 (☐) apartment = 3
 (☐) own home = 4
 (☐) other _____ = 5

Appendix B (continued)

Length of time with HIV _____ months

HIV illness stage: () asymptomatic = 1
 () symptomatic = 2
 () AIDS = 3

Antiretroviral therapy () none now = 0
 () on treatment = 1

Most recent HIV RNA _____
DATE: _____

Most recent HCV RNA _____
DATE: _____

HCV subtype _____

Liver biopsy _____
Date _____

Appendix C

Parent Study Alcohol and Drug Dependency Questionnaire

I would now like to ask you some questions about alcohol and drug use.

Have you had any problems with alcohol or drugs?

No () 0

Yes () 1

IF YES – please complete the following

Substance	0 = No 1 = Yes	If yes, when was the last time?
Alcohol		
Heroin		
Speedball (coke & heroin injected)		
Cocaine		
Crack		
Marijuana		
Amphetamines (non-prescription)		
Tranquilizers (non-prescription)		
Street Methadone		
Street Morphine		
Ecstasy		
Oxycontin		
Other		

What has been the most problematic substance for you?

Appendix D

Parent Study Mental Health Questionnaire

Have you ever been told that you have any of the following by a healthcare provider?	0 = no 1 = yes 8 = don't know
Depression	
Anxiety	
Panic Disorder	
Bipolar Disorder (manic / depressive illness)	
Post Traumatic Stress Disorder (PTSD)	
Schizophrenia	
Personality Disorder	
Obsessive/Compulsive Disorder	
Other	
Have you ever been admitted to a hospital to treat depression or mood problem?	0 = no 1 = yes
Are you currently taking any medications to treat mental health problems?	0 = no 1 = yes
Have you ever tried to kill yourself?	0 = no 1 = yes
How long ago was this?	___ months

Appendix E
Receipt for Data

Contents of Data Set: _____

Date Received: _____

Tapes and number: _____

Transcripts and number: _____

Notes and number of pages: _____

Additional Data (list each item): _____

Investigator of Parent Study: _____

Signature of Researcher Receiving Data Set: _____

Return of Data Set

Date Data Returned to Principal Investigator: _____

Verification of Contents upon return: _____

Additional Information: _____

Appendix F

Secondary Data Inclusion/Exclusion Extraction Criteria Tool

Participant # _____

Inclusion criteria:

1. Did the participant have a history of substance abuse: yes/no?
 - a. Must be yes to be included in the final sample.
2. Did the participant talk about substance abuse: yes/no?
 - a. Must be yes to be included in the final sample.
3. Did the patient the participant talk decisions surrounding HCV treatment: yes/no?
 - a. If the participant did not talk about these decisions, the interview is not automatically excluded. This will be discussed with the dissertation chairperson.
4. Did the participant talk about substance abuse influencing HCV treatment decisions: yes/no?
 - a. If the participant did not talk about these decisions, the interview is not automatically excluded. This will be discussed with the dissertation chairperson.

Does the interview meet the inclusion criteria: yes/no?

If no, please explain.

PhD student comments:

Chairperson comments:

Second committee member comments:

Appendix G

Secondary Data Extraction Tool

Participant #: _____

1. Substance Abuse Experience

- Decision Problem
 - Alternative/choices
 - Probability outcomes/consequences
- Contextual Factors
 - Provider interactions
 - Environmental demands
 - Information (education)
- Patient Factors
 - Personal Values
 - Decision Styles
 - Expectations
 - Physical state
 - Physiological state

2. Describe experiences of substance abuse as it relates to HCV decision-making treatment:

- Decision Problem
 - Alternative/choices
 - Probability outcomes/consequences
- Contextual Factors
 - Provider interactions
 - Environmental demands
 - Information (education)
- Patient Factors
 - Personal Values
 - Decision Styles
 - Expectations
 - Physical state
 - Physiological state

Appendix G (continued)

3. New and emerging factors not captured by theoretical framework

- Decision Problem
- Contextual Factors
- Patient Factors
- Any other emerging factors

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