

**“SO HOW DID YOU GET THAT?”: EXPERIENCES OF INDIVIDUALS LIVING
WITH HEPATITIS C VIRUS (HCV)**

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Submitted to the faculty of the University Graduate School
in partial fulfillment of the requirements
for the degree
Doctor of Philosophy
in the Department of Sociology,
Indiana University
June 2006

Accepted by the Graduate Faculty, Indiana University, in partial fulfillment of the requirements for the degree of Doctor of Philosophy.

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May 29, 2006

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ACKNOWLEDGEMENTS

There are many persons who played a pivotal role in my journey through graduate school and especially with the dissertation. Financially, I am forever grateful to the Sociology and Anthropology Department at DePauw University for awarding me two years as a pre-doctoral scholar. My position allowed me ample time to write and provided wonderful, supportive colleagues. I especially want to thank Rebecca Bordt, Angela Castaneda, and Nancy Davis for enriching my time at DePauw. The Sociology Department at Indiana University also provided financial assistance through the Stuart Simon Fellowship.

There are numerous professors who deserve accolades . First, I credit Katherine Rossier with sparking my interest in sociology when I was an undergraduate at Louisiana State University. I am forever indebted to Bernice Pescosolido and Brian Powell, who co-chaired not only my master's thesis but my dissertation. Bernices' expertise in medical sociology was invaluable for this project as was her support. The emotion work alone by Brian deserves unending praise, not to mention the detailed comments on drafts of chapters. Thank you for believing in me. My other committee members, Elizabeth Armstrong and Stephanie Kane were especially vital with the theoretical and methodological development of the dissertation.

I am grateful to my undergraduate research assistants, Stephanie Cecil, Meghan Meyers, Colleen Reilly, Tiffany Stephens, Valarie Taulman, and Sara Wright. Their hard work allowed me to analyze the data much sooner than if I would have been working alone. I must mention my dear colleagues Janice McCabe, Jenny Stuber, and Karen

Kaiser. Thank you for all of your help, support, and kindness over the years. I could not have done this without y'all.

Lastly, none of this would be possible without the love, support, and encouragement of my family. Mom, thank you for encouraging my love of reading as a child. I also need to thank my Mom, Dennis, and Patience for housing me (and Bruno) during data collection in Louisiana. My interest in health and medicine was influenced by my father and my research in Louisiana was also facilitated by him. My sister was always there to listen when I struggled. Of course, there is no way I could have done this without the love and very real, daily support of my wonderful partner, Mark. Finally, thank you baby boy, Asher, your sweet smile after a day of writing made me forget all my worries.

PREFACE

Media attention to Hepatitis C virus (HCV) has begun to increase over the last several years. HCV is a blood borne pathogen that can culminate in chronic and severe liver disease.¹ Only recently, *Newsweek* ran a cover story about the disease: “Hepatitis: The Insidious Spread of a Killer Virus” (Cowley 2002). Recent ads, paid for by Roche Pharmaceutical, show a man with a bruised face and the words, “If Hep C Was Attacking Your Face Instead of Your Liver, You’d Do Something About It.” HCV is often called the “silent killer” because of the asymptomatic nature of the disease and the public silence surrounding it. Many persons are unfamiliar with HCV although there are an estimated 5 million Americans infected with HCV (Erickson 2006).

Despite the lack of direct sociological inquiries regarding HCV, attention to health has a longstanding tradition within the discipline (Bird et al. 2000). Social scientists have shown the correlations between social and cultural factors and experiences with health and illness (Albrecht and Levy 1991; Bury 1991; Cockerham 2001; Kelly and Field 1996; Link and Phelan 1995). As the average life span has increased, so has the number of Americans living with chronic illness, leading to scholarly interest in illness experience (Albrecht and Levy 1991). A chronic illness can be defined as an illness that often does not have a severe acute onset, early symptoms may be difficult to recognize, the course of the illness is variable, and finally, the outcome of the illness is uncertain (Bury 2000). Sociologists have developed a rich body of research concerning illness experience with a wide variety of diseases including epilepsy, mental illness, HIV and cancer (Garmaz 1991; Fife and Wright 2000; Goffman 1961; Link 1987; Schneider and

¹ See Appendix 1 on page 26 for a detailed description of HCV.

Conrad 1983). Research on illness experience has generally focused on subjective meanings associated with illness including notions of stigma, coping actions including patients' interactions with others, and more recently, the effects of social structure on the illness experience (Pierret 2003). The bulk of this research focuses on well known chronic illnesses (see Joachim and Acorn 2000 as an exception).

Although HCV is not rare in prevalence, it is relatively unknown to the public and unexamined in medical sociology. The focus on HCV offers a unique window into lay response to illness that does not have cultural spotlight characteristics of diseases such as cancer, HIV/AIDS, and depression. In essence, I assess the efficacy of applying current understandings of chronic illness experience to an illness lacking in cultural imagery. It is unclear based on prior research whether the existing discourse on chronic illness experience is sufficient to explain the experiences of individuals living with a potentially stigmatized illness that is culturally shrouded. I specifically discuss how persons with HCV navigate their illness careers including their disclosure practices, reactions from others, and the meanings they give to their experiences.

More broadly, I explore how social structure affects micro-level processes and interactions. No studies have specifically examined the effects of race, class, and gender and how these dynamics affect the experience of having HCV. Thus, this research addresses how a culturally invisible chronic illness is experienced with attention to locating individuals within the broader social structure. Chronic illness is just one major life-changing event that individuals may experience in their lifetime. The emergent research concepts apply to processes individuals undergo in an array of life-changing events. This study adds to the existing discourse on stigma and how social structure

affects stigma. My research strengthens social psychological understandings of how issues of race and ethnicity affect meaning making processes. Thus, while my dissertation clearly speaks to the sub-areas of medical sociology and deviance, the study also contributes to knowledge about stratification, in terms of how inequality is distributed and how public discourse or lack thereof affects experiences of illness.

In the following chapters, I present the existing literature regarding illness experience, my methodological approach, my analyses and conclude with final thoughts. In Chapter 1, I detail what is known regarding the illness career. I outline what is known about biographical disruption experienced with chronic illness. Chapter 1 addresses the literature about disclosure and stigmatization. The pertinence of race, class, and gender to illness experience is highlighted. I also include a discussion of what is missing in existing discourse, and how HCV can extend our current conceptualization of illness experience. In Chapter 2, I describe my methodology of in-depth interviewing. This chapter addresses experiences at the recruitment sites, the interview experience, and the respondents. I also explain my approach to data analysis including the incorporation of undergraduate research assistants and qualitative data analysis software. The chapter addresses reflexivity with regards to various aspects of the research process, ethical issues in the research, and study limitations.

In Chapters 3, 4, and 5, I present analyses of the data. Each chapter incorporates data analysis and the relationship to existing theory and literature. Chapter 3 addresses issues of disclosure. Respondents offered a variety of reasons for disclosing health status and for not disclosing. The reasons were either because of a concern for others or a concern for self. People had different levels of disclosure, which are related to

race/ethnicity as well as other factors. After the discussion of disclosure, I turn to the reactions from others in Chapter 4. People did engage in deprecatory self-labeling or felt stigma. Some respondents did report acts of enacted stigma, while others were unaware that HCV was stigmatized. Again, race/ethnicity is related to stigmatization. People also had no reactions to disclosure of their health status and positive reactions which involved various kinds of support. Respondents devised a variety of ways to cope with stigma including information control, condemning the condemners and collective action. Chapter 5 examines the diagnostic experience and respondents' reactions. People had various levels of knowledge of HCV which were stratified by race/ethnicity. Respondents made sense of having HCV through abstract conceptualizations of their illness, HIV/AIDS discourse and through faith.

Chapter 6 summarizes patterns in the data and offers concluding thoughts. The global theme of race/ethnicity and inequality is discussed with attention to theoretical and empirical research. I conclude with a discussion of the contributions of this research to sociological discourse along with suggestions for future research.

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“So How Did You Get That?”: Experiences of Individuals Living with
Hepatitis C Virus (HCV)

Living with a chronic illness is challenging at both the individual and societal levels. How do individuals with Hepatitis C Virus (HCV), a culturally invisible disease, experience their illness? This dissertation examines the illness careers of 53 men and women with HCV through in-depth interviews. I explore how individuals experience their illness through an extension of the concept of biographical disruption. This concept is further developed by incorporating disclosure patterns of health status and experiences with stigmatization. This research addresses how people make sense of their illness on an individual level while still locating individuals within the larger social structure. Three main findings emerge from this study. First, individuals disclose their health status at various levels with some people practicing quite open disclosure and others maintaining a veil of secrecy. Whites disclose their HCV status more openly than do racial or ethnic minorities. Reasons for revealing or hiding their illness are couched in terms of concern for others or a concern for self. Second, not all persons with HCV believe that there is any stigma associated with the disease or have experienced any stigmatization. Again, race plays a role with Whites reporting more experiences with stigmatization. Individuals employ numerous coping mechanisms to deal with stigmatization. People with HCV do experience other reactions to disclosure besides stigmatization including social support from family, friends, and in the workplace. Third, persons with HCV make sense of having the disease through a variety of processes.

Experiences with diagnosis are diverse including respondents' initial reactions. Knowledge about the disease is stratified along racial lines but not by social class or gender with Whites having more accurate information about HCV. Over half of the sample turned to HIV/AIDS discourse to give meaning to their illness because of the lack of available imagery on HCV. Persons conceptualize their illness in different fashions with some relying on their faith to cope. These findings underscore how race shapes the illness experience of persons with HCV and propose ways to eliminate further inequalities.

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CHAPTER 1: CHRONIC ILLNESS EXPERIENCE AND HCV

Biographical disruption involves the combined effects of disabling symptoms and the cultural imagery surrounding chronic illness (Bury 2000). It entails three features. First, the onset and problem of recognition of the disease is a disturbance in individuals' lives (Bury 1982). Secondly, persons may experience uncertainty regarding not only their health, but their sense of self. Thirdly, biographical disruption involves mobilizing resources to deal with the illness.

To extend our understanding of biographical disruption, I focus on individuals with Hepatitis C virus (HCV).² This research broadens the concept of biographical disruption by including disclosure patterns and reactions to disclosure. Individuals with chronic illness must decide whether to disclose their health status. Choosing whom to tell, when and why, has consequences, including possible stigmatization. Disclosure may also affect notions of self and interactions with others. HCV provides an interesting case as it is not like other illnesses that have ample cultural imagery (Bury 1982).

In this chapter, I address existing theoretical and empirical literature regarding disclosure patterns, stigmatization, and sociological conceptions of illness. The discussion is organized in line with how people with HCV experience their illness. People make decisions regarding disclosure and experience reactions to their disclosures. These behaviors and interactions affect how they conceptualize their illness. Illness experience can also be shaped by race, class, and gender.

² See Appendix 1 on page 26 for a detailed description of HCV.

DISCLOSURE

Similar to HIV, HCV is an unpredictable disease in terms of long-term consequences and fluctuations in active symptoms. HIV positive individuals must gain a sense of control over their lives to overcome feelings of uncertainty, although some choose uncertainty over a bleak reality (Weitz 1989). This uncertainty may also be a defining characteristic of persons with HCV. Persons may choose to live in secrecy rather than face their illness. Some research has found that persons with HCV are reluctant to disclose because of fear of discrimination (Glacken et al. 2001). Part of this secrecy may manifest itself through lack of disclosure to others, yet secrecy often leads to more stress and negative effects on health (Paxton 2002). Thus, the individual is faced with the dilemma: to tell or not to tell. To not tell may result in strained social interactions and demoralization. However, to disclose may result in actual rejection.

Persons disclose their illness status for a variety of reasons. Preventive telling is one way to thwart a potential rejection once the illness is known about. Passing and withdrawal may become too difficult or impossible because of the physiological manifestation of the illness. Tewksbury and McGaughey (1997) discuss how the stage of HIV affects the management of stigma. Persons in the early stages of the disease often pass as healthy by using selective disclosure (Tewksbury and McGaughey 1997). Individuals with HCV may not have to employ selective disclosure because of the lack of cultural knowledge about the disease. Conversely, HCV positive individuals may be less likely to embrace the identity of being HCV positive because of these same reasons. Persons with HIV who embrace their identity often feel a sense of purpose, an option

which may not be viable for HCV positive individuals (Tewksbury and McGaughey 1997).

Lee and Craft (2002) argue that disclosure is centered on one theme: maintaining pre-existing relationships and identities. They found that persons with genital herpes disclosed to persons who they felt already accepted them. Persons revealed their status when the nature of the relationship demanded disclosure. The need to self-verify personal identities supersedes the fear of rejection in some situations (Lee and Craft 2002). By disclosing, individuals can reject public definitions of the illness and further validate their self-identities (Lee and Craft 2002). Others discuss how individuals sometimes disclose for seemingly unapparent reasons (Kelly 1991). Kelly (1991) found that persons sometimes revealed their health status to gain sympathy, explain unsatisfactory role performance, to manipulate others, and to get attention. These disclosures, however, may lead to social ridicule and rejection as others tire of persons occupying the sick role, especially once well (Kelly 1991).

Medical personnel may indeed fall into the category of persons or relationships described above, where the nature of the relationship demands disclosure. Healthcare workers know more about HCV than the general public. It is important to inquire into acts of disclosure with a group of individuals (medical personnel) who are familiar with HCV. An extensive body of research has documented the stigmatization of HIV patients by physicians (Brown et al. 2003; Kelly et al. 1987). Some research on HCV also finds stigmatization of HCV patients in healthcare settings (Zickmund et al. 2003).

It is unclear how the existing discourse concerning disclosure will apply to a disease without the same cultural visibility. Thus, this research examines several issues

regarding disclosure: *What motivates people with HCV to disclose? What reasons do persons with HCV give for not disclosing? What affects disclosure practices for persons with HCV?*

STIGMA AND LABELING THEORY

Goffman's (1963) classic work on stigma has had tremendous impact on numerous areas within sociology. The stigma concept grew out of a symbolic interactionist approach and was embraced by those advocating labeling theory and more recently, modified labeling theory (Best 2004; Link 1987). Labeling theory generally proposes that persons who experience a negative social reaction to their behavior and/or identities will experience numerous obstacles in society and may further accept their deviant label, leading to secondary deviance, that is deviance that follows from accepting the deviant label (Becker 1963; Lemert 1962). Labeling theorists were generally concerned with power dynamics, in terms of who was defining behavior as deviant (Best 2004). Critics have argued that labeling theory is a passive process whereby persons simply accept and embrace a negative label attached to them by more powerful others (Glassner 1982; Gove 1980).

While labeling theory lost eminence in studies of deviance and crime, modified labeling theory emerged within medical sociology as a fruitful theoretical approach (Best 2004). Modified labeling theory offers a more complex portrayal of individual reaction to labeling that allows for agency and negotiation (Lee and Craft 2002). Link (1987) discusses how persons have expectations of what it means to be a mental patient. Upon diagnosis, persons must then reevaluate these expectations as now they apply on a more personal level (Link 1987). Persons may engage in what is called *felt stigma* defined by

Jacoby (1994) as, “Shame associated (with being epileptic) and the fear of enacted stigma” (270). Expectations of rejection may actually elicit a negative reaction through strained social interactions (Link 1987). Individuals who are especially likely to label themselves as stigmatized are those who feel they have not lived up to some type of societal expectation or norms in which they believe (Greil 1991). People who feel stigmatized may be hurt by comments made by people who do not even know about their illness status nor are referring to the particular illness (Greil 1991). Some researchers argue that felt stigma is more damaging than enacted stigma (Greil 1991; Scambler and Hopkins 1990).

Numerous social scientists have examined the relationship between stigma and disease (Brown et al. 2003; Conrad and Schneider 1992; Goffman 1963; Kelly et al. 1987; Link and Phelan 2001). For this research, Link and Phelan’s (2001) definition of stigma will be used: “Stigma exists when elements of labeling, stereotyping, separation, status loss, and discrimination occur together in a power situation that allows them” (Link and Phelan 2001). Stigma decreases individual’s life chance in a diverse array of areas including housing, employment, health, and quality of life itself (Link and Phelan 2001). Persons may experience social rejection, social isolation, and a negative sense of self (Fife and Wright 2000). These factors have been studied in relation to a variety of diseases (especially mental illnesses), but diseases that are all generally *known* to the public (AIDS, cancer, tuberculosis, herpes). Few studies examine rare or more invisible diseases and the relationship with stigma (Joachim and Acorn 2003) .

Many chronic illnesses are what Goffman (1963) calls discreditable stigmas; they are not immediately apparent in interactions and the individual must therefore

manage information. Some ways to cope with stigma are passing, withdrawal, and preventive telling (Lee and Craft 2002). Passing simply means concealing information about one's stigma. Passing may become problematic for the individual in that they may learn to identify with the persons who make disparaging remarks about those with the stigma they possess, which could lead to self-deprecation (Goffman 1963). This may be less likely with HCV because of the state of public discourse surrounding the illness. On the other hand, people may simply feel it is unnecessary to reveal their illness status to others when the roles involved in those relationships are unrelated to their illness identity (Lee and Craft 2002)

Withdrawal involves putting physical or social distance between those who are "wise" to the stigma and the "unwise" (Goffman 1963). Managing the worlds of those who know and do not know may become onerous. Finally, individuals often may begin to disclose at a more frequent rate, depending on the stage of their illness career (Lee and Craft 2002). Persons may choose to not discuss having HCV because of the ambiguity surrounding the disease in the general public. With preventive telling, individuals with HCV may attempt to deal with others' fear (of a virus they do not know) and also to educate others. How the individual constructs the disease to others will undoubtedly have an effect on other's reactions.

STIGMA AND HCV

Yet, it remains to be seen what kind of reactions persons with HCV receive from others in light of the current public discourse about the disease. Persons with HCV may *not* be stigmatized based on the aforementioned definition. The supposition that HCV is a stigmatized disease is feasible considering the linkage to intravenous drug use. In fact,

the disease is often thought of as the 'junkie's disease' (Krug and Hepworth 1999). Certainly, diseases that are seen as linked to behavior and in some ways preventable are often highly stigmatized (Schulte 2002). Vietnamese immigrants in the 1970's experienced discrimination in housing and schooling when the high prevalence of Hepatitis B in this population was discovered (Gilmore and Somerville 1994). Thus, stigma associated with other types of Hepatitis may affect beliefs about HCV. However, it is important to locate the actual state of public discourse concerning HCV as the discussion of stigma is predicated on there being cultural imagery available.

Knowledge concerning hepatitis and the liver is poor in the United States. According to the American Liver Foundation, more than 1 in 4 U.S. adults did not know the liver was the primary organ affected by hepatitis (Orr 2006). In addition, the vast majority of U.S. adults erroneously believe that alcohol abuse is the leading cause of liver disease (Orr 2006). The American Gastroenterological Association commissioned an online survey conducted during 2003 as part of the "Be Hep C S.M.A.R.T." (Shattering Myths and Reinforcing Truths) campaign (AGA 2003).³ Findings reflect the lack of knowledge among the general public. Slightly more than half of the general public believes HCV is a serious health threat compared to the vast majority of HCV sufferers, specialists, and primary care physicians (AGA 2003). Less than half of those surveyed are familiar or very familiar with HCV although more than half know that HCV can result in liver damage. Nearly one in three persons thinks that HCV can be spread through fecal contaminated food or water and does not know that HCV can be spread

³ The sample was 1229 members of the public not infected with HCV, 493 HCV sufferers, 198 primary care physicians (PCP), and 217 specialists (gastroenterologists and hepatologists). The sample was weighted by age, sex, race, education, and number of adults in household to reflect actual proportions in the population, although it was not a probability sample AGA. 2003. "Stigma of Hepatitis C Stops Americans from Getting Tested." Bethesda, MD: American Gastroenterological Association..

through any contact with infected blood (AGA 2003). One in five Americans thinks there is a vaccine for HCV (as do 15% of HCV sufferers). Approximately one third of Americans are unaware that there are prescription treatments for HCV (less than 1 in 5 persons with HCV are unaware of this.) Finally, 38% of the public is unsure about any of the symptoms of HCV(AGA 2003).

Evaluating levels of knowledge concerning HCV among intravenous drug users (IDUs) is a further reflection of public awareness as IDUs are at such high risks for infection and would presumably have more awareness. Heimer and colleagues (2002) studied 493 IDUs in inner city neighborhoods in Chicago, IL, Hartford, CT, and Oakland, CA to assess HIV and hepatitis knowledge, in addition to injection related risk factors.⁴ The hepatitis knowledge addressed awareness of both HBV and HCV.

Overall, there was significant difference between hepatitis knowledge and HIV knowledge (Heimer et al. 2002). Respondents were almost three times more likely to answer, “don’t know” to items in the hepatitis scale compared to HIV. Less than half of the sample knew there was no vaccine for HCV and could correctly answer items concerning the transmission of hepatitis through dried blood. About half of the sample knew that persons with hepatitis could be recognized by disease symptoms. Finally, half of the respondents “correctly” knew that there is no cure for HCV (Heimer et al. 2002: 1282).⁵ Factors predicting awareness of hepatitis included a history of HBV or HCV, HBV vaccinations, or having been in drug treatment (Heimer et al. 2002).

⁴ The sample consisted of both males and females with a mean age of 41 and had similar levels of education, income, and drug use histories. Over ¾ of the sample was either African-American or Hispanic. In addition, over ¾ had been in a substance abuse program at some time and over half described their health as fair or poor. In short, these were not young neophytes, but chronic IDUs.

⁵ These researchers state that respondents, “...knew correctly that there is no cure for hepatitis C” (Heimer et al. 2002: 1282). However, others, including most specialists, disagree that HCV cannot be cured (AGA 2003).

Heimer and colleagues (2002) research suggests that IDUs obtain information about hepatitis from various types of healthcare facilities. Because this population and other non-drug using low income and minority groups have lower rates of healthcare utilization, their potential for hepatitis knowledge may be less than other groups who have more interactions with healthcare workers. However, only slightly more than half of primary care physicians ask their patients about risk factors and only 3% include testing for HCV as part of standard check-ups (AGA 2003). Thus, those with greater health care access, who are less at risk for HCV, are not necessarily getting information either.

In direct relation to HCV and stigma, almost 1 in 3 of the non-infected public believes that HCV mostly affects drug addicts and others with unhealthy lifestyles (AGA 2003). However, individuals may engage in a process of “imaginative rehearsal” of how others may respond to them (Link 1987). Persons with HCV may be aware of the stereotypes and sentiments associated with persons with HIV/AIDS. For example, some researchers have found that 1 in 5 Americans believe that persons who got AIDS through sex or drug use “have gotten what they deserve” (Herek et al. 2002). Likewise, Herek and colleagues (2002) report that nearly half of Americans agreed that persons with AIDS are responsible for their illness. Individuals with HCV, especially those with a history of drug use, may fear similar reactions if their illness was revealed to others thus experiencing felt stigma (Brown et al. 2003). The AGA suggests that HCV is simply not as stigmatized as sufferers might think. Another explanation for the discrepancy in what sufferers versus the public believe could simply be the lack of correct information about HCV among the public. In other words, if the public properly understood HCV, they

might indeed have a more stigmatized view of both the disease and people infected with it.

Based on the preceding discussion, this research addresses the following points:

What do people know about HCV prior to diagnosis? Do they think HCV is a stigmatized disease? Do people engage in felt stigma? Do persons experience enacted stigma? How do they cope with the fear of stigmatization and/or experiences with stigmatization?

SOCIAL SUPPORT

There exists a strong link between social relationships and health and morbidity (Turner and Marino 1994). Persons with strong social support experience less depression, cope better with stressful life events and have lower rates of overall morbidity (Ross and Mirowsky 1989; Wethington and Kessler 1986). Individuals who have strained social relationships report worse physical health (Marmot 1998). Evaluating the relational content is especially relevant when trying to understand how persons experience a chronic illness, as they often need practical help.

Through disclosing health status an individual can access direct social support from others. Upon disclosure, if the persons have a negative affect towards HCV as some do towards HIV, the afflicted individual may receive little to no social support (Brown et al. 2003). Mobilization of resources is an aspect of biographical disruption according to Bury (1982). Being involved in religious activities or organizations may serve as one resource (House et al. 1988). The presence of symptoms and stage of the illness may affect the ability to access resources. Garnering resources and actions people take to minimize effects of illness are referred to as their strategy (Bury 1991). Strategies change over time and by context. People may exploit the enactment of the

“sick role” and lose social support especially if they have had success with treatments or surgeries (Bury 1991). However, accessing social support is not restricted to either negative or positive reactions from others. Bury (1982) points out that persons may diminish their interactions with others because of actual physical limitations, embarrassment, or fear about limitations. Indeed, withdrawal from social situations and social isolation are features of chronic illness.

In order to evaluate social support for persons with HCV, this research asks: *Do people with HCV receive social support as a result of disclosure? What affects the likelihood of receiving support?*

SOCIOLOGICAL CONCEPTIONS OF ILLNESS

COPING

Persons with chronic illness often develop an illness concept. An illness concept is “understood to comprise interpretations, explanations, and predictions with regard to one’s health status” (Schussler 1992). Individual’s illness concepts and subsequent illness accounts will affect their levels and use of social support (Schussler 1992). Schussler (1992) found that illness concepts, as well as a feeling of internal versus external control over illness, are related to ability to cope with illness. Bury defines coping as “the processes whereby the individual learns *how* to tolerate or *put up* with the effects of illness” (Bury 1991) Persons who see their illness as a challenge or something of value and who feel like they have some control over their illness tend to cope more favorably with their illness as well as have less depression (Schussler 1992). Whites, those with higher levels of education, younger people and non-Catholics are more likely to feel in control of their lives (Ross and Mirowsky 1989). Persons who conceptualize

their illness as an enemy, punishment, or as relief are more likely to cope less effectively and more likely to experience depression (Schussler 1992). Finally, there is an association between complete denial of illness status or lack of any denial and experience with symptoms (Schussler 1992).

Two ways to approach the meaning of illness are a problems or consequences approach and meaning as significance approach (Bury 2000). Research using a problems approach investigates patients' difficulty or ease dealing with practical and material problems, including disruptive symptoms, treatment regimens, family, work, and daily activities (Bury 1991; Bury 2000). However, the meaning of illness as significance is directly related to the previous approach. Having a chronic illness inevitably affects the physical body in a variety of ways, be it physical appearance or performance, thus affecting personal identity (Bury 2000; Kelly and Field 1996). The significance is also related to the connotations associated with the illness or symptoms. The significance of illness is not static and changes with the life course. Context is important in understanding how persons give meaning to their illness.

Despite the lack of discourse concerning HCV, persons with HCV will eventually have to make sense of the illness both to themselves and to others. Bury (1991) employs the concept of style that refers to presentation of self or the performance aspects of illness. A person's style refers to how they respond to and present features of their illness and treatment. Style is affected by beliefs about the self and the body (Bury 1991).

Individuals offer accounts about their health status, meaning that people actively construct their views about illness and health in relation to their own unique position in the world (Popay et al. 1998; Radley and Billig 1996). An account, in the original

conception by Scott and Lyman, is defined as “a statement made by a social actor to explain unanticipated or untoward behavior” (Scott and Lyman 1968). While the concept of an account used to be limited to explaining deviance, it has been expanded to incorporate more social phenomenon. Williams (1984) describes a similar phenomenon as narrative reconstruction. Narrative reconstructions are “attempts to account for and repair breaks in the social order” (Williams 1984). Kelly (1991) conceptualizes accounts as “vocabularies of motive or coping” (122). Any time a person offers a health account, they are constructing their illness through interactions with another. Thus, persons’ illness accounts are not static and the accounts given to others may actually change depending on who they are interacting with and their reaction. An account is simply the *telling* of the illness concept.

People often feel the need to legitimize their situation through the accounts or reconstructions given. Thus, the accounts of persons with HCV may be especially interesting as they may be educating others about the disease through their account. Their discussion of the disease may be more or less accurate in order to protect perhaps the other’s reaction to the illness, lest it be stigmatizing. The larger, structural consequences of these educational interactions may have disastrous consequences if misinformation is continuously given in acts of disclosure.

Several questions emerge regarding coping and HCV: *How do people with HCV conceptualize their illness? What factors influence style? Do people vary their illness accounts for different audiences?*

DIAGNOSIS, UNCERTAINTY, AND KNOWLEDGE

In regards to HCV, persons may experience symptoms before they are aware of their infection. Or in contrast, persons may feel perfectly fine and suddenly be diagnosed with HCV. Biographical disruption begins, according to Bury (1982), as soon as a person experiences symptoms, seeks help and/or is diagnosed with HCV.

The process of diagnosis is crucial in understanding how persons first reacted to their disease. People's experiences of illness are shaped by their interactions with their doctors (and others) as well as influenced by race, class, and gender (Brown 1995). Individuals with HCV are especially vulnerable to being affected by the actual diagnostic experience, as this may be the first time they have even heard of the disease. Persons with HCV most likely do not have any expectations or understandings about what it means to have HCV and thus do not have a readily available conception of what their experience means.

Another aspect of biographical disruption involves the emerging disability and problem of uncertainty (Bury 1982). While some sociologists discuss the labeling of illness as problematic, Bury (1982) argues that the diagnosis can be a relief for individuals in that their symptoms are legitimized and that medical intervention becomes available. In addition, patients may conceptualize disease as an outside force, yet still have the contrary experience of having the illness infiltrate their lives. Not all persons with HCV experience active symptoms and even for those who have experienced symptoms, there may be times when they have no symptoms. Actual physical experiences of symptoms affects how individuals conceptualize the disease (Albrecht and Levy 1991). The course of the illness will also impact how an individual conceptualizes

the illness over time (Bury 1991). Experiences with intensive treatment regimens is disruptive to previous activities and social roles and leads to the illness as a master status (Greil 1991). Thus persons who have undergone treatment for HCV may be more likely to incorporate having HCV into their identity.

The problem of uncertainty involves the unpredictable course of the illness and also medical discourse. Younger persons with milder symptoms are often more interested in instrumental styles of intervention and for information about tests and treatments (Bury 1991). Older patients with more severe symptoms are more concerned about the broader implications of their illness and how to communicate these concerns with physicians (Bury 1991). Chronically ill people realize medical knowledge is limited and often combine medical knowledge with their own biographical experiences. Bury notes that, “moral concerns and scientific-based knowledge overlap” (Bury 1982). Thus, persons do not passively accept expert knowledge, but reinterpret this knowledge along with lay experience. Chronically ill individuals often explain causation through reference to the self, the body, and society (Williams 1984). Thus instead of persons being disillusioned with medical knowledge, they appropriate it. Medicine can be both a relief and a constraint in making sense of illness.

The lack of cultural imagery about HCV leads to several questions regarding diagnosis, uncertainty, and knowledge: *How do people with HCV come to be diagnosed? What are their reactions to diagnosis? Do people with HCV experience uncertainty? What do people with HCV know about their disease? What are the implications of their knowledge about HCV?*

RACE, CLASS, AND GENDER AS MEDIATORS OF ILLNESS EXPERIENCE

The previous discussion focused on various aspects of illness experience. When studying illness experience, however, it is crucial to situate individuals within the larger social structure. In order to understand different persons' experience with HCV, there must be an appreciation of individuals' position in society.

IMPORTANCE OF STUDYING RACE, CLASS, GENDER AND HCV

Attention to race, class, and gender is especially important as medical researchers have noted differences by race and gender in rates of chronic HCV and responsiveness to treatment. Blacks have disproportionately high rates of HCV compared to Whites in the US with Blacks accounting for 22% of the HCV population (Alter et al. 1998; Palmer 2006). The disease progresses more quickly in men and among Blacks (Palmer 2006; Reddy 2002). In terms of treatment, women and Whites in general respond better to treatment (Reddy 2002). Blacks, however, are less likely to receive treatment once diagnosed (Palmer 2006). Blacks with HCV have a slightly higher history of intravenous drug use (36%) compared to Whites (28%) and Hispanics (23%) which may affect experience with the illness (Lepe et al. 2006). Thus, the need to investigate the actual *social* experiences is paramount to understand these differences by socio-demographics.

Of course, race, class, and gender are not homogenous categories. Indeed, there will be variation within and across each group and overlapping influences based on race and class, for example, on gender. My intention is not to reify these categories, but to explore how these social statuses do and do not affect lived experiences with HCV, all the while realizing the varied and intricate embodiment of these categories.

Researchers should not assume that having HCV is especially salient for all persons or that this unifies these persons as a group. Some researchers criticize much existing research on stigma and disease as being too individualistic and overly simplistic in the quest for causality (Link and Phelan 2001; Parker and Aggleton 2003). The danger in these typical conceptualizations lies in the outcomes for intervention as being too narrowly focused and not addressing the larger processes of stratification, as is much of the research on AIDS stigma. For example, in a review of interventions to address AIDS stigma, Brown and colleagues (2003) suggest that contact with people living with HIV/AIDS (PLHA) appears to be the best approach currently. However, none of the reviewed studies evaluate how PLHA are also stigmatized or not based on race, class, and gender and not just their health status. Thus, the proposed interventions also ignore the larger implications of social stratification. In other words, the experience of having HCV will be mediated by an individual's status and the associated benefits or costs of those statuses. By addressing these structural effects and their manifestation on an individual level, subsequent interventions in prevention methods or care of HCV individuals may be attuned to these dimensions.

RACE, ETHNICITY AND HEALTH

The relationship between race/ethnicity and health has been well established by numerous researchers (Krieger 2000). Rates of infant mortality, for example, vary greatly for Black versus White Americans (LaVeist 1993) Blacks have an infant mortality rate roughly twice that of Whites in the US although this varies dramatically by city (LaVeist 1993). Native Americans and some Hispanic groups also have higher infant mortality rates (Smaje 2000). Black Americans are more likely to suffer heart

problems and high blood pressure than White Americans (Krieger and Bassett 1986). Mortality rates are higher in general for Blacks than Whites in the US and Hispanics in younger age groups also have higher mortality rates (Smaje 2000).

Historically, these differences were explained through a genetic model, while more recently, most researchers recognize the socially constructed nature of race and ethnicity (Krieger 2000). Some have argued that researchers should stop studying race and ethnicity as it reifies difference and is a socially constructed and unscientific category (Stolley 1999). Of course, many concepts studied by sociologists are socially constructed and others argue that race and ethnicity will not stop affecting health just because they are not studied (Krieger 2000). Race and ethnicity affect lived experiences as they are schemas for orienting individuals in the social world (Smaje 2000).

In addition, race and ethnicity cannot be reduced solely to social class, as morbidity and mortality rates cut across class lines in terms of race and ethnicity as discrimination affects all minority persons (Krieger 2000) (although this is contested, see (Robert and House 2000; Smaje 2000)). There is an interaction with race and class in that among poor people, Blacks and Hispanics are considerably more likely to live in high poverty areas (Robert and House 2000). Other facets of race/ethnicity that impact health are lifestyle and social capital (Smaje 2000). Lifestyle factors include levels of exercise, diet, smoking, alcohol and drug usage, and high risk sexual or leisure activities (Smaje 2000). Of course, community context affects the ability to engage or not in lifestyle choices. Social capital refers to coping resources, such as social networks for social support and community institutions (Smaje 2000). Different racial and ethnic groups have varying norms about familial support and collective action. Race/ethnicity may affect

health care utilization rates although see Schnittker, Pescosido, and Croghan (2005) (Smaje 2000). Blacks are less likely to receive preventative care and are more likely to report low levels of satisfaction with health services (Smaje 2000). Finally, race and ethnicity have been found to affect the management of stigma for HIV positive individuals (Tewksbury and McGaughey 1997).

This research thus addresses the following issues regarding race/ethnicity and illness experience with HCV: *Does race/ethnicity affect disclosure patterns? Does race/ethnicity influence reactions to disclosures, including stigmatization? Are coping patterns or knowledge about HCV impacted by race/ethnicity?*

SOCIAL CLASS AND HEALTH

There are health disparities independent of race based on social status (Marmot 1998; Mirowsky et al. 2000; Robert and House 2000). This disparity does not just apply to those in lower socioeconomic groups, but applies across the hierarchy, although there are diminishing returns in higher socioeconomic groups (Marmot 1998; Robert and House 2000). Mirowsky and colleagues (2000) see social status as being composed of education levels, work status, occupational prestige and economic status. They argue these components cannot be reduced to one measure but should be evaluated and analyzed independently (Mirowsky et al. 2000). It is clear that persons with lower education, lower income, lower status occupations, and less wealth have higher rates of morbidity and mortality (Marmot 1998; Mirowsky et al. 2000; Robert and House 2000). Socioeconomic status has a large effect on health for infants, less of an effect for adolescents, a slightly larger effect for younger adults increasing through adulthood and then again dropping in old age (Marmot 1998; Robert and House 2000). Access to

medical care may help explain some of the differences although this is debated within the field (Robert and House 2000).

Marmot and colleagues (1998) found that education levels predicted health based on a multi-level measurement. Education, like socio-economic status, has a gradient effect on health (Marmot 1998). Education is also related to lifestyle factors with the more highly educated engaging in more healthy behaviors such as exercise and good diet habits (Mirowsky et al. 2000). Educated individuals are less likely to be unemployed, they are more likely to work full-time, more likely to be autonomous at work, have higher incomes, feel more in control of their lives, and have higher levels of social support (Mirowsky et al. 2000).

Employment affects health in that the unemployed experience higher rates of morbidity and mortality (Mirowsky et al. 2000). Work conditions, such as less controlling environments and more rewarding work, are related to health (Mirowsky et al. 2000). Bury (1982) discusses how social class and occupation affect the ability to compensate for disability through resources acquisition. Higher prestige jobs are more flexible and persons can easily take time off to keep medical appointments or to attend to symptoms of their illness (Anderson 1991). In addition, the way that people conceptualize and talk about their illness and bodies may be affected by employment and work conditions. Anderson (1991) reports how middle class women were able to adapt their work experiences to manage their illness, while working-class women could not. Income literally affects the ability to engage in prescribed self-care in that some persons simply do not have the financial resources either to purchase necessary medical equipment or for transportation to and from medical appointments (Anderson 1991).

Bury (1991) notes how class affects style in that middle class people conceptualize the body and the self in more abstract terms, while working class define the body more in pragmatic terms. Blair (1993) also found that working class persons described how they felt more in terms of physically located experiences compared to middle class who discussed mental states more (Blair 1993). Middle class respondents in Blair's study (1993) were generally more verbally engaged. Smaje (2000) also notes that racial minorities may define health in more functional terms and with attention to effects on day-to-day life, rather than biologically. Although, Anderson (1991) found that what appeared to be ethnic differences in illness experience were in fact class differences (Anderson 1991).

A sense of control may be one of the strongest effects of social status on health (Mirowsky et al. 2000). As previously mentioned, a sense of control is related to illness concept. Those with higher education, better employment conditions, and good economic status feel more in control of their lives (Mirowsky et al. 2000). Education fosters not only a sense of control, but helps foster sharpened analytic and problem solving skills. Middle class individuals, who conceptualize their experiences more so in terms of mental rather than physical states and solutions, feel more in control (Blair 1993).

Thus, those with higher social statuses have more resources to gain information concerning illness. Middle and upper class individuals are more likely to seek out a more complex understanding of the disease from their physician, while the lower class patients may ask fewer questions (Anderson 1991). Lareau (2003) has found that lower class individuals have a decidedly different interaction style in institutional settings including

interactions with physicians. This may be in part from a lack of sense of control of one's life whereby one is less motivated to actively try to solve problems (Mirowsky et al. 2000). Middle class persons often ask more questions and feel more of a sense of entitlement to appropriate care (Anderson 1991; Lareau 2003). In addition, some individuals may be more adept at appropriating medical knowledge and jargon. Arksey (1994) discusses how sufferers of Repetitive Strain Injury (RSI) become familiar with different theories of causation and treatment for their illness. However, she does not discuss whether the access and acquisition of this knowledge is equally distributed across sufferers (Arksey 1994).

Social class and illness experience with HCV are examined along several dimensions: *Are disclosure patterns affected by social class? Is there a relationship between social class and reactions to disclosure or experiences with stigmatization? Does social class influence coping patterns or knowledge about HCV?*

GENDER AND HEALTH

Gender also has profound effects on health. While men have higher mortality rates and rates of chronic conditions, women have higher morbidity rates especially acute conditions (Rieker and Bird 2000; Verbrugge 1989). This difference can partially be explained by biological differences between men and women but also through social and cultural factors (Lane and Cibula 2000; Rieker and Bird 2000) Women visit doctors more, have more disability days than men, and use prescription and non-prescription drugs more (Rieker and Bird 2000; Verbrugge 1989). Race interacts with gender in numerous ways in effects on health (Rieker and Bird 2000). Non-white women report worse physical health than white women, although this pattern of self-reported health

differences is not seen in men (Marmot 1998). Some explanations for higher morbidity risk for women are their lower levels of paid employment, more emotional stress, feeling more vulnerable to illness, fewer time constraints, and less physical activity than men (Verbrugge 1989). Men's mortality is partially linked to male engagement in high-risk behaviors such types of work and leisure activity (Lane and Cibula 2000). Men are also more likely to drink and use illicit drugs (Lane and Cibula 2000; Rieker and Bird 2000). In terms of distress and psychological health, women are more likely to experience depression and men to have substance abuse problems (Rieker and Bird 2000).

For some aspects of HCV, biological factors related to sex may be affecting health outcomes. However, in terms of dealing with the illness, the social aspects of gender are monumental in explaining the illness experience. Bury (1991) notes how gender may affect the coping process as women may worry more about their illness. Illness accounts may be affected by beliefs about gender in terms of explaining not being in the workforce or having to be cared for by others (Radley and Billig 1996).

Illness experience with HCV may be especially affected by gender even more so if the assumed mode of transmission is from IV drug usage. Women, in general, are often seen as deviant simply for not being men (Schur 1984). Drug use is seen as deviant for both men and women, however, as women are all ready devalued, female drug addicts are "double deviants". Women who contracted HCV through drug use may be even more condemned for violating traditional gender norms concerning substance use. Apart from drug use, women and men, in general, who violate gender norms are labeled as deviant (Schur 1984). Thus, men and women who cannot perform roles associated with their gender because of their illness (such as wage earning or child care)

may experience heightened stigmatization. Other researchers have found that management of stigma for HIV positive individuals is affected by route of transmission, race, gender, and sexual orientation of the individual (Tewksbury and McGaughey 1997) (although see Lee 2002 for an exception). Of course, labeling from others may lead to integration of these ideas into their illness account.

Gender, especially in conjunction with assumed mode of transmission, may also have an affect on level of social support received from others (although see (Thoits 1995). Some have reported that HIV positive men have more social support than HIV positive women especially if the women contracted the virus through drug use (Lichtenstein et al. 2002). Women often are providers of social support to family and friends and may have difficulty receiving social support (Anderson 1991). However, women are more likely to join support groups than men (Rieker and Bird 2000).

Research on gender and health leads to several issues regarding gender and illness experience with HCV: *Do women disclose more or less than men? Are reactions to disclosure or experiences with stigmatization different for men and women? Do women cope with HCV more or less effectively than men? Do women have more knowledge about HCV?*

CONCLUSION

The goal of this research is to examine illness experience with a culturally invisible disease, HCV. I build upon the idea of biographical disruption by also addressing issues of disclosure and stigmatization. In addition, I address how social structure impacts illness experience. The use of in-depth interviews allows for rich, textual data while a diverse sample gives insight into social structure.

In the following chapters, I present the methodological approach, patterns in the data, and concluding remarks. In Chapter 2, I discuss recruitment sites, the respondents, the interviews, issues of reflexivity, and limitations of the research. In Chapters 3, 4, and 5 contain analyses of the data. I begin with respondents' experiences with disclosure in Chapter 3. Chapter 4 addresses reactions to disclosures of health status including social support and stigmatization. Chapter 5 assesses how respondents made sense of having HCV in light of their experiences with disclosure and stigmatization. In Chapter 6, I highlight the theme of race and inequality, address contributions to existing discourse, and suggest implications for future research.

APPENDIX 1

DESCRIPTION OF HCV

Hepatitis is a general term that refers to inflammation of the liver. Hepatitis may be caused by numerous sources including drugs, toxic chemicals, and viruses. There are several strains or types of hepatitis viruses, such as hepatitis A, hepatitis B, hepatitis C, hepatitis D, and hepatitis E, that are related only in that they affect the liver. The numerous types of hepatitis have different etiology, an array of consequences, and varying treatment protocols. Currently, there are vaccines for both hepatitis A and B. Hepatitis C has been more recently discovered compared to hepatitis A and B and there is currently no vaccine available.

RATES AND PREVALENCE OF HCV

Hepatitis C virus (HCV) is a blood borne pathogen that leads to chronic infection in 80-85% of infected persons (Franciscus and Highleyman 2003). Worldwide, it is estimated that over 170 million people or 3% of the world's population have been infected with HCV (Reddy 2002). The Centers for Disease Control estimate that 3.9 million Americans or 1.8% of the population is infected with HCV, the most common blood borne infection in the United States, although only 2.7 million may have chronic infection and 70% of these persons may be unaware they are infected (AGA 2003). More recently, others estimate that over 5 million Americans are infected (Erickson 2006). Approximately 25,000 people are infected each year (<http://www.cdc.gov/ncidod/diseases/hepatitis/c/fact.htm>). Persons aged 30-49 years old have the highest rates of infection in the US (Reddy 2002) (although others state that

persons 40-59 have the highest rates of HCV-<http://grants.nih.gov/grants/guide/rfa-files/RFA-DK-03-011.html>). Seventy percent of persons with HCV will develop chronic liver disease at some point in their life (<http://www.cdc.gov/ncidod/diseases/hepatitis/c/fact.htm>). Currently, 40% of chronic liver disease in the United States is related to HCV (Reddy 2002). There are an estimated 8,000-10,000 deaths a year in the US from complications associated with HCV, although this number is expected to triple in the next ten to twenty years (Franciscus and Highleyman 2003). According to Erickson (2006) the number of deaths per year from HCV, have exceeded deaths from HIV/AIDS since 2000.

TRANSMISSION

HCV is spread through exposure to infected blood. Parenteral transmission (outside of the intestines) of HCV is 10-fold more efficient than HIV (Thorpe et al. 2002). Intravenous drug users (IDUs) are at especially high risk for new infection. It is estimated that 60% of current transmissions are through IV drug use (<http://www.hepnet.com/hepc/aasld00/alter.html>). The Centers for Disease Control (CDC) estimates that within 5 years of initial IV drug use, 90% of most IDUs have contracted the virus (Alter et al. 1998). Young IDUs are infected with HCV at four times the rate of HIV (Alter et al. 1998). Prior to routine screening of blood and blood products in 1992, transfusions were the most common method of transmission (Franciscus and Highleyman 2003; Reddy 2002). Transfusions accounted for 20% to 40% of all infections up until the last fifteen years, although now they account for less than 5% of infections (<http://www.hepnet.com/hepc/aasld00/alter.html>). Sexual transmission is rare (1-3%) with an estimated transmission rate of 1.5% between long-

term, heterosexual partners where one individual has HCV although risks such as sexually transmitted infections (STI) or drug abuse may raise the chances (Franciscus and Highleyman 2003; Reddy 2002). Having multiple sexual partners, anal sex, working in the sex industry, and having contact with a sex worker have been cited as possible means of sexual transmission but is unclear how these sexual practices could increase rates of transmission (AGA 2003; Highleyman 2002). Needle-stick exposure in health-care settings and mother-to-infant transmission are also means of transmission although the rates are not high with less than 10% of needle-sticks resulting in HCV and 5%-6% of mothers passing HCV to their children (Franciscus and Highleyman 2003; Reddy 2002). Evidence is inconclusive regarding tattooing and body piercing in the US as a means of transmission (Alter et al. 1998). Finally, there are individuals with HCV where no recognized source of infection can be identified (<http://www.hepnet.com/hepc/aasld00/alter.html>).

EFFECTS OF HCV

After exposure to HCV, the incubation period is generally 6-7 weeks and acute infection is asymptomatic in 60% to 70% of patients (Reddy 2002). Many persons will have few to no symptoms for the first twenty years after infection, thus accounting for the many persons who are unaware they are infected (Franciscus and Highleyman 2003). The virus attacks cells in the liver leading to chronic inflammation of cellular tissue in the liver and eventual fibrosis or a hardening of the liver tissue, which may result in cirrhosis (Franciscus and Highleyman 2003; Reddy 2002). Cirrhosis may lead to hepatocellular carcinoma and/or liver failure. Factors that affect the rapid progression of the disease

include alcohol use, over forty years old at time of infection, male sex, and severe histology at time of initial diagnosis (Reddy 2002).

Histology is measured by levels of ALT (alanine aminotransferase) and AST (aspartate aminotransferase), which are both liver enzymes (Franciscus and Highleyman 2003). High levels of ALT are often the impetus for testing persons for HCV, although ALT levels will fluctuate over the course of the disease (Reddy 2002). After proper testing and diagnosis, many physicians eventually recommend a liver biopsy to determine inflammation levels and fibrosis of the liver (<http://digestive.niddk.nih.gov/ddiseases/pubs/chronichepc/index.htm#E>). In addition, specialists will determine which of the six genotypes of the virus the patient has as well as viral load (Reddy 2002). Symptoms experienced by some with chronic infection include nausea, chronic fatigue, mood swings, loss of appetite, muscle or joint pain, headaches, indigestion, depression, “brain fog”, and abdominal pain (Franciscus and Highleyman 2003).

TREATMENT

Treatment is available with the goal of staving off progression of the disease, although it is not recommended for all persons with HCV as there are some factors that are known to affect responsiveness to treatment (Reddy 2002). Treatment usually consists of a combination of pegylated alpha interferon and ribavirin for a period of 24 or 48 weeks (<http://digestive.niddk.nih.gov/ddiseases/pubs/chronichepc/index.htm#H>). This regimen often reduces ALT levels and detection of HCV antibodies in the blood (<http://digestive.niddk.nih.gov/ddiseases/pubs/chronichepc/index.htm#H>). 65% of specialists do believe treatment can cure people, meaning the virus can no longer be

detected in the blood for a sustained period of time (AGA 2003). However, response rates are currently around 50% depending on virus genotype, viral load, and several other factors, including race, sex, and age (with women, younger people, and Whites more responsive to treatment) (Reddy 2002). In addition, side effects may be severe, including fatigue, muscle aches, headaches, nausea and vomiting, low-grade fever, weight-loss, irritability, depression, and reversible hair loss (<http://digestive.niddk.nih.gov/ddiseases/pubs/chronichepc/index.htm#H>). Some patients quit treatment because of the debilitating side effects (AGA 2003).

CHAPTER 2: METHODOLOGICAL APPROACH

In-depth interviewing is the most appropriate methodology in terms of my research questions, similar to much of the research on illness experience (Morse 2001). Methodologically, in-depth interviewing allows for the uncovering of taken for granted assumptions that are not easily voiced by individuals (Johnson 2002). In addition, allowing persons with HCV to express their “narratives,” helps alleviate the tension between agency and structure as people give narratives to make sense of their place in society (Popay et al. 1998). This methodology allows for a deeper, rich assessment of the multiple perspectives and experiences of the diverse group of individuals with HCV.

This chapter addresses issues pertaining to qualitative research including experiences and challenges with recruitment and the interview experience itself. I describe the sample which consists of white and racial and ethnic minority men and women of varying social economic backgrounds, allowing for comparisons across class, gender and racial lines. My approach to data analysis includes my use of undergraduate research assistants and ATLAS.ti. I address reflexivity regarding my interactions with healthcare providers and respondents. Reflexivity is also outlined with regards to the process of data analysis and ethical issues inherent in this type of research. Finally, I describe the limitations of the study.

ENTRY AND EXPERIENCES IN RECRUITMENT SITES

The data collection took place in Baton Rouge, Louisiana and surrounding areas during the summer of 2004. Baton Rouge is a city with nearly a quarter of a million inhabitants and has slightly more African-American (50.02%) than White citizens (45.7%) (U.S. Census Bureau 2000). This location allowed for a diverse research

sample. The over-representation of African-Americans is important as this group is disproportionately affected by chronic HCV infection (Alter et al. 1998). I chose Baton Rouge because of my familiarity with it and personal contacts there.

I worked with Dr. Cassidy, an Associate Professor of Medicine at Louisiana State University because of the diversity of his patients. Dr. Cassidy has clinics at a local charity hospital affiliated with Louisiana State University that served as one recruitment site. The majority of Dr. Cassidy's patients utilizing the public clinic are poor or working class. As a comparison group, recruitment also came from Dr. Cassidy's private practice. This allowed for a more relatively privileged group of individuals (these persons can either afford private health care and/or have health coverage) to be included in the sample as well.

PRIVATE PRACTICE

The private practice ran efficiently and smoothly. Each Thursday when patients were seen, the nurses asked if they were interested in the study and gave them a Study Information Sheet. The Study Information Sheets introduced the study, detailed the benefits and risks of participation in the research, described confidentiality, and provided my contact information.⁶ Willing patients filled out a Consent Form Sheet with their name and phone number on which the nurse wrote their race/ethnicity and gender to help me with my sampling.⁷ I generally called people either the same day they had seen Dr. Cassidy or the next day so that it would be fresh in their mind although many forgot they had filled out the form and for some, it took a good bit of explaining who I was before they remembered.

⁶ See Methodological Appendix on page 205.

⁷ See Methodological Appendix on page 205.

PUBLIC CLINIC

The atmosphere at the public clinic was much more chaotic than the private practice. While the nurses at the private clinic recruited for me, my presence and active recruiting was very necessary at the public clinic. This clinic was very rushed and over 100 patients were seen in a number of hours. The residents vied for Dr. Cassidy's attention because they had to go over the charts with him before a patient was released. I introduced myself to the residents on my first day and tried to briefly explain to them my research. There were different residents in rotation there and I shortened my request over time to just asking them if their patient(s) had HCV or not as most were uninterested in my research. I quickly learned that the residents were overworked and mostly unconcerned with helping me recruit for my research. I had to be pro-active in asking them constantly if they were seeing someone with HCV as they never volunteered the information. Once I had established that the patient had HCV, I entered the exam room, gave patients a Study Information Sheet, and asked if they were interested in participating. People then completed the Consent Form Sheet providing their name and contact information.

My time spent at the public clinic was invaluable for gaining some appreciation of what it was like to receive healthcare there. Warr (2004) discusses the insight researchers can gain from situating research in the lived environments of participants (Warr 2004). I was able to see rushed nature of the encounters at the public clinic and how there was little continuity in care for the patients as they often had a new resident hurriedly reading their chart. For example, one respondent, Rick, commented, "Matter fact every time I go to that Hepatitis clinic I got to see a different intern every month. You know, they don't

really do anything about my case except for the few minutes they look at the file.” From my experience at the clinic, I could better understand how he felt this way.

I also was privy to backstage behavior by staff that helped me appreciate how some of the staff conceptualized at least some of the patients (Goffman 1959) . One nurse discussed with me a “non-compliant” patient who was a young, Black woman. The nurse felt she was not honest because she had sought out another doctor to help with her lack of appetite. The nurse stressed that she had told this woman that lack of appetite could be a consequence of the treatment and was aggravated that the woman saw another physician as he prescribed steroids that were contra-indicated with HCV treatment. The patient claimed to have only taken one or two pills but the nurse did not believe her. The nurse was angry that a patient taking such expensive treatment would possibly ruin it through her non-compliance.

I met this patient when trying to solicit her to participate in the study. Upon entering the exam room and introducing myself, she asked me if having HCV meant she would get AIDS, too. She said people had told her that and that she never felt sick and didn't really understand what Hepatitis C even was. Although my research does not specifically address doctor and patient interactions, it is clear that the way health care staff conceptualizes patients affects their interactions. While the nurse saw the young woman in this example as non-compliant, my brief experience with her reflected her lack of knowledge and fear rather than willful non-compliance. This woman had such a lack of understanding of even having HCV that it is not surprising she was not more careful in terms of receiving health care from other physicians which might interfere with her HCV

treatment. Thus, future research should perhaps focus more on doctor-patient interactions to help broaden our understanding of patient's experience of HCV.

OUTSIDE RECRUITMENT

Accessing persons with HCV who may or may not be under the care of a physician is important in attempting to sample a wide array of persons with HCV. Before arriving in Louisiana, I intended to recruit from Narcotics Anonymous meetings in Baton Rouge and a HCV organization in New Orleans. I called the leader of the HCV organization once I was in Louisiana and learned that there was no longer a support group affiliated with the organization. I found another support group in a suburb of New Orleans.

I attended one meeting of the support group to solicit respondents and was welcomed by the group. I provided Study Information Sheets to all attendants at the meeting. There were fifteen people there besides me, all of whom were White, including a drug representative, a nursing student, two partners of people with HCV and the facilitator's child. Numerous people mentioned how they got HCV and at least two said through IV drugs. There were a few stories shared about stigmatizing experiences or diagnosis stories. After everyone went around the table, the meeting became a free for all in terms of people just asking questions and receiving answers. Numerous people mentioned the stage of fibrosis of their liver as well as their viral loads. Viral loads have a dubious status as far as clinical meaning but seemed very salient to these persons. The pharmaceutical representative answered a few questions from people and the facilitator spoke a great deal as well. After the meeting, I gathered contact information from people for interviews.

In addition, I did interview several respondents that I found through my informal social networks. None of these persons were formally under the care of a physician, thus I would not have found them through my formal recruitment sites. Two of these persons were quite secretive about having HCV and their interviews were especially useful in understanding persons who do not readily disclose.

CHALLENGES IN RECRUITMENT

I did experience some difficulties in the recruitment process. Being introduced by the nurses at the private practice seemed to give more validity to my request and many people gladly gave me their names and numbers. For example, I had six interviews scheduled the day after my first time spent at the private practice. A drawback of these introductions may have been an association of me with the healthcare providers perhaps skewing the respondent's perceptions of me and coloring our interactions as they may have thought I was reporting back to the providers. I did re-introduce myself at each interview and emphasized that I was a sociologist from Indiana University and not affiliated with any health care provider in an effort to prevent misunderstandings. The initial experiences at the private clinic were a good segue into recruiting at the public clinic.

I spent Tuesday mornings at the public clinic recruiting respondents⁸. I learned to blend in to the busy environment and stay out of the nurses' way. I brought cookies and donuts on different occasions to remind staff that I was there and needed their assistance.

⁸ On a number of occasions I walked into an exam room only to find out that the patient was incarcerated and in an orange jumpsuit with a guard. I did not have IRB approval to interview individuals who were incarcerated. I learned to ask nurses and residents if the patient was an inmate before entering the room.

As a whole, patients at the public clinic tended to be more skeptical than those at the private clinic although some at the public clinic were almost the opposite in terms of obsequiousness I think because they thought I was a doctor or associated with their health care. I received many names and numbers through the public clinic but had more trouble scheduling interviews with this population than the private clinic. I mentioned this to Dr. Cassidy who pushed me to interview respondents while they were at the clinic. I tried this as will be described in detail later, but did not feel this was a good environment for the interview. Instead, I tried to schedule interviews while collecting names and numbers and then I just called to remind people of the interview. This method did work somewhat better although many people just wanted me to call to set it up rather than commit then.

Regarding Narcotics Anonymous, I had planned to arrive at Narcotics Anonymous meeting locations before the meeting time and ask the chairperson if I may leave Study Information Sheets on display. I would not attend the meetings and interested persons would have to contact me. My goal was to recruit at least ten people outside of the health care system and I was fairly successful with recruiting through the support group. I thus dropped Narcotics Anonymous meetings as a recruitment site. Although I might have gotten a different perspective from persons there who were unlike those who went to a support group for HCV, I was doubtful that this method of recruitment would prove fruitful.

RESEARCH PARTICIPANTS

This research focuses on male and female adults eighteen and over who have HCV. Persons under 18 are currently not eligible for combination therapy treatment for HCV, according to the National Digestive Diseases Information Clearinghouse

<http://digestive.niddk.nih.gov/ddiseases/pubs/chronichepc/index.htm#E>). Thus, the experiences of minors may be fundamentally different than adults, as they do not have the same options available. I interviewed any eligible adult who may or may not have gone through treatment in the past as well as persons who were undergoing treatment. Many individuals are co-infected with HCV and HIV, however this group was not eligible, as their experiences with HCV will be affected by their HIV status. This co-morbidity is increasingly common and important. This research will complement the abundant discourse on HIV to better understand the plight of those with both HIV and HCV.

Based on these methodological considerations, my goal was to interview 20 respondents from the public clinic and 20 respondents from the private practice. At both of these two locations, I hoped to interview five white women, five minority women, five white men, and five minority men. This design allows for clear comparisons across race, class, and gender. I also anticipated interviewing 10 respondents from outside the health care system within which I was recruiting.

Because I had the three different recruitment sites, I obtained a fairly diverse group of respondents as can be seen in the Research Participants Demographics Table.⁹ My sample is reflective of the sampling goals. The research participants are 53 men and women ranging from age 22 to 70 with a mean age of 48. Thirty-four persons were White. Sixteen respondents were African-American and 3 respondents were Asian one of whom was Middle Eastern.¹⁰ Years of education among the respondents ranged from 5 to 20 years with a mean of 12.5 years. The average household income was \$32,000 a

⁹ See Appendix 2 on page 63.

¹⁰ At times, I refer to the minority respondents as “Black” because Blacks comprise the bulk of this group.

year.¹¹ Respondents from the private practice had the highest average household income of \$42,000 a year. The ten persons recruited who were not under the care of Dr. Cassidy had an average household income of \$36,000 a year. The persons recruited through the public clinic had the lowest average household income of \$21,000 a year.

Qualitative research often determines sample size through theoretical saturation. Theoretical saturation refers to the point during data collection (and analysis) when there are no new themes in the data in regards to the emergent categories seen through data analysis (Strauss and Corbin 1998). After forty or so interviews, I originally thought I had a good sense of the recurrent themes in the data. However, I was surprised when new themes emerged fairly late in the data collection process concerning conceptions of HCV and HIV. After being able to explore this new thread, I felt that I had reached theoretical saturation as I was not collecting any surprising data from subsequent interviews.

IN-DEPTH INTERVIEWS

While the interviews were flexible or semi-structured, I did use an Interview Guide based on my research questions.¹² Johnson (2001) notes that researchers should have a protocol of questions as a starting point for the in-depth interview. I wanted to know how people conceptualized HCV, whom they told about having it, and reactions to their disclosures. The interviews followed the same general pattern using the Interview Guide but I did not adhere to a strict ordering of questions and instead let the interview flow more naturally. I started the interviews with asking respondents where they were from and about their families of origin following a chronological order to bring the

¹¹I estimated the mean based on income categories from the Background Information Sheet.

¹² See Methodological Appendix on page 205.

conversation up to present time. Next, we turned to discussing social relationships with family and friends. People often offered additional information especially about their children or grandchildren although some lamented their estrangement from their families. Beginning with these questions allowed the respondent a chance to feel more comfortable with me and for us to develop some rapport.

The next part of the interview focused on respondents' lives before they were diagnosed. I asked about knowledge of HCV including whether the respondent knew anyone with HCV, what they had heard about it, how they thought people got it and what they thought about HCV or people with HCV. These questions are important in terms of how modified labeling theory applies to persons with HCV as discussed in Chapter 1.

We then discussed the diagnostic experience. Often respondents talked freely and essentially told the story of their diagnosis with little prodding on my part. I gathered detailed information about how the health care provider informed them about having HCV and what they were told about HCV including information about treatment, transmission and effects on the body. I asked about the respondent's emotional reaction to the diagnosis. Some respondents described in detail the aftermath of diagnosis while others had very little to report about their experience.

Many persons addressed disclosure practices at this point of the interview. I usually asked if they had not already mentioned who they told immediately, why they told that person and what they revealed. People often went on to talk about other disclosures and reactions to disclosures. I asked them who they currently told and if they could describe a recent disclosure experience to me so that I could understand what information they were revealing and why. I made sure to ask if any reactions to

disclosure have made them uncomfortable and why. At this point, people often revealed stigmatizing experiences if they had had any. I asked how these experiences affected them and if they felt different about themselves or about having HCV after these experiences.

Following a discussion of any uncomfortable reactions, I asked about support received from people they had disclosed to or if they had not received support, what they would have liked to happen. Although I asked if anyone has been unhelpful or not supportive, this question did not elicit the data I was looking for. Respondents often described a stigmatizing experience they had already told me about. I was interested in ascertaining what respondents *wanted* in terms of support but did not tap into this well. Respondents also spoke about any experiences with support groups or why they would not go to one.

Next, respondents talked about their current health status including the presence of any symptoms, if any. I asked how symptoms have impacted their lives and how they explained them to other people. We often discussed various testing that persons have undergone and continued to undergo as well as experiences with a liver biopsy. If the person had done treatment or was currently on treatment, they usually spoke extensively in regards to how bad it was or how well they had fared with it. Respondents also discussed any effects that treatment had on their family lives or work environments and reactions from persons to their experiences. If the person was thinking about trying treatment, they often expressed trepidation. Several respondents described and justified why they were not going to take treatment.

I then addressed the meanings they associate with HCV as well as basic knowledge of the disease. Some respondents discussed what they would like to know about HCV. I asked if having HCV had impacted how they thought of themselves and how they made sense of having this illness. People talked about how meanings fluctuated over time because of interactions with others or because of new information gained. Finally, respondents spoke of the overall consequences of having HCV such as impact on physical health, emotional stability, relationships, work opportunities, and lifestyle changes.

THE INTERVIEW EXPERIENCE

I completed three pilot interviews in the spring of 2004 in Indiana to refine my interview guide. These three interviews are included in the final sample. As others have found, these initial interviews were useful learning tools (Johnson 2002). I knew two of the respondents and thus opportunistically included them in the research. My first pilot interview was with a friend who has HCV. A benefit to this dynamic was he was able to offer some feedback after the interview about the process. I was stiff during this interview and did not allow for the natural flow of conversation to develop because I was so concerned with following my guide to ensure I asked all my questions. My second pilot interview was also with an acquaintance. This interview went more smoothly than the first. Again, he offered some advice afterwards about questions I might ask respondents. Both of these experiences did help prepare me for my third pilot interview that was with a stranger. By this time, I was more comfortable with the Interview Guide and more familiar with the questions I wanted to ask. While there may have been disadvantages to interviewing persons I knew first, it was also useful in that my

awkwardness was more easily forgiven perhaps. My interviewing style evolved through the data collection process. The first few interviews in Louisiana were similar to the pilot interviews in that I heavily relied on the Interview Guide. However, by the time I finished data collection, I no longer needed to look at the Guide during interviews as I was so familiar with the line of questioning.

I started all the interviews in the same fashion. I re-introduced myself or introduced myself to the few respondents I had not yet actually met. I told them I was affiliated with Indiana University in order to distance myself from any local source and explained that I was interested in hearing about their experience having HCV. Although each respondent had all ready been given a Study Information Sheet, I gave them a nearly identical informed consent statement that they had to sign and date for me. While the respondent read the statement, I prepared the digital recorder.

The majority of the interviews felt like conversations and most respondents spoke fairly freely and naturally. Of course, I guided the conversation more so than in a natural conversation (Johnson 2002). Depending on the location, some respondents answered phones, changed channels on the television, drank beverages, ate food, smoked cigarettes, took bathroom breaks, etc. during the interview. At respondents' homes, most treated me like a guest and kept offering me drinks. At the end of the interview, respondents filled out a Background Information Sheet.¹³ I assisted two respondents in this endeavor. One respondent asked me how to spell "minute" and "Baptist" and misspelled "nurse" and "retired" on the form and another respondent had poor eyesight and asked me to read and fill out the form for him, which I did. I had not anticipated having respondents who could not read and should have planned for this.

¹³ See Methodological Appendix on page 205.

The interviews ended in similar fashion with quite a few respondents wanting to chat. I offered the Hepatitis C Support and Information Sheet to some respondents because they had expressed interest in support groups or requested information about HCV from me.¹⁴ Several respondents expressed gratitude and kept telling me how much they enjoyed talking to me. Meredith, a hairstylist twice mentioned she wanted to do my hair for free so she could, “do something for me.” Andrew insisted on buying me a coke at the gas station near the library after the interview and Tom also insisted on paying for my coffee at Shoney’s. Others repeatedly thanked me because it felt good for them to talk about their experiences and/or because they were happy I was researching an issue that they felt needed attention. These responses to the interview experience indicate that many respondents did reveal confidential information about themselves and that the data reflect their sincerity. Catherine told me as I was leaving that she felt like she really knew me. I barely spoke during our interview but Catherine revealed a great deal to me and she obviously felt close to me afterwards because of her revelations. Catherine along with many other respondents, usually female, impulsively hugged me when I was leaving. I did not, however, establish the same level of rapport with all respondents and some persons maintained more of a distance.

LOCATION OF INTERVIEW

Interviews were done at a location chosen by the respondent. I conducted over half of the interviews in respondents’ homes. At times I had trepidation about going to some respondents’ homes because they lived in crime-ridden neighborhoods. I never felt unsafe, however, upon arriving at anyone’s home. At least a few potential respondents expressed that they did not want me to see their homes presumably because they were

¹⁴ See Methodological Appendix on page 205.

poor, when trying to schedule interviews. Interviews conducted in respondents' homes were probably the best environment as the respondents felt comfortable, safe, and did not worry about privacy. They did not try to hurry through the interview and spoke in a regular tone. The recordings were also better without background noise although several respondents did have the television on during interviews which affected the quality of the recording. Two respondents who lived in rural areas that I was unfamiliar with met me at gas stations off the interstate or highway to allow me to follow them to their homes.

I interviewed the other respondents at libraries, restaurants, coffee shops, and a few other public venues. I was concerned that an interview in a library would be disruptive but most went smoothly and we quietly chatted in a secluded nook of the library. One respondent, however, spoke very loud and we were chastised by a librarian much to my embarrassment. Most of these interviews went very well. For example, I met Tom at a Shoney's. He was sitting in the smoking section and was a bit reserved at first as we had never met. He quickly warmed up to me and spoke freely in a fairly quiet tone. I did feel that a woman in the next booth might have been eavesdropping at one point but Tom did not seem to notice. I recruited Meredith through the public clinic and met her at a local coffee shop. She was forthcoming during the interview. I interviewed another woman, Melissa, at a coffee shop. She, too, was quite open and spoke at length about her experiences. A drawback of interviews conducted in public was that there was a good bit of background noise on the recording making transcription more difficult.

Other public venue interviews were perhaps less than ideal. I met Roxanne at a McDonalds while she was on her lunch break. She was fairly clipped in her answers and seemed to be watching the time closely so she could get back to work on time. It was

also very loud and crowded at that time. The interview I did at an off-track betting facility was the worst interview experience in terms of data collected. The respondent, Eric, was watching the television screens of different race tracks the entire interview which was incredibly short, lasting less than four minutes! Although this was obviously not an ideal location, I am not sure I would have gotten any better information in another location as Eric was in denial about having HCV.

Finally, I conducted three interviews at the public clinic. I experienced some difficulty recruiting through the public clinic. Despite receiving many names and contact information while at the clinic, I had difficulty actually scheduling interviews and had many cancellations and no-shows. Dr. Cassidy encouraged me to interview patients while at the clinic. I was hesitant to hold interviews at the clinic as I knew there would be issues with privacy and constant interruptions. I, nevertheless, interviewed Ellis, a middle aged Black man. We started the interview in the exam room and then moved to the nurses' office as they were at a meeting. Ellis rushed through his answers as he mentioned several times that he wanted to "get this over with." In addition, the nurses came back from their meeting during the interview which was uncomfortable although we did stay and finish. The other interviews there fared better although the public clinic was not, however, an optimal environment for conducting interviews.

APPROACH TO DATA ANALYSIS

After returning home after interviews, I downloaded the interview onto the computer and immediately assigned the respondent a pseudonym. No identifying marks were kept on the discs or tapes linking the data to a particular respondent. The consent form with the respondent's name and number was shredded after each interview. All of

the informed consent forms were kept separate from any other data. I wrote field notes about the interview within 24 hours or less in order to remember details. These notes often described the location of the interview, the body posture and dress of the respondent, and/or other details either not actually recorded or non-verbal data. The field notes have been useful while analyzing data in order to remember specifics about the interview process and interactions with respondents.

WORKING WITH UNDERGRADUATE RESEARCH ASSISTANTS

In order to facilitate the speedy transcription of the interviews, I worked with six undergraduate research assistants. I had students sign a document outlining the responsibilities associated with the position.¹⁵ Each assistant had to pass the Institutional Review Board's "Protection of Human Research Participants Certification Test" so that they understand rules regarding confidentiality when working with human subjects. The research assistants transcribed all verbal utterances in the interviews, although I do not include all utterances in this document for sake of presentation. After transcribing an interview, each assistant filled out an Interview Outline Form.¹⁶ This form helped to manage the data by noting the socio-demographics of the respondent and then outlining an initial, brief overview of the respondents' illness concepts, patterns of disclosure, levels of social support, and experiences with stigmatization.

We met every other week to discuss these initial analyses and responses to the data. Each transcription was read and checked by another assistant to ensure high accuracy. I also reviewed all transcripts for accuracy as there were some initial problems with the assistants misunderstanding some of the respondents due to dialectical

¹⁵ See Methodological Appendix on page 205.

¹⁶ See Methodological Appendix on page 205.

differences in speech. While the assistants' work of transcribing was invaluable, the meetings discussing the data were also very useful for me because this first stage of analysis prevented me from starting to code prematurely without a grasp of the data.

USING ATLAS.TI

After this first stage of analysis, the transcribed interviews were entered into ATLAS.ti. (Scientific Software Development 1997.) ATLAS.ti is a qualitative data analysis software package that allows the user to organize data and discern themes in the data. This second stage of analysis of the data involved initial coding of the data (Charmaz 2002)¹⁷. My approach falls between what some see as a technical approach versus an emergent intuitive approach in that I approached the data with regards to my research questions in mind in terms of initial coding so as to not get overwhelmed by the data (Marshall and Rossman 1999). For example, I started labeling data in terms of broad categories, such as disclosure. I later, further refined the category of disclosure into typologies, such as disclosure at work, disclosure to family, and disclosure to friends (Lofland and Lofland 1995). Thus, I read all the transcripts with attention to disclosure practices yet also noted other themes that emerged. I repeated this entire process numerous times with attention to different research questions. This repeated process helped me become very familiar with the data and allowed me to see emergent patterns in the data. I often re-read the field notes I had written when looking at a transcript to help remember details that I might not remember from the transcript alone. Reviewing the field notes helped the analysis in that I could think of the person and their experience holistically. I continuously revised, collapsed, and expanded codes as I went through the data. I did not separate the transcripts by race, class, or gender in the coding process but

¹⁷ I performed all of the coding. The research assistants did not participate at this stage of analysis.

looked at the sample as a whole. I sorted data by codes to allow for patterns to emerge rather than forcing any clusters by demographics, for example, on the data.

After I coded the data, I then began to explore how race, class, and gender did or did not affect experiences with HCV. While these data are qualitative and most appropriately analyzed with that methodology in mind, I did perform some quantitative comparisons. While there are limited approaches to quantitatively assessing this type of data, the results do strengthen the arguments set forth from the qualitative analysis.

Many interesting themes emerged from the data and I chose to write about the patterns that seemed most salient to respondents as well as relevant to existing discourse on chronic illness. In the writing process, I used ATLAS.ti's sorting tools to find relevant chunks of text associated with certain codes to support my assertions. I intersperse many comments from respondents through out this document as in depth interviewing provides rich and thick description. My analyses were further developed through conversations with research assistants as well as colleagues. I presented a chapter at a regional conference as well as a departmental colloquium. Thus, my analyses benefited from others' feedback. My reading of the data while grounded in sociological literature is also a product of my own history and identities and must be situated as such.

REFLEXIVITY: RESEACHER'S PLACE IN THE RESEARCH

Many researchers have documented the importance of acknowledging the researcher's own place in the research (Ellis and Berger 2001). It is important to note how my own characteristics and beliefs shaped this research. Who I am as a person affected my entry into the field, interactions with Dr. Cassidy and the nurses, the

interactions with respondents, the data I collected, and the subsequent analysis of the data. I also address my own emotional reactions to the research.

At the time of data collection, I was 28 years old. I am a Hispanic woman of average height and weight. I grew up in an upper middle class family in Louisiana but do not have much of a Southern accent and speak fairly articulately often unwittingly signaling my social class status to others. I am fairly charismatic and chatty and can easily spark up conversation with most anyone which definitely helped in the research process. I have an extensive amount of tattoos that I covered not always successfully. I chose to wear long sleeved shirts and pants or skirts despite the extreme heat and humidity because of social stereotypes and prejudices concerning tattoos. I did not want potential respondents to be distracted or not participate because of my appearance. I dressed slightly more conservatively than usual in rather plain, business casual style clothing. Most importantly, I have HCV as a result of intravenous drug use although, of course, this was not obvious by my appearance. Although my upbringing kept me mostly surrounded by middle class whites, my past drug usage facilitated interaction with people of varying socio-economic statuses and racial identities. These interactions helped in relating to people very different in some ways than me during data collection. Regarding my HCV, I have undergone a liver biopsy but not treatment, which limits my ability to fully understand experientially what some of my respondents have undergone. Nevertheless, my own experiences with HCV have undoubtedly shaped this research as will be discussed.

INTERACTIONS WITH MEDICAL STAFF

My introduction to Dr. Cassidy was a result of his professional relationship with my father who is also a physician. I first met Dr. Cassidy and one of his nurses in 1995 when I was diagnosed with HCV. All of Dr. Cassidy's nurses at the private practice knew I had HCV, while this was not common knowledge at the public clinic. From what I could tell, the nurses at the private clinic did not necessarily have stereotypes about persons with HCV perhaps because they saw so many different types of people with it. The other explanation is that they did not reveal any prejudices in front of me because I also have it although this did not seem to be the case. I did witness some derogation of persons with HCV at the public clinic by some of the residents based on comments they made but these seemed to pertain more to people who continued to drink alcohol and/or use illicit substances once infected with HCV.

My own experiences being a patient of Dr. Cassidy's may have allowed me to relate better to my respondents than someone who had not had this experience. However, I was always seen privately and "under the table" so to speak as a courtesy to my father. Thus my experience is in some ways different from the people I interviewed because I was given special treatment by Dr. Cassidy and his staff.

Another result of my privileged position was the ability to even conduct this research with the ease that I did. Conducting social scientific research in the medical field is not always easy and many researchers have difficulty gaining access (Morse 2001). I did not have any difficulty for the most part. I was treated perhaps better than a researcher with no affiliations might have been. I was constantly being referred to at the public clinic as "Dr. Suarez' daughter". This recognition seemed to influence how

people interacted with me in that they seemed more willing to help me with my research once they knew who I was. This “name-dropping” was quite effective with the residents at the public clinic as well since they all knew my father. When I thanked Dr. Cassidy at the end of the data collection process, he shrugged it off saying that it was a way for him to repay my father for his kindness when Dr. Cassidy first began teaching there. Thus, my social capital definitively helped my entry and status in the field.

INTERACTIONS WITH RESPONDENTS

I relied on various aspects of my multiple identities when interacting with respondents. While I never pretended to be someone I was not, I emphasized different aspects of my identities with various respondents to establish rapport. This tactic is used not only by ethnographers but by all persons in daily interactions with others as has been addressed by symbolic interactionists (Harrington 2003). For example, sometimes I tried to downplay my upper middle class status or my education while other times I drew on these identities to form connections with respondents. I related to respondents as a woman, pet owner, food lover, Southerner, Midwesterner, minority, tattooed person, ex-drug user and someone with HCV. I had the most internal conflict regarding my identities as an ex drug user and person with HCV.

My gender did affect my interactions with respondents. In some ways, being a young woman helped with recruiting as I was perhaps seen as non-threatening. Based on several comments from male respondents about my physical appearance, it seems that several male respondents agreed to be interviewed because I was a young and in their view, attractive woman. For example, when I asked Jerry if he was pretty happy most of the time, he replied, “When I see beautiful people like you.” At the end of another

interview, a respondent, David, asked where all I was tattooed and told me how beautiful I was. I became uncomfortable and began to get ready to leave. He asked for a hug to show that I didn't think he had leprosy (a fear he had expressed during the interview). I hugged him and he tried to kiss me. I quickly left and was quite upset. I did learn to keep up my guard especially with male interviewees as another male respondent asked me out to dinner.

Schwalbe and Wolkomir (2001) suggest that inappropriate sexualizing by heterosexual men being interviewed by women is a way to reassert control (Schwalbe and Wolkomir 2001). They comment how some remarks might seem innocuous such as when Little Brother remarked on how pretty my hair was (Schwalbe and Wolkomir 2001). Other situations may be indicative of a man trying to disempower the female interviewer and de-legitimize her role. While David's attempt to kiss me was at the end of our interview, he may have been trying to assert his power to counteract the potentially discrediting information he had told me during the interview. Men may have seen the nature of the interview as more threatening than women because to be ill is often frightening and thus may question a sense of fearlessness and invincibility associated with masculinity. Sparky addressed this fear outright when he started crying for the third time during the interview and said, "I'm a big cry baby. Ever seen a fifty-one year old cry baby?" I told him that men expressing their emotions was a good thing and he responded with, "I tell people if you don't cry you ain't human." Sparky's outright emotional reaction was rare among the men I interviewed but more common among the women.

Eliciting emotional stories from my female respondents may have been easier because of culturally sanctioned norms regarding gender and the expression of emotions.

Women might have felt more comfortable talking to me than they would have a male researcher. My interviews with women were longer on average than men lasting 64 minutes compared to 52 for men with the overall average interview lasting 57 minutes. However, I cannot discuss the issue of gender as if all female experiences are the same (Reinharz and Chase 2001). The meshing of race and gender also affected the interviews.

My racial identity is tricky with regards to interactions with respondents. While technically I identify myself as Latina/Hispanic, culturally many regard me as White, especially in Louisiana. Race affected the interactions between respondents and me as can be seen by the length of the interviews. The average length of the interview for my minority respondents was 37 minutes while the average length for White respondents was 63 minutes. In addition, there were gender differences with regards to average length of interviews for minority men (29) compared to White men (65) and minority women (46) compared to White women (76).

Thus, my shortest interviews were with minority men. Perhaps these men felt the least comfortable with me because of our disparate identities. Ellis, a 49 year old Black man, constantly called me “ma’am” during the interview thus indicating the distance he felt from me. Short responses from interviewees may be a result of the questions seeming too simple, rhetorical, or culturally insensitive (Dunbar et al. 2001). I may have asked questions in a manner that was inconsistent with the cultural understandings of my minority respondents, especially the men. Likewise, the women of color may have not seen me as another woman of color but as a White woman and felt more distance from me than the White women in the study. Thus, the stories I elicited from my White respondents may be richer in detail as these interviews were generally longer. Another

explanation for the racial differences could be the different knowledge of illness as a whole by minorities as will be discussed in Chapter 5.

Finally, part of the differences in length of the interviews may be educational obtainments as respondents with some college had an average interview length of 63 minutes compared to 52 minutes for respondents with a high school education or less. My own educational background may have been seen as intimidating for some respondents as David remarked upon finding out I was working on a PhD that he thought I was a “common person” like him. Thus, respondents with more education may have been either more comfortable with me or more comfortable with the whole concept of being interviewed because of their appreciation of our interview society (Gubrium and Holstein 2001).

My identity as a person with HCV affected my interactions with respondents. When I first was planning this research, I thought my insider status would be extremely important in establishing rapport with respondents (Adler and Adler 2001; Ellis and Berger 2001). As I began to refine my research plan, I began to question how disclosing my own HCV status would affect my research. Ironically, considering my research questions, I was afraid of respondents asking me how I got HCV. I asked respondents how they got HCV and if they knew I had HCV, they might have felt entitled to ask me the same question. If my sample would have been limited to persons who were infected through drug use only, I might have disclosed to them. I was, however, concerned that respondents who were infected through other means would judge me and more importantly affect the information they gave me in the interview because my credibility might have been questioned. The more I thought about this issue, I came to believe that

by appearing to be a “normal”, I would actually collect more detailed data (Goffman 1959). By presenting myself as wanting to learn about their experiences, respondents explained things on a level as if they were teaching someone who knew nothing about having HCV. If they knew I had HCV, they might assume shared experiences or understandings between us and not explain their perspectives. Reinharz and Chase (2001) address that there is little literature about the effects of self-disclosure on the interview and that disclosure may lead the respondents to feel constrained (Reinharz and Chase 2001).¹⁸

I did struggle with my decision to not disclose to respondents. Following feminist models of research was important to me and I did not want to encourage an unequal one way exchange (Reinharz and Chase 2001). For the most part, I realized that I was providing something to respondents—a listening ear that many greatly appreciated as discussed earlier. I decided that if anyone flat out asked if I had HCV I would not lie. Ronald is the only respondent who asked me this question and it was at the end of his interview. I told him yes and that I was willing to have coffee with him at another time to discuss my experiences as he was interested. This did not end up happening because of scheduling issues.

I did reveal my potentially discrediting identities to four other respondents besides Ronald. I interviewed a woman from the support group, Samantha and disclosed my status to her after the interview. Samantha was a young woman with a history of drug use and I related to her so much I felt compelled to share my experience. I was almost apologetic in that I hadn't told her initially and said I hoped she didn't feel tricked. I

¹⁸ It is interesting to note that my interview with Eric who knew I had HCV before our interview lasted a brief four minutes and thus our shared identity alone did little to facilitate rapport.

explained why I was not telling respondents because I thought it would affect the dynamics of the interview and I feared judgment. She said she understood and appreciated me telling her and that my experience was inspiring to her. She did however relay how another woman from the support group mentioned how cool she thought it was that someone who did not have HCV was studying it. I definitely felt dishonest and uncomfortable hearing that. I asked her to not tell anyone from the support group as I was interviewing some of them and didn't want them to have that information before our interviews.

I also revealed my status to Meredith. Meredith was an astute woman in her forties with a history of drug addiction. Meredith was unfazed by my revelation after the interview and was just excited about the research. Finally, I also disclosed my past history with drugs to Jeff and Karla. Karla asked during the interview if I had ever "been on drugs" and I told her yes and briefly explained my battle with addiction. My impetus to disclose then was first that I did not want to lie when someone asked me a direct question and also as a means to relate to the respondents who were in many ways quite different than me. I did not reveal my HCV status as it was not directly relevant at that point in the interview. I also used my tattoos to relate to Jeff and Karla as he was a tattooist.

My choices to reveal my full history to Meredith and Samantha were motivated by my feeling a connection to these women because of our similarities. However, looking back, my own disclosures might have been more useful for more disadvantaged women and men to hear about. Meredith was confident and not afraid of revealing her status. Samantha was more careful and fearful of revealing her status. My disclosure

might have been more useful for persons who were very afraid of disclosing. It might have helped them to feel more comfortable. Ultimately, I made decisions regarding disclosure that felt right at the time. If I were a man or older, it might not be as discrediting to reveal these identities. However, being a woman and young, I made the right choices.

REFLEXIVITY AND DATA ANALYSIS

Having HCV myself has been both advantageous and a liability in looking at the data. West (1990) discusses how researchers either get public or private accounts from respondents. Public accounts refer to behavior or experiences that persons “ought” to have while private accounts are thought to refer to actual experiences (West 1990). West cautions that first interviews often lead to public accounts and that follow-up interviews often produce private accounts (West 1990). My insider status of having HCV may help counteract some issues and serve as an informal means of triangulation that is recommended by West (1990) to check the validity of accounts. Johnson (2001) notes that many researchers rely on lived experiences as a member or participant of what is being studied and that the subsequent data is often richer than if the researcher was inexperienced in the issues. My own experiences, however, are just that, *my* experiences. I learned through the interview process that I brought biases about how I thought people should respond to their illnesses. Davis and colleagues (2004) note that people are expected to “think of their health as a self-made project and therefore monitor their bodies and behaviours, assess these for risk and apply the appropriate adjustments in lifestyle” (1809). I realized that I brought some of this type of bias to my research in my own reactions to respondents. It became important to me to recognize my own privileged

position with regards to information about the disease and ability to act autonomously regarding my health. Acknowledging my biases helped me to analyze data as there are many different experiences with HCV.

ETHICAL ISSUES

Researching illness can be difficult for the researcher for a variety of reasons. I struggled with how to deal with a few of my respondents who seemed to really need help or be confused about their disease. I had decided that during the interview I would not correct people when they spoke erroneously about the disease. For example, several respondents told me they got HCV through drinking alcohol, which is impossible. I was not going to correct them as they believe that is how they got it reflecting their lack of understanding about the disease. Afterwards, if they asked, I would offer some information and always give them a Study Information Sheet so that they could seek out more information themselves. However, I felt torn between being attempting to be the elusive impartial observer and wanting to intervene and help educate people.

The most poignant case was my interview with Sherri. Sherri cried during the interview and revealed other health problems that she thought were because of HCV. She mentioned blood in her bowels and urine as well as inability to hold her bowels which really concerned me as this is not at all a symptom of HCV and seems indicative of other serious health problems. In this interview, I felt I really broke out of my usual role and crossed the line in terms of advice giving. She was going through a divorce, struggling financially, was obviously having serious health issues, had a history of depression, and had told virtually no one about her HCV. She said she had some sort of test done about her stomach but had not been given the results. I encouraged her to ask at

her next appointment about the results and to make to sure to mention her depression. I also asked if she could talk to any of her friends and family about any of this. She said no. I told her about a hepatitis hotline that was toll free that she could call. In addition to feeling totally helpless during this interview, Sherri seemed to think I was a doctor at first and kept asking me about treatment for HCV. I explained to her what treatment entailed and then she asked about her bleeding wanting me to explain that. I was befuddled and said, "I don't know about that. Cause I'm not a medical doctor. I'm a social scientist." To which she replied, "You don't know anything about the, um, the disease itself?" I felt even more confused and responded with,

"I do. I do know about it. But not the same that a medical doctor would. Because what I'm studying is more how it affects people like in their mind and in their heart. You know, um, not as much the physical aspects of it. Does that make any sense?"

Thus,as other qualitative rese archers have noted, despite my introduction with the informed consent, it was evidently not clear to Sherri who I was or what I was doing, further adding to my concern about the interview (Warren 2001). While I handled the interview the best I knew how, I left feeling that I could have done more for her or that I had let her down in some way. These feelings reflect a problem experienced by many researchers studying disadvantaged populations in that they are unable to change the dismal realities of many of the people they interact with.

STUDY LIMITATIONS

While this study will offer numerous contributions to existing discourse, there are also limitations. This research is not representative of all persons with HCV in the United States, Louisiana, or Baton Rouge. The majority of the respondents are patients

of Dr. Cassidy, which may affect their illness experience as the diagnostic experience does affect this process. This similarity may limit the sample, but as the illness experience is so multi-layered, the effects are probably minimal. Also, the same doctor will interact with different patients in various manners. While I did recruit outside the healthcare system, my respondents are more representative of persons who are receiving healthcare for their illness. Because of the racial and ethnic makeup of Baton Rouge, my sample is mostly limited to Whites and Blacks and as discussed earlier, my data may better represent a White experience with HCV. My sample reflects respondents who agreed to be interviewed. These persons may be different than those who decline to participate, especially as there was no monetary compensation or material incentive to participate.

There are also limitations with recruitment. While the introduction of the research by the nurses at the private practice may have been beneficial in gaining participants, on at least one occasion a nurse chose to not tell a patient about the study. She told me that I would not want to have talked to the patient because she thought he was difficult and disliked him. She and the other nurses would often look at who was coming in for that day and make remarks about how a certain patient would be a good person for me to talk to. I assured them that I wanted to talk to any of the patients and to please tell all of them regardless of their disposition. A limitation of relying on the nurses may be that they used their discretion at times despite my urging otherwise.

In terms of the data, I caught a snapshot by interviewing just once. Many of the concepts I am studying are processes that are constantly changing. Multiple interviews are often desirable in terms of illness careers in order to assess some of the changes

(Conrad 1990). While I agree with this approach idealistically, feasibility becomes more difficult especially when studying respondents in another state with no funding.

Collecting sensitive data concerning possible illegal behavior also makes record keeping for follow up interviews a dicey issue with regards to confidentiality and protection of respondents.

Thus, while the research has some limitations, it is also one of the first of its kind in addressing the experience of having the most common blood borne disease in the United States. While the findings cannot be extrapolated to all persons with HCV, they do reflect the multiple ways that persons deal with having a relatively unknown disease. The respondents' experiences are as varied as their backgrounds and the research allowed them to express their often silent sufferings as well as their empowering experiences with HCV.

APPENDIX 2

2.1 RESEARCH PARTICIPANTS DEMOGRAPHICS

PRIVATE PRACTICE (N=22)

Minority Men	Age	Years of Education	Household Income Range (in Thousands)
Jerry	51	10	\$10-19
Stick	52	9	\$30-39
Andrew	44	12	\$10-19
Maruf	43	12	\$30-39
Minority Women			
Connie	70	15	\$50-59
Don Yi	68	8	\$20-29
Ann	51	13	\$10-19
Tari	39	14	\$60-69
Jamie	53	13	\$20-29
White Men			
Sparky	51	13	\$40-49
Mark	35	12	\$30-39
Donald	70	5	\$60-69
Larry	53	16	\$10-19
Charlie	53	18	\$90+
Jason	22	14	\$90+
David	48	14	\$30-39
Tom	51	15	\$50-59
White Women			
Lucy	53	13	\$60-69
Sharon	60	14	\$0-9
Lauren	59	13	\$10-19
Melissa	49	16	\$80-89
Roxanne	35	13	\$30-39
AVERAGE	51	13	\$42

PUBLIC CLINIC (N=21)

Minority Men	Age	Years of Education	Household Income Range (in Thousands)
Little Brother	42	12	Missing
Ellis	49	12	\$50-59
Grant	51	10	\$20-29
Matthew	53	12	\$0-9
Mack	52	13	\$10-19
Minority Women			
Catherine	41	11	\$10-19
Sherri	46	12	\$0-9
Vanessa	41	13	\$20-29
Emma	54	9	\$10-19
White Men			
Daniel	46	9	\$60-69
Joey	50	12	\$10-19
Nick	47	8	\$0-9
Rick	54	12	\$0-9
Jeff	40	6	\$0-9
Derrick	36	12	\$20-29
White Women			
Liz	53	12	\$40-49
Cece	45	9	\$10-19
Daisy	61	11	\$10-19
Sally Anne	50	12	\$20-29
Karla	37	11	\$0-9
Meredith	46	14	\$20-29
AVERAGE	47	11	\$21

OUTSIDE RECRUITMENT (N=10)

Minority Men	Age	Years of Education	Household Income Range (in Thousands)
Eric	49	12	\$20-29
White Men			
Yellow	50	13	\$10-19
Harold	47	16	\$40-49
Ronald	54	18	\$40-49
Bob	33	15	\$10-19
Eddy	47	20	\$40-49
White Women			
Jenn	50	14	\$50-59
Samantha	26	12	\$0-9
Isabella	41	16	\$30-39
Peggy	53	13	\$70-79
AVERAGE	45	15	\$36

CHAPTER 3: WHOM TO TELL AND WHY? LEVELS OF DISCLOSURE AND IMPLICATIONS

Disclosure of health status can have numerous benefits as well as possible costs for the individual. Some research posits a link between disclosure of illness status and positive mental health outcomes (Figueiredo et al. 2004). Conversely, through disclosing an individual may be stigmatized, and actually experience poorer mental health, strained relationships and possible loss of autonomy (Charmaz 1991; Comer et al. 2000).

In this chapter, I discuss levels of disclosure, motivations for lack of disclosure and reasons for revealing health status. I compare these findings to the extant literature to reveal some support for current discourse although much of the literature better explains culturally visible diseases. Thus, this research can help broaden our understanding of disclosure patterns beyond well known diseases. In addition, I show the influence of race, as well as other factors, on disclosure patterns and the ensuing implications.

The respondents in this research varied a great deal in terms of how much they disclosed to others. Their patterns of disclosure can be organized along four categories: persons who practice *Activist Disclosure*, respondents who exhibit *Open Disclosure*, persons who have *Limited Disclosure*, and finally, those who employ *Reluctant Disclosure*. Disclosure is a dynamic process and persons may shift their disclosure patterns over time. Respondents described a variety of reasons for not wanting to tell others about their HCV status. The main themes that emerged fall along two dimensions: not disclosing because of *Concern for Others*, and not disclosing because of *Concern for*

Self Interestingly, reasons for disclosing also fall along the same dimensions in terms of *Concern for Others* versus *Concern for Self*.

PATTERNS OF DISCLOSURE

ACTIVIST DISCLOSURE

Activist disclosure refers to a type of disclosure whereby a person often reveals their health status in a quasi-public environment, a technique Charmaz (1991) calls strategic announcing. Such a strategy is often necessary when the illness is more invisible or minimized by others, thus applying to HCV. Corrigan and Matthews (2003) discuss levels of disclosure in regard to mental illness. They report a pattern of disclosure similar to activist disclosure called “broadcasting” where the goal is to educate others about mental illness (Corrigan and Matthews 2003). Broadcasting “fosters their sense of power over the experience of mental illness and stigma” (Corrigan and Matthews 2003). Activist disclosure does seem to be a coping mechanism for some respondents perhaps in response to experiences with enacted stigma as well as engaging in felt stigma.

Five persons, or 10% of the sample, fall into this category.¹⁹ Bury (2000) points out how some current conceptualizations of the chronically ill as political activists are perhaps limited in nature and more readily apply to younger and middle class persons. Based on education and income, everyone in this category including Sharon could be seen as middle class, as Sharon used to earn over \$70, 000 per year and her current income does not reflect her middle class status. However, in discord with Bury (2000), Connie and Sharon, 70 and 60 years old respectively are not young, chronically ill individuals. All five persons were involved in support groups, which may help explain

¹⁹ See Appendix 3.1 on page 103.

their desire to share information with others although it is unclear which came first.

Corrigan and Matthews (2003) also found that support groups facilitate the coming out process for sexual minorities as well as individuals with mental illness.

Several of the persons in this group described disclosing at work and all had openly disclosed to family and friends. Sharon, who was recently retired from a business in the medical field, told all the people she worked with, including physicians, management, and patients as well as all her friends. “I told everybody. I am not a person who’s ever found it easy to hide what I do. It may not be somethin’ people approve of but I’m not gonna hide it.” She said later:

“It’s, I just never had a problem in telling. I guess it’s because I don’t care, I mean I am who I am, and if I did something twenty years ago or thirty years ago that was a mistake, I’m probably terribly sorry now that I did it, but I did it. I mean and I’m not gonna say somethin’ that’s not true.”²⁰

Sharon’s statement shows that she recognized a connection between HCV and deviant behavior, yet she disclosed regardless. Connie had been diagnosed twenty years ago. She freely told people when she was still working. Harold told clients where he worked at the rehabilitation center for substance abuse.

The difference between respondents who are in this category and other persons who disclose openly is their activism. Isabella had been the founder and leader of a support group for HCV for a number of years. Despite verbal attempts to minimize her contributions, Isabella was very proud of her work with others with HCV and showed me a plaque she had been given in recognition of her work. HCV was very salient in her life because of this. She described why she started the support group:

“So I said Okay, I guess I’m kinda like the pioneer. And, you know, it’s kind of a spiritual thing I think in me and I, I’m somewhat of a spiritual person and you

²⁰ Verbal utterances have been removed from quotes for ease of reading.

know, I think, you know, God guides you in different areas and you just listen and he, I really think that he guided me in a way because of how devastated I was and how I didn't give up. You know, I could have either gave in to the Hep C, committed suicide or, you know, I coulda stood up and fought, even though I wasn't clearing the virus I could do somethin. So, you know, that's the birth of the support group. Uh, I think what the brute of my goal was not to let anybody suffer mentally like I had."

Charmaz (1991) suggests that strategic announcing can help confidence for chronically ill persons which seems to be applicable to Isabella's statements about being a "pioneer" as well as her showing me her award. She did, as did others, truly enjoy helping others. Isabella regularly received phone calls from strangers who have found her information on the internet or through a crisis hotline. Sharon also received calls from strangers seeking support or information because she published a memoir in a widely circulated national magazine using her real name. She said,

"But people had gone to the trouble, to find my name and find my city and find my phone number. And then they all told me, please excuse me for bothering you. And everybody asked, did I mind talking about it, and of course I don't. I am so willing to do anything to promote awareness, I mean it doesn't hurt me and perhaps it can help someone else."

Connie had a story written about her in the local newspaper not long after she was first diagnosed, chronicling her struggle with diagnosis. She brought the article to show me when we met for the interview. She has also been very involved in a local support group. Harold has been involved in a fundraiser put on by an HCV awareness group and has raised his hand at public events showing he was infected. He has also done HCV educational lectures at facilities where he has worked. Harold described disclosing to people who come into AA with hepatitis:

"...the, AA, there's so many people that, you know, that come in on occasions, and some of will come in and say I have Hep C. And you know, I'll talk with

them and you know, give ‘em suggestions of what I’ve done. And how I get through you know, each day with this disease.”

Jenn, like Harold, disclosed in a work related environment. She attended a conference for work about public health, specifically HIV. She was in a session on hepatitis and felt compelled to disclose when the session leader began describing symptoms of hepatitis:

“And so what, he, when he got to the part about the general malaise, the flu like symptoms and all that stuff, you know, and I just stuck my hand up [J laughs]; and said and that’s the truth. I said I’ve now been on treatment six weeks. I said after my trip here yesterday I was totally exhausted last night, I couldn’t even make it to dinner.”

These patterns of disclosure were not the norm in this sample although they may be an effective means of combating ignorance and silence surrounding HCV. These behavior patterns, however, may not be readily available to all persons and may be more limited to middle class Whites as all respondents except Connie, a Japanese woman, were White.

OPEN DISCLOSURE

The next pattern of disclosure includes those who were also fairly open about their HCV status although they have not involved themselves with activism. Nineteen people or 37% of the sample are in this category²¹ Most of the respondents are White with the exception of Maruf, a Middle Eastern man, Catherine, a Black woman, and Don Yi, a Chinese woman. Eleven men and nine women follow this pattern of disclosure. The household income and educational obtainments are quite diverse for persons in this category. More than half of the people in this group believe drug use many have been the

²¹ See Appendix 3.2 on page 103.

source of infection. Thus, mode of transmission is not related to the level of disclosure ($\chi^2 = .01, p > .1$) as has been found with HIV (Tewksbury and McGaughey 1997).²²

Similar to persons involved in activism, persons who openly disclose had told family, especially spouses and parents, as well as friends. When I asked who they had told about having HCV, a typical response was, “Everybody knows.” When I asked Maruf if he told all his family, he replied, “Yeah everybody knew, everybody, you know, it’s normal to tell, you know, your immediate family that you have a problem, and they all supportive, and they willing to help whenever they can.” Yellow managed to communicate with his son who was in the Navy through e-mail.

Many persons in this group had also disclosed at work. Cece worked at a halfway house where she had been a client when she was diagnosed. After diagnosis, they had a meeting and she told her life story to the whole house. So everyone knew at her work. Peggy has told everybody in the area of the hospital where she worked. She had been infected by a needle stick at work. Lucy, a postal office worker whose husband also has HCV, had also told everyone at work. Many of these persons seemed to disclose very casually. Daniel and his wife talked about how Daniel, a brick mason, had worked at a woman’s home who had HCV and the woman called to tell them she had been treated and Daniel’s wife then told her about Daniel finding out he had it. He said he has been open about it since first finding out. Jeff, a who is married to Karla who also has HCV, said that, “Yeah, I mean, we don't keep it from nobody. I tell 'em. I mean, they gonna be my friend, they gonna be my friend. The way I am, like I told 'em, you know.”

Another respondent presented conflicting views of his level of openness. Maruf said, “I’m wide open. I mean I, I, I, don’t have to hide from anybody. I don’t care what

²² See Appendix 3.5 on page 105-6 for cross tabulations for all chi-square calculations in Chapter 3.

others think.” Yet later, he says, “Doesn’t matter really, and I wouldn’t discuss it with anybody that I don’t really feel comfortable with anyway.” This seeming contradiction in terms of Maruf’s statements may be indicative of the fact that the interview is an account given by the respondent to myself. Maruf may have been trying to present himself as someone who is immune to other’s opinions, based on the first statement. His second statement may reflect more of the tension inherent in disclosure.

Again, similar to persons who follow an activist disclosure pattern, this type of pattern seems to be limited to mostly Whites. While these levels of disclosure may allow for more social support than silence would, it also opens opportunities for discrimination, a consequence perhaps many people of color are unwilling to risk.

LIMITED DISCLOSURE

The next level of disclosure is a more limited or reserved behavior pattern. This group comprises 38% of the sample and is more racially diverse than the previous two patterns as almost half are Black.²³ Education ranges from 8 to 18 years. Income again varies widely with some respondents earning little and others earning ninety thousand or above. Again, more than half of the persons in this group reported drug usage as a means of transmission.

Persons following this pattern typically have told some close family and some friends. Stick talked to a friend who had hepatitis C. David said about disclosure, “Well just my direct family. Most of my direct family though doesn't even know that it's come back (he did not sustain a response after stopping treatment).” Tari has told some of her sisters but not all of them. Grant had told his girlfriend at the time of diagnosis, but has

²³ See Appendix 3.3 on page 104.

not told his sons. Melissa has not told her sister while Jerry said he only talked with siblings and his children about it.

A few persons have disclosed at work, but often only to friends at work. Stick, a construction worker, has told several people at work. He thinks several people there probably have it. Tari, whose husband is also infected, works at a doctor's office and she has told a handful of people there including a nurse practitioner, a doctor, and several friends. Tom, an electrical supervisor, and Jamie, a correctional officer, have both told a few people at work, but with minimal details about it. Meredith, a hair stylist, has told her boss everything and he even allows her to go to AA meetings when she isn't busy at work. She, however, is not as forthcoming with others at work:

“People who, I try to consider the source and like, there's a couple a people I work with who I just tell 'em that I'm in treatment, that I'm doing, that I have a liver disorder and that I'm part of a research team and that's it, you know. I just leave it at that.”

The main difference between this pattern of disclosure versus an open disclosure pattern, is that these people mentioned not telling others specifically and/or described less general disclosure than other respondents. David says that, “I mean, cause it's, but there's not a whole bunch of people, I mean I don't tell most people.” Little Brother said, “Like anybody else, you know, I try to keep it down, you know what I'm talkin about. It ain't nothin like to be just spreadin”. Bob revealed that, “Is, is enough to make me gun shy to, to where now I don't, I don't wanna tell women, you know, that I sleep with that I have it.”

Charlie expressed an interesting contradiction within this interview about his level of disclosure. Early in the interview, Charlie told me, “Nah, I didn't really tell a lot of people”, but later said, “I have talked to a lot more than you really think”. Charlie's

statements are similar to Maruf's comments previously discussed where he described different levels of disclosure. Similar to Maruf, Charlie may have been trying to distance himself from any sense of feeling stigmatized or reticent about disclosing.

A limited disclosure pattern is practiced by a wide variety of men and women in regards to race/ethnicity and class. This option may allow individuals to access some benefits of disclosure while shielding them from too many potential negative consequences of disclosure. However, disclosing in a limited fashion does not promote awareness.

RELUCTANT DISCLOSURE

The final pattern, reluctant disclosure, refers to those who are virtually silent about their HCV status and have told very few people. These respondents are different from those practicing limited disclosure in that they mentioned secrecy or shame and took pains to avoid disclosure as a whole. This group is 15% of the sample or eight people, although this is probably an underestimate because of the data collection process. In other words, the most reluctant persons may not be getting healthcare or if they are, chose to not participate in this study. This category is diverse in terms of education, household income, gender, and race.²⁴

Persons who are reluctant may have disclosed to a family member(s) although it often took time to even do that. Ronald said, "I have told my family. I finally--it took a while. I didn't tell anybody for, uh, you know a long time. I didn't tell a soul." Lauren reported that she only told God at first and eventually her mother. Vanessa limited what her family knew, "But my family was, was good with it now. I didn't--my-my brothers

²⁴ See Appendix 3.4 on page 104.

and sisters and stuff, they don't really know what I have now.” Those who have a spouse or partner have told them. Mack has only told his wife. Vanessa revealed, “Cause I really didn't want anybody to know, you know, except just, uh, you know, my husband knows, but my kids now, they just know that I'm sick, you know. They don't know exactly what it is.” Andrew, who lived with both parents, has only told his mother, although he said his father knows a little bit about it.

In regards to disclosure to friends, there is some variety within this group. Lauren said, “But I just, I, now I'm not interested in sharing anything with any of the people that I knew before, I haven't told any of my friends. Like I told you just my family.” While Ronald revealed, “I gradually told my best friend, and I, I presented it to him that I had, I didn't never, I didn't come right out and say it was Hepatitis.” Sherri, who had told no one that she specifically has HCV did say that, “Some of the people-like my pastor, his momma, his wife- they know I have problems with my liver but they don't exactly know what it is.” None of these people have disclosed at work. Mark, a law enforcement officer, is adamantly opposed to disclosing at work. Vanessa also doesn't want anyone at work to know. Eric has told no one except a physician he knows from off-track betting who has run a few blood tests for him. Ronald said, “But, I'm actually, since you're doin' this research, and for your thesis, I'm, I was kinda grateful in a sense to be able to have a interview about it because I don't talk about it hardly at all.”

Following a reluctant disclosure pattern is seemingly exhausting for some. Mark was adamant about not meeting me near the town where he lived, a sentiment also expressed by Lauren. Sherri started crying in her interview because of her fears possibly because she never talks about it with anyone (although numerous respondents cried).

Ronald also expressed how he had at times been consumed by fear and worry about the disease and finally had to talk to someone. Thus, this pattern of disclosure does not afford accessing any benefits of disclosure which at least for some, has real consequences. However, Andrew and Vanessa who practice reluctant disclosure did not express distress in the interview process, although this could reflect a more sophisticated presentation of self than other respondents.

DYNAMIC PROCESS

Levels of disclosure are not static and change depending on circumstances and across time, as others have also found (Charmaz 1991). Several persons described how their levels of disclosure have changed. Samantha has moved from being quite reluctant to more limited disclosure as she has gained information. Sallie Anne has also transformed her disclosure as she has realized the severity of the diagnosis compared to her Non-A, Non-B diagnosis in the 1980's. "Right, they told me it was, if it wasn't Hepatitis B, it was non communicable, it was don't worry about it you know, it was basically like it was a kidney infection and stuff". Thus, she simply didn't take it seriously or think it was important enough to share with others. Only once being diagnosed with HCV and gaining information did she begin to disclose. Larry, who described a limited disclosure pattern, could move in the direction of being more reluctant because of a very negative reaction he had recently received after disclosing at his former job. Catherine changed over time from being more limited in her disclosure to more open. This transition was because of her strong religiosity. She centers her health and illness around her faith and felt that she should be more open as a testament to her God. She had been diagnosed eleven years ago, but started to more openly disclose two

years ago. “But then I you know, I just started coming out with it, because I remember God’s word, he said if you be ashamed of me before men, I be ashamed for you. So I started letting people know.” However, Catherine iterates how disclosure can fluctuate even on a daily basis:

“You know and it's still sometime there are like days ok you just feel like ok this is not anybody’s business, and then there are days that just like I don't care, you know so, it has it's days, but I’m at the point now, to where I look out to the world. Cuz I’m a picture of health. I'm here to prove it.”

Finally, Roxanne seemed to be moving in the direction of more open disclosure because she has cleared the virus through treatment and could talk about it in the past tense.

Gray et al. (2000) found a similar pattern among men who had undergone a prostatectomy in that they could now disclose because they no longer “had” the disease.

REASONS FOR LACK OF DISCLOSURE

As seen from the preceding discussion, many respondents choose not to disclose to a few or many people. According to Charmaz (1991), avoiding disclosure keeps illness apart from notions of self and skirts any potential experiences with stigmatization. Throughout the interviews, various reasons emerged for not telling others about having HCV. The reasons mentioned fall into two broad categories: lack of disclosure because of a *Concern for Others* in some regard and lack of disclosure because of a *Concern for Self*. Persons mentioned a lack of disclosure because of the self slightly more than silence because of concern about others.

CONCERN FOR OTHERS

Prevent worry. Seventeen percent of the sample mentioned not wanting to worry or bother others. Although cultural notions of gender may indicate that women would be

more likely to express not wanting to cause concern, in this sample, men and women who disclosed at varying levels expressed this. Others have found that HIV positive persons are reluctant to disclose for fear of disappointing or burdening others, especially family (Chin and Kroesen 1999; Mason et al. 1995; Simoni et al. 1995). Older respondents in a study on men with prostate cancer were especially likely to say they did not want to burden others with disclosing their health status (Gray et al. 2000).

Interviewees in this sample often mentioned family when talking about not wanting to worry others. Grant explained why he had not told his sons, “My one in prison, out of town somewhere in Shreveport. And the other little one he just got grown, so I'm gonna let him be grown.” Catherine expressed a similar sentiment about telling one of her children that it was hepatitis:

“And I don't want him going around worrying about you know my Mama, you know, is my Mama gonna die. Is something gonna happen to my momma. Cuz he had enough of disappointments in his life, just growing up you know, with his daddy, you know, not really being there for him, being in and out of jail, so I don't want to do that to him.”

Tari has not told one of her sisters: “And my other sister she just recently had some heart trouble. And I just didn't want to worry her with that, but I don't mind telling my, I just don't want to worry her with it right now, cause she's going through so much.” Eddy says of when he told his family, “I don't remember if I told my parents, I told them relatively quickly. I told the whole family relatively soon. My delay would not have been embarrassment, but being, creating worry for them.”

Others believe that persons may associate hepatitis with dying and will cause them tremendous anxiety. Sherri doesn't want to tell her kids that she has HCV (although they know she has a problem with her liver) because, “Ah, well. They know I

have problems with my stomach. And they think every time I get sick I gonna die, so I try not to talk about it.” Vanessa’s children also know she is sick, but don’t know exactly what is wrong. Vanessa said about disclosing to a friend:

“My friend, and it was, it was a while before I told her you know, because I just didn't, you know, I just didn't want everybody, you know, to say oh my God, you know, and start you know, because then they start lookin' at you and they're wonderin', you know, they're, you know, and it starts and go, you know I don't want her to die or whatever, so I mean, I don't want people to get that mentality, so I just, I just kinda, I guess sugar coat it, yah.”

Derrick describes how his grandparents might know, but he doesn’t discuss it with them.

“They don't think of me dying anytime soon. So I'm not gonna even go there with that with them so.”

Reminder of past lifestyle. Hepworth and Krug (1999) found that diagnosis of HCV brings up reminders about past drug usage for many persons with HCV which in turn generates fear about interactions with others concerning their HCV. Many respondents mentioned that their drug use was widely known about in their family and perhaps this knowledge suppresses any concern about reminding them. Considering that 58% of the sample reported past drug usage either intravenously or intranasally as a possible means of transmission, it is curious that only three respondents or 6% of the sample mentioned this as a reason for not disclosing. Bob who had only recently re-established ties with his family took care to not remind them of his past:

“Well I think a lotta the estrangements on my family runs back maybe from the time I was like twelve and it’s really just recent years, the last maybe five years that those have been starting to be bridged and I have a decent relationship with my close, closest family now but even then, yeah I can remember not too long ago at a like a family get together probably around a holiday at a, at the dinner table we’re having dessert and coffee or something after dinner and like direct families and grandparents and just a bunch a people and like me saying something about the past, I don’t know if it was about shooting drugs or living on the street or what but I remember saying something and my mom just being like don’t tell me, I

don't wanna know, you know, like I can just imagine I don't wanna know and so there's def-you know there, just sorta this like don't, don't tell don't-what's the policy in the army about gays?"

It could be that for many of the respondents, their drug usage had not led to complete estrangements with their families such as the case with Bob and therefore they did not need to go to the lengths to distance themselves from past behaviors.

CONCERN FOR SELF

Fear of discrimination and prejudice. 25% of respondents mentioned not disclosing because of a fear of discrimination and/or prejudice, the most common reason given among this sample for not disclosing. People who mentioned these fears were also more likely to have disclosed in a more limited fashion or be reluctant ($\chi^2 = 6.6, p < .01$). HIV positive Asian Pacific American women feared discrimination because of ignorance about HIV (Chin and Kroesen 1999). Part of the fear among persons with HCV may stem from the public's fear of contamination similar to what Tewksbury and McGaughey (1997) found in regards to disclosure and HIV.

The theme of being seen as contagious permeated many comments. Vanessa explained:

"You know because people get kinda, you know--if you say certain things especially if you're dealin' with somethin' that's contagious or whatever people get kinda scared and stuff. You know, and I don't want everybody to you know, but, it's, you know it's not been easy dealin' with it, you know."

Isabella worried at first that her husband would leave her because she had a disease that could be sexually transmitted. Larry's mom reminded him frequently to not tell other family members because they have small children and she didn't want them worrying about being around him. Larry agreed with her fears. Several researchers have found

among other chronically ill persons that family members have encourage silence around others (Charmaz 1991; Chin and Kroesen 1999). Catherine had intense fears at first:

“You know I was looking at my life, I say, God, you know, I say, nobody will ever marry me. You know, you know I was sad (Catherine crying) because you know with the hepatitis, I say, you know I say, you know I'll have this the rest of my life, you know, and I say, you know, I'll always be alone, I say, because if somebody know the truth, they will not you know want to be around me.”

David also felt he might be shunned. “I fear that most people when they hear that I have it, I feel most people react like that. Even you right now, I feel like you feel like well glad he's over there he's got leprosy.” Samantha told me that, “...but I mean I'm embarrassed to go tell the doctor, here, test my daughter for hepatitis C because she might have caught it from me because of my irresponsibility.”

Part of being seen as contagious would mean being interpreted in a new light by others. Tari was afraid a friend of hers at work would treat her differently. Mark, a law enforcement officer, feared disclosure would affect cohesion at work and that others might hesitate to save him in the case of an emergency, “...some of em' will get kinda antsy being around you if they knew.” Roxanne feared losing her job if they knew she had HCV because it is a healthcare organization. Larry spoke about future decisions in regards to work:

“If I don't have to work with them, or be around them, or we're not forced to be together in a situation, I won't, you know, I don't care. But if we're forced to be in a situation, like at work, I won't say a word anymore. That's it. I know it can't be contracted that way, but they don't. And I can't blame them for that. So I'm not going to, I'm just not going to say anything.

Fear of being shunned was so strong that Samantha described letting her ex-boyfriend shoot up with the syringe she had used despite knowing her HCV status. “And I just, I couldn't say it. You know? I couldn't and I guess in a way I justified by saying, oh we

shared needles so many times before I knew I had it.” Bob also expressed internal conflict about his lack of disclosure to sex partners:

“...it sorta weighs on me actually, not sort of, it does weigh on me, weighs on my conscious because I don’t, it’s one a those things that I live with [B clears throat]; that’s a moral kinda twist because morally, I think I should.”

His feelings of guilt from not disclosing are similar to what Nack (2003) found when women with herpes did not disclose.

Waiting to disclose. Numerous researchers have delineated the aftermath of diagnosis as a stressful, uncertain time for people (see Chapter 5) (Glacken et al. 2001; Hepworth and Krug 1999; Weitz 1989). This uncertainty however helps explain the phenomenon of waiting to disclose mentioned by 23% of the sample. Gray and colleagues (2000) also found that men diagnosed with prostate cancer discussed waiting before disclosing with family. Most people explained that they wanted to have more information before telling others about having HCV. Tari says in reference to one of her sisters, “But the other one I just didn’t tell her cause she’s too emotional, but now I can tell her, cause now I have more facts. And I can tell her now.” Grant told me, “I was more depressed myself... I just wanted to think about this awhile. And see what I was gonna have to do to correct this.” Jerry said about waiting to tell his family, “I don't know. I just--I go through a lot. Wanted to go through it by myself, you know, then I'd see what it was then I'd tell 'em, you know?” Jenn waited to tell her kids for about a month after being diagnosed. I asked her why and she said, “I’m not sure, I th-I, I think that I was afraid that they’d probably didn’t know that much about it and cause my older son in fact says you’re gonna die (when she did tell him).” Ann also mentioned wanting to gather more information before telling her kids. Samantha also waited quite a while to

tell her family. “No, I didn’t tell anybody for a while, just probably in the last couple of months when I started learning about it.” Many of these comments suggest that for these persons, they wanted to avoid what Charmaz (1991) calls “spontaneous disclosure” which is often wrought with emotion, and instead have a protective disclosure that is much more controlled. Interestingly, a “Fact Sheet” on a HCV website suggests that persons “should be advised to wait until they feel emotionally ready and have enough facts before divulging their status” (Franciscus 2002). Thus, numerous respondents are practicing what “experts” are advising persons with HCV to do.

Private information. Finally, 17% of the sample explained that they did not disclose because it was simply private information. Charmaz (1991) describes how illness status is as private as sex and finances for many people. Racial and ethnic minorities in this research were more likely to report this ($\chi^2 = 13.26, p < .001$). To some people, their HCV status is simply private and of no concern to others. Jerry, a Black man, does not discuss his health with certain family members. “Well, I don't talk to nobody but my family about my sickness, you know? I don't talk to no outsiders. I don't even talk to like my cousins, first cousins.” Catherine said that, “... not nobody, it was just something I really didn't want to talk about to people.” Tom said, “Well yeah they're my friends and I don't, you know, I used to consider it private but I guess the better word would be I'm a reluctant person. I don't, I don't put my business out on the street.” Andrew commented about disclosures by people with HCV at the dialysis center he attends:

“But I figure that’s personal business so I don't discuss it out there. They sit there and, they sit there and talk about it. But I figure that’s personal business so I don't discuss it out there with a couple with it that come in and a guy and they have

Hepatitis C. But they talk about it freely. And I'm thinkin, I'd just rather not talk about it. I mean in a public area. You know”.

He reiterated again later, “That's not really anybody's business. Not that I'm ashamed of it. You know, but just, it's nobody's business.” Of course, a respondent might have said they didn't disclose because it was private to save face during the interview rather than reveal other fears that kept them from disclosing.

Fear association of HCV and deviance. 12% of the sample feared others would associate HCV and drugs or homosexual behavior. Andrew has not outright told his father, “No, cuz he's kinda [makes a noise]. You know. It get out in the club, somebody do too many drugs, go oh you know you got hepatitis.”

Mack fears an association with homosexuality, a theme that came up several times in his interview. He has not told his sisters because:

“No, I mean it's like, I think that people are, like I say, there's not much known about it, and I feel that people will draw a adverse inference as to how a person got it. You know the ignorant factor comes into play. You know I've been to prison, so you know they'll probably be thinkin' some of everything. You know what I'm sayin'. And I, you know I don't have time for that...Worst case scenario, is that about any type of involvement in homosexuality. ”

Roxanne's mother did at first associate her being a lesbian with HCV and Roxanne said she feared that association as well at one time. “Because of my lifestyle I knew people would say that was how I caught it”.

REASONS FOR DISCLOSURE

Reasons for disclosing also can be looked at in regards to disclosure because of a *Concern for Others* and disclosure because of *Concern for Self*. In contrast to reasons given for not disclosing, people mentioned disclosing for others' sake almost twice as much as disclosing because of a concern for the self.

CONCERN FOR OTHERS

Protect others. Forty percent of the sample mentioned disclosing to protect others from HCV, although men were less likely to mention this ($\chi^2 = 6.42, p < .01$). People who mentioned wanting to protect others as a reason for disclosure were more likely to practice limited or reluctant disclosure ($\chi^2 = 7.08, p < .01$). In addition, respondents with at least some college were more likely to mention disclosing to protect others ($\chi^2 = 11.48, p < .01$). Peggy explained she told everybody because she had to take precautions. Tari talked about her reasons for disclosing to her son:

“Before I knew anything, because...I wanted him to know so that he can be careful, you know, with his life and his decisions that he make, and that if you know, sometimes you don't know what your kids have done. Like if he's used Lonnie's razor or even my razors, cause I have my own now too. When Lonnie got diagnosed we always kept everything, like razors and stuff, his, being a boy, we made sure he had his own, but you never know when we're not around. We didn't tell him about Lonnie, when it happened to me I did tell him about me, and he knows about Lonnie now.”

Mack also told his wife to urge her to get tested. Sharon said,

“I had my children tested, I had my daughter in law tested, and I had the baby tested (referring to grandchild). Because although it's not an easily transferable disease there is a possibility that you can get it by brush--, by using somebody's toothbrush, and I couldn't remember whether my children had ever gotten cut, when I was cut, you know?”

When I asked Andrew about his mother's reaction when he disclosed to her, he said he explained to her how he had to be careful with his toothbrush and razors around the house and that she eventually understood.

Ann eventually told her son although she almost seems to have told him to absolve herself of any responsibility:

“But then I found out that my youngest son, after my mind kinda bottled, I settled down and got things settled in my mind, I told him he need to go and be

checked because I remember a while back, he's gettin' pneumonia quite often. And one the doctors at, the Lake, had told us that he, it look like he might have had hepatitis. So I don't know if he end up gettin' it from me I guess. But you know how these young people are you know, I'm a go mom, I'm a go, I'm a go, I mean he's twenty-six I can't really make him go. It's not like he a little bitty kid and I can do it, he grown now so, all I can do is inform him about he need ta be checked, and I advise the other of it too. To do the same. That's all I can do."

Roxanne's statement suggested she disclosed to protect her own sense of responsibility perhaps more than to warn others. "So I mean I really wasn't too worried about it but I didn't, I didn't lie to anyone? Straightforward, I mean this is what I had and there is a chance, ya know." (Scheon and Crosby 2004) found that among some HIV positive gay men, disclosing HIV status is a welcome release from responsibility which is perhaps seen in these statements about disclosing HCV status.

A few respondents mentioned wanting to contact persons who they may have used drugs with or knew they had a history of drug use as was the case for Melissa. She fretted over telling her sister who she does not have contact with:

"It was a real hard thing for me to decide, and I also was concerned about my sister, who I'm estranged from, and I knew that she had been through the same thing. And I know she's not as I am, well read on it or anything, and I thought she probably didn't know if she might ask about being tested. And I really went around in circles with that, because I wanted so bad to let her know to do it. And it was very hard for me to decide not to do that. I guess through just talking. I guess I got the impression that she would probably find out, because it was becoming more wi----, you know, widespread and people who've been involved... Again it was a very, very hard decision. I thought about how to do it anonymous. There just didn't seem to be a way to be able do that without her realizing I didn't want to be contacted."

Charlie said he plans on calling a family member. "I have a cousin who's just like a brother, I'm gonna call him and tell him he needs to go (get tested). He and I are thick as thieves for a long time. I mean, we ran together for a lot of years." Charlie also spoke of

as he found out more information after diagnosis, he became concerned about friends. He told them to get checked for it:

“But, yah, the more I found out about it and the more I sit there and knew people who ran with me and we did things that we shouldn't do together, you know, like toot cocaine with the same rolled hundred dollar bill. And it might give you a nose bleed, no body would think nothin' about it. And, uh, you know I was concerned--I still am. I mean, I'm not finished.”

It is interesting that Charlie mentioned two times during the interview how he planned on contacting these people yet he had known about having HCV for eleven years.

Others mentioned telling romantic and sexual partners out of a sense of responsibility. Sallie Anne told a boyfriend she had while her and her husband were separated so that he could get tested. She wanted me to know that she was not, “spreading it around”. Nick also mentioned telling anyone he was with and that neither his girlfriend nor wife ever contracted it and that it was the first thing he told them. Bob as previously mentioned was torn about disclosing to sexual partners and usually did not and then felt guilty. Simoni and colleagues (1999) discuss how HIV positive women disclose to partners out of sense of ethics as well.

Several people mentioned disclosing to protect health care workers. Sharon talks about when she fell and cut her head and had to go to the emergency room:

“And I kept tellin' everybody, Listen, I have Hepatitis C, please wear gloves. And one guy looked at me and said, What are you so worried about? We're not gonna give you anything. And I was furious, Alicia, because I wasn't worried that he was gonna give me somethin', I didn't wanna give him somethin'.” [S laughs].

Lauren also stated that if persons about to draw her blood seemed like they were not going to wear gloves, she made sure to tell them she has HCV to warn them. Vanessa said,

“Yes, yes I make sure, I make sure I tell every one because, I, you know, I don't want, you know them not to know because they have to treat me and if somethin', you know, if somethin' happens, well, they, they... Yah, and they need to know what they're doin' in order to be able to protect themselves just, like, you know, if I go see the dentist or somethin' I make sure, you know, you know, I circle it on the little paper or whatever, but I make sure I tell them, you know because sometimes people don't read”.

Charlie told me he tells all doctors he sees as did Eddy. Eddy explained,

“It's usually not something that is a big deal, but, uh, every time I go in to a, a health care person, or dentist or anything like that, I do say it, because I don't want them to get infected. I want them to know that if blood splashes, they should (Alicia and Eddy laugh because Eddy makes ducking motion), you know?”

Lucy has told many people at work to warn them:

“Yeah, yeah. I mean I wouldn't care, you know, like, like I work with eight people. Eight people that work on the weekends so when I first found out that I had Hepatitis C I told them all I said You know, if I cut myself or fall out, don't touch anything. You know, cuz, you know we will get a paper cut or, you know.”

The tone of many of the descriptions about disclosing to protect others was often ethical in nature, that the individual had an obligation to tell others. Gray and colleagues (2000) found that men with prostate cancer described disclosing when they felt obligated to prepare their family for a possible death during surgery, genetic risk or because the family would want to know. While many of the respondents in this study certainly felt obligated to tell others to warn them, part of the impetus to do this could stem from medical discourse. Hepworth and Krug (1999) discuss the medicalization process of persons with HCV that begins at diagnosis. They posit that doctors and other health practitioners teach newly diagnosed persons that to be a “good patient”, persons with HCV must disclose their status. In addition, pamphlets given to HCV patients encourage disclosure without attention to the ramifications of disclosure (Hepworth and Krug 1999).

Thus, respondents in this research may be reflecting pressure from the existing medical discourse to disclose their status. Vanessa and Lauren, both of whom are reluctant to disclose, explicitly mentioned telling health care workers in order to protect them, lending support to Hepworth and Krug's (1999) assertions. Another interpretation of this type of disclosure is that people are simply informing others objectively about their illness to help them avoid getting it (Charmaz 1991). According to Charmaz (1991) people who inform do not see informing as risky or view having the illness as discreditable (121). While this may apply to a few people who mentioned this, such as Peggy or Sharon, overall, the connection between mentioning this and lower levels of disclosure does not support Charmaz' (1991) findings.

To explain atypical behavior. 32% of respondents mentioned disclosure to explain their behavior because it deviated from their previous or usual behavior. All who mentioned this reported symptoms from the disease itself and/or treatment which corroborates findings by Figueiredo, Fries and Ingram (2004) in that they also found that women with breast cancer disclosed in relation to their increasing levels of fatigue, pain, functioning, and energy. In addition, those who mentioned this were likely to be activists or open ($\chi^2 = 6.07, p < .01$). Kelly (1991) described how individuals with ileostomies also told others when they needed to explain unusual behaviors.

Several respondents described disclosing to friends. Sharon talked about telling all her friends through a letter she found off one of the hepatitis support websites. The letter exemplified what she was feeling, "...people had to understand that you are exhausted, you are drained, your liver is not filtering. And, you may be able to walk fifteen minutes one day and the next day you might not be able to get out of bed". Cece

told a friend of hers who came to pick her up that, "...this last shot did a number on me. I said it's like it's just suckin' the life outta me or something." Daisy talked about telling her friends at church preemptively in order for them to know about the possible side effects of treatment so they would understand her behavior. David also told friends he practiced tai chi with because he felt they were noticing his endurance was down.

Several people discussed disclosures at work in order to explain absences or inability to perform in an appropriate fashion. (Munir et al. 2005) found that chronically ill individuals are more likely to disclose at work if management of the illness involves specific regimens. Jason told people at work when he started treatment to explain his frequent doctors' appointments. Larry disclosed at work:

"So when I was out there, trying to swing a sledgehammer in this heat, it was just, it was killin' me. And I could, I could drive a stake half-way down, I'd have to squat down. [Makes panting sound] And everybody was saying what's wrong with you, what's going on, so I finally I leveled with everybody out there."

Charlie has told the nurse at work and also some co-workers to explain any deviant behavior while on treatment. "Yah. I went to human resources and I talked to them. I went to everybody. I went to human resources and I said there's side effects from takin' this medicine and one of them is you can lose your temper." He also said that,

"I've talked to everybody who works for me and told 'em what I'm doing. And I said, now if I seem stupid or kinda scatter brained or forgetful 'cause I'm not a forgetful person, I said, ya'll have to abide by it. I mean, there's nothing wrong, I'm just I'm on this medication and it makes you kinda goofy. And it does, it makes me goofy sometimes."

While at a conference with coworkers with whom she used to drink alcohol, Jenn felt she needed to explain why she no longer drank. Jenn also made sure to tell her superiors at work about the possible side effects of the treatment:

“Uh huh. And I gave him a list a the possible side effects, you know, espec-and then I one day I did get, not into it but I got smart with the assistant director he goes There’s that irritability! [A laughs]; cause they know what the side effects are, I wanted to make sure they knew, so.”

Vanessa’s comment supports the idea that disclosure is necessary when one can no longer pass as healthy. “So I’m glad I didn’t start to lookin’ like I was sick, so I didn’t have to answer any questions because if you start to look like somethin’s wrong with you, then you have to tell, you know.”

Activism 29% of the sample mentioned the desire to educate and or help others. Women were more likely to mention this ($\chi^2=3.86, p<.05$). While all the people who disclose at the activist level mentioned this, people who disclose across varying levels also frequently mentioned wanting to help others. (Joachim and Acorn 2003) also found among some persons with scleroderma, a rare disease, a desire to educate others. While Gray and colleagues (2000) found that younger men with prostate cancer tended to disclose widely with the intent of educating others, I found no differences by age among those mentioning wanting to help or educate others. Larry mentioned talking with old friends of his at the methadone clinic who he has known for decades:

“Oh yah. Oh yah. Let’s see. Joe, Joe, two three of them have Hepatitis C, and you know we all talk about it. And they always come to me, and say how’s that medication treatin’ you. And I say, you know, sometimes it’s better, and sometimes it’s good, sometimes it’s bad, but I keep tellin’ em’, they need to have get a blood test, cuz about the same amount of time, and I they need to Jerry my friend that died, very good. I said, you saw what happened to Jerry. They say I’m gonna go, I’m gonna go...when they say it, I, you’re not going anywhere. But the clinic does test once a year, to see if the enzyme level has changed, and that’s an indicator right there, that something’s wrong. And so they’re getting tested once a year.”

Several respondents talked about wanting to contact persons who may be at risk as discussed in terms of wanting to protect others. This could also be seen as wanting to

educate or help others. Respondents' levels of disclosure are related to their experience in disclosing to help others. For example, Sparky, who discloses openly, told others at work in limited detail. He revealed to some coworkers how a safety meeting they had where hepatitis was discussed "...was fifty percent wrong. I said it's not, not real accurate, some of its, okay, if you wanna really know ask somebody that's into it then you'll know." Sharon, an activist, said, "And I had offered, and still offer, and will continue to offer myself... for the awareness of Hepatitis. I've done a radio show for a friend of mine who does it all over Louisiana."

Catherine said, "And, you know I just wanted to let them know, to give them some knowledge on it. That I'm still Catherine, that I'm not poisoned, I'm not contagious, that I live a normal life everyday just like you." Catherine also mentioned telling other to give them knowledge and help them find God:

"Because sometime I will meet people and it's like, they'll be sick, they'll have like cancer or something like that, and they'll be talking about, you know, my cancer, and that's when I get to minister to them, about it's not your cancer, and I let them know you know about the hepatitis and what God did for me. And that's when his word gets out, but I just don't run around telling everybody."

She told an interesting story about disclosing to address others' ignorance. She was among a group of women who were discussing hepatitis:

"She say, they say it's worst than AIDS, and she say, it make them, you know, she just saying how it makes them look, and how they get when they get it, and she say you know if you catch that, she say you know that they don't have no cure for that, she say, because you know they don't have medication for that...I say well how does hepatitis C look. And she say, you know they be sick, all poor and you know they just don't look like their self. I said really, I say because I have hepatitis C. I say so how do I look...I say, and no you can't catch hepatitis from shaking someone's hand. I say, and you can't catch it from kissing a person or none of that. I say hepatitis is given through blood. I say through somebody sticking you or something like that...I said, I've been to where they pierced my ear with this little gun thing...You know I say, we don't none of us know where it

came from, you know, I say, it's just something probably been around long time, that they just gave it a name.”

Thus, as Catherine’s story indicates, wanting to educate others may be a means for addressing stereotypes about HCV and can serve as a means of empowerment. Because in this sample women were more likely to mention wanting to help or educate others, it is important for future research to ascertain whether this is a viable means of empowerment for men also.

As a Symbol of Trust. Disclosure is a means of feeling close to others and this came up for 10% of the respondents who indicated that telling people they were close with was a symbol of their intimacy or trust. Lee and Craft (2002) found a similar phenomenon among people with genital herpes. They mentioned that persons with herpes disclosed because to not tell would impede on a valued relationship. Gray and colleagues (2000) found that men with prostate cancer mentioned telling family because they didn’t want to hide anything.

Catherine talked about how when she had a “friend” for several years that, “he knew, and this was no secret. You know, because this was the man I was going to marry.” Ronald also told his girlfriend who does not speak English and he is not sure she completely understands. He wanted to bring her to a bilingual doctor so that it could be explained to her as his Spanish was not that good. “I don't know what she thinks. But I told her, and I'm gonna make sure she understands. I just--that's just only fair.” This comment also reflects the obligatory, moral aspect reflected in comments made by others about disclosing to protect others. Andrew said he did not tell the last woman he was with because they used protection and were only together six months. His statement also supports the idea that disclosure is only necessary for serious relationships. Bob has told

the women he has been in serious relationships with, "...so when I was like talkin' to her we were in love and I was like tellin' her about my history and who I am and, you know, and certainly this was part a that and I was being intimate with her."

CONCERN FOR SELF

Seeking Compassion. While many disclosures could seemingly be interpreted as being for compassion, only 33% of the sample specifically mentioned disclosing for this reason. At least some of these disclosures can be seen as "spontaneous disclosures" in that they are not planned and intensely emotional (Charmaz 1991). Joey's mother told me about how he called her crying when he was diagnosed. Samantha also mentioned crying and finally telling her partner after he kept asking her what was wrong. Ronald finally talked to his best friend. Because of his secrecy, he was experiencing thoughts about death and mortality and needed to talk with someone. He also eventually told his AA sponsor. Isabella, Maruf, and Jenn all told co-workers before anyone else either because they were at work when they got the news or going to work in Maruf's case. All were looking for support in post diagnosis concern. Ann, Sherri, and Daisy have all told their pastors (although Sherri only revealed it was a liver problem).

Daniel talks about wanting to talk to others on treatment because only they understand how difficult it is:

"And I was tryin', and really and truly it's good to be able to talk to other people that's on it, cause the person that ain't on it, they don't know what it's like. They, they can't even imagine. You can, you can try to imagine but you can't. And everybody that's ever been on it will tell you the same thing. You can't imagine the way you feel, there's no way to explain it. Um, you can tell somebody you're depressed, you can tell somebody you're edgy, you can tell somebody, but you can't explain the way you really, you really don't feel like yourself at all."

Bob talks about reasons for disclosing to some friends:

“...like my friend Joe and a couple other people who are, I, I’m very close with in confidence with about either sharing myself for kinda to get stuff off my chest or to and, kinda talking with people and finding out things about them like kinda sharing, sharing in myself and, you know, to kind of a, I guess to sort of ease that feeling of like, that I talked about earlier about like social outcast kinda thing, you know, that, that wow, you know, here I have it too, you know, to kinda, sort of demystifying or devaluing the, the kind of junkie’s disease sort of stigma.”

While Bob is seeking compassion, his comments also mesh with research findings concerning herpes where people disclose to self-verify their non-HCV identities although he is the only respondent who explicitly mentioned this (Lee and Craft 2002).

David told his employers at a previous job, “Because I felt like I needed to. And I felt like by telling that I would get, some moral support, or support”. He goes on to tell me that he lost his job there perhaps as a consequence of his poor performance because of being on treatment.

Some respondents said they feel more comfortable telling medical personnel. David believed health care workers would understand because they had education about HCV. Ronald finally talked with his family doctor because he trusted her. He has had difficulty telling people about his HCV:

“She’s known about my drug use and different things and she explained more. I finally came out and told her, and she explained more to me about this issue and said you know, that--I can’t remember if it was her or Dr. Ruth that convinced me we needed to know how much damage was already done.”

Ronald’s decision to disclose to her may have been for instrumental help, which he did receive. Thus, for persons such as Ronald, the decision to disclose to his doctor was quite beneficial. She gave him information and recommendations that he followed.

Derrick was the only respondent who seemed to go beyond disclosing for compassion to the point where it was for sympathy or as an excuse, a phenomenon

described by Charmaz (1991) as flaunting illness and links back to Parson's notion of secondary gains (Parsons 1951). Kelly (1991) discusses how some persons with ileostomies disclose for sympathy or because they enjoy being in the sick role and that these disclosures may lead to social ridicule or rejection by others. Derrick, a horticulturalist, explained how he could no longer work outside, "Do the things I used to do. It kills me, literally, when I get home at night I'm, my legs turn red from heat rash or whatever." He told of his last work experience:

"You know fourteen hours a day out in the hot sun anymore. I just, I was killing myself. I just told the people I had to go. I can't do this, I turned in my uniforms. Thank you, but no thank you. I can't handle this."

However, he told me he goes fishing whenever he can out in the sun. He told me about his experience at work shortly after his biopsy:

"And they told me I couldn't go to work for you know four or five days because of the type of work I did. And my boss didn't like to hear that....My boss sent me out all by myself 102 temperature, sick as a dog, to do irrigation work down out at Cortana Mall. I did that for the first day, the second day, I only did it for half the day. And I just told him, I'm going home or I'm going to die."

Later, I asked Derrick how he felt most of the time and he replied, "Uh, usually pretty good, you know." He also relayed an interaction with someone at the disability office because he applied for disability. "And I told him look I'm not an idiot. I said I have Hepatitic C, I'm terminally ill, I'm dying here. And they told me I could work in a restaurant. They said I wasn't sick enough." Derrick was a stage two in terms of liver fibrosis which is moderate scarring and numerous other respondents reported similar stages if not much worse. It is also curious that Derrick told me information that is inarguably incorrect about the biopsy experience. No doctor recommends not working for a period of days after biopsy. In addition, one would not have fever because of a

biopsy. Thus, it is unclear why Derrick told me these things when I was studying HCV and would presumably know they were inaccurate.

In short, Derrick was not upholding the expectations delineated by Parsons (1951) with regards to the sick role. While he felt that he should be exempt from normal social obligations, such as working, the government (disability office) did not sanction this as his illness was not seen as severe enough. Derrick discussed how his girlfriend, a person with paranoid schizophrenia, was on disability and got brand name Xanax because of her benefits while he had to take generic, suggesting how he would like to use his HCV as a means for secondary gains (Parsons 1951). He did not seem dedicated to getting “well,” another expectation associated with the sick role. While he had sought technically competent help, he did not cooperate with the physician in terms of getting well in that, he still drinks alcohol and has rejected treatment because among several reasons, he would have to quit taking Xanax (Parsons 1951). During my interview with him, Derrick did seem to be performing. Charmaz (1991) describes how persons flaunting illness may “objectify self and illness and treat them as products that they manipulate for audience effect” (127).

For Instrumental Help. In order to receive support or assistance of various kinds, individuals have to tell others on occasion about their HCV status. 23% of the sample talked of disclosing one or more times for some pragmatic purpose. Cece told me about calling a woman who worked at the halfway house because the woman’s husband worked at the Department of Health and Hospitals. She was having trouble getting an appointment at EKL as they had given her an appointment for many months ahead. Mack did talk with a guy in prison who was doing interferon because he wanted to know

how the guy felt. Charlie told a friend of his whom also had it because Charlie was feeling that he needed to see a specialist again. His friend referred him to Dr. Cassidy. Jenn talked to all her friends that had gotten tattoos together in attempts to understand how she was infected. Tari told her friend who worked in the lab at her work in the hopes of getting her labs run without identifying information attached to them, which her friend did. Rick in trying to get information disclosed widely, “Yeah, well I go asked everybody I knew about havin it...Then I started talkin to more and more people and gettin information...” David disclosed at work thinking he might get some help as he was having a hard time. Derrick also disclosed at work because he was so sick he felt he needed to go home. Both men described these work environments in a negative fashion, so it is surprising that they disclosed as Munir et al. (2005) state that employees are less likely to disclose if they feel work is a negative environment. Isabella had already disclosed at work but had to go to them again about the trouble she was having on treatment.

Self-care. Few respondents (6%) mentioned telling others about their health in order to attempt to get proper care for their disease. Tom reminded his doctor about his HCV in order to make sure they didn’t prescribe any medication that may hurt him. Thus, one reason for disclosure to medical personnel is to protect one’s health. Nick also told staff when he was admitted to prison to try to get proper care for himself even though he said, “...sometimes when you say you got it it’s like [N sighs]”. Rick, too, tried to get care while in prison, “No, in the in the jail system I just I tried to inquire about and get into some kind of program when I heard they had some kind of treatment for it.” Several

respondents mentioned trying to get help or treatment for their HCV while incarcerated. This information is important considering the extremely high rates of HCV in prisons.

CONCLUSION

Understanding varying levels of disclosure is important to grasp a holistic understanding of the overall illness experience across this diverse group. Previous research on HCV has found that some people are afraid to disclose because of fear of discrimination (Glacken et al. 2001; Hepworth and Krug 1999; Zickmund et al. 2003). This research also reflects a group of individuals who are reluctant to disclose about their HCV status. However, a large portion (47%) of the sample is disclosing very openly. Similar rates of disclosure were found in research among HIV positive women in Los Angeles with nearly half of the women having disclosed completely to their whole social network (Comer et al. 2000). The few existing studies on HCV have not focused on these disclosure patterns.

The most important finding resulting from this research is the connection between race and disclosure patterns among persons with HCV. While my research is mainly limited to African Americans and Whites, significant differences emerge in terms of race ($\chi^2=6.34$, $p<.01$). Racial or ethnic minorities, again who were mostly Black, were significantly more likely to be reluctant or disclose in a limited fashion. HIV positive Latino men disclose less than Whites (Mason et al. 1995). HIV positive Spanish speaking Latinas disclosed less than English speaking Latina, White, or African American women (Simoni et al. 1995). However, Comer and colleagues (2000) found no differences in levels of disclosure among HIV positive women by race or ethnicity. Chin and Kroesen (1999) studied HIV positive Asian Pacific American women and disclosure

because of the collective nature of Asian culture compared to an individualistic Anglo-Saxon culture. As suggested by Mason and colleagues (1995), African-Americans in this sample may disclose less because of their fear of being further marginalized, discriminated against, or stigmatized. Simoni and colleagues (1995) posit that Latinas disclose less because of less education about HIV in the Spanish speaking Latino population. Thus, perhaps knowledge of HCV is even poorer in the black population than among Whites.

Other research that did not find racial or ethnic differences in terms of levels of disclosure for HIV positive women, did find differences related to mental health and levels of disclosure (Comer et al. 2000). For Latinas, higher levels of disclosure were related to poorer mental health although this was not the case for White or Black women (Comer et al. 2000). While my data does not allow for an evaluation of mental health status, future research should focus on any correlations with race, ethnicity, and mental health among persons with HCV. Furthermore, the racial differences I found appear to be cultural in nature and not linked solely to socioeconomic status, as income was not related to levels of disclosure.

Factors that affect disclosure with regards to other disease and that would seemingly matter for HCV are not especially useful in explaining levels of disclosure in this research. Some researchers have found that disclosure of having HIV was affected by disease severity, among other factors (Mason et al. 1995; Tewksbury and McGaughey 1997). However, others have not found such a relationship (Comer et al. 2000). For the respondents in this research, the presence of symptoms either because of the disease itself or because of treatment, whether a person has or has not undergone treatment, and years

since diagnosis are all unrelated to level of disclosure although presence of symptoms does affect reasons mentioned by respondents for disclosing. Route of transmission is also unrelated to levels of disclosure ($\chi^2 = .002, p > .97$) which has affected disclosure for HIV positive persons in some research (Tewksbury and McGaughey 1997). Persons who were infected through intravenous or intranasal drug usage are just as likely or unlikely as those infected through other means to disclose their HCV status. This finding supports the premise that there is a lack of discourse about HCV in the United States, including accurate knowledge. Therefore the public may not associate HCV with drug usage. As mentioned previously, the AGA survey found that 30% of the non-infected American public connects HCV with drug addiction and other unhealthy lifestyles (AGA 2003). This finding contrasts with research in Australia that contends that there is readily available cultural imagery associating HCV and drug usage (Hepworth and Krug 1999). Although (Krug 1995) argues in an earlier article that HCV was not predominately associated with intravenous drug usage in print media or TV coverage in Australia.

While there are some findings that gender affects stigma management, including disclosure, for other diseases (Tewksbury and McGaughey 1997), others find no differences by gender (Lee and Craft 2002). We could also expect gender differences in disclosure patterns because of gendered conceptions of illness and risking being seen as a “double deviant” (Anderson 1991; Radley and Billig 1996; Schur 1984). However, in terms of these persons with HCV, there are no gender differences in terms of varying levels of disclosure. Age and education are also unrelated to levels of disclosure. These are factors that have affected disclosure of HIV status in other research (Comer et al.

2000) although Mason et al. (1995) did not find age to be relevant to disclosure patterns in their sample.

In this chapter, I discussed the various patterns of disclosure among persons with HCV ranging from *Activist Disclosure* to *Reluctant Disclosure*. Persons' reasons for disclosing and not disclosing can be organized along the lines of being focused on others or the self. As a whole, many persons with HCV do disclose and at fairly high levels. The higher rates of disclosure among Whites appear to be cultural and are unrelated to income. In the next chapter, I address the various reactions to acts of disclosure including stigmatization, lack of reactions, and positive reactions as well as the consequences of these reactions for the individuals.

APPENDIX 3

3.1 ACTIVIST DISCLOSURE

Name	Gender	Age	Race/Ethnicity	Education (Years)	Household Income	Reported Mode of Transmission
Isabella	Female	41	White	16	\$30,000-39,999	Transfusion
Jenn	Female	50	White	14	\$50,000-59,999	Sex/household
Sharon	Female	60	White	14	\$0-9,999	Transfusion
Connie	Female	70	Japanese	15	\$50,000-59,999	Transfusion
Harold	Male	47	White	16	\$40,000-49,999	IV drugs

3.2 OPEN DISCLOSURE

Name	Gender	Age	Race/Ethnicity	Education (Years)	Household Income	Reported Mode of Transmission
Cece	Female	45	White	9	\$10,000-19,999	IV drugs
Daisy	Female	61	White	11	\$10,000-19,999	Transfusion
Karla	Female	37	White	11	\$0-9,999	IV/sex/household
Liz	Female	53	White	12	\$40,000-49,999	IV drugs
Lucy	Female	53	White	13	\$60,000-69,999	Sex/household
Peggy	Female	53	White	13	\$70,000-79,999	Needle stick
Catherine	Female	41	African-American	11	\$10,000-19,999	Snorting drugs
Don Yi	Female	68	Chinese	8	\$20,000-29,999	Surgery
Daniel	Male	46	White	9	\$60,000-69,999	IV drugs
Derrick	Male	36	White	12	\$20,000-29,999	Snorting drugs/tattoo
Donald	Male	70	White	5	\$60,000-69,999	Transfusion
Eddy	Male	47	White	20	\$40,000-49,999	IV drugs
Jason	Male	22	White	14	\$90,000 or above	Transfusion
Jeff	Male	40	White	6	\$0-9,999	IV drugs
Joey	Male	50	White	12	\$10,000-19,999	Snorting drugs
Rick	Male	54	White	12	\$0-9,999	IV drugs
Sparky	Male	51	White	13	\$40,000-49,999	IV drugs
Yellow	Male	50	White	13	\$10,000-19,999	IV drugs
Maruf	Male	43	Jordanian	12	\$30,000-39,999	IV drugs

3.3 LIMITED DISCLOSURE

Name	Gender	Age	Race/Ethnicity	Education (Years)	Household Income	Reported Mode of Transmission
Melissa	Female	49	White	16	\$80,000-89,999	IV drugs
Meredith	Female	46	White	14	\$20,000-29,999	IV drugs
Roxanne	Female	35	Hispanic/White	13	\$30,000-39,000	Transfusion
Sally Anne	Female	50	White	12	\$20,000-29,999	Transfusion
Samantha	Female	26	White	12	\$0-9,999	IV drugs
Ann	Female	51	African-American	13	\$10,000-19,999	Transfusion
Emma	Female	54	African-American	9	\$10,000-19,999	IV drugs
Jamie	Female	53	African-American	13	\$20,000-29,999	IV drugs
Tari	Female	39	African-American	14	\$60,000-69,999	Sex/household
Bob	Male	33	White	15	\$10,000-19,999	IV drugs
Charlie	Male	53	White	18	\$90,000 or above	IV drugs
David	Male	48	White	14	\$30,000-39,999	IV drugs
Larry	Male	53	White	16	\$10,000-19,999	IV drugs
Nick	Male	47	White	8	\$0-9,999	IV drugs
Tom	Male	51	White	15	\$50,000-59,999	IV drugs
Ellis	Male	49	African-American	12	\$50,000-59,999	Drinking
Grant	Male	51	African-American	10	\$20,000-29,999	IV drugs
Jerry	Male	51	African-American	10	\$10,000-19,999	Unknown
Little Brother	Male	42	African-American	12	Missing	Earring/Drinking after others
Stick	Male	52	African-American	9	\$30,000-39,999	Tattoos

3.4 RELUCTANT DISCLOSURE

Name	Gender	Age	Race/Ethnicity	Education (Years)	Household Income	Reported Mode of transmission
Lauren	Female	59	White	13	\$10,000-19,999	Transfusion
Sherri	Female	46	African-American	12	\$0-9,999	Transfusion
Vanessa	Female	41	African-American	13	\$20,000-29,999	Tattoo
Mark	Male	35	White	12	\$30,000-39,999	Transfusion/sex
Ronald	Male	54	White	18	\$40,000-49,999	IV drugs
Andrew	Male	44	African-American	12	\$10,000-19,999	Drug related
Eric	Male	49	African-American	12	\$20,000-29,999	Unknown
Mack	Male	52	African-American	13	\$10,000-19,999	IV drugs

3.5CHI-SQUARE CROSS TABULATIONS

Levels of Disclosure and Mode of Transmission ($\chi^2=.01$ p<.97)

	Drug Related	Other Mode	Total
Limited/Reluctant	15	13	28
Open/Activist	13	11	24
	28	24	52

Levels of Disclosure and Fear of Discrimination ($\chi^2=6.6$ p<.01)

	Expressed Fear	No Fear	Total
Limited/Reluctant	11	17	28
Open/Activist	2	22	24
	13	39	52

Race and Private Information ($\chi^2= 13.26$ p<.000)

	Private Information	No Mention of Private Information	Total
White	1	33	34
Minority	8	11	19
	9	44	53

Gender and Protect Others ($\chi^2= 6.42$ p<.01)

	Protect Others	No Mention of Protect Others	Total
Female	14	10	24
Male	7	22	29
	21	32	53

Levels of Disclosure and Protect Others ($\chi^2= 7.08$ p<.01)

	Protect Others	No Mention of Protect Others	Total
Limited/Reluctant	16	12	28
Open/Activist	5	19	24
	21	31	53

Education and Protect Others ($\chi^2= 11.48$ p<.01)

	Protect Others	No Mention of Protect Others	Total
Less than High School	1	12	13
High School	4	10	14
More than High School	16	10	26
	21	32	53

Levels of Disclosure and Atypical Behavior ($\chi^2= 6.07$ $p<.01$)

	Atypical Behavior	No Mention of Atypical Behavior	Total
Limited/Reluctant	5	23	28
Open/Activist	12	12	24
	17	35	53

Gender and Activism ($\chi^2= 3.86$ $p<.05$)

	Protect Others	No Mention of Protect Others	Total
Female	10	14	24
Male	5	24	29
	15	38	53

Levels of Disclosure and Race ($\chi^2= 6.34$ $p<.01$)

	White	Minority	Total
Limited/Reluctant	14	14	18
Open/Activist	20	4	24
	34	18	52

CHAPTER 4: IS HCV A STIGMATIZED DISEASE? REACTIONS TO DISCLOSURES

Disclosing health status for persons with HCV can be a perilous endeavor or a relatively mundane experience, as discussed in Chapter 3. Respondents cited numerous reasons for not disclosing. However, people with HCV do frequently disclose their health status.

Much of the literature on stigma begins with an assumption that certain traits or attributes are stigmatizing for persons having the attribute. As discussed in chapter 1, I use Link and Phelan's (2001) definition of stigma in which labeling, stereotyping, status loss, and discrimination occur because of the attribute. Previous research finds that HCV is stigmatizing yet does not elucidate what factors affect who is stigmatized (Hepworth and Krug 1999; Hopwood and Southgate 2003; Zickmund et al. 2003). Existing research on HCV presumes that HCV is a salient identity for those who have it and that persons with HCV experience discrimination.

I contend that persons with HCV are a heterogeneous group and should be conceptualized as such. Slightly over half of the sample had heard of HCV before diagnosis, but *Prior Knowledge* varied. Not all respondents seemed *Aware of Stigma* associated with HCV. More than half of the respondents engaged in self-labeling or felt stigma and/or had experienced enacted stigma with race affecting likelihood of stigmatization. Felt stigma usually centered on the idea that others would associate HCV with a *Deviant Lifestyle*, that people would fear them because of *Contagion*, and that they would be seen as *Dirty*. Respondents reported that enacted stigma was based on an

association with HCV and *Deviance* or a *Fear of Contamination*. Several persons mentioned experiences of stigmatization in *Healthcare Settings* or the *Workplace*. Some disclosures led to others *Minimizing the Illness*. Not all responses were negative as some respondents described *No Reaction* to disclosure or *Positive Reactions* from *Family, Friends* and in the *Workplace*. Finally, I address methods of coping with stigma including *Information Control* as a means to avoid stigma as well as resist stigma, *Condemning the Condemners*, and *Collective Action*.

PRIOR KNOWLEDGE OF HCV

For most diseases, there exists vast cultural imagery and discourse. Once becoming diagnosed, individuals must then come to terms with what that discourse means now that it applies to them. This phenomenon is the crux of modified labeling theory. It is more difficult, however, to apply this theoretical approach to HCV because there is a lack of expectations about what it means to have the disease. Many have never even heard of it. Of the 45 interviews in which I could establish their previous knowledge about HCV, 56% said they had heard of HCV before diagnosis. However, 29% of the sample either admitted to just having heard of it, but not knowing anything about it or gave no indication that they knew anything about the disease. Harold said, for example, “I’ve heard, you know I’ve heard a Hepatitis A, Hepatitis B, and I’ve heard some people talking about Hep C. But I did not really look into it.” David also reported, “I had heard of Hepatitis A and B and I heard that there were some other varieties of hepatitis, which I didn’t know anything about, I just, was nothing I even thought about really.” Daniel explained, “I didn’t know what it did to you, I didn’t know that it, I didn’t know it was a liver sickness, nothin. I didn’t know any of that, I just knew that it was, it

was hepatitis, and it was a, it was a sickness.” Others echoed these sentiments and in some cases I feel respondents may have said they have heard of it when I asked them so as to not appear ignorant. For example, I asked Emma if she had ever heard of it and she told me yes. When I asked her what she knew about it, she told me “nothing”.

Slightly over a quarter of the sample had information beyond having heard of the disease. Daisy said, “Well, I'd heard of it, but I, you know I never dreamed I'd ever you know have it. I've always heard of A, B, and, and C. I always heard it was the silent disease, killin' disease and all. That's the first thing that goes through a person's mind, you know.” Some learned of HCV because of their drug use. Ronald said, “But I had heard of Hepatitis C plenty because of bein' part of the drug culture.” Samantha adds, “The last time when I went out and really messed up in life, like everybody I was around had hepatitis C and I saw some people die from it, you know”. Grant, Stick, Larry and Daniel had heard of HCV because they had friends who had it. Tari's husband was diagnosed years before her. Peggy worked in a hospital so she was familiar with it and Jenn worked with a health education organization so she was informed. Mark worked in law enforcement where he said many people have HCV. Derrick's mother worked in healthcare, as did Matthew's mother, so they knew of it through their mothers.

Thus, some respondents did have some previous knowledge about the disease before being diagnosed, albeit not always accurate knowledge. Many did not. Because there is still such a lack of larger, cultural imagery surrounding HCV, knowledge about it did not necessarily give respondents a sense of what it meant to have HCV. This invisibility accounts in part for some respondents being unaware that HCV is seen as stigmatizing by some.

AWARE OF STIGMA

Over three quarters of the sample gave some indication in the interview that they were aware that HCV could be seen as stigmatizing. Those respondents who have experienced enacted stigma, an act of discrimination, from disclosure were more likely to be aware of stigma ($\chi^2 = 6.51, p < .01$).²⁵ Respondents who were aware of stigma were also more likely to describe fear of discrimination ($\chi^2 = 5.04, p < .05$).²⁶ Whites were more likely to be aware of stigma than racial and ethnic minorities ($\chi^2 = 6.41, p < .01$). Whites disclosed at higher rates than other respondents and perhaps through more disclosure, they have become more attuned to possible stigmatization although level of disclosure alone is unrelated to awareness of stigma ($\chi^2 = .54, p < .5$).

Some comments simply reflect the idea that hepatitis scares others. Sherri explained, “Cause I know some people get terrified when they hear hepatitis.” More generally, others expressed a sentiment that any contagious disease is stigmatizing. Rick said, “Oh, of course, a lot of people do [think HCV is stigmatizing]... Or link it with AIDS or any kind of disease that they think is contagious.” Ann said of why people might be secretive about it:

“Well, the enemy'll keep they mind focus on, don't nobody need ta know I have that, people a not gonna wanna talk ta me anymore, or they not gonna wanna be around me anymo'. So those type a things that make people afraid not to openly talk about what they're goin' through.

People feared an association of HCV and deviant behavior including sexual behavior, drug use and alcohol abuse as mentioned in Chapter 3. Many interviewees recognized the association between HCV and drugs and that this could be stigmatizing,

²⁵ See Appendix 4.1 on page 145.

²⁶ See Appendix 4.4 on pages 146-7 for cross tabulations for all chi-square calculations in Chapter 4.

although as previously mentioned, only some of the respondents felt this personally affected their own disclosures. Ellis says, “I never talk to nobody who, got it from no drugs, if they did, they didn’t admit it.” Liz tried to start a support group and no one showed up. She said it was because no one wanted anyone to know they had HCV. When I asked why, she responded,

“Most people connect it with a drug disease. You know. And, and I mean it depends on who you hang around with [L laughs], but you know, but I don't know...I don't understand why people have such a problem with that.”

Maruf outright denies any stigma when I ask about it. Yet he adds,

“And a lot of people think whoever had hepatitis C may have AIDS or may have other diseases, but I don’t... Yeah most people think oh if you have hepatitis C you did drugs before, you shot needles or you if you have hepatitis C probably have AIDS. I know people will think like that [M sighs], but anyway the people that know about my problem is the family so I mean I don’t think they gonna go.”

Numerous respondents brought up the issue of stigma before I could even ask them. Karla had actually stigmatized others before she and her husband were diagnosed. She says of a conversation with a friend whose girlfriend had HCV, “What the hell is that? Oh it's like AIDS. And that was--I just left it at that. I said you slept with her, you nasty thing.” Sharon says,

“The stigma. There's a huge stigma attached to Hepatitis C. It's a lot better now, but two years ago, five years ago, I mean it was worse than HIV. (I ask what the stigma is about)...IV drugs. It's always been called, Hepatitis C. There was an article in Times, in April of that year— Hepatitis C was always called the drug, a drug disease, because it was transferred mostly in those early 70's and 80's and 60's by IV drug users, and tattoos and stuff like that.”

Twenty three percent of the sample seemed unaware of a stigma associated with HCV although I did not always specifically ask if they thought HCV was stigmatized.

Yet most others explicitly or implicitly mentioned it. So either these people did not find it salient enough to bring it up or are aware of stigma but did not mention it.

FELT STIGMA

Felt stigma refers to the process of self-labeling. People may use Mead's concept of the generalized other to "take on" how they believe others perceive them (Link 1987). Persons may change their interaction style if they engage in felt stigma because they are expecting rejection of some sort. Some suggest that felt stigma is even more damaging than enacted stigma (Greil 1991), while others feel that felt stigma actually reduces enacted stigma (Jacoby 1994).

While several studies looking at HCV have focused on enacted stigma, there is less attention on felt stigma or it is briefly mentioned. Hopwood and Southgate (2003) remark that "people newly diagnosed with hepatitis C often describe a sense of being perceived differently by those around them" (254). Hepworth and Krug (1999) also state that persons with HCV must grapple with the knowledge that they have a stigmatized disease.

In this research, over half of the sample mentioned various types of felt stigma. The three themes that emerged were fears that others would associate HCV with a certain lifestyle, that others would fear them because HCV was seen as contagious, and finally a sense that others would see them as dirty because of having HCV. Engaging in felt stigma was not related to having experienced enacted stigma ($\chi^2=3.31, p>.07$).

HCV AND DEVIANT LIFESTYLES

Almost a third of people mentioned that they worried that others would associate HCV with lifestyle choices involving drugs, alcohol, or sex, supporting findings by

Zickmund and colleagues (2003). Some of these respondents did not get HCV through drugs but feared others would think they did. Jenn says of disclosing to people at work:

“... course my kids knew I’d never injected drugs or anything so I knew they weren’t gonna think that that’s how I got it you know, but people I’ve only known for four or five years [J chuckles] those are the ones I kinda wondered about.

Donald mentioned how he drank some during his life, but not enough to hurt his liver.

He recognized that liver disease is associated with alcohol. Lucy also explained how she was previously married but was never promiscuous and never even drank a beer. Lucy mentioned again that “But you know, I don't even drink. Never drank, never smoke, never did dope, you know, nothin.” She also spoke of how surprised she was when Donald was diagnosed because he wasn’t a “dopehead.” Lauren said, “And, that, that worries me too that people even think I was an alcoholic and, or on drugs, because that’s the main thing that goes wrong with your liver, most people think.” Other respondents who did contract HCV through drug use worried what others would think. David says, “And especially when you have that and people know well, if you have that, you did something you shouldn’t a did, done.”

Like Lucy, Sallie Anne noted that she was not infected from promiscuous sex. She talked of when she and her husband were separated, “And I did not, but at that time you know I did not have multiple boyfriends, or multiple sex or anything like that. So I know that I didn't get it then.”

HCV IS CONTAGIOUS

Nearly a third of respondents worried about being seen as contagious. Tari feared being treated differently because of having a disease. Likewise, Vanessa adds,

“Because people get kinda, you know--if you say certain things especially if you're dealin' with somethin' that's contagious or whatever people get kinda

scared and stuff... but you know, if you say [whispers] Hepatitis, every body knows that, that it's deadly.”

Part of Lauren’s fear was also about the contagious aspect:

“Right, yeah. And, nobody wants to give a chance to, you know, I mean, if, I heard that you had somethin’ you know, anything, and it worried me that, oh, I don’t want to be around you cause I might get it. I felt stuff like that.”

Roxanne says, “...and if they knew I had Hepatitis C, they wouldn’t let me work.”

Three respondents associate HCV with leprosy. They may be relying on the history of leprosy as being an extremely stigmatized disease to emphasize their fears about having HCV. David says,

“I was, my, one of my fears was rejection from people because I felt like I was gonna be, you know, be treated like a leper...And you know like, get away from me, you know, don't breathe on me, don't touch me, you know, and, you hate for people to make you feel like that”.

Ronald says,

“Was that I kinda put the, you know I felt like that, you know, anyone that knew I had it, you know, they'd shy away or get... I'm ashamed. You know, basically shame and not wanting to deal with their reactions to it. In other words, I'm afraid they'll be afraid of me, like I'm a leper or something.”

Meredith said when I asked about what she thought others associated when they heard the word hepatitis:

“Somebody who had a really fucked up life. Um, somebody, they think of hep-- when they think of Hepatitis they think *unclean*... That, that you, you are unclean, you know [M chuckles], it's kind of like, it's almost like a, to me, if I were, if I were to write it down I would associate it with like leprosy.”

Zickmund and colleagues (2003) had a respondent who said, ‘They treated me like a leper’ (835). Thus, the reliance on this imagery is not unheard of in other populations of persons with HCV.

PEOPLE WITH HCV ARE DIRTY

The association of HCV with contagion and leprosy closely follows with the theme of being seen as dirty, expressed by 13% of the sample. Isabella said,

“Cuz you think that you know, you’re poison. You’re, I mean, I felt, when I was dia-- I felt dirty you know and I’ve heard a lot of people with IV drug histories say they were dirty but I felt dirty too. You know, with the, just, and the stigmatism that’s attached to Hepatitis.”

There were no associations in this sample between describing this feeling and mode of transmission. Eddy also said, “Dirty, dirty. It was, it was, the thing, it’s been, I mean it hasn’t come up for a lot of years, but it occasionally comes up again, it’s the, it’s the my blood is toxic feeling.” Samantha feared, “I’m thinking, shit, I gave it to him, he’s gonna hate me, I’m dirty, how can you look at me, I’m disgusting and I just felt so filthy.” Mark said, “You’re a nasty person...Dirty, yah, you’re not a clean person, or something like that.” Hepworth and Krug (1999) also note how persons with HCV described feeling dirty and unclean.

AWARENESS OF FELT STIGMA

Several respondents recognized that their self-labeling may affect their interpretations of interactions with others. David, despite asserting that he had trouble at work because of HCV said this when I asked him if he had had a negative reaction from disclosing to anyone:

“I have felt like that, but I don’t know specifically if it was-if I was really seeing that, or if it was just me, you know, thinking that they were feeling like that--I mean I didn’t have any, I didn’t, I can’t really say that I had somebody definitely, that I definitely know reacted that way.

Isabella states, “Um I felt...I’ve had feelings of rejection. Which, you know, you think

that people are rejecting you, maybe they're not, maybe they are, they could be." Bob said,

"Not because of it, because I, so few people know and I think that most of the...most of it comes from myself. I really do, I think that most of it comes from myself because and, and that's maybe why I'm, you know, I don't broadcast that, cause I tend to be someone who broadcasts a lot of things about myself, personal things that aren't necessarily nice, I don't necessarily paint always a pretty picture of myself but I don't tell that, you know, and there's a certain perception that I have like it's the plague."

FACTORS LINKED TO FELT STIGMA

White respondents are more likely to report felt stigma ($\chi^2 = 4.71, p < .05$).²⁷

Whites do disclose at higher levels and similar to their awareness of stigma, the higher rates of disclosure may allow more opportunities to project how others might view one and thus engage in felt stigma, although there is no direct relation between felt stigma and levels of disclosure. How a person acquired the disease is unrelated to engaging in self stigmatization. Thus persons who acquired the disease through drug use are no more or less likely to self stigmatize.

ENACTED STIGMA

Enacted stigma refers to the process whereby persons are labeled as different, stereotyped, seen as the "other," and experience status loss and discrimination (Link and Phelan 2001). Nearly half of the respondents (49%) in this research indicated that they had experienced some type of enacted stigma as a result of disclosing their health status. "Othering" persons with HCV and discriminatory behavior surfaced as a fear of contamination resulting in status loss in various forms. Labeling and stereotyping often had to do with associating HCV with drugs, alcohol, or sex. Some respondents felt that

²⁷ See Appendix 4.2 on page 145.

people used their HCV as an excuse to shun them. Respondents also discuss specific experiences in the workplace as well as in healthcare.

DISCRIMINATION AND FEAR OF CONTAMINATION

Over one third of respondents revealed that they had experienced discriminatory behavior that centered on fear of contamination. Several respondents described interactions that could be defined as discriminatory, although they did not portray them as such. Sharon's son was worried that she might give it to the grandkids so she sent him to talk to the doctor. Liz describes telling some of her friends:

“What's--well, I've got Hepatitis C. And it was like all of them, 'bout six women, stepped backwards. Only one of 'em stayed in position. And I was like, I'm not contagious. They went, oh we didn't do that, you know. I said, that's ok, whatever, you know I'm just pickin' on you all anyway, I mean.”

Daniel experienced mild anxiety from others a few times: “Not much, but I did have people like I would tell somebody about it like in the store or whatever and we'd be talkin', they would say stuff like, well you can't catch that from somebody, can ya?”

Roxanne said, “Um, some of my friends it made a difference, some I had over or something somebody pop a mosquito and then it had blood in it or somethin' they'd freak out, you know, I am like, it's cool.” Cece recounted people shying away from her as did Yellow and Roxanne. Nick mentioned that in jail some of the guys were wary of touching any of his things. He mentioned that the Black men were scared but not the White men. Rick said, “Yeah, people that still think you can catch it sexually. There's comments you know, when you are tryin' to have a general conversation, like in a group.” Jerry said that some people stare at him (he has severe skin problems from HCV) but that it doesn't really bother him. He said,

“No. It's just some people that I know of look at me and they go talk to their friend and they point at---He got a bad rash. Just get back to my home. I just ignore them. I don't call and tell em' nothing and the people I hear it from, they something wrong with them' they family, I won't get out there and say nothin' about it, you know? “

When I asked if that doesn't hurt his feelings, he admittedt does a little bit but that, “I don't stop goin' and doin' the things I--I go out in public. I go to the grocery store, you know, and that.”

Several interviewees described experiences surrounding eating utensils. Isabella said, ““And it's you know, I, they did it when I first got diagnosed they specified that I used this particular cup at the house.” Tom had noticed people were scared to eat off the same plate as him. Joey's mom told me how people at the blood bank were scared to touch things and then she mentioned how she does not let anyone else in the family drink out of Joey's cups.

Other stories centered around objects of potential contamination as well.

Meredith told me about an acquaintance not wanting her to use his eye drops:

“Just like, son of a bitch, you know, cause I knew what it was all about cause, you know, even though they're considered like, he considers himself an open minded individual, you know, whatever still there is that. And you know, I mean, there is a lotta stuff runnin' around out there but to, I try not to get it too mixed up with paranoia.”

Karla said of one of her sisters:

“When Jeff first got diagnosed with Hepatitis C, was when he was in the hospital. I was covered in blood, and, uh, my sister acted real funny because she wanted me to take all my clothes off and she wanted to burn 'em instead of washin' 'em.”

A few respondents had intense negative reactions from others. Samantha told an acquaintance about her HCV status:

“She was talking about how her dad had it and I was like oh yeah, you know, and I mentioned how I had it and stuff and well, next thing you know, her grandma was calling like some people that we both knew saying Samantha has this hepatitis disease and she was around her, my friend, her little baby...and her grandma was like you know, she was around the baby. I just want to find out what is going on, because I need to get the baby tested because the baby probably has it, you know, I’m going to get tested because I probably have it now because she was at our house, you know”.

Jenn’s good friend was furious with her because she was going to school to be in healthcare and feared she might have gotten it from Jenn and would not be able to work. Ellis said about his ex-wife, “...to the Hepatitis thing, full time she kinda lost her trust in me. And so uh, we kind a separated by it.” Yellow said in regards to his ex-wife of twenty-eight years, he said, “Everything went fine 'till, 'till, until I got this Hepatitis C and, and she was lookin' for other angles out, and, you know when it happened it happened”.

Of all the respondents, Karla and Jeff reported the most discrimination. Karla disclosed to her daughter, “...and I told her I had Hepatitis C, so that right there tell ya that she don't have nothin' to do with me. She said it ain't no different than havin' AIDS to her.” Karla has no contact with one of her brothers either:

“Yeah. My brother Mike said Jeff couldn't come to his house because if he catch any diseases, he wanted to catch 'em on his own. And he said but you can come. I said well, I can't come either. Why not? I said I got Hepatitis C too, so I'll see you when you die in hell, ok? [K chuckles] I hung up on 'em. I hadn't talked to him since then.”

Jeff explained:

“But some people feels that they can catch it just by being around you. You know, by--ok, you sit there, I can't sit there. Some people are--my, like Kenny and them, they know, you know they--Kenny knows, he lives with us. And this--her, well, her kids live across the street. Now, their grandpa-- he says no. They don't know--can't nobody tell him no different. They can get it from me just by talkin' to me. I said alright, whatever you want to believe, you know. So if she wants to see her kids, she has to go over there. They can't come here.”

Karla adds that she is not allowed to hug or kiss her kids. Karla talks about her children's father's mother's behavior. "But Miss Patsy, she does it for spite. She kisses and hugs on me. She says maybe if I waller all over you, he [her husband] won't have nothin' to do with me." Another study found similar responses with regards to hugging and kissing among families when someone has HCV (Crofts et al. 1997).

LABELING AND STEREOTYPING HCV AND DEVIANCE

Almost one in four respondents described some type of labeling and stereotyping linking their HCV with deviance. Yellow says, " Ah, it's just, my sister, my oldest sister came up to me one day and she says, It's only because of the lifestyle that you lived, is the reason why you gonna die. And, uh, it really tore me up." Likewise, Larry says of his mother:

"She doesn't come out and say it, but you know, that's what it's all about, the bottom line, it's because I got it through drug use, I know that's what it's all about, and she'll go to her grave you know blamin' me, it's done, it's over with, get over it, I've gotten over it."

Bob told one of his girlfriends:

"I remember talking to her about it and looking into it cause I was nervous and I think she was really nervous too like wow-and she didn't know what it was, you know, and it was like, wow you gave me junkie's disease, I'm not even a junkie, you know."

Roxanne's mother attributed it to her being a lesbian. "Like I said at first, she treated it as AIDS, as well, you know. This is you're lifestyle, see I told you, this is gonna get in trouble and all this stuff." Tom said, "People act like it's a dirty disease, like you gave it to yourself." Ellis revealed

"Well my mother, she is a very religious lady and all she did was fuss. I told you bout drinkin'. I told you 'bout bein' out in the streets. I told you about bein' with people, these certain people, these people are gonna get you in trouble, get you

killed. But my wife, she didn't. Well I been married two times my first wife, she didn't, she didn't take it too well. I think she may have thought I was foolin' around or somethin'."

These persons were blamed by others for contracting the disease from behaviors they had engaged in. They have experienced status loss in that they are seen as deserving of the disease and different from others.

STIGMA IN HEALTHCARE

Discrimination in healthcare settings was not nearly as common of a problem as prior research suggests (Hopwood and Southgate 2003; Zickmund et al. 2003). Seven respondents reported discrimination in healthcare settings. One drawback of my recruitment method is that I went through one hepatologist. It could be that he treats his patients well and thus they report little discrimination. However, numerous respondents had seen and continue to see other physicians in different healthcare settings for various other healthcare needs. Another possible explanation is that perhaps there is simply less discrimination in healthcare currently than when previous research was done, although quite a few respondents in this research have had HCV for many years. Several respondents did, however, describe negative experiences. Eddy recalled,

"I don't remember what it was-Ahh, no it was, maybe it was at the dental school that I had to get, if I had hepatitis C, I had to get some kind of certificate from a doctor saying something, you know just something ridiculous...it was either that they said, we won't treat you or we have to get a certificate, uh, and so I lied. And this is just a really vague memory, so I may be wrong, but I think that's what it was."

After Isabella gave birth, a nurse put a big sign on the room door saying she had HCV, which her in-laws did not know about it at the time. Lauren also had a traumatic experience:

“This doctor. Dr. Ray. Um, I went up to see him, forgot what he was oh, he’s an internist...he came in and he stood over in the corner with his arms folded and I said, what’s wrong with you? And he said, I consider you highly contagious...And he stood across the room, but he had to feel my liver so he put on gloves, and very, you know like, my liver was gonna jump up and bite or something, but, I just, I couldn’t stand him, I was supposed to see him and I could not”.

Bob revealed a patronizing experience from healthcare workers:

“I was in the hospital for, um, liver related illness and even other illnesses and kinda gotten the response like why would you do that to yourself, don’t you know what you’re doin’ to yourself? And it’s sort of like very motherly kind of finger pointing and not in a really oppressive way but just in a in enough way to really make me uncomfortable and question why I even bother telling them, you know, um.”

Several respondents experienced stereotyping about HCV. Two women were teased by their female doctors when they disclosed their HCV status. Cece told me about her experience with a pain management physician. “She’s an Asian lady about in her 50’s and she says Cece, you was a bad girl, you know, ‘cause when I told her my history, you know.” Jenn had a similar interaction with her dentist. “She said, she laughed about it, she said oh just admit you were a wild little thing when you were young. I said well yeah I did do a lotta runnin’ around when I was young and unmarried.” Neither woman was offended by these comments and both seemed to be amused by them instead. However, others could possibly have a very different reaction to similar comments perhaps if made by a man or someone much older. Both Cece and Jenn were fairly open with disclosure in general and were white women. While Cece and Jenn did not seem to experience status loss as a result of these interactions, the same behavior by healthcare professionals could have drastically different results with different people.

STIGMA IN THE WORKPLACE

Crofts, Louie, and Loff (1997) found numerous problems with discrimination and HCV in the workplace. Over a quarter of respondents in research by Zickmund and colleagues (2003) reported problems at work. Four persons in this research spoke of discrimination and employment. When David told a manager at work, “I think it even made it worse, so uh, I think my manager had it in for me, and I think she was looking for-so I ended up, what I did, was I finally made a realization that I wasn’t gonna make it.” He also said about this job, “That I had to work at a hundred percent or not at all. That was, that was the words from 'em, I tried ta, seek help through an attorney but and disabilities...” Roxanne had lost jobs from having HCV. Derrick also attributed losing his job to disclosing at work. He said more about this:

“Everybody has their conspiracy theories but I was costing this insurance company which is United Health Care, I was you know, I was thinking about going on the medication, and they had approved it, and they knew that it was a thousand dollars plus a month. So I think because he was a small company, they told him it would be better for him to just cancel his policy, and then my policy would be cancelled also”.

Larry, when working construction, disclosed to several guys at work. He told me this story:

“And so I got a little shot of water, and it hit me all over the face, and everything cuz I was so far away from it. And a little while later, I noticed some, they were all standing over there talking, the cups had gotten there. And they were all standing there talking, and all of a sudden, one of the laborers threw the water barrel, in the uh, in a little bobcat, and run up to the front to get some fresh water. I said, I wonder if that water was left over from yesterday. And then my buddy came over, he had been standing over there, he said, you better watch how you drink your water around here, these people gonna kill you. I said what you talkin' bout. He said, they saw you uh, leaning over and getting water. I said, yah, but my lips didn't get no closer than 80 inches from the spigot. I said, you can't get it that way anyway. But I said, I'm even super careful then. He said, well I don't know what to tell you. He said, they gettin' clean water. And that was the

deciding point there. I said, you know, if it's going to be like that out here. I might as well just go to the boss and about ten minutes later I went to the superintendent, cuz see he found out about it too. And he already, he knew that something was going on. So I went ahead and explained it to him, and pretty much quit right then and there. So, I've learned one thing, I never tell anybody again. That's the last time I'll ever tell anyone, on the job, that I have to work with, you know.”

INTERPRETATIONS OF ENACTED STIGMA

Several respondents, as previously mentioned, did not describe discriminatory reactions to disclosure as negative. However, I categorize their experience as stigmatization based on the working definition of stigma that I am using. When I first asked Eddy if he had experienced any weird or uncomfortable reactions, he said no. However, he then remembered the previously mentioned experience he had with a dentist. The experience either did not have a lasting effect on him or he pushed the memory away in order to distance any feelings of stigmatization. He added later that, “I'd be very offended, take legal action if anybody discriminated against me because of it.” Sharon also did not feel she had ever been stigmatized. Yet she relayed this interaction, “They, you know my son's a little nuts and so he, he's a little afraid that I might do something that would hurt his children and then that's when we all got tested and I sent him to talk to my doctors because it is a concern for him and I understand that.” Joey's mom did not let anyone else in the family drink out of his cup, yet this is not a viable means of transmission. Finally, Daisy was repeatedly asked by doctors if she drank or did drugs, yet she did not feel that she had ever had a negative reaction from anyone:

“Yeah, but that was so funny because when they told me I had Hepatitis, they wanted to know how much I drank, I said, I don't, I'm not a drinker. They went, how much drugs do you do. I said, Mhmm. I don't like needles and I don't do drugs, and they looked at me like I was kind of storying to 'em.”

These persons may be interpreting these experiences in such a way as to minimize any impact on their sense of self-worth, a frequently used strategy in coping with stigma (Shih 2004). Or it could be that they simply did not evaluate these behaviors as stigmatizing, which does seem to be the case for Joey.

FACTORS LINKED TO ENACTED STIGMA

Hopwood and Southgate (2003) discuss HCV related discrimination as occurring at the governmental, institutional and interpersonal level. Zickmund and colleagues (2003) found that 57% of their sample recruited through a hospital reported stigmatization (they did not include felt stigma). Age, education, professional status, and mode of transmission were all unrelated to likelihood of experiencing stigmatization. They found that women were more likely to report stigmatization than men.

Roughly half of this sample experienced enacted stigma. Unlike Zickmund's research (2003), I found no gender differences in experiences with stigmatization²⁸. Reported mode of transmission was not related to experiences with stigmatization. However, mode of transmission may be unrelated because of the lack of knowledge among the public about how people get HCV. Even with HIV, fear of contamination is often the source of discrimination more so than any association with homosexual behavior (Tewksbury and McGaughey 1997). Fear of contamination was also a large source of enacted stigma in this sample.

Whites are more likely to report enacted stigma than black respondents ($\chi^2 = 13.12, p < .001$). Perhaps because of their more open patterns of disclosure as a whole, Whites have had more negative reactions to their disclosures than minorities with more

²⁸ See Appendix 4.3 on page 145.

than half of Whites reporting a negative reaction compared to one fifth of minority respondents. However level of disclosure alone is unrelated to enacted stigma ($\chi^2 = 2.79$, $p > .1$). As stated previously, Whites are more aware that there is a stigma associated with HCV. Having experienced enacted stigma is related to awareness of stigma ($\chi^2 = 6.51$, $p < .01$), although causality cannot be determined with this data. It could be that Blacks experience similar behaviors, but because of already having one stigmatized status, do not attribute discriminatory behavior to having HCV per se. Conversely, it could be that Black people in general are less discriminating towards persons with HCV than Whites assuming social interactions are mainly with one's own racial and ethnic group, which in the research locale is not presumptuous. Whites have been found to blame people with AIDS and have more negative feelings towards them than blacks (Herek and Capitano 1993), which could translate into feelings about HCV as well. Finally, Whites in this sample had a better understanding of the disease than blacks as will be discussed in Chapter 5. Although this is speculative, Whites generally may have more knowledge of HCV and thus more negative affect towards it than Black laypersons. Future research needs to assess levels of public knowledge among different groups.

OTHER REACTIONS TO DISCLOSURE

There are numerous other interactions respondents described besides stigmatizing experiences in response to disclosures. Some respondents had persons minimize their illness, give little to no reaction, or described positive or supportive reactions.

MINIMIZING ILLNESS

Three respondents mentioned that they felt others minimized their illness. Liz described how some of her family discounted her symptoms while undergoing treatment.

“Well, I was sick most of the time, and certain members of my family were like, there ain't nothin' wrong with her, she just don't wanna be, you know--she just wants to sit around at home all day, you know.” Isabella’s sister also seemed to doubt the seriousness of HCV. “One of my sisters kept callin’ me one time tellin’ me about a girl she was workin’ with that had Hepatitis C and sayin’ this girl's takin’ off too much work, I don't really think she's all that sick. And I think she's makin’ it up.”

While minimization of illness was not commonly reported among this sample, it is not surprising considering the lack of discourse about HCV. Numerous “syndromes” in the twentieth century have been denied full, legitimate disease status, such as myalgic encephalomyelitis, repetitive strain injury, and multiple chemical sensitivity (Cooper 2001). While HCV is different in that it is fully recognized as an organic disease by the medical profession, it does lack easily identifiable symptoms to the public. A person can have HCV and “look” fine. Even more confusing is that many persons can have active HCV and have no symptoms. Persons with myalgic encephalomyelitis commonly experience disbelief and misunderstanding concerning the symptom of fatigue (Cooper 2001). Cooper (2001) describes how “when patients talked of ‘fatigue’, they explained afterwards that they meant something different from what was commonly understood by the term” (115). Sharon, a woman with HCV in my research, made a similar statement. “If you don't, if you've never had fatigue you don't know the difference. But once you've had fatigue you understand that there is a humongous difference between tired all the time and fatigue.”

Fatigue is a main symptom for people with HCV. However, there is even debate among medical specialists about whether fatigue is even a “real” symptom. Compared to

persons with Hepatitis B virus (HBV), persons with HCV do have a reduction in quality of life for both physical and mental health aspects (Foster et al. 1998). Yet numerous researchers assert that it is a labeling effect that makes patients suddenly start complaining of fatigue in addition to other symptoms and that those who are unaware of their HCV status have similar quality of life measures as control groups (Cordoba et al. 2003; Rodger et al. 1999; Schwarzingler et al. 2004). Several of my respondents did make statements supporting a labeling effect. Peggy had very elevated liver enzymes at the time of diagnosis, which often translates into severe fatigue as well as other symptoms. However, when I asked her if she felt poorly, she responded with a laugh, "Not until they decided I had it." Samantha comments on the difficulty of establishing whether her physical symptoms are even from having HCV. "I don't know if it's because of the hepatitis, or the medication I take. I'm tired, I feel worn out a lot. I don't know what it could be, I just feel worn out a lot."

Numerous other respondents, however, described debilitating, severe fatigue. Sharon described, "I got to a point where I would walk in this door and I would on hands and knees crawl upstairs to my bedroom. I could not make it standin' up." Connie told me about an experience that led to her diagnosis and negates a labeling effect. I can't stand anymore. I was so tired. So I sit down on the front of the building there little space you could sit, and I said this is not like me. Because I always have some energy, anymore. And I can't stand up you know."

Some persons with HCV may have only started experiencing symptoms once diagnosed while others had and continue to experience symptoms. While it is unlikely this debate has moved much beyond medical specialists studying hepatitis, the

implications are foreboding in terms of doctor patient interactions as well as knowledge and discourse about the disease emanating from physicians who discount the existence of symptoms.

NO REACTION

Fifteen percent of the sample reported others had no reaction to their disclosure. Stick's wife told his son and daughter and law. He told me that they "Didn't say anything." Grant's siblings also did not say anything to him when they were told. When I asked if they were worried, he replied, "No, they didn't never say nothin'." When I asked Andrew about his mother's reaction, he said, "Well, you know, she, wasn't too much she could of said." Lauren's live in friend did not express a lot of emotion. "Mmm, all I remember him sayin' was, oh baby, you know and that was it. He's not very, he doesn't know how to put his emotions into feelings and stuff." When Emma told her family, "Wasn't really like they broke down or nothin' but I know they was, like, hurt...I could see it in their faces." Grant's wife seemed more concerned about her health when he disclosed to her:

"She said, you've got Hepatitis I said yah, she said well, when I go back to my doctor I'm gonna ask my doctor to check. That's about it. Cuz she's kinda worried but the doctor I told her the doctor said you couldn't catch it."

These type of reactions from family or friends may be disappointing for persons with HCV if they expected more outward signs of concern or support. Persons who mentioned others having little or no reaction are less likely to report enacted stigma though ($\chi^2 = 5.04, p < .05$). Thus, no reaction may be seen as more desirable than a negative reaction.

In some situations, no reaction is desirable because they are people who one would not expect compassion or support from. In addition, often in these situations, no reaction indicates that the person does not see you as different after disclosure, thus reaffirming your non-HCV identity. Jeff said that all the people he tattooed still kept going to him after he told them and that they were not concerned because he wore gloves. Roxanne said her tattoo artists have had little response when she has told them. Others report their physicians had little to no reaction when told. Connie said her dentist simply thanked her for telling him. Eddie also said he got no reaction upon disclosure to some physicians. Vanessa mused about healthcare workers' lack of reaction, "Yah, they, uh, they don't really say anything. I guess they are maybe educated about it or somethin'-so they don't." Lauren said this about disclosing to most healthcare workers, "In fact the majority of them appreciate it and go, whoa, most people don't tell us 'till after, you know."

POSITIVE REACTION

While quite a few respondents described negative reactions to disclosure, over a third of respondents talked of some positive reactions when they disclosed their HCV status. These positive reactions to disclosure are a reflection of social support when it is conceptualized as "positive, potentially health promoting or stress-buffering aspects of relationships such as instrumental aid, emotional caring or concern, and information"(House et al. 1988). Research shows social support is a beneficial coping resource (Thoits 1995). Persons mentioned family most commonly and then the positive reactions of friends and at work.

Support from Family. Family can provide various types of support for individuals with HCV. Persons in this research mentioned emotional support frequently. Liz says, “My mother was--my mother's worried about me. She's been worried about me.” She talked about how her mother always tries to offer her medicine, food, etc. to make her feel better. Several respondents mentioned overall positive reactions from family. Ronald says, “But the people that I've told were the people that I'm the closest to and they've all just mainly shown concern. None of them were negative about it. They were all--showed, you know, were concerned about it.” Harold describes similar reactions from his family, “No, it's all been positive. Uh, you know they ask how I'm doing from time to time, and everything. So uh, you know there's an overwhelming support.” Jamie made almost an identical statement, “...but like I said all my friends, neighbors, and everything, supportive family they all know.” Eddy explains, “It hasn't really, I mean, nobody has been anything but supportive. It's all been very straightforward, which is fine.” Tari said of telling one of her sisters:

“Told the one that's in North Carolina, because she's a nurse, and I told her, and she was like, ‘well they have treatment for that.’ You know, she was very, trying to encourage me that it's okay, and she was like, “well let's see what your biopsy say.” Because she, she wanted to see what the facts are before she gets too.”

Jeff told of numerous negative reactions but pointed out that his mom and one of his sisters still love him.

Other types of support were instrumental help, for information, and social regulation or control (House et al. 1988; Thoits 1995). Yellow's wife's cousin looked up information for him after diagnosis. Donald's family and Rick's family also did internet research for them. Connie told her children, “They said anything we can do? So I told them you know they might thinking about a transplant. The first things they say was, ‘get

mine, get mine, get mine,' you know." Cece said about telling her daughter, "You know, said 'you need to stop drinkin', you know, oh she was so-my little God send child, I tell you."

Support From Friends. Friends were also mentioned as providing support through their positive reactions. They offered emotional, instrumental, and informational support. Cece got help in securing a doctor's appointment from a woman who worked at the halfway house where she was staying. Daisy says of her friends from church, "Yeah, and they hung right in there with me." Religion has been found as a means to increase social integration, especially in rural areas (House et al. 1988). Another friend of hers found information about HCV on the internet for her. David said his tai chi friends were all very supportive. "They're really good, people that are good listeners. They, they just were there and listened and whatever I wanted to pour out or say they were there, they didn't ask a lot."

Support in the Workplace. Support from work was either emotional or instrumental. Jason says of people at his work, "And I mean you know they were all for me to take the treatment." Connie said everyone at work was "so nice." Jenn, who works in HIV prevention and education, explains, "I think partly because of where I work they're very understandable about what I'm doin." Isabella, who was pregnant when diagnosed immediately told her boss and she said, "She was like oh my God. She goes, well go do whatever you gotta do. Just, you know, take care, of it, you know, we'll, well you'll, you know, just go. Go take care of yourself."

Tari works at a gastroenterology practice. "They offered, and even my CEO knows, they offered to give me free treatment there to see their doctors for nothing."

Sharon's old employer in the health care industry continues to pay for her medical insurance although she no longer works there. She describes people at work as being wonderful in their reaction when she disclosed. "So, I had great feedback, my patients were my mainstay." Respondents reporting positive reactions at work were more likely to have a household income above \$50,000 ($\chi^2 = 10.97, p < .001$). Thus, job status may be related to reactions at work. Future research should assess the impact of type of job and disclosure at work as persons with less prestigious jobs may be at a disadvantage in this regard, disproportionately affecting lower socio-economic status groups.

COPING WITH STIGMA

While some responses to disclosure are positive, other responses have been stigmatizing. Stigma may be conceptualized as a stressor and there are numerous methods for coping with this type of stress (Miller and Kaiser 2001). The most frequently used coping mechanism in this study is information control. Respondents reveal or hide information about having HCV to others. Some of this information control seems to be efforts to avoid stigmatization while other behaviors concerning information can be seen as acts of resistance. Condemning the condemners is another coping technique used to deal with stigma. A small minority of respondents involved in support groups or education resist stigma through various types of collective action (Miller and Kaiser 2001). Miller and Kaiser (2001) discuss disengagement coping, which involves avoidance and denial or minimization of prejudice and discrimination. Persons who did not mention being aware of stigma could be denying awareness of stigma. As mentioned in the section on interpretations of enacted stigma, respondents may have explained away enacted stigma through denial and minimization as well. As with disclosure patterns,

coping mechanisms are not a static process and people often experiment with different techniques to adapt to new social situations.

INFORMATION CONTROL AS STIGMA AVOIDANCE

Information control can be seen as a type of avoidance in that people reveal certain information in order to manipulate situations. All persons practice information control in some regard in that they don't tell every person about having HCV or how they got it. For some respondents, this avoidance is undoubtedly related to their awareness of stigma and their expectation of devaluation and discrimination (Link 1987). Many respondents choose to disclose certain information to certain people. For example, Sparky said, "I told 'em I had you know, about the liver part of it, and, a few of 'em I told about, you know, what it was. I mean I showed 'em the paperwork."

Persons who practice reluctant disclosure often do not reveal to others when disclosing their health status that they have hepatitis. Ronald told his girlfriend:

"I have not told her the name of it, but I told her, you know, and they've been real, you know, specific and open and honest about I have a disease, it's, there's a possibility it could be transmitted. It's a disease in your blood that it, you know, attacks your liver, and, you know, it can--and there's no cure for it, or no sure cure."

He revealed to another friend:

"I presented it to him that I had, I didn't never, I didn't come right out and say it was Hepatitis. I just said that I had a blood, a disease in my blood that could kill me and that affected your liver primarily, destroyed your liver..."

Sherri said, "Some of the people-like my pastor, his momma, his wife- they know I have problems with my liver but they don't exactly know what it is." Vanessa, another person who is a reluctant discloser said:

“The only thing I told them was I had a viral infection in my liver or whatever 'cause I just didn't want, you know, I just didn't want everybody to know... whenever I had to take family leave at work or whatever, you know, I just had Dr. Cassidy's office just put, you know, viral infection or liver problem or whatever, you know.”

Information control was used as a technique by persons who disclosed at various other levels also. Catherine told her kids:

“I told them, I was telling them like in riddles. Ok, mama has a liver condition. The doctors say that there's something wrong with mama's liver. And mama has to take medication, and if the liver, something goes wrong with the liver, you know that mama will die. You know I was going around in riddles with them, I didn't completely come out and say hey kids, look mama has hepatitis C.”

Tom says, “If I tell 'em I'm sick I tell 'em I have a viral infection. You know, I, I have a viral infection in my liver.” Roxanne told people she was undergoing chemotherapy when on treatment for HCV because cancer was to her less stigmatizing than HCV.

Respondents also use information control when asked how they got the disease. To my surprise, only 30% of the sample has been asked by one or more persons how they got HCV. Respondents who have been asked how they got HCV are more likely to report enacted stigma ($\chi^2 = 6.17, p < .01$). I had thought that perhaps being young may influence whether others ask this question but age was unrelated to this experience for this sample. In fact, gender, race, education, income level, and mode of transmission were all unrelated to a person's likelihood of being asked this question. The inquirer's curiosity may stem from an innocent quest for knowledge about transmission of HCV, especially in the light of the lack of public education about HCV. Other queries seem to be motivated by a desire to blame the individual or to absolve them of responsibility. For example, Ellis said his mother and ex-wife, “Wanted to know how did I catch it. Uh,

what did I do to get it?" Cece said, "And everybody asks me well, how did you get it? That's the first question. People say well, where did you get it?"

Responses to these inquiries varied. A few respondents simply lied or omit the truth about the believed mode of transmission to some people. Melissa says, "I did not tell her how I got it. This would be so far removed from her... No, I pretty much offered that in the thing, but I lie about it. I told people it was through a transfusion is how I got it." Tom says, "So I very rarely tell anybody that I work with how I truly got it." Others stressed how it is just so hard to tell how they got it. Mack explained, "Uh, so drug use is something that I did when I was younger. You know what I'm saying. And it could have been from that, and that would be the only thing." While Mack says that his drug use is the only possible means of exposure, he still does not say it *has* to be from that. Jeff said, "They say tattoos or I was once an IV user... Yeah. He says you know--I said well, I never can--I honestly can't say I ever used a needle after nobody, but tattoos, I been in jail before, and I said I did, you know, you don't, ain't no way to get needles." Liz says of possible ways she got it, "I don't really know for sure. I said I did shoot drugs a couple of times. I had a Caesarean. I've had injuries, cuts, stitches. I don't know for sure. Could have been any of those number of things." David also first mentioned IV drug use as a means of transmission but then added other incidents such as a hospital visit, occupational needle stick, etc. that could have been sources of transmission. Catherine revealed to me she might have gotten HCV through inhaling cocaine. She told a group of women:

"I say where it came from, I say I can't even begin to tell you. I said, I've been to where they pierced my ear with this little gun thing. You know I say they don't sterilize that stuff. I said they have fifty people come in the store to get their ears pierced. When do they have time to stop and sterilize their little gun? You know

I say, we don't none of us know where it came from, you know, I say, it's just something probably been around long time, that they just gave it a name.”

These statements seem to be trying to minimize the means of transmission from drugs in order to absolve responsibility for the illness.

INFORMATION CONTROL AS STIGMA RESISTANCE

Information control, or lack there of, can also be conceptualized as a means of resistance in that quite a few respondents candidly discuss issues concerning HCV including questions about how they got it. Numerous respondents described frank discussions about their health with friends and family members. Jenn said, “They had these brochures that says for family and friends so I gave one a those to each a the kids too, which has the transmission risks and stuff in it so I think it helped ‘em understand it more, you know.” Sharon also gave out letters she got from an online support group to friends. Jason revealed, “And, you know pretty much when I told ‘em you know I had Hepatitis and I had leukemia, you know, I laid it out all on the table and, you know, kinda, you know, answered all their questions.” Larry said,

“I told em' that I'd contacted Hepatitis C. I said this has been thirty years ago, when I was a young man. And I said after 25-30 years your immune system just, you know can't, I told them exactly what the doctor told me.”

Eddy tells houseguests:

“I think I have told the last two people who have stayed for any length of time, like who were watching the house. And, it was just kinda a very A,B,C, kinda you oughta know I have hep c and it is bloodborne, so don't touch any razors and don't touch the toothbrush.”

Samantha finally told her family, “Cuz’ I told them I had like some information on it, said it’s hepatitis C is like really hard to catch and you know, usually blood transfusion, like that and , they were just like, you know, so.”

At least 9 respondents were clearly upfront with the majority of people they disclosed to that they got HCV from drug use. Daniel reveals:

“I told ‘em that it was, it was a disease that you, a sickness that you catch, that you get, from drug related things, such as, and I told ‘em that I got mine shootin’ up drugs, and there’s other ways that you can get it, but that’s the most common way and what it does, is I just told ‘em that from what they told me that it, it attacks your liver.”

Harold said, “I told my family that, it’s more than likely through my drug use okay.”

Cece discloses, “You know, intravenous drug use. Or that, you know, there’s probably that or snorting, you know, ‘cause I mean, it--either or.” Bob said, “And I’m usually out forthright and say that I got, I’m pretty sure I got it from sharing needles and I don’t think there’s any other way that I could have got it...” Meredith told me about an exchange with her sister-in-law:

“And I said I’m doin’ treatments right now and she said treatments, your mother said you had a liver biopsy and you were alright and I said well I have Hepatitis C and instantly it was like, like how did you get that... I said well, you know, it’s probably because of the consequences, is, it’s part of the consequences of my drug use for so many years. *OH*. I think people are more taken aback by me being straightforward about it.”

Meredith’s roommate in a halfway house tried to play the role of a stigma coach, someone who tried to warn a person that others might see the particular attribute as stigmatizing (Schneider and Conrad 1983). “My roommate actually said you know you might not wanna let people around here know, you know how they are about that sorta thing, you know, and I said well I really don’t give two fucks about [M laughs].”

Meredith, Bob, Cece, and Harold are all fairly open about contracting HCV through drug use. All four individuals are also involved in Alcoholics Anonymous and/or Narcotics Anonymous. The nature of these recovery programs demands an acceptance of past addiction and eventual redemption from shame which may explain

their ease in disclosing this aspect of their lives as they are now “recovering”. Daniel is also an ex- drug addict who has been “saved” by Christ and thus also feels absolved of shame over his past. There may be a relationship between frank disclosure of transmission through drug use and acceptance of past identity as a drug addict, either through religion or recovery groups.

CONDEMNING THE CONDEMNERS

Condemning the condemners was originally conceptualized as a technique of neutralization or a behavior used by persons before they engage in deviant acts to justify their behavior (Sykes and Matza 1957). In this research, condemning the condemners is a coping technique used as a cognitive restructuring tool in that instead of feeling badly about themselves when anticipating or experiencing stigma, persons place blame on the those treating them negatively (Miller and Kaiser 2001). This technique is also used by persons to cope with a courtesy stigma of having a family member with Alzheimer’s (MacRae 1999).

One respondent, Liz, chided persons who ask how she got HCV. Liz tells people, “Yah. And I usually tell 'em it's not polite to ask. But I don't mind tellin' you. Yah, I say, but remember in the future, it's not polite to ask people how they got anything that they got.” Most other examples of condemning the condemners are harsher. Liz says of her stepson’s mother who was unpleasant concerning the HCV, “But she was always lookin' for some excuse to do somethin'.”

The most common reason given for inappropriate behavior by others concerning HCV was that they were ignorant. Harold says that when people are stigmatized it is because of ignorance. Rick says,

“Too many people got stigma with it, they got lack of knowledge and they ignorant of the facts. And you can't plan your whole life tellin' things to each individual person, tryin' to explain somethin' to 'em that it took you forever to learn.”

When I asked him what people have said, he responded, “Nothin', it's just ignorance stuff, uh, it's not even worth explainin' when people are ignorant.” Roxanne says, “But I mean it's not their fault, they're uneducated and they don't know, ya know?” She adds, “Cause if they're that uneducated, they don't wanna be educated.” Tom explains why people think it is a “dirty disease”, “No cuz they don't know, it's ignorance.” Nick says, “Oh yeah, they didn't like touchin' nothin', I told 'em you can't contact this like that, so there's a lotta ignorance out there.” Isabella says when discussing the nurse putting the sign on her hospital door, “This is then again the idiots and I'm sayin' idiots because I think the medical profession should have at least known somethin' about it if they were treating people for it with the drug.” Mack says, “I said, you know I don't discuss it with a lot of people, because of the ignorance that exists behind it the stigma, what people would think.”

Another means of condemning the condemner is stating that persons who stigmatize are too concerned about what others think or are bad people in some regard. Samantha says she thinks her boyfriend is ashamed that she has HCV. She explains:

“He's one of those people that's just the typical all-American white boy, you know, people pleaser, you have to look this way, act a certain way, you know, watch out what cuz' you know people will say this about you, you know, I mean he's a business man, he's got his own business, so it's kinda, he's gotta be I guess.”

Derrick condemns the employer who laid him off because of having HCV through describing their terrible employment practices regarding Mexican immigrants.

Two respondents made disparaging comments about doctor patient interactions.

Lauren says of the doctor who treated her poorly, “See I don’t think they’re little gods.”

Karla discussed how interactions with Dr. Cassidy at the public clinic are often in front of medical students and/or interns. Karla was diagnosed after her husband, who is covered in tattoos and a former drug addict. She talks about confronting Dr. Cassidy who she thought assumed drugs or tattoos are the culprit of HCV:

“So when I went to Dr. Cassidy, sittin' in this room and had all these people comin' in, so I sat there and I said well, why don't you sit there and tell everybody how I got it. And he, he looked--he just looked at me, and I said you don't see no eight balls on me. [Referring to her husband’s tattoos]. I'm too fat to be a drug addict. I said so how do I got it? He didn't say nothin'. He turned around and went.”

Although I cannot verify the accuracy of this interaction, Karla clearly enjoyed telling me about her interaction with Dr. Cassidy as she seemed proud of her confrontation. As I mentioned previously, she and her husband have experienced more discrimination than any other respondents and she may have engaged in this confrontational interaction with Dr. Cassidy as a means of trying to resist the ever present stigmatization she experiences. If she exaggerated the interaction, she still was presenting herself as someone who does resist stigma perhaps indicating what she wishes to do.

COLLECTIVE ACTION

The small of group of individuals actively involved in support groups are engaging in collective action in order to cope with stigma. Although not all of these persons have experienced stigma, they all participate in activities that promote education and compassion concerning HCV, thus resisting stigmatization. Sharon, who participates in an online support group, says,

“Didn't matter to me and it, one of the first things they say, they, everywhere we go, I mean everywhere you go to read or on the bulletin board or for support and

help, the first thing you're told is, we don't wanna know where you got it, we don't care where you got it. The issue is, you have it, we wanna help you deal with it.”

Harold talks about someone in his support group who has experienced discrimination because of HCV:

“You know, it makes me want to be there for them and give my support. Whatever I can do to help. I think that as prevalent as this disease is in society today that people hopefully will get educated, you know, and that they will do whatever it takes to learn about the disease.”

Isabella runs a support group and discusses how she deals with people who got HCV through IV drugs. “And you know I tell those people, you know we and I don't discriminate against anybody you know how you got it, or how you know, or how you didn't.” Isabella told me about how some people at the support group discuss how they got it, but that she tries to not continuously do that herself because she does not want, “(To) Make them [person who got HCV through IV drugs] think that I am somewhat superior you know than them.”

CONCLUSION

HCV is not definitively stigmatizing. Persons lack ample cultural imagery to rely on for internalization of what a diagnosis of HCV means. Thus, some respondents are unaware that HCV is even seen as stigmatizing. Needless to say, these folks are not engaging in felt stigma unless their seeming unawareness is a ruse used as a coping mechanism. Race and ethnicity are important factors affecting these processes, a finding suspected by some researchers who feel that studies of stigma have too often excluded structural inequalities when evaluating stigmatization (Parker and Aggleton 2003). Whites are more aware of stigma, more likely to engage in felt stigma and more likely to have experienced enacted stigma. Whites could be more sensitive to stigmatization

relative to Blacks because of their un-stigmatized racial identity. In other words, Blacks may experience similar rates of stigmatization but are less likely to recognize the discrimination as being about HCV per se because they occupy other stigmatized statuses. However, some posit that, “individuals with less power are more likely to be chronically more attuned to the situation, to shifts in affective and nonverbal tone of the other, generally paying more nuanced attention to the other”(Oyserman and Swim 2001)(6). Blacks may indeed recognize HCV related stigmatization but don’t feel it was as salient to their HCV experience to discuss it in the interview process. Blacks may also rely on minimization or denial of stigmatization as a coping mechanism to protect self-worth more so than whites (Shih 2004). Future research should focus on racial differences as this factor seems to be one of the crucial differentiating characteristics delineating experiences with stigmatization.

More than half of the sample did deal with felt stigma and/or enacted stigma. However, respondents also had other reactions to their disclosures including minimization of their illness, no reaction, and positive reactions. Positive reactions in the workplace may be a function of type of job and merits further research attention. Persons with HCV have a variety of coping mechanisms to deal with the real or imagined threat of stigma. Respondents controlled information often as a means of stigma avoidance but also as resistance. Condemning the condemners and collective action through support groups also helped some persons cope with the experiences of having HCV. While in some ways, the percentage of the sample that have experienced stigmatization is encouraging in that not everyone feels stigmatized, I am not optimistic about future trends as I fear levels of stigmatization are related to levels of public awareness about

HCV. Unfortunately, if HIV/AIDS education is any indication of trends, we may see that with more public education and awareness, there will be more HCV related discrimination (Herek et al. 2002). Future research assessing public knowledge about HCV should stay attuned to changes in levels of stigmatization and coping mechanisms. If rates of stigmatization rise, perhaps rates of collective stigma resistance will rise as well. In addition, we should note how possible rising rates of stigmatization interact with racial effects on experiences with stigma. In the next chapter, I discuss how having HCV is a biographical disruption for individuals. Persons must experience diagnosis and subsequent reactions. As people continue in their illness careers, some gain a great bit of knowledge about the disease while others have little information. Persons conceptualize their illness in variety of ways with some incorporating faith in order to make sense of their illness.

APPENDIX 4

4.1 AWARE OF STIGMA

	χ^2	P
Enacted stigma	6.41**	<.01
Fear of discrimination	5.04*	<.05
Level of disclosure	.54	<.5
White	6.41**	<.01

4.2 FELT STIGMA

	χ^2	P
Enacted stigma	3.31	<.07
White	4.71*	<.05

4.3 ENACTED STIGMA

	X^2	P
Aware of stigma	6.51**	<.01
Gender	.02	<.90
Level of disclosure	2.79	<.09
Mode of transmission	2.34	<.12
No reaction ²⁹	5.04*	<.05
White	13.12***	<.001

²⁹ Those reporting no reaction to disclosure are less likely to report enacted stigma.

4.4 CHI-SQUARE CROSS TABULATIONS

Aware of Stigma and Enacted Stigma ($\chi^2 = 6.51, p < .01$)

	Enacted Stigma	No Enacted Stigma	Total
Aware of Stigma	24	17	41
Unaware of Stigma	2	10	12
	26	27	53

Aware of Stigma and Fear of Discrimination ($\chi^2 = 5.04, p < .05$)

	Expressed Fear	No Fear	Total
Aware of Stigma	13	28	41
Unaware of Stigma	0	12	12
	13	40	53

Aware of Stigma and Race ($\chi^2 = 6.41, p < .01$)

	White	Minority	Total
Aware of Stigma	30	11	41
Unaware of Stigma	4	8	12
	34	19	53

Aware of Stigma and Levels of Disclosure ($\chi^2 = .54, p < .5$)

	Limited/Reluctant	Open/Activist	Total
Aware of Stigma	21	20	41
Unaware of Stigma	7	4	11
	28	24	52

Felt Stigma and Enacted Stigma ($\chi^2 = 3.31, p < .07$)

	Enacted Stigma	No Enacted Stigma	Total
Felt Stigma	18	12	30
No Felt Stigma	8	15	23
	26	27	53

Felt Stigma and Race ($\chi^2 = 4.71, p < .05$)

	White	Minority	Total
Felt Stigma	23	7	30
No Felt Stigma	11	12	23
	34	19	53

Enacted Stigma and Race ($\chi^2 = 13.12, p < .001$)

	White	Minority	Total
Enacted Stigma	23	3	26
No Enacted Stigma	11	16	27
	34	19	53

Enacted Stigma and Levels of Disclosure ($\chi^2 = 2.79, p < .1$)

	Limited/Reluctant	Open/Activist	Total
Enacted Stigma	11	15	26
No Enacted Stigma	17	9	26
	28	24	52

Enacted Stigma and Little/No Reaction ($\chi^2 = 5.04, p < .05$)

	Little/No Reaction	Reaction	Total
Enacted Stigma	1	25	26
No Enacted Stigma	7	20	27
	8	45	53

Workplace Support and Income ($\chi^2 = 10.97, p < .001$)

	\$0-19,999	\$20,000-49,999	\$50,000 and Up	Total
Support	1	1	5	7
No Support	21	18	7	46
	22	19	12	53

Enacted Stigma and Asked about Mode of Transmission ($\chi^2 = 6.17, p < .01$)

	Asked	Not Asked	Total
Enacted Stigma	12	14	26
No Enacted Stigma	4	23	27
	16	37	53

CHAPTER 5: WHAT DOES IT MEAN TO HAVE HCV? DIAGNOSIS, KNOWLEDGE, AND COPING

Having HCV is stigmatizing for some people. As discussed in Chapter 4, Whites are more aware of HCV related stigma, more likely to engage in felt stigma, and more likely to report enacted stigma. Not all reactions to disclosure are negative, however, and some respondents received positive support as a result of disclosure. People devised different coping mechanisms to deal with the possibility of stigma.

Before a person can disclose their health status, they must first be diagnosed. Being diagnosed with a chronic disease can be a life altering event. In this chapter, I discuss persons' diagnosis, which came either as a *Surprise Diagnosis* or *Individual Initiated Diagnosis*. Respondents experienced a multitude of reactions to diagnosis including *Fear of the Unknown*, *Shock*, *Fear of Imminent Death*, *Sadness*, and *Ambivalence*. After persons experience diagnosis and the initial reaction, respondents' behaviors and outlooks further diverge in terms of coping. People had varying degrees of knowledge about their illness: *Expert Knowledge*, *Moderate Knowledge*, and *Little/Inaccurate Knowledge*. Levels of knowledge are related to numerous outcomes for individuals and society. A phase of the illness career involves learning how to make some sort of sense of their illness. Respondents often turned to discourse about HIV/AIDS to understand their experience. In other attempts to explain their illness, people employed a variety of approaches including conceptualizing the illness as *Punishment*, *Challenge/Acceptance*, as *Loss*, and as *Value*. Many persons with HCV mentioned their *Faith* as a coping resource.

DIAGNOSIS

SURPRISE DIAGNOSIS

For many persons with HCV, their diagnosis came as a complete shock as they had no idea that they were sick in any way. Over half of the respondents found out they had HCV in this fashion.

Routine Screening. Nineteen persons were diagnosed because of results from routine screening. Andrew said, “And that's when they determined that I had Hepatitis. And when they caught me off by surprise...”. Mark recalled, “Had to take a physical, cuz we were changing the insurances at work, and the liver enzymes showed up high.” Jenn was trying to get involved in a research study for her diabetes and was diagnosed as a result. Eddy explained,

“I had not had health insurance for a while and for some reason, I got health insurance, I guess my business might have just picked up enough so I had, I had health insurance and I think that is the reason, not sure, but I got health insurance... so I went just to get a regular physical and he did a blood test, he did kind of a basic everything blood test and one of the things he checked for was Hep C and he said, you've got it.”

Ronald relayed a very similar experience:

“I had insurance, and I thought that I was in real good health, so in-- to, to go and just to celebrate my great health, I just, you know, took advantage of the insurance and went in for a physical. A routine, general physical. And that led to this diagnosis. When they did the blood work they said you have elevated enzymes in your liver and we need to kinda, you know, see what that's about, and so I didn't you know, really wadn't thinking about what that meant, but that's what it meant. So it led to the diagnosis.”

Maruf also was trying to check on his overall health:

“Uh...but I decided to go and have a real full physical and all kinda blood test. Just for the hell of it, just a coincidence. And the tests came back, and she said well the doctor said we gonna have to do the test again there's something there that um kinda need to be sure about.”

Joey said, “Oh, I went into rehab. Cuz I was doin' too many drugs and stuff. And they ran blood tests on me and told me I had Hepatitis.” Samantha also found out while in a rehabilitation center, “Yeah, and I went to go ahead and you know, they gave me a blood test and all that to make sure, because they were going to put me on Antabuse and make sure my liver all right.” Meredith found out while in prison for a drug related charge, “But while I was there they, right before I left for boot camp they took blood tests and the longer you're there the more they'll do different blood tests. And that's when they found out. And they told me that I had Hepatitis C.”

Blood donation/Plasma Center. Eight respondents were informed because they had donated blood or sold plasma. David said, “My mother was havin' surgery and she needed some blood on reserve, and so me and my brother went in”. Nick described how he gave blood as a way to get tested for blood borne diseases because he had been an IV drug user. Rick and Charlie were informed about having HCV from letters from the blood donation organizations. Sparky was mad that they had not told him because he had been to the plasma center before. “I almost went ballistic. I said what are you sayin? I said I been here numerous times.” Bob, who also found out from a plasma center had a different reaction, ““You have Hep C and I was like, I didn't know what that was and that's pretty much what I said, I was like so what does that mean, do I get the rest of the money or...”

Informed by Hospital. One respondent was informed about possibly having HCV through a letter she received from the military. While in the service, she had a blood transfusion. The hospital went back through the records and contacted anyone who

had received blood before a certain year that they may have been exposed to HCV because it was before blood was being screened for it. She was tested and diagnosed.

INDIVIDUAL INITIATED DIAGNOSIS

While many respondents were completely caught off guard regarding their diagnosis, 20 respondents were experiencing symptoms and sought medical attention and 3 other respondents requested or were advised for specific testing for HCV.

Symptoms. Numerous respondents sought care because of fatigue and or problems/pain with their stomachs, sides, or backs. It took several months after first seeking care that Sharon was diagnosed:

“It took us till about May to go through all the tests that are natural and normal and I was fine. I mean everything about me was fine, I was just so tired. Uh, and then I got to a point where I would walk in this door and I would on hands and knees crawl upstairs to my bedroom. I could not make it standin' up. And I went back and I said, John I can't stand this. You know, this is not right. That's when he said, let's try the Hepatitis.”

CeCe also battled with fatigue. She told me,

“And in, in '99 I woke up and said I gotta do somethin'. Somethin's not right with me. You know, I could feel my body just goin'--suckin' the life outta me...I kept gettin' sick and wouldn't work for two or three days and just fall out with exhaustion.”

Catherine had a similar experience, “Yah, right after my mother passed. I kinda, I was like, was feeling tired all the time, or you know I just thought maybe I wasn't getting enough sleep or something. And I went to the doctor.”

Several respondents had severe symptoms that led to their diagnoses with HCV.

Daisy had a frightening experience. Her husband explained,

“Then one day here she started bleedin' real bad and she went to the bathroom and she was just, full of blood, you know. So we took, I took her and she got weaker and weaker and weaker. So I took her to the doctor in Baton Rouge, and they, they checked her as to whether there's somethin' wrong you know, they went

down into her esophagus, and all that, and checked all that, and found out she was bleedin' from the inside. Come to find out she had varices veins..."

Jeff also had extreme symptoms that prompted his diagnosis, "And when I stood up, it was like a hose. Somebody put a hose in me and made me sick. I mean, blood comin'!"

Donald had a strange reaction to an alcoholic drink:

"Well we went to some neighbor's house I think that's when you actually kind of found out. And one of the neighbors gave him a drink. And he drank it and like ten minutes later he couldn't walk, he couldn't you know, could not do anything... Well a few days later he was still very disoriented and all that."

All 3 of these respondents had poor prognosis when diagnosed and when I interviewed them. Such acute and severe symptoms of HCV indicate very advanced liver disease.

Asymptomatic Testing. Two respondents asked to be tested because of suspicions about HCV. Tari's husband was first diagnosed with HCV and she said,

"Uh huh, and I used to use his razors and stuff, and after, when we got married earlier on, and after he got diagnosed with it, it was always in the back of my mind, you know, cause I kept thinking well I used his razors back then. And we never knew when it happened to him so it was like...God."

She subsequently asked her doctor to test her. Larry found out a friend died from HCV:

"So I start really researching, and you know, looking into it. I had heard, that you know, Hepatitis C could be, is fatal in some cases. And the more and more research I dig in to, I said, well I better go and get tested. Cuz I got it from him, I know I did."

While Lucy did not have symptoms, she was advised by a physician to get tested because of her husband's diagnosis of HCV.

REACTION TO DIAGNOSIS

According to Link (1987), once patients are diagnosed, they must now apply what it means to have that label on a personal level. As discussed in Chapter 4, 56% of respondents had heard of HCV before diagnosis. However, only 27% of the sample had

any substantial knowledge of HCV and some of that knowledge was deeply flawed. The lack of information regarding HCV or misinformation shaped respondents' reactions.

Fear of the unknown. A classic reaction to diagnosis is a feeling of uncertainty, according to Bury (1982). Several respondents explicitly discussed how they were fearful because they did not have any knowledge of HCV. Catherine said of first finding out:

“Cuz at first when I, when they first told me, it did scare me, because I didn't have the knowledge that I did have. And when they first told me it was like, ok it's like a light that goes off, it's like, you know, you quite don't know what Hepatitis is, but you know it's somethin' scary.”

Melissa said, “And, I was stunned. I was really, it was one of the surreal things, you know, when- I had some questions, but not a whole lot, because I didn't know what to ask. I was, it wasn't like I didn't care. I was just kinda shocked...” Rick explained, “Well, I was inquisitive. I wanted to know what the hell it was...and that scared me worse, had me freaked out for a long time not knowing what the hell was going on. After I realized they didn't know too much either you know.” Andrew described,

“And then when I found out, it was kinda, it hit me hard cuz, I was really lookin forward to a [kidney] transplant, not that I can't get one, but I'm kinda frustrated you know what I mean cuz when I found out you know I really wasn't too up to date what hepatitis do to the liver.”

Shock. Many respondents mentioned feeling shocked by their diagnosis. Sharon relayed information her doctor had told her:

“Eventually we'll check you for Hepatitis but I know you don't have that cause you didn't do IV drugs. You know and I knew during all that time and he said, anyway, it's a hell of a way to die. And at the time it was, cause there was no Interferon or anything when he had said that, those words stuck in my head. And I probably cried for three solid weeks.”

Daisy said upon being diagnosed, “Oh Lord, I thought the world was comin' to an end...”

Emma echoed Daisy's sentiments, "I felt like that was the end of the world, you know." Lauren said, "No, because I went numb. [L chuckles] I'm still numb about it...And but really when he first told me about it, I just, I just kinda went into shock." Charlie revealed, "Well, it's kinda like, what the hell is this? I said it's all I need. It was kinda like a, it's like bein' hit between the eyes." Samantha said,

"I don't know, it was almost like finding out you know, you had, a terminal illness, it is (laughs). You know and it was like, you know I am just like, everything sort of flashed before me, you know and I remember just being real scared, a lot of fear..."

Jenn's shock resulted more from her knowledge of the disease and the means of transmission. She explained,

"He called me at work Monday morning about 9:30 said well negative for A, negative for B, but positive for C. And I just said huh? You know 'cause I knew I'd never, you know, I knew the main reasons [people got it]. Shocked. I mean I was, when I was talkin' to Cheryl [her boss] I was almost in tears."

Maruf's shock resulted from the dissonance in his conceptions of self and reality after diagnosis:

"I'm a strong person, and I can't, I don't give up that easy, but I felt bad I mean I couldn't sleep that night knowing that, thinking I'm healthy all my life I'm not...That I've had something in me for the past ten or twelve years and I didn't even know about."

Connie and Isabella feared rejection from their husbands. Connie had remarried a few months before diagnosis. She said, "So, first things come to my mind was, my gosh, my husband married me and is gonna be burdened. That was my first reaction. I almost feel like, [C laughs] I thought he must think he got tricked." Isabella explained, "Well first of all I mean, I mean my first thought was he's gonna leave me. I mean I've got, they, a disease that could be sexually transmitted."

Fear of Imminent Death. Several respondents mentioned feeling they were going to die. Liz said,

“He said, he said I had Hepatitis C and I was moderately active cirrhosis, and I thought, I'm gonna die. You know, that's it, I'm gonna die. Ya'll just, you know, I guess I better go get myself in order or whatever, you know. Ellis said, “I worry about it all but when the first doctor told me about it I really truly, I thought I was gonna, gonna die.”

Ronald said,

“Oh, I felt, um...pretty much devastated. Emotionally pretty much devastated and, and I felt, you know, like, I tend to sort of, I don't know if you call it overreact or what to some circumstances, but I felt like I had been given a death sentence and that my life was basically over.”

Catherine said, “So it's like ok if I'm a die with this then let me. And that was just my first reaction from it.”

Sadness. A few respondents specifically mentioned feeling depression as their reaction to diagnosis. Grant said after being diagnosed, “I'm like ooh man, it's just like I'm feelin' depressed--like I went into depression.” Sherri was all ready suffering from depression at the time of diagnosis, said, “It depressed me more.”

Ambivalence. In contrast to respondents who felt shocked, depressed, or fearful, other respondents reported a lackadaisical response to their diagnosis, possibly as a means of denial for some. Daniel explained how he did not really follow up with medical care after diagnosis because of lack of insurance:

“And, and I went and seen the other man one time and he, I did some more tests with him and, to, to, make, you know, clarify that I did have it and I did. And, he wanted to start checkin' into it, but I didn't have insurance...So I went, I guess I went almost a year without doing anything about it.”

David said, “I just didn't, put a lotta seriousness into it, it's hard for me to put serious-seriousness into it right now even, because a the fact that I feel pretty good.” Tom also

did not place a lot of importance on the initial diagnosis. He said, “Not really. Like I had, I had other stuff going on.” Nick explained, “Uh, about the disease, I took it for granted.” Sallie Anne said, “I mean when I first found out, when I found out, I was kinda upset, and then when I re-re found out again [she was diagnosed with non-A, non-B hepatitis years before], I was really upset, for about 2.5 seconds.” Peggy was concerned about the inconvenience, “Just that it would be a pain in the ass though until you got well, you know with the costs and everything.” Unlike respondents who cited the lack of information about the disease as a source of fear, Jamie’s lack of knowledge kept her from worrying. Jamie said,

“Well, I mean, well, I was, I was, like I said I didn’t know anything about it, and I think I was thinking it was something that could be cured cause he was saying he could put me on this medication and it would help clear up my liver and different things like that. So, I thought it was something that you know that could be cleared up.”

KNOWLEDGE ABOUT HCV

Previous knowledge or lack thereof about HCV may affect the initial reaction to diagnosis. Medical knowledge can be a response to uncertainty experienced after diagnosis (Bury 1982). It is important to assess respondents’ understanding of HCV at the time of the interview to evaluate how current knowledge impacted coping.

EXPERT KNOWLEDGE

Almost one third of respondents (29%) knew a great deal about HCV.³⁰ These respondents understood the disease and the treatment available. For example, Meredith said, “They said something about the years I had in clean time, of clean time, the, when I was diagnosed and the fact that I was female and my age group made me a good

³⁰ See Appendix 5.1 on page 188.

candidate for this treatment.” While there was a range of knowledge within this category, all of the persons accurately discussed numbers, such as viral loads and biopsy scores. Isabella said, “He did the viral load which, you know, shows you how many copies per mil--, milliliters is in your blood.” Not all of the respondents were familiar with genotypes of the virus in this category but some were.

An overwhelming trend among these respondents was their impetus to seek our information. Melissa said, “And, I remember leaving his office, and the first thing I did, although I don’t quite remember it is, I drove straight to Barnes and Nobles book section...And then just read, you know, devoured them, highlighted, you know.” She talked about contacting one of the pharmaceutical companies:

“And spoke with the people in the research department there, and I got information sent to me at the time, which I can’t get now. Um, evidently they’re really tight about their research, and I didn’t tell them who I was, and they didn’t ask. So, they sent it to me like I was a doctor [M laughs]”

Connie, a Japanese woman, was diagnosed in the early 1980s when little information was available. “So, I wrote to Japan and they send me any of the news that all the information how you contract and how you going to be and how to do those blood tests and those kinda things. There was much more information [in Japan].” Sharon said, “I hounded the Internet for information. I ordered books upon books upon books.” Catherine, the only African American in this category as well as the only African American who practices open disclosure, said,

“I just started reading, I started going to the library, I started reading up stuff on it, and just picking up pamphlets everywhere, and every time I would go somewhere, and I would see something about hepatitis I would get it and read it and everything. I just got all the knowledge that I can get off of it, cuz I wanted to know everything there was about it.”

Cece commented, “Once, once I got the literature, because I demand literature. I wanna know. And I read, and I read, and I read until I was completely satisfied with what I had.

I had, but I had to get all points of it.” Despite the public clinic being very busy,

Meredith described her experiences there:

“I have no qualms about asking a million questions and clinics are a good atmosphere. They always have people involved that are just so willing to answer, you know,— I mean it's not like they're [indecipherable] and just seein' me like cattle, no, if you're articulate and you speak to them and you have, and you have a legitimate question or if they see that like you're, you're writing down your question oh by the way, you know, oh yeah this is what I want to, you know, that sorta thing, they actually like that sorta thing because it's like, well my efforts aren't being wasted, you know. “

Meredith discussed how persons being seen at the public clinic can get extensive information, but that they must be proactive and engaged with the staff to do so.

Meredith is a White woman with some college who may have the skills necessary to extract this knowledge in that setting. It is unclear however, whether persons of varied social class and ethnic backgrounds have the same interaction skills available or whether medical personnel would interact with diverse persons in a similar fashion.

Several respondents discussed researching past records as to how or when they were infected. Liz tried to find records from her when her child was born and she had a cesarean. Connie contacted the military hospital from her childbirth experience. David tried to assess when he might have been infected:

“I went back as far as possible trying to find all lab blood reports that I had, where I had complete blood counts, and, blood work done. In the earliest one I remember was done when I was in my early twenties, twenty, twenty-one, twenty-two years old, and they, they didn't even have a record of it, they had to dig it up on microfilm. Had to pay 'em money to do that, had to research this stuff to find it. But they did locate it...and the enzymes on the, were elevated.”

Gaining knowledge about the disease was beneficial for numerous respondents.

Catherine said,

“But you know, they started telling me about the medications, and you know the things I needed to do. And you can actually live with this thing for ten years, and stuff like that, and you know then got some knowledge of it, and I changed a lot of things you know.”

Jenn discussed her experience getting her biopsy results when she knew less about the disease: “Cause not having that much knowledge about the disease when I was first told about it, you know, then when she says it’s level two inflammation and swelling and it’s like ok what’s that mean, you know.” For David, acquiring more information changed how he conceptualized the disease:

“But you gotta realize the first time, even though it was when I began treatment I still, I don’t think I was takin’ it as seriously, because it’s such a, it’s it’s so hidden, you can’t see it, you can’t tell, so it’s like I’m doin’ this but I don’t even know if I need to be doin’ this. But since then, on up to now, I’ve read so many articles and I’ve heard so many things, it seem, the instances of liver cancer and liver cirrhosis, ad, know th at this is real. So I just I understand it a lot better and I understand the possible seriousness of it, where back then I didn’t take it as serious.”

MODERATE KNOWLEDGE

Over half of all respondents have what can be conceptualized as moderate knowledge of HCV.³¹ These respondents understand the disease for the most part, but few talk in numbers or are perhaps inaccurate if numbers are mentioned. Some of these persons did, similar to those with expert knowledge, mention researching the disease.

Vanessa said,

“I read on the internet about, you know, the facts and that kind of stuff, but then I was, you know, I felt blessed because I wasn’t, I guess I wasn’t as bad as some of the people that I read about, you know [with regards to side effects from medication].”

³¹ See Appendix 5.2 on page 189.

While Vanessa did not speak in specifics, her understanding of the disease and comparison to others helped her to feel better about her own experience. Jeff said, “And she [his wife]...has got so much stuff off the computer that I mean, we just sat and talked about it--me and her together, you know, look, you know.” Roxanne said,

“Um, Dr. Cassidy kept me really informed, really, really well. I looked it up on the Internet, a lot of websites and stuff. I'd actually go in some of the chat rooms with, that had it. I mean, different, different things. Be In Charge [a program by a pharmaceutical company], informed me the most, I got to say. They gave me all the statistics that I need, you know, to decide whether to do it [treatment] or not.”

Bob said, “I think I looked up stuff in the library, I think I actually like checked out books in the library.” Not all respondents sought out information as Ronald said,

“I, and I'm still not well-educated. I've been kind of in denial. I've stayed in denial to some degree about it. Now, I mean, you know, I don't study it very much or anything...I guess they just gave me some general--they gave me some literature to read, a nice booklet that looked real professional and scientifically based, which I haven't read.”

Although some respondents did seek out information about HCV, respondents with moderate knowledge were often unfamiliar with the language used to describe the disease and tests or discussed results in general terms. For example, Tari said of her biopsy results, which are presented in terms of grading and staging, “I can't remember, there was a one, which it wasn't that, that was like the, it wasn't like stage one. It was more like a percentage.” She did mention that “---my labs you can't tell that anything is wrong with me.” Andrew said of his biopsy, “Then, there wasn't you know, there wasn't too much corrosion, it was lookin fine.” Jamie said of her biopsy, “Uh...he said I had a lot a scar tissue.” Ronald said, “I think they said somethin' about like B, a B. I remember them mentioning, I think I remember mentioning like a B, a B amount of scarring.”

Several respondents did seem to understand liver enzyme testing although again,

knowledge varied. Daisy's husband said of her liver enzymes, "The enzymes were up, you know, to a a positive level, you know. It wasn't exactly where it should be, but said it was up to a positive level. She oughta be doin' little better." Liver enzymes are high when there is a problem, thus his comment is perplexing.

A few respondents seemed to almost have expert knowledge with regards to details such as their viral load or even the genotype of their virus but mentioned other fairly important aspects of the disease that were inaccurate. Larry could speak about side effects of treatment. "And this medication, the way I understand it, it eats up red blood cells, and that's what carries oxygen to the muscles and the organs of your body." Larry, however, erroneously believed that there is a Hepatitis F and G. Eddy said of having hepatitis decades earlier, "I think that what leaves me open to Hep C where I might have gotten both at the same time or something like that but it's that the liver never healed itself from the first infection." Having other kinds of hepatitis does not make one more vulnerable to becoming infected with HCV. Derrick understood his liver enzymes were high which led to his diagnosis. He also knew his liver staging and his genotype. But he added that, "So I mean I knew that there was no cure, that it was really slow, and that you would either need a liver transplant or you're gonna die." HCV is estimated to lead to serious liver disease in roughly 20% of those infected (Franciscus and Highleyman 2003). Charlie, who catalogued his liver enzyme tests in an Excel file, said of his friend, "He has Hepatitis, and he has it bad, like his viral count is at least 8 million. Mine's 825,000." Viral count however, is not related to prognosis per se. Lauren knows her viral load and understands the medications. She did say no one in her family had a history of Hepatitis C, but HCV is not a genetic disease. She also said, "That it's always

fatal, and gettin' liver cancer and I think and I don't know, I forgot, 40 percent of people that get liver cancer or 70?" Most research indicates that chances of HCV leading to liver cancer are less than 15% with most citing less than 5% chance (Franciscus and Highleyman 2003).

Several people discussed a "fast" or "worst" kind of HCV which was perhaps a reference to genotypes although the genotype of the virus is unrelated to progression of the disease. Genotype is, however, related to responsiveness to treatment and length of treatment which may be what confused some. Lauren explained,

"I haven't heard any, except the other doctor said that mine must be the very slow kind. I have the worst kind....And probably been, all, all different kinds [of donor blood], mixed in together, that's how I wound up with the worst kind."

Ronald also mentioned this:

"And that it progresses--there's a slower progressing and a faster progressing and that, you know, depending on your own immune system and your own lifestyle, you know, so what I decided to do was to, was to wait and get another liver biopsy and determine which if it was progressing--how fast it was progressing."

Larry said, "I have genotype 1, which is the worst one. Or, I forget if they call it 1 or A."

In addition to discussing "worse" kinds of HCV, a few respondents compared HCV to other types of viral hepatitis. Although their knowledge of HCV was moderately accurate, their awareness of other types of hepatitis was highly inaccurate. Derrick said, "And they know that A and B are highly contagious and are highly aggressive and can kill you in a week." Charlie explained an interaction with his brother:

"So he fretted all weekend, he finally called me up on Sunday and says, you don't have Hepatitis B, do you? I said, hell no, man, I've got C. Don't--God. Thank God...Well, he said, yah, because B's worse than C...With B you're--you've got one foot in the grave and the other one on a banana peel. So he was kinda--because you've got longevity with it, you know, people get Hepatitis C and it never jumps up in their face."

Bob said, “I mean he basically told me that it wasn’t Hepatitis B; so it wasn’t, you know, fatal in the immediate sense.” These respondents may have been using other types of hepatitis as a deviance exemplar (Ronai and Cross 2002). In other words, their confusion about the nature of hepatitis B may have allowed them to feel better that they had HCV which was not as severe or bad in their mind.

Respondents with moderate knowledge understood HCV in general, but often also held other inaccurate beliefs regarding HCV. Karla said, “See he hadn’t put me on insulin yet, ’because if I go on insulin, the Hepatitis C, it’ll speed up rapidly and, and I, I could die before Jeff.” Karla added, “When I first got it, it wasn’t really bad. I could have took a pill and got rid of it, you know, but now it’s so bad that I have to have the Interferon.” There was confusion among several respondents regarding sexual transmission. Sexual transmission of HCV is regarded as rare (Franciscus and Highleyman 2003). Andrew said, “...where I got this sexually transmitted disease you know and you got to be very careful and if you date somebody you got to be extra careful and this and that.” Mark alludes that he may have got it from promiscuity. It is not unfeasible that persons are confused about sexual transmission, however, as sexual transmission is sometimes listed as a means of transmission despite the improbability.

LITTLE/ INACCURATE KNOWLEDGE

One fifth of persons interviewed had either little to no knowledge of HCV and/or grossly inaccurate information.³² These respondents often did not know anything about various tests and had a rudimentary understanding of HCV, if any. Ellis understood that his previous experience with treatment kept the virus at bay while on treatment. He

³² See Appendix 5.3 on page 190.

talked of having a “spot on his liver”. He was on treatment again and said, “...and all my blood tests showed up negative I asked them what that meant and they told me that it means that the medicine's workin and I think that's fine.” Jerry did not know who diagnosed him with HCV or when he was diagnosed. He said the doctor told him, “And he got the results back and he said my liver's 95% good.” While Mack knew he had lower levels of the virus and that doctors did not recommend treatment for him, he did not know if he had had a biopsy or not.

The main confusion for this group of respondents was with regards to modes of transmission. Several respondents told me implausible modes of receiving the virus. While Sparky is knowledgeable with regards to treatment and tests regarding HCV, he told co-workers and believed he may have got it through binge drinking. Sparky explained, “I think I got it from drinking...I drank, I'd buy a fifth of Wild Turkey, and drink straight whiskey til I'd throw up, and drink some more, and drink some more, and drink some more.” Later he revealed “Uh, I did...I did IV drugs for awhile.” He did not offer this as a means of transmission however. Ellis said, “And I think that's why I got the Hepatitis, from drinkin' alcohol that's what started that feelin. The other thing only thing I can know, we used to swim in the canal as a kid over there. Back then we drank a lot.” Matthew, who talked mainly of his drug addiction during the interview, added, “And that's anotha thing you know they say that my Hepatitis C come from drink.”

Little Brother did not know anything about the results of his biopsy or that there could be side effects from the treatment which he was on. Little Brother said about how he might have contracted HCV:

“Yeah, said it could be a earring, could be drinkin' behind somebody. She said it could be a couple a things. Cause in that plant [chemical plant where he used to

work] you know, you just can't say, she say, you never know, could be a couple a things."

He said of avoiding transmission to others, "Yeah they told me. Uh...use rubbers and use some other kinda liquid stuff. Don't use, you know, straight out naked, you know what I'm talkin about, you give it to somebody else." Jerry did not know how people get HCV or how he got it.

A few other respondents were aware of how they probably got HCV. Sherri knew that she probably got HCV through a transfusion before a surgery but she knew nothing about treatment or the disease except that it affected the liver. Mack did say he might have gotten HCV through IV drug use, but was confused about sexual transmission and kept making comments about homosexual behavior. Although Ann said she was infected from a transfusion, she seemed confused about how it was transmitted:

"Um...well if in a sense like wanted to know, what could people really do to prevent it. What people could do, I feel sometime a lotta things have to do with the type of food we eat, not being clean. You know, not using the proper utensils, like when you get to doin' something, I mean I just use the example, workin' out in your yard and cleanin' the, the flowers or whatever and some people have a tendency to come in and not wash their hands, and I guess wit me workin' with children, I got in the practice of always washin' your hands. That's a part of sanitary-well if you don't, if your hands are dirty, whatever you touch, your mouth, your, you know if you have a open sore, and that leaves openin' for other things ta happen to your body. So I guess that part I've always been kinda interested in hearing what I been wantin' to know about that."

Grant said he could have gotten it from needles, tattoos, or eating raw oysters, which is not a means of transmission. Stick told me had hepatitis B, not C but then accurately described how HCV is transmitted. He said he told his wife. "So, I came back and I told her I had Hepatitis B and ... she said somethin like that and I said, well I said you don't catch it, I don't mean you catch it through sex... You gotta share a needle or something like that." Stick, did, however, have HCV as well as HBV.

RAMIFICATIONS OF HCV KNOWLEDGE

Knowledge about HCV is variable for this group of respondents supporting findings by Heimer and colleagues (2002) as well as Davis, Rhodes, and Martin (2004). The majority of respondents have a moderate understanding of the disease with some misinformation. A select minority has incorporated physician's terminology into their parlance and can speak eloquently about their disease. Unfortunately, another group has very little understanding of their disease. The most troubling finding regarding HCV knowledge is the strong relationship to racial and ethnic identity whereby minorities are much more likely to have little or inaccurate knowledge ($\chi^2 = 18.38, p < .001$).³³ Knowledge is not related to educational attainments, income, or gender. The majority of respondents were patients of Dr. Cassidy thus suggesting that the doctor patient interactions may be affected by the race of the patient in terms of information discussed.

Knowledge about HCV has both costs and benefits for individuals. Greater knowledge is related to reporting felt stigma ($\chi^2 = 7.77, p < .05$) and enacted stigma ($\chi^2 = 6.85, p < .05$). Thus, understanding HCV promotes self labeling and attunement to negative reactions from others. As discussed in Chapter 4, Whites reported experiencing felt and enacted stigma more so than racial and ethnic minorities. Whites also disclosed more openly as discussed in Chapter 3. HCV knowledge and levels of disclosure are also related to each other ($\chi^2 = 9.06, p < .01$). Persons reporting positive reactions from disclosure in the workplace are more likely to have accurate knowledge ($\chi^2 = 7.26, p < .05$). Positive reactions from the family are also related to accurate knowledge ($\chi^2 = 6.58, p < .05$). Thus, while having an advanced understanding of HCV may lead to greater

³³ See Appendix 5.4 on page 191 for cross tabulations for all chi-square calculations in Chapter 5.

feelings of stigmatization it also leads to greater levels of disclosure and accessing positive support in the workplace and from family. Knowledge can be empowering and provide hope for individuals especially as individuals struggle with a tenuous future after diagnosis.

Part of the process of biographical disruption according to Bury (1982) involves the problem of uncertainty as discussed in Chapter 1. Numerous respondents discussed how uncertainty regarding their illness affected their lives. Ronald explained,

“I was havin' all these thoughts about death and dying and mortality and everything and, and it was causin' me to re-evaluate my course of action, uh, and what I wanted to do with the rest of my life, not knowing how much time there was because of this, and also, thinkin' a lot about, you know, whether to accept treatment or not, and stuff like that.”

Sallie Anne said,

“Well, yah, I worry about it some of course. I might, that's what I'm saying, I don't, just cuz I've said I've given it to the lord I do worry about it, cuz I think about, there are times I'll go and do, I was thinkin' about this the other day, geez I'm gonna start to cry, I thought about, you know will my grandchildren, my youngest ones, remember me.

Catherine also worried about her family's future:

“I was like you know God, who's gonna raise my children? You know and I, it's just hard you know, I kept asking God, why me. You know, I said God why me why me, you know and uh, I just you know I just kept thinking about my kids you know. Leaving them here, not knowing who's gonna take care of them, because at that time my daughter was young, my son was younger. And uh, that was my most concern.”

Yellow tearfully explained, “When I first found out I had it, I didn't know much about it.

I didn't know how long I had to live, how long I was gonna live, uh, I didn't know anything about it. And the last couple of years it got really bad I didn't know when I was gonna die.”

Gaining knowledge about the disease can help alleviate some aspects of the uncertainty. Samantha said, “Knowing how common it is, knowing that a lot of people live productive lives with it, knowing that there’s medications for it. I guess that what keeps me not depressed about it. Pretty much, I guess that’s helpful.” As mentioned previously, David only began to take his disease seriously as he gained more knowledge. Harold said, “But, I come to realize if you know the education that I’ve learned and that it’s not a death sentence.” While ignorance may be bliss in terms of not engaging in felt stigma or recognizing enacted stigma, the risks to physical health, lack of support because of low levels of disclosure, misinformation provided to others by those with little knowledge, and possible transmission because of a lack of knowledge are deleterious and harmful for not only those with little or inaccurate knowledge but for society as a whole.

HIV/AIDS DISCOURSE

As I have argued, there is little discourse available to persons diagnosed with HCV to understand their disease. In the absence of ample available discourse concerning HCV, respondents turned to the widely available discourse about HIV and AIDS. Over half of the sample made some type of unsolicited reference to HIV/AIDS during the interview, thus indicating that this is a powerful means of making sense of having HCV for individuals. Persons relied on these cultural images regardless of their knowledge about HCV.

Cultural imagery regarding HIV/AIDS is so pervasive that numerous respondents expressed relief that they had HCV and not HIV. Several persons mentioned being afraid when the doctor called to tell them they needed to discuss some blood tests because they thought that they were being diagnosed with HIV. Similar to persons comparing HCV to

Hepatitis B, HIV serves as a good deviance exemplar. Derrick said, “I just felt like shit, you know, I was like, well it could be worse, you know they could have said I had, you know, AIDS.” Larry said, “And now there's AIDS out there now. And that's what scared me to death.” Research of IDUs reveals a preoccupation with HIV and less concern or fear about HCV (Davis et al. 2004). I also found this trend among respondents without a history of drug use. Sharon said, “And so I was always, in the back of my mind, afraid of AIDS...Once I tested negative for HIV, I was so happy it took me a while to get frightened about the, about the hep C.”

HIV/AIDS was used as a contrast to show how HCV is different. Jason said regarding disclosure of health status, “And I guess I'm lucky, you know, I don't know, as far as I know, I know, you know, a lot of people who have HIV, you know, that they tell someone I'm sure their reaction's gonna be different.” Eddy explained the irony in his diagnosis, “You know it is kinda this, this big deal in San Francisco was a gay man getting, not having AIDS and somehow having dodged that bullet through no good work on my part and now all of sudden I am going be hit by this truck instead.” David discussed differences in transmission: “Not even as much as, I mean, not like AIDS, you only receive it through blood contact, where as with AIDS it's, it could be other body fluids.” Mack told me what he would like the public to know about HCV:

“I would like to understand I would like for them to understand the comparison between that and hepatitis, I mean...HIV. I think it's going to be potentially the worst epidemic because like I say, the in hepatitis mean, in HIV, the virus once it hits the air is dead. And so but this, you could have this all over your house; you know what I'm saying. You know it never dies. The virus doesn't die like that in the air so potentially I think, does this out number HIV already?”

Respondents also addressed similarities to HIV/AIDS. Isabella compared HCV to AIDS in terms of research and treatment. “And, I mean, look how far we've come with AIDS. Now, you can live a full life with AIDS.” Ann compared the diseases to try to understand transmission:

“I mean when you think about it, I mean like AIDS, it's another virus, some people say that, the just the virus itself, you can carry it, nobody can catch it. But then with, with HIV, I mean you know, one is really catchin' it and the other one you just carry. I wanna know how can you carry it and can't give it to somebody. And it's the same thing with this. They say H, I mean C, you can't give to nobody.”

Mark said that the public needed to know:

“That you can't catch it from talking to people. Same thing it is with HIV. You know what I mean, can't catch it by touching, just general contact with them...People don't know a thing about it, HIV is the same way, I mean they don't know.”

When I asked Lauren if she had heard of HCV, she replied, “I, I had heard of the AIDS, but none of the rest of them, and now there's even more.” I asked Matthew if he knew anyone with HCV. He replied that he did not but, “No, they haven't told and I know a couple people got AIDS, I know them.” Similarly, Emma said she only knew people with AIDS, not HCV.

While Jason viewed disclosing HCV as less stigmatizing than HIV, Ronald explained his fears about disclosing his HCV, “Because of the way they react to people with HIV.” Maruf also offered that HCV is linked to HIV in people's minds. Meredith said,

“It's like of course, you know, but, it's, it's strange because automatically when you say treatment, disease, anything people automatically and with drugs they automatically say, oh you, you're saying that you have this but you really have AIDS.”

Bob also linked drug usage as the connection between HIV and HCV:

“You know, especially in this day with HIV, you know, which is, I mean certainly not as in the forefront as it was maybe in the 80s, late 80s and 90s when I, you know, found out I had Hep C but I think it still resonates with that and if you say you got a junkie’s disease, you got a disease from like, you know, from, from sharing needles that it resonates really strongly with social perceptions of HIV and AIDS and, and I think that plays heavily on myself in my own interpretation of what, what it means of what I have and what it means for me to have it.”

Several respondents expressed that HIV/AIDS and HCV were nearly the same thing. Emma says,

“At first they thought it was AIDS, AIDS. And then they found it was Hepatitis... Then I though, I really started reading more on it, and reading up on AIDS to see what is the difference between them... And basically, there’s no difference... It’s new. Um, I wanna say it’s not, I, it’s, there is a difference. Then again, I don’t know. All I know is, Hepatitis you not supposed to have no sexual intercourse, well, you can have sex, protected sex.”

Karla’s daughter told her having HCV is the same things as AIDS to her. Karla explains stigmatization towards her and Jeff because people think HCV is like AIDS.

Roxanne said, “It’s kinda like the AIDS almost, to be honest... Or if I’m cleaning the swimming pool or something they treat it like it’s AIDS... I mean in the early nineties, like I said, they treated you like somebody who had AIDS.” Derrick said,

“You know I know I probably couldn’t get a job in food services you know because of it. I mean--You’re touching food, and having to do knife work and stuff like that. The employers don’t want you, you know, cooking for them, it’s like you having an AIDS patient working in your kitchen. You know that’s a blood borne illness, so you know people are gonna be scared of that kind of stuff.”

Samantha said, “I felt, I felt like somebody who had AIDS.”

It is not surprising that persons related HCV and HIV especially with regards to drugs as a means of transmission. Relying on HIV discourse, in addition to

misinformation regarding sexual transmission of HCV, may explain the propensity of quite a few respondents to discuss promiscuity as either a possible means of transmission or as not a viable means because they were not promiscuous.

The most important consequence of relying on HIV discourse is the likelihood of engaging in felt stigma ($\chi^2 = 4.25, p < .05$). Roxanne repeatedly referred to AIDS in her interview and then said, “ ... And, mean to be honest, even though I know can't catch AIDS by sittin' right beside somebody, if I knew somebody had AIDS, I wouldn't put my little boy right next to 'em.” Thus, she is using a discourse about people she discriminates against to understand her own illness.

CONCEPTIONS OF ILLNESS

While some respondents relied on HIV/AIDS discourse to attempt to make sense of having HCV, people also conceptualized their illness more broadly. Illness concepts are individual meanings associated with illness, as discussed in Chapter 1 (Schussler 1992). Similar to Schussler (1992), I found that respondents reported numerous conceptions of their illness. For some persons, one concept seemed most salient. For others, they fluctuated throughout the interview in terms of stressing one conception versus another.

ILLNESS AS PUNISHMENT

Seeing their illness as a punishment of some sort was a common theme especially among the respondents who contracted HCV through IV drug use. Daniel spoke extensively and repeatedly about how HCV was consequences of his bad behavior:

“So unfortunately, I, I did it, and I had to pay for it. Just like a venereal disease...It is, that's exactly right, it is a consequence of decisions that I made when I was young... You know, if we live under the blessin' of God, we're blessed, if we take that and don't and we live under the curse of the enemy, the

devil, that means when we don't live under God's blessing and we, we choose the other way unfortunately we have to pay for it.

Bob echoed this sentiment:

"I think I remember like, I just, there was a, there was a feeling in me like kinda like an outcast sorta feeling, you know, kinda like, you know, sort of, oh paying for your sins now you're an outcast kinda thing, you know. But, you know, I don't, I don't know what to, what to really put my finger on."

Ann described a similar conception although she did not contract HCV through IV drug use:

"Really, in a sense, well really truly, I looked at it as a attack of the enemy... Attack from Satan. I use that word. Because a lotta things are generational curses. A lotta things have been brought in from our foreparents. And sometimes certain people bodies are just gonna experience, and I guess to me, it didn't botha me that much because I've, I've had a lotta tragedies happen in my body.

Charlie exclaimed, "When I got that, that's all I could think about, now what have I done?" Samantha described her initial feeling that she was being punished:

"I guess at one point I said, I even blamed myself, I said you know I was like, you know, this is your fault, you know, this is what you know, you, you're being punished for the way you lived, you know and so I guess I was a little hard on myself, you know, and then I was like you know, you know what you got it, you know how you got it and yet it's not my fault that I did get it but it's not that I'm being punished. It's just one of those things in life that happens. I mean you choose a certain lifestyle, you know, you taking more risks, you know, and so I'm not superwoman, shit's gonna happen and just like a lotta other things happen in my life. I can't go, oh, poor me, I mean that's the life I chose. So certain consequences are, you know, inevitable...I guess as many times as feel like I am ok with it, there's always that thing in the back of my head, you know, that I think will always be there as long as I have it, you know there will always be that, that feeling of just like, (pause) a reminder of my past. A reminder of what I've done in my past.

ILLNESS AS CHALLENGE/ACCEPTANCE

HCV was also seen by some respondents as something to be accepted. The comments above by Samantha show her transition and vacillation from seeing her illness

as punishment to seeing it as something to be accepted. Acceptance can mean different things to different people. Some respondents suggested that they must accept their disease. However, they may still conceptualize the disease as a challenge and actively try treatment to eradicate it. Andrew explained how he understood having HCV:

“But basically, you know I done accepted it, you know, I mean, it could be worsen... Things go through my mind if I would be this different, if I lived my life this way or that way. Yeah, I think about all that. But uh, I'm not lookin back I mean I'm still livin.”

Jamie revealed, “Yeah, well, not really scared, but just because I knew what kind of lifestyle you know I had lived, and so I accepted it, but not really scared.” She added, “So, I mean the way I see it, we all die of somethin. I just take it one day at a time. I mean like I said, if the medicine helps, it helps, if not I just go on.” Jerry said, “Uh, well, I just put one day at a time, you know. Just say whatever.” Daisy explained,

“And it's just one thing after another but still takin' with a grain of salt, if it's meant to be, it's meant to be. But I, I've never been one that, well why me or question it. I, I've never been that way. In, in fact I tried to, you know after the initial shock of it and everything, I tried to make a joke of it, you know.”

Maruf said, “I didn't [ask why did this happen to me] because you know I'm realistic I'm not a kid anymore...oh my God why did this happen to me because it happened already and I done it to myself.” Larry explained, “But anyway, I wouldn't change anything to be honest with you, with my life, it's just happened, I'm not blaming me, I'm not blaming society, anybody. Catherine said, “And reality is ok, this is what you've got to deal with, Hepatitis C is here, so we can't really worry about what happened back then, I mean that's not gonna help us right now.” Peggy added, “Probably because, you know, what are you

gonna do, it's done. You know all you can do is what they tell you to do and hope for the best.” Jason summed up his conceptualization:

“So, I mean, if even if I don't get cured you know, I mean, I've tried--if it's the best I can do, you know. I mean, I've, you know, I've laid off alcohol, you know, I've done everything that they've told me to do, you know, if God doesn't want me to cure--want to cure now then hey, six months, a year down the road when they have a better treatment, you know.”

Sharon's increasing symptoms led to her acceptance of her illness.

“Um, when I had to have the wheel chair, I probably don't have the words to articulate what it felt like. Once that wheel, I had, I knew I had to have that wheel chair because of the disease I had those Eureka moments where I understood that this was a disease I couldn't just brush off. And in a year say, I'm fine, I'm gonna go back to bein' me. I mean I was fifty eight then, I'm sixty now. Um and I understood with that wheel chair the changes my life was gonna take. And I didn't know how I was gonna, I still don't know how I'm gonna deal. Uh, I mean I'm still in the process of learnin' to be a different person...So I have to take whatever happens to me and find a way to deal with it, which is what I'm tryin' to do.”

Others take a more fatalistic approach when accepting their illness. Matthew said,

“What's gonna happen, I could not change you know. I could get treated for this, an' treated for that...I can't change what's already been did... Like I say, gonna do this, gonna do that, the good lord gon' take me, he gon' take me. I don't care how much treatment or whateva you gon' get. Your time for you to go, you gon' go.”

Stick held a similar sentiment. “So, just, if I die, just, maybe just the Lord just call me.”

Derrick, who was more knowledgeable than Stick or Matthew, decided to not pursue treatment explained:

“You know, I still drink beer every now and then. Cuz I've always liked beer. I don't drink it like I used to, I don't drink it everyday, but I know every time I open that beer that it's you know, it's probably one less day I'm going to be here. And I just say well, it's the quality of life. If it makes me happy then I'm going to do it. And if I die I die, so what everybody dies.”

ILLNESS AS LOSS

While respondents spoke of accepting HCV, some also spoke of the various types of loss experienced as a result of the illness including reactions to treatment. Most of the loss associated with HCV stemmed from changes experienced in the body which affected other aspects of life. Several respondents spoke of negatives changes to their moods.

Lauren said,

“Oh, yeah. I’m not as outgoing as I was, I’m not, I know that. I think my personality has changed for the worse. And I’m probably grumpier than I was. I don’t have as much patience with things that I used to have. I’m tryin’ to be that way again, you know? Um, I got really angry and bitter for a while and I took it out on my David, who bless his heart, took all that garbage and I’ve told him, you know, I’m sorry.”

Sherri explained, “Sometimes I feel it more then ever when I’m by myself. Cause I know it's still there ‘cause all I wanna do is just lay down and just sleep. Don't wanna go no where. Get irritated.” Tom said, “It's uh made me a little more pessimistic about the outcome of the ending of this life you know. Uh, I don't have the energy that I did you know, a lot of times I don't think I have the energy to get up today.”

Liz lamented,

“And I have been sick as a dog. I've lost weight. I've lost my hair. I've lost friends. I was a bitch. I couldn't handle the medicine, it was just--I hated myself too, I mean, God, I'm not, I'm not a mean person. You know, I have a lot of anger in me, but I'm not a mean--I don't set out to be mean.”

Daniel also struggled with the medication, “Depression, short fuse, you could go off real easy, uh, all these things, and I didn’t, and it’s true, you don’t have any patience at all, patience is the thing you can just throw that out the window, you have no patience.”

Symptoms of HCV or side effects from treatment affected several people's ability to do daily chores or tasks. Liz discussed how her inability to perform chores affected her sense of self:

“You know, I'm the house wife and laundry and all that good stuff, and, you know, Roy come in and not have underwear and things like that and, and it's just like, at that period of time when I was really goin' through the worst part of the medicine, not only did I feel like crap because of the medicine, I felt guilty because I couldn't keep the house up, I couldn't take care of him like I used to. Even the dog, he was sufferin', he was, you know, and I was, I was just like, it wadn't that I didn't care about any of that it was just I physically couldn't pick myself up and do any more. I just can't, it just makes me angry 'cause I'm like if I didn't have this stupid disease I, I would be healthy and energetic and my mind would be alert.”

Jamie, Lucy, Daisy and Jenn also talked of not being able to keep up with household chores. Daisy added,

“You can walk, I can walk out there and I just, it, if I have any energy it sucks it out of me. You know, so I pretty much stayin' until the sun goes down or if it's real cloudy and I loved, used to love to work in the yard. And I can't even do that no more.”

Daisy also spoke about how she and her husband can no longer travel. Connie spoke of her loss of creativity:

“Then another thing, see I'm a potter, and I do sculpture. Well, I can't come up with any idea. And its almost like I dry up. So, I was telling the doctor about that. I said the one thing I pride in accomplish to occupy my time, and now I can't come up with any ideas. And that's sad, you know.”

Liz also mentioned feeling that her artwork suffered as she was not feeling creative anymore.

Others discussed the impact of HCV with regards to working. Ann said,

“And them um, as I start takin the medication, I started keepin' kids in my house, and I really found out that it wadn't gonna work. Cause the kids bein' active and I would wake up tired and sometimes didn't have a lot of energy. And I had a little bitty baby that I was keepin' he used to holler so much I asked his mama to take him, cause he just start workin' on my nerves.”

Larry and Derrick discussed how they were not able to do manual labor in the hot sun anymore. Rick said, "I woulda been workin this last month if I wouldn't be feelin so bad."

Daniel described,

"Doin' the type a work I do, I have to, I bid jobs and I do payroll...I couldn't hardly do it, I would start doin' it, I would get so aggravated, I don't even know how to explain it, and I just have to put it down, and say I can't do this. It's a really really hard medicine, it, it is. Uh, I dealt with anger a lot with it, it brought out some anger in me, and...just tough."

Isabella discussed how not working impacted her sense of self:

"So I came from this really strong family that was oriented in work. So, you know, my parents taught me, you gotta get out there and take care of yourself and be responsible. And so I did, and the hardest thing for me I mean, was to give that up. That, I mean, you know, due to my, my illness. It was the hardest thing to give up. To say I can't do this because I'm so sick. I have to have somebody else take care of me and that was hard because I was always, you know, independent and on, in, in, not that I'm, well in control if I."

HCV also impacted interactions with family and friends. Rick said,

"I'd be doin a lot of things more socially, if I wasn't feelin bad. I can't plan a big party here or nothing, like we used to have a little weekend gatherings here, the bonfire, and volleyball, and horseshoes, and people come by boat, bring their campers and shit. Cuz I don't never know when I'm gonna feel good enough to do that. And I don't wanna be feelin bad tryin to be a host."

Donald explained, "Oh, the few things I've wanted to do before I kick on outta here and I know I'm not gonna get to do 'em...Well, stuff with Chad [son] and go a few places, do a few things...We used to ride horses all the time, can't do that anymore." Cece said about her boyfriend,

"And he's very angry at my disease. And bitter. And pissed off. He's tired he said. He's tired of comin' home to a sick person. You know, it's, it's taken a toll on 'em...But it's caused him to fall out of love with me. You know, I, know this much. I know he still loves me, but it's just, it's just hard right now. Very hard."

Mark said treatment caused problems in his marriage because of his volatile emotions. He expressed great concern about the future of his marriage. Daniel confessed that, “me and Jill [his wife] had a big fight one time and, you know, I hit her.” He felt that the medication caused his moods to be very unstable.

ILLNESS AS VALUE

While numerous respondents experienced HCV as a loss with regards to various activities and relationships, people also spoke of the value of having HCV. Several persons mentioned the positive impacts on their outlooks or perspectives especially with regards to feeling grateful about their lives. Maruf commented, “Yeah I been, lately, I been more responsible, more calm. I don’t know why...Yeah. I been more calm. I don’t get upset as easy as I used to.” Sparky said,

“More or less I started to change my outlook on it. I used to dwell on it and made a lot of BS, it’s not worth it. I look for all the positive, and I don’t know where it come from, but you see it here and there, and uh, how does it go...live everyday like it was your last.”

Vanessa said, “You know, it gives you something to think about and it, I mean, I tell ya, I think you really appreciate life and you don't take life for granted like some people.”

Ronald said,

“And but it, it got me in touch with my mortality. It made me definitely made me aware, more aware that I'm not gonna live forever here, you know. I mean, I'm a believer, so I believe I'll, you know, continue on, but in, in terms of my just stayin' in a rut, actin' like I'm gonna live forever here, not doin' some of the things that I would like to do. It's changed that. It's given me a different perspective on life ...It's also kind of given me more of a sense of freedom in terms of having these choices because I do feel like, you know, I mean the doctors have told me it's gonna shorten my life, and I don't know how much shorter. So if I feel like doing something, then, you know, then I'll go ahead and do it—“

Connie said, “Well, I’m glad uh the illness, you know, the hepatitis let me see that life square in the face. Everybody’s dying its just that I had a warning, you know. So, you know I appreciate it.” Daniel explained,

“But I did learn a lot through the treatment, learned a lot about myself, I learned a lot about bein’ humble, and, you know, course, I may not be practicin’ it all the time but I, but it will humble you. It will teach you that there is more in life than you.”

Sharon discussed, “But, had I not been knocked down with the Hepatitis C, I’m not a hundred percent sure that I would’ve taken the time to get to know my grandchildren and to be as good a grandmother as I am....Yeah. I am a lot less focused on me.”

Several respondents mentioned how having HCV made them especially grateful for their recovery from alcohol and drug use. Ronald commented, “And so it’s helped me to apply my [Alcoholics Anonymous] program, and it’s helped me to have more, appreciation and awareness of my own freedom from drugs and alcohol. Eddy said,

“Umm, it’s made me really grateful that I am sober. It has yeah, it’s affected my life.” It’s, you know, I, it’s not, I mean, it’s been a basically a positive thing for me. It’s made me focus in my body and do some good things for my body and beyond that, it hasn’t really affected me, so, but I was really lucky that I had stopped drinking five years before.”

Samantha said,

“I value it [sobriety] more, you know, I value it, I value my health more, you know. I even value my daughter more. It made me think, made me realize that, Yeah, I could die of something else a lot sooner, but I mean, it ain’t the same, I maybe feel, I guess I really think that, I guess, I want to be with my daughter more in her life and see her grow up.”

FAITH

Reliance on God or faith of some sort was repeatedly mentioned by persons as a means of dealing with their illness. Jeff turned to prayer after being diagnosed:

“So I'm like Ok, you know, I, so in other words, I'm gonna die. And they said yeah. So I--so it took--I mean, it, it still bothers me, but I just--I told 'em I said well, you know, you can tell me this, but I got right with the Lord... It was like, what do I do? You know, so, I just started prayin'. I said you know, it's, it's got to be a way something, some--either way, I've just got to find it. And started prayin'. I still do every night, and I been here, goin' on two years now.

Numerous respondents discussed how God could take care of them. Ronald said,

“It's kind of like a faith issue. It's an issue to where you rely on your higher power and your high--we believe that, that my higher power has the power to somehow impede it or cause it to, you know, go slow enough or, you know, whatever. I mean, I'm religious enough that I believe he has the power to cause it to actually go in remission. And, and so that's where I'm putting my, my hope is in my--in his power.

Ellis said, “Give it up for the Good Lord, I'm gonna pull through. I'm gonna be cured from it. I want him to send me up to heaven.” Daisy expressed a similar sentiment: “I just put it in the Lord hands and, he's the only one that got me through all this stuff.”

Sallie Anne explained,

“I feel, well I'm a Christian, and that right there gives me a lot of the staying power that I have, that right there is the fundamental rock that I'm you know sitting on I think, I just feel like, whatever they need to do, they'll do, and the Lord, it's in the Lord's hands and he's gonna handle it, you know, he handles everything else.”

She told me how she read her bible when she felt down and that it made her feel better.

Cece explained how her faith changed her response to having HCV:

“But you know it's like I was sayin', I did this to myself. I got this way because of me. Now I'm tryin' to do somethin' about it because I have God in my life today. And it, it's a major difference. Phew. Major difference.”

David said, “I don't believe that it bothers me as much because I feel I'm a very spiritual person and I feel close to, to God, to my creator, and so, I'm not afraid of death, I'm not afraid of it in that sense.” Vanessa also relied on God,

“And so, I mean, you know, and I just, you know, I talk to God about it or whatever. I mean, it really, that there really kinda kept me goin'... If I start to think about it-- I, you know I just believe, you know that the Lord will see me though this, you know, that it's just you know I, you know, I let myself know that this is just a test, it's just a trial, it's just somethin' that I have to go through for now, but one day it'll be over and, and I'll be victorious.”

Two respondents, Daniel and Catherine, spoke of their faith and God throughout the entire interview. Their faith and religiosity was incredibly salient to their illness account. Like Vanessa, Daniel saw his illness as a test:

“But you know, I told the Lord, I told God, I said look if this is what you want me to do, if I have to go through treatment again, as bad as I hate it, I'll do it if you want me to. But I really don't think he does, and at this point I don't feel like I'm gonna. Uh, so, I think God wants me to trust him and I'm not sayin' we don't need doctors by any means... I believe that this is a test, I believe this is, this is a life that we live that's gonna determine the outcome of where we gonna spend the rest of our eternity, and I think we have choices to make in, in this journey.”

Catherine also mentions that doctors are crucial but that her faith upon God is even more important:

“I'm first of all I'm a Christian, and I truly believe that God can do anything, and I have seen God do miracles, so besides what a doctor tells me, my faith relies in God. Cuz I know the doctor can tell you anything, but I know when God says something he's gonna do it. So, I my faith you know, I have to keep my faith up, you know, and just knowing, that ok, you know God, the doctors say that I have this, they say I have that. You know ok. Now, I've seen what you've done with other people now, what are we gonna do with this.”

Catherine explained that God has seen her through turmoil before and would continue to take care of her. Catherine relied on her faith to combat stigma. She is the only African American, as mentioned previously, who practiced open disclosure. She explained this because of her reliance on God:

“But then Gods started showing me things you know, he started showing me that you know, his love was stronger than anybody’s love. And you know, he was showing me, that no matter what people thought about me, that he loves me, and that he was gonna take care of that. And he's doing that today.”

CONCLUSION

The process of diagnosis is crucial to the labeling process of having HCV. HCV is according to Brown’s (1995) typology, a routinely defined condition, meaning that there is a biomedical definition applied and that this condition is generally accepted (41). While there is little conflict between doctors and patients about whether this type of diagnosis is accurate or real, the consequences of the diagnosis are an issue. The manner in which persons came to be diagnosed, either as a surprise or individual initiated diagnosis, appears unrelated to the reactions to diagnosis.

The ensuing reactions of fear of the unknown, shock, fear of imminent death and sadness are all typical reactions to diagnosis with chronic illness (Bury 1991; Bury 2000; Charmaz 1991). The scant research on HCV suggests that persons experience a severe and negative reaction to diagnosis (Glacken et al. 2001; Hepworth and Krug 1999; Hopwood and Southgate 2003). Hepworth and Krug (1999) note,

“The identities that people have through their relations with others are directly affected by a diagnosis of HCV in that histories and stories about self are challenged, rewritten, and forced to take on new meaning as new discourses intrude into people's lives” (242).

While I also found that many respondents did have an intense reaction to diagnosis, not all did. As discussed, some respondents had an ambivalent reaction to their diagnosis. For some, the lack of symptoms associated with the diagnosis made it easy to deny the severity or salience of the diagnosis. Bury (2000) discusses how the impact on the body is crucial to understanding identity changes. Other respondents did have symptoms, but

still did not describe having an emotional reaction. For Jamie, the ambivalence was related to her lack of knowledge about the disease but Peggy had fairly accurate knowledge of the disease and was still ambivalent. Perhaps the respondents who described an ambivalent response are simply organizing their illness account along these lines to minimize disruptions to their identities. Yet, for most, at other points in the interview, they described how HCV did impact them later. While Radley (1989) suggests that indifference to illness increases as social class decreases, I found no relationship between an ambivalent reaction and social class, race, or gender. An ambivalent reaction to diagnosis was linked to practicing reluctant or limited disclosure ($\chi^2 = 4.39, p < .05$) most likely because the illness was less salient for these individuals.

The diagnostic process itself may affect knowledge about the disease. Persons may or may not receive testing and subsequent treatment after an initial diagnosis. Most of my respondents were under the care of a physician and had some diagnostic testing done if not also treatment. While there was diversity in terms of previous knowledge about HCV before diagnosis, we might expect there to be more of a convergence in knowledge after diagnosis, especially for persons seeing the same physician. Instead, I found various levels of knowledge about HCV at the time of the interview. Krug (1995) notes "the impact of an initial positive diagnosis [of HCV] carries with it an almost inevitable desire for information" (312). Krug (1995) performed discourse analysis including,

“Naturalistic observation at HCV support group meetings; from casual conversations with HCV-positive persons, physicians, and others; from interviews, from cultural texts such as newspapers and television documentaries; and from the written texts that HCV positive people and support groups generate, share, and discuss” (301).

The racial and class makeup of Krug's sample is unknown. I, however, found an intense desire for information among persons with expert levels of knowledge or moderate knowledge. Among my sample, there is a connection between attending support groups and expert levels of knowledge. Krug (1995) did study support groups, which may affect his findings. Certainly not all of the respondents in this research described wanting more information which may be linked to preferring uncertainty than a stark reality (Weitz 1989).

Most importantly, minorities are more likely to have little or inaccurate knowledge about their disease. As discussed, knowledge about the disease leads to more open levels of disclosure but also negative self-labeling. Disclosure does lead to more experiences with stigmatization. Yet disclosure also allows for positive reactions from others. Persons with more knowledge about HCV reported positive reactions from family and in the workplace. Finally, gaining knowledge about one's illness can an important coping mechanism (Bury 1982). Thus, future research needs to further address the impact of race on illness experiences.

While knowledge varied about HCV, many respondents turned to the more readily available information regarding HIV/AIDS to understand having HCV. Zickmund and colleagues (2003) found that persons with HCV explain stigmatization because of an association with HIV. Among this sample, persons who relied on HIV discourse were more likely to engage in felt stigma thus indicating the negative consequences of using HIV imagery to understand HCV.

Similar to some persons with HIV, several respondents conceptualized their illness as punishment (Weitz 1989). Yet at the same time, some of these persons as well

as other respondents saw their illness as a challenge that they must accept. Persons also described their illness in terms of loss and value. Schussler (1992) found that persons who see their illness as a challenge or as having value tend to cope with their illness better. Seeing illness as a punishment is related to poorer coping skills and increased levels of depression (Schussler 1992). Yet these conceptualizations and coping mechanisms are related to presence and use of support.

Faith emerged as an important means of support for numerous respondents including those who saw their illness as a punishment. Seeing illness as punishment may not have the same deleterious effects that Schussler (1992) described for these individuals because they have now been redeemed in their mind in God's eyes. Numerous respondents explained that their health was in God's hands and that their faith sustained them. Research on Black women has found a similar coping mechanism regarding illness and encouragement within the church to define illness as sin (Abrums 2000).

Interestingly, mentioning faith is not, however, related to gender, race, or class in this study. Respondents who discussed faith as a coping mechanism were more likely to be Baptist or some other Christian affiliation (mostly Evangelical) versus Catholic, some other religion, or no religion ($\chi^2= 8.75, p<.05$). Likewise, respondents who mentioned faith were more likely to attend services frequently ($\chi^2= 12.59, p<.01$). Thus, future research should be cautious when linking faith solely to race and gender and instead focus on religiosity.

Despite the lack of ample cultural imagery, respondents found ways to make sense of having HCV. Diagnosis did give rise to trepidation for some. The issue of uncertainty was a salient issue for many as seen in the discussion about fear of the

unknown as well as the role that knowledge plays in alleviating uncertainty. Even respondents who reported an ambivalent reaction to diagnosis had to deal with some repercussions regarding interactions with others even if minor. HCV knowledge is quite variable, as mentioned, and unequally distributed by race leading to different illness careers for respondents. If the trend of promoting HCV education and awareness continues, future research should monitor the implications for the illness career of persons with HCV. Public awareness could change an individual's reaction to diagnosis as well as knowledge about the disease thus alleviating some of the current inequality.

APPENDIX 5

5.1 EXPERT KNOWLEDGE

Name	Gender	Age	Race/Ethnicity	Education (Years)	Household Income	Reported Mode of Transmission
Cece	Female	45	White	9	\$10,000-19,999	IV drugs
Isabella	Female	41	White	16	\$30,000-39,999	Transfusion
Jenn	Female	50	White	14	\$50,000-59,999	Sex/household
Liz	Female	53	White	12	\$40,000-49,999	IV drugs
Melissa	Female	49	White	16	\$80,000-89,999	IV drugs
Meredith	Female	46	White	14	\$20,000-29,999	IV drugs
Sharon	Female	60	White	14	\$0-9,999	Transfusion
Catherine	Female	41	African-American	11	\$10,000-19,999	Snorting drugs
Connie	Female	70	Japanese	15	\$50,000-59,999	Transfusion
David	Male	48	White	14	\$30,000-39,999	IV drugs
Harold	Male	47	White	16	\$40,000-49,999	IV drugs
Jason	Male	22	White	14	\$90,000 or above	Transfusion
Rick	Male	54	White	12	\$0-9,999	IV drugs
Tom	Male	51	White	15	\$50,000-59,999	IV drugs
Yellow	Male	50	White	13	\$10,000-19,999	IV drugs

5.2 MODERATE KNOWLEDGE

Name	Gender	Age	Race/Ethnicity	Education (Years)	Household Income	Reported Mode of Transmission
Daisy	Female	61	White	11	\$10,000-19,999	Transfusion
Karla	Female	37	White	11	\$0-9,999	IV/sex/household
Lauren	Female	59	White	13	\$10,000-19,999	Transfusion
Lucy	Female	53	White	13	\$60,000-69,999	Sex/household
Peggy	Female	53	White	13	\$70,000-79,999	Needle stick
Roxanne	Female	35	Hispanic/White	13	\$30,000-39,000	Transfusion
Sally Anne	Female	50	White	12	\$20,000-29,999	Transfusion
Samantha	Female	26	White	12	\$0-9,999	IV drugs
Emma	Female	54	African-American	9	\$10,000-19,999	IV drugs
Jamie	Female	53	African-American	13	\$20,000-29,999	IV drugs
Tari	Female	39	African-American	14	\$60,000-69,999	Sex/household contact
Vanessa	Female	41	African-American	13	\$20,000-29,999	Tattoo
Bob	Male	33	White	15	\$10,000-19,999	IV drugs
Charlie	Male	53	White	18	\$90,000 or above	IV drugs
Daniel	Male	46	White	9	\$60,000-69,999	IV drugs
Derrick	Male	36	White	12	\$20,000-29,999	Snorting drugs/tattoo
Donald	Male	70	White	5	\$60,000-69,999	Transfusion
Eddy	Male	47	White	20	\$40,000-49,999	IV drugs
Jeff	Male	40	White	6	\$0-9,999	IV drugs
Joey	Male	50	White	12	\$10,000-19,999	Snorting drugs
Larry	Male	53	White	16	\$10,000-19,999	IV drugs
Mark	Male	35	White	12	\$30,000-39,999	Transfusion/sex
Nick	Male	47	White	8	\$0-9,999	IV drugs
Ronald	Male	54	White	18	\$40,000-49,999	IV drugs
Andrew	Male	44	African-American	12	\$10,000-19,999	Drug related
Maruf	Male	43	Jordanian	12	\$30,000-39,999	IV drugs

5.3 LITTLE/INACCURATE KNOWLEDGE

Name	Gender	Age	Race/Ethnicity	Education (Years)	Household Income	Reported Mode of Transmission
Ann	Female	51	African-American	13	\$10,000-19,999	Transfusion
Sherri	Female	46	African-American	12	\$0-9,999	Transfusion
Sparky	Male	51	White	13	\$40,000-49,999	IV drugs
Ellis	Male	49	African-American	12	\$50,000-59,999	Drinking
Grant	Male	51	African-American	10	\$20,000-29,999	IV drugs
Jerry	Male	51	African-American	10	\$10,000-19,999	Unknown
Little Brother	Male	42	African-American	12	Missing	Earring/Drinking after others
Mack	Male	52	African-American	13	\$10,000-19,999	IV drugs
Matthew	Male	53	African-American	12	\$0-9,999	IV drugs
Stick	Male	52	African-American	9	\$30,000-39,999	Tattoos

5.4 CHI-SQUARE CROSS TABULATIONS

HCV Knowledge and Race ($\chi^2 = 18.38, p < .001$)

	Minority	White	Total
Little/Inaccurate	9	1	10
Moderate	6	20	26
Expert	2	13	15
	17	34	51

HCV Knowledge and Felt Stigma ($\chi^2 = 7.77, p < .05$)

	No Felt Stigma	Felt Stigma	Total
Little/Inaccurate	8	2	10
Moderate	8	18	26
Expert	5	10	15
	21	30	51

HCV Knowledge and Enacted Stigma ($\chi^2 = 6.85, p < .05$)

	No Enacted Stigma	Enacted Stigma	Total
Little/Inaccurate	8	2	10
Moderate	13	13	26
Expert	4	11	15
	25	26	51

HCV Knowledge and Levels of Disclosure ($\chi^2 = 9.06, p < .01$)

	Limited/Reluctant	Open/Activist	Total
Little/Inaccurate	8	1	9
Moderate	15	11	26
Expert	4	11	15
	27	23	50

HCV Knowledge and Workplace Support ($\chi^2 = 7.26, p < .05$)

	No Support	Support	Total
Little/Inaccurate	10	0	10
Moderate	24	2	26
Expert	10	5	15
	44	7	51

HCV Knowledge and Family Support ($\chi^2 = 6.58, p < .05$)

	No Support	Support	Total
Little/Inaccurate	9	1	10
Moderate	17	9	26
Expert	6	9	15
	32	19	51

HIV Discourse and Felt Stigma ($\chi^2 = 4.25, p < .05$)

	No Felt Stigma	Felt Stigma	Total
No HIV/AIDS	15	11	26
HIV/AIDS	8	19	27
	23	30	53

Ambivalent Reaction and Levels of Disclosure ($\chi^2 = 4.39, p < .05$)

	Limited/ Reluctant	Open/Activist	Total
Ambivalent Reaction	9	2	11
No Ambivalent Reaction	19	22	41
	28	24	52

Faith and Religious Preference ($\chi^2 = 8.75, p < .05$)

	Baptist	Catholic	Other Christian	Other/None	Total
Faith	7	1	7	1	16
No Faith	11	11	6	9	37
	18	12	13	10	53

Faith and Attendance at Services ($\chi^2 = 12.59, p < .01$)

	Never	Once/Twice per year	Once/Twice per month	Weekly	Twice or more per week	Total
Faith	2	2	2	5	5	16
No Faith	13	7	10	6	1	37
	15	9	12	11	6	53

CHAPTER 6: CONCLUDING THOUGHTS AND FUTURE RESEARCH

PRIMARY FINDINGS

From the stories of men and women with HCV in Southern Louisiana, illness experiences have been shown to be fundamentally tied to individual decision making processes as well as larger structural factors. Through in-depth interviews with fifty-three persons with HCV, I found that respondents shaped disclosure patterns and motivations for disclosure. Individuals reported a range of social reactions to their disclosures including stigmatization and support. People with HCV devised ways to give meaning to their experience despite the lack of cultural imagery. This chapter summarizes the main findings, addresses the global theme of race and inequality that clearly came to the fore in their stories, and outlines the implications of the research. Using a loose illness career framework, I trace the overarching findings from disclosures of HCV status, reactions to disclosures, and how individuals made sense of having HCV all in the absence of widely available cultural discourse.

DISCLOSURE PRACTICES

Persons with HCV reported a range of disclosure patterns, as discussed in Chapter 3. A small group of people, all of whom were involved in support groups, engaged in “activist disclosure” defined by their goal to educate others about HCV. Those who practiced activist disclosure were more likely to be White. The bulk of respondents, however, were either “open” or “limited” in their revelations regarding their HCV status. Thus, the majority of persons told some family and friends about their health status. Another smaller group of persons were quite secretive. People remained silent because

of not wanting to burden others or remind others of their past lifestyles. Yet, they were quite clear that they feared stigmatization of some sort. Some respondents described waiting to disclose while others simply felt their health status was private information.

Reasons for disclosure centered on concern for others such as protecting others, to explain atypical behavior, to educate others, or as a symbol of trust. Persons also disclosed because of their own concerns for care, help, or sympathy. The mode of transmission of HCV did not affect disclosure patterns which is not surprising considering the lack of cultural imagery about HCV. While gender and social class were unrelated to patterns of disclosure, race had a key effect. Minority respondents were less likely to be “activists” or even “open” about their HCV status. Research needs to address whether this is a general pattern for minorities as this may reveal insight into racial health disparities as disclosure patterns had associated benefits and risks.

REACTIONS TO DISCLOSURE

One risk of disclosure respondents reported is stigmatization, as discussed in Chapter 4. Over half grappled with some type of stigma. A quarter of respondents were not even aware of a stigma associated with HCV. Nearly half of the sample, however, revealed experiences which researchers have come to call “felt stigma”, that is feeling shame because of imagining how others would react if they knew about the stigmatizing attribute (Jacoby 1994). People had a number of fears about reactions from others including an association of HCV with deviance, seeing HCV as contagious, or viewing people with HCV as dirty. They also reported experiences with “enacted stigma” which are acts of discrimination, thus confirming those fears as most incidents concerned a connection between HCV and deviance or fear of contamination. Racial differences

emerged as a whole as Whites with HCV were more likely to be aware of stigma, engage in felt stigma, and report experiences with enacted stigma. Several people did have negative experiences in the workplace or in healthcare settings. These stigmatizing experiences centered on an association with HCV and deviance and/or contagion.

Not all disclosures, however, were met with stigmatization. Some respondents described little to no reaction to their disclosures or minimization of their illness. Again, the lack of cultural imagery and knowledge about HCV may play a role here. Disclosing health status was beneficial for some respondents who received support through family, friends or at work. People coped with stigmatization through information control, which can be seen used to avoid stigma or resist stigma. Individuals also coped through condemning the condemners whereby they minimized any stigmatizing response by degrading the person as ignorant. Finally, some persons participated in support groups which facilitated “activist disclosure”.

MAKING SENSE OF HCV

People employed numerous mechanisms to understand their experiences with HCV, as discussed in Chapter 5. Over half of all respondents experienced a “surprise diagnosis” in the course of a medical exam or blood donation. Others initiated the diagnostic process because of symptoms of some sort. Upon diagnosis, some individuals experienced fear of the unknown, shock, fear of imminent death, or sadness. The “uncertainty” experienced after diagnosed was exacerbated by the lack of cultural imagery about HCV. Others, however, described a rather ambivalent reaction to diagnosis perhaps abetted again by the lack of cultural discourse concerning HCV. Persons who described an ambivalent response were less likely to disclose their health

status. Thus, not all respondents who practiced reluctant or limited disclosure did so because of a fear of discrimination. For some people, having the often asymptomatic, culturally invisible disease of HCV is just not that important. People may minimize the significance of the disease compared to other difficulties in their lives.

Knowledge about HCV appeared to shape disclosure patterns. Some people could expertly discuss the disease while others had little or incorrect information. The majority of the respondents possessed moderate knowledge about HCV. Knowledge helped reduce uncertainty. Those with less information were less likely to openly disclose their health status. Minorities with HCV were more likely to have vague or inaccurate knowledge, thus perpetuating the cycle of minority health disparities.

In the absence of available cultural discourse, people relied on discourse about another disease, HIV/AIDS, to make sense of their experiences. In this regard, modified labeling theory is relevant. While some saw their illness as a punishment or loss, others described the challenges or value that resulted from having HCV. Finally, a diverse group of respondents relied on faith to understand their illness. Relying on faith was not related to race/ethnicity, class, or gender but linked to attendance rates at religious services and religious affiliation.

THE INDELIBLE STAMP OF RACE AND ETHNICITY

The effects of race permeate illness experience with HCV. Blacks represent over 1 in 5 person with HCV in the United States (Palmer 2006). HCV progresses more quickly in Blacks and they are less likely to receive treatment once diagnosed (Palmer 2006). Even when treated, Blacks respond less favorably to treatment than Whites (Palmer 2006). While hepatologists have been studying these differences from a

physiological approach, this research sheds light on variations from a sociological perspective. Persons of all racial and ethnic backgrounds had different experiences with diagnosis. Most people were largely unaware of HCV before diagnosis or had little knowledge. Initial reactions to diagnosis were undifferentiated by race or ethnicity. The ensuing behaviors were, however, influenced by race.

Black respondents did not disclose in the same manner as White respondents. Blacks may have discussed their health status with some close family and friends but were unlikely to practice “activist” or “open” patterns of disclosure. Surprisingly, these patterns did not appear to be explained through gender, education, income, or mode of transmission. Some research on HIV has found a connection between disclosure rates and race/ethnicity (Mason et al. 1995; Simoni et al. 1995). An explanation for the discrepancy in disclosure regarding HIV is the lower levels of knowledge about HIV/AIDS in minority communities thus discouraging open disclosure patterns (Simoni et al. 1995).

Minorities in this research were more likely to have inaccurate or little knowledge about HCV. Their lack of knowledge may have inhibited more open disclosure practices because of confusion or misunderstandings of their own about HCV. Black respondents’ lack of knowledge may reflect the dearth of available information regarding HCV in the larger Black community. If there is indeed less information in the Black community about HCV, the lack of open disclosure practices among Blacks with HCV will only perpetuate the problem. This lack of knowledge represents what Link and Phelan (1995) discuss as a “fundamental cause” of disease as it involves access to resources, specifically knowledge, which can minimize the impact of a disease. Future research must evaluate

public knowledge about HCV with attention to sampling various racial and ethnic groups. Another factor affecting disclosure patterns is cultural norms regarding discussions of health status. Blacks were more likely to mention not disclosing because it is private information. Being a racial or ethnic minority already potentially places persons in a stigmatized identity, they may be unwilling to risk further stigmatization through disclosing their HCV status (Goffman 1963).

Ironically, disclosure does lead to more experiences with stigmatization. Correspondingly, since Blacks were less likely to disclose, they reported fewer experiences of stigmatization. While Whites did mention engaging in felt stigma more than Blacks, this is likely a result of their greater understanding of the disease as a whole. Thus, with greater education about HCV, Blacks may also self label. Some research suggests that Blacks are more aware of discrimination because of being part of a stigmatized minority group (Oyserman and Swim 2001). Yet in this research, White respondents reported more acts of enacted stigma. Whites may attribute discrimination to their HCV because they do not hold other visible stigmatized statuses. While it may seem beneficial for Blacks to continue lower levels of disclosure to avoid stigmatization, they are missing the health benefits that can accrue from disclosure. Research reflecting this tension shows that persons labeled as mentally ill do face stigma, but also receive necessary and beneficial services as a result of the label (Rosenfield 1997).

Disclosure of health status does allow for support from family, friends, or in the workplace. Social support has profound effects on mental and physical health status (Thoits 1995). Thus, while Blacks do not experience stigma as much as Whites, they miss opportunities for social support. Levels of knowledge were related to positive social

support thus limiting social support for Blacks. Positive social support in the workplace was related to higher incomes also disenfranchising Blacks as they are more likely to have lower paying jobs than Whites.

Black respondents in this research are clearly experiencing HCV in a different fashion than white respondents. This racial inequality reflects larger trends in health in the United States. These differences in experiences with HCV are not attributable to social class supporting research that claims education and income do not explain racial discrepancies in health seeking behaviors (Schnittker et al. 2005). Instead, racial differences may be an outcome of provider patient interactions and style.

Numerous researchers have examined provider patient interactions. Waitzkin (1985) found that physicians believed they spent more time giving information to patients than they actually did. Physicians' social class as well as patients' social class affected the informative process (Waitzkin 1985). Doctors tended to underestimate the amount of information they thought patients wanted. There were no social class differences in patients' desire for information. Patients' thirst for information was unrelated to the information actually given to them. Length of acquaintance and a busy clinical load were related to less information being given to patients. In short, sociolinguistic patterns affected the information received by patients (Waitzkin 1985).

The majority of respondents in this research were patients of one physician. However, a provider does not interact with all patients in exactly the same manner. In fact, providers take on a variety of roles tailored to meet the needs of individual patients (Lutfey 2005). Lutfey (2005) also found that residents interacted with patients in a different fashion than seasoned physicians. Respondents in this research who were seen

at the public clinic were likely to see a different resident at each visit. Thus, these patients do not have the benefits of establishing a long term relationship with one person possibly affecting information given to them as found by Waitzkin (1985). However, the racial differences in experiences with HCV spanned both recruitment sites thus limiting the explanatory power of organizational setting.

Style is another factor that influences racial discrepancies. Style refers to how people present their illness (Bury 1991). Research has repeatedly found that social class affects style (Anderson 1991; Blair 1993; Bury 1991; Radley 1989). Middle class persons focus on the body in a more abstract fashion and are more verbal while lower class persons are concerned with how symptoms affect day to day functioning. Anderson (1991) states that what appeared to be racial differences in illness experience were in fact, class differences. In this research, however, differences are not linked to educational obtainments or income. There is some support that racial and ethnic minorities experience illness differently regardless of social class (Smaje 2000). Zola (1966) noted differences in presentation of symptoms among Irish Americans and Italian Americans. These findings point to the importance of culture in how individuals experience their bodies and illness (Zola 1966).

Illness experiences with HCV were also cultural. As evidenced by the length of the interview process, Whites in this sample talked longer about their experiences than minority respondents, providing a window into their interactions with providers. While Blacks may desire just as much information about HCV as Whites, they do not obtain the same levels of knowledge. Blacks' lower levels of knowledge about HCV and more inhibited disclosure patterns are contributing factors to these racial variations in illness

experience. These differences are also a result of illness style and subsequent provider and patient interactions. Physicians may unwittingly interact differently with Black patients with HCV because they are aware of racial differences in responsiveness to treatment, thus setting up a self-fulfilling prophecy (Lutfey 2000). Future research should focus specifically on provider and patient interactions among persons with HCV to further explicate racial differences in illness experience.

RESEARCH IMPLICATIONS

My research has implications for literature in the areas of medical sociology, sociology of deviance, race and ethnicity, and social psychology. These findings also offer contributions to address the plight of persons with HCV and the lack of public health education in the United States.

Current models of illness experience are applicable albeit in a limited fashion to HCV. Although some respondents experienced troubling symptoms before diagnosis, for most, diagnosis was the trigger or beginning point for their illness careers. Biographical disruption, according to Bury (1982), presumes that diagnosis is the first stage of disruption. Not all respondents with HCV reacted to diagnosis with feelings of shock, fear, or devastation. Some respondents were rather ambivalent. These findings question the presumption of a diagnosis of chronic illness necessarily leading to a biographical disruption. Diagnosis does lead to different trajectories of the illness career depending on how stable an individual's biography was before diagnosis. In other words, a diagnosis may be fairly irrelevant for some persons in light of other life stressors.

Nevertheless, most persons with HCV do experience some level of biographical disruption but not always starting with diagnosis. Addressing disclosure practices and

subsequent reactions provides some insight into how disruptive illness is for individuals. The lack of cultural imagery about HCV provides more options for persons with HCV in that they are less limited by available discourse compared to other diseases. Respondents themselves often had no sense of what it meant to have HCV. The people they disclosed to often had even less familiarity with HCV. Thus, respondents had much more freedom in terms of giving meaning to the illness experience compared to a culturally visible disease such as cancer. As a consequence, we see an array of disclosure practices. Modified labeling theory posits that persons have expectations or understandings of what it means to have a particular disease (Link 1987). Once diagnosed, individuals must now apply that understanding to their own situation. Most persons with HCV did not have an understanding of what it meant to have HCV before diagnosis because of the lack of cultural imagery. Yet, this theory is still somewhat useful in addressing HCV because in the absence of cultural imagery about HCV, many respondents turned to other available discourse: HIV/AIDS. Persons do attempt to make sense of their situations with the available cultural tools. While public education about HCV is desirable on many levels, it may confine individual decision making with regard to disclosure practices.

These findings also contribute to the discourse on stigma. Unlike much of the research on stigma and HIV/AIDS, this research approaches the data with attention to structural factors (Parker and Aggleton 2003). I find that Blacks report less experience with stigma than Whites. It is unclear whether Black respondents really experienced less HCV related stigma or whether they attributed stigmatizing experiences to other factors. Future research should focus on how occupying multiple stigmatized statuses may lead to attributing discrimination to the most salient or visible status.

My findings emphasize the salience of race and ethnicity also with regards to style and provider patient interactions. As discussed in the previous section, medical sociologists need to focus on how race and ethnicity affect illness experiences. Most research on style has focused on social class (Bury 1982; Radley 1989). Findings from this research instead highlight the salience of race and ethnicity for style. Furthermore, the research suggests attention to the social construction of illness within the Black community which may shed further light on racial health disparities. Much of the research on provider patient interactions has examined social class and gender (Waitzkin 1985). Again, this research points to the relevance of race and ethnicity in these interactions. These findings also highlight the erroneous assumption that race, class, and gender always affect social processes in a predictable fashion. As mentioned, to my surprise, gender and class did not appear to affect illness experience with HCV. Thus future research should not presume an inevitable significance.

I have continuously emphasized the lack of cultural imagery surrounding HCV. There is some evidence that this trend is currently changing as HCV advocates pressure government agencies for changes (See www.hepcadvocacy.org). Public education may in some ways have detrimental affects in terms of increasing rates of felt and enacted stigma. Persons with moderate or expert knowledge of the disease are more likely to engage in felt stigma. Currently, many people openly disclose and are not stigmatized perhaps because of the lack of cultural imagery. Unfortunately and ironically, with increased education, the public may associate HCV with deviance because intravenous drug use is currently the main mode of transmission in the United States. Educational programs must tailor information to prevent blaming persons with HCV for their illness.

The benefits of public education, however, outweigh the potential costs. Increased knowledge about HCV among the public will lead to greater prevention, more people getting tested for the disease, increasing chances of early treatment, and prolonged life span. With greater cultural discourse, people would then have some sort of understanding of HCV when diagnosed, thus alleviating some of the associated uncertainty. Knowledge about the disease facilitates more open disclosure practices and subsequent support from family and in the workplace. More public awareness would also diminish persons with HCV fearing others might see them as contagious as well as others minimizing the illness because of a lack of understanding. Most importantly, increased public awareness and patient education will address the stark contrast in illness experience by race and make headway in alleviating racial health disparities.

METHODOLOGICAL APPENDIX

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INTERVIEW GUIDE

INTRODUCTION

Introduce myself and explain the background of the study.

Tell the respondent how long the interview will probably take. Explain that I will tape record the interview, where the tape will be stored, and that they can refuse to answer any question or stop the interview at any time.

We will go over the consent form and the respondent will sign it.

I will ask the respondent to pick a pseudonym or explain that I will pick one if they like.

I would like you to tell me a bit about yourself. How long have you been in this area?
Can you tell me a bit about your time here?

SOCIAL RELATIONSHIPS

I am interested in you telling me about your social relationships and by that I mean family and friends that you are close with.

What is your marital status?

If not married, do you date or have a romantic partner?

How long have you been with your spouse/romantic partner?

Do you have any children?

If yes, how old are they?

If minors, do they live with you?

If not, how often do you see them/talk with them?

If adults, do they live in Baton Rouge?

If adults, how often do you see them/talk with them?

Does anyone else live in your household (*besides* ____, ____, and ____)?

Do you have other family in Baton Rouge?

If yes, how often do you see them/talk with them?

Who would you say are the 3 persons you are closest to?

How often do you see/ talk with _____? (*If not one of the abovementioned persons.*)

PRE-DIAGNOSIS

Tell me about your life before you were diagnosed.

What activities did you participate in?

How were your relationships with family and friends?

Did you have any previous medical conditions?

What were your previous experiences with health practitioners?

Had you ever heard of Hepatitis C?

If yes, what did you know about it?

What was it? How did people get it? What did it do to people?

Did you know anyone with Hepatitis C?

What did you think about Hepatitis C (or people who got Hepatitis C?)

DIAGNOSTIC EXPERIENCE

When were you diagnosed with hepatitis C and by whom/where?

How did you come to find out you had Hepatitis C?

Were you feeling sick? Did you have symptoms?

What was it like when the doctor told you that you had Hepatitis C?

How did he/she tell you?

What did they tell you about Hepatitis C?

Did he/she explain what the disease does to your body and the possible consequences of the disease?

Did he/she explain possible treatments for you?

Did he/she explain how to avoid transmitting Hepatitis to others?

Were you told that you would have to make any changes in your lifestyle?

What were you told about how you may have gotten Hepatitis C, if anything?

Do you agree that is how you probably got Hepatitis C?

Do you have any feelings about that?

Do you have any ideas about how long you have had it?

How do you think most people who have Hepatitis C get it?

What do you remember most about how you felt when you were diagnosed?

What did you do upon finding out?

At that time, what did you think having this disease meant to you/for you? How could you make sense of having this illness? In other words, did you ever ask yourself, “Why has this happened to me?” How did you answer?

DISCLOSURE

When you first found out, did you tell anyone right away, why or why not?

Who did you tell?

Why did you tell this specific person?

What did you tell them?

How did that person(s) respond?

How would you have liked them to respond?

Who have you told about your illness?

Nowadays, who do you tell about your illness?

What specifically do you tell people about Hepatitis C, if anything?

Can you describe a specific incident where you told someone recently?

Why did you tell this person?

How do you explain how you got it?

What do people ask you about HCV?

Have you had any reactions from anyone you have told that have made you feel uncomfortable in any way?

What did they do or say?

How did you feel when that happened?

Did you think differently about yourself or that you have Hepatitis C?

What about telling healthcare workers, either at your doctor or the hospital?

Has anyone there asked questions about having HCV?

What did they ask you?

How did you respond?

How did you feel about this interaction?

SUPPORT

Do you feel you have people you can count on for help? Who are they?

Of the people you have told about having Hepatitis C, who has been the most helpful or supportive?

What did this person do that was helpful or supportive?

What kind of help/ support have you or do you most need?

What kind of advice have persons given you?
Do you feel you can rely on your family/friends for support?

Has anyone been unhelpful or not supportive? Why, what did they do?

Have you gone to a support group? Why or why not?

HEALTH STATUS/ TREATMENT

How would you generally describe your overall health right now?

Are you aware of symptoms of HCV?

Have you experienced active symptoms, either at the time of diagnosis or since?

What are they?

How do you explain these symptoms to others?

Have these symptoms affected your day-to-day activities? How?

Have you had to make changes to your lifestyle because of your illness?

Have you had further testing concerning your health status, why or why not?

Have the test results been explained to you in a way that you understand?

Have you had a liver biopsy?

What was your experience with the procedure?

Where the results explained to you clearly?

Were you told about treatment options?

What were you told about the treatment, if anything?

Have you had treatment or are you currently undergoing treatment, why or why not?

Tell me about your experiences with this regimen.

Did you experience side effects?

If yes, what were they?

Was it difficult to stick with the treatment? Why or why not?

Did your family or friends help you with sticking to the treatment?

If you completed treatment, was it successful?

If you did not complete treatment, do you think you will try it again?

Did you tell family or friends know about the treatment before or after you started, why or why not?

What has been their reaction?

Did you have to tell your employer about your treatment?

What was your employers' reaction?

Were they helpful?

INFORMATION/MEANINGS

Have you sought out information about Hepatitis C from other sources, such as the internet, friends, library, etc.?

Do you feel comfortable asking for more information from your doctor about your illness?

Can you tell me about an example when you have done this?

What information would you like to have about HCV?

What would you like people to know about HCV?

How do you make sense of having this illness today?

Do you ask yourself, "Why has this happened to me?" How do you answer this today?

Have your ideas about what it means to have hepatitis C changed over time?

Has having treatment/active symptoms changed what it means to you?

Have others' reactions affected what it means to you?

How much do you feel you can control or not control the course of your illness?

How has having HCV changed the way you see yourself?

CONSEQUENCES

Do you think having Hepatitis C has affected your life?

Has it affected relationships with your spouse/partner, children, or other family members or friends? How?

Has it affected your employment? How?

Has it affected your day-to-day functioning? How?

Do you still engage in _____, _____, and _____ activities that you did before diagnosis?

Has having Hepatitis C affected any plans for the future or goals?

Have you had to change anything about your life?

Food or beverages?

Physical activities?

INDIANA UNIVERSITY - BLOOMINGTON
STUDY INFORMATION SHEET

EXPERIENCES OF PERSONS WITH HEPATITIS C VIRUS

You are invited to participate in a research study. The purpose of this study is to learn about people living with hepatitis C virus (HCV).

If you are interested in being interviewed for this study, please contact Alicia Suarez: (225) 247-1996.

INFORMATION

If you choose to be interviewed for this study, you will be part of approximately 50 persons with HCV who will be participating in this study. The interview will take approximately 60 to 120 minutes and will be conducted at a location of your choice. I will be asking you about: your life before you found out you had HCV, your experiences with diagnosis, whether you have told others, what you have told others about your illness, reactions from others about your illness, experiences with treatment if any, and general reaction to having HCV (how it affects your day to day life). You may request a break at any time. You may also request that the interview be stopped and completed another day. You may refuse to answer any question during the interview. You may terminate the interview at any time.

Audiotapes will be used for research purposes. Only the principal investigator and a paid transcriber will have access to the audiotapes, which will be stored in a locked filing cabinet. You may request a copy of the audiotape and/or transcript of your interview, and it will be provided to you free of charge. You may also request a copy of any published paper based on this research and one will be provided free of charge. The audiotape of your interview will be destroyed by September 1, 2006.

RISKS

Some persons may experience discomfort or embarrassment in discussing personal details of their lives in relation to their illness with the researcher. However, you may refuse to answer any question that makes you uncomfortable and may stop the interview at any time if you wish.

BENEFITS

Participating in this study will contribute to knowledge about personal experiences of those living with HCV. Little is known about how persons with HCV deal with their illness and how it affects their lives. This research will help both physicians as well as the

general public better understand what it is like to have HCV, as well as how to better assist those living with this illness. In addition to helping others with HCV, you may enjoy discussing your experiences and opinions, and may gain a clearer understanding of these issues as well.

CONFIDENTIALITY

This study is completely confidential. Data will be stored securely and will be made available only to persons conducting the study unless you specifically give permission to do otherwise. No reference will be made in oral or written reports that could link you to the study. Your response will be stored under a pseudonym with no identifying markers linking your responses to you. These pseudonyms will be used in any reports resulting from this study in order to maintain your confidentiality. Individual responses may be described in research reports; however, all possible precautions will be taken to disguise individuals' identities so that readers of the report will be unable to link you to the study. After each interview, the actual contact information for you and your name will be destroyed so there is no way that your responses can be linked to you. Audiotapes will be destroyed upon the completion of this study (no later than September 2006).

CONTACT

If you have questions at any time about the study or the procedures, you may contact the researcher,
Alicia Suarez, Ph.D. (candidate) at the Department of Sociology, Ballantine Hall 744, 1020 East Kirkwood Avenue, Indiana University, Bloomington, IN 47405, or at (812) 855-2924 or at asuarez@indiana.edu.
Local number: (225) 247-1996.

If you feel you have not been treated according to the descriptions in this form, or your rights as a participant in research have not been honored during the course of this project, you may contact the office for the Indiana University Bloomington Human Subjects Committee, Carmichael Center L03, 530 E. Kirkwood Ave., Bloomington, IN 47408, 812/855-3067, or by e-mail at iub_hsc@indiana.edu.

PARTICIPATION

Your participation in this study is voluntary, you may refuse to participate without penalty. If you decide to participate, you may withdraw from the study at anytime without penalty and without loss of benefits to which you are otherwise entitled. If you withdraw from the study before your data collection is completed your data will be returned to you or destroyed.

Form date: April 21, 2004
Study # _____

INDIANA UNIVERSITY – BLOOMINGTON

Experiences of persons with Hepatitis C Virus

Contact sheet

I agree that Dr. Cassidy may give Alicia Suarez my name and phone number to contact me about an interview for her research concerning Hepatitis C virus.

Date _____

Signature _____

Name _____

Phone Number _____

(Optional) This is a good time to phone me _____

BACKGROUND INFORMATION

Please fill in or circle the answer.

1) What is your age? _____

2) What is your racial/ethnic background?

- a) African-American
- b) Hispanic
- c) Asian-American
- d) Native American
- e) White
- f) Other_____

3) What is your religious preference, if any? _____

4) How often do you attend services? _____

5) How often do you meditate and/or pray? _____

6) What is the highest grade of school or level of education you have completed?

7) What is your employment status? _____

8) If employed, what is your occupation? _____

9) If married/living with someone, what is your spouse's/partner's employment status? _____

10) If employed, what is his/her occupation? _____

11) Considering all sources of income and all salaries, what range best describes your household's total annual income for the last year?

- a) 0-9,999
- b) 10,000-19,999
- c) 20,000-29,999
- d) 30,000-39,999
- e) 40,000-49,999
- f) 50,000-59,999
- g) 60,000-69,999
- h) 70,000-79,000
- i) 80,000-89,000
- j) 90,000 or above

12) In general, would you say you/your family has?

- a) More money than you need
- b) Just enough money for your needs
- c) Not enough to meet your needs

HEPATITIS C SUPPORT AND INFORMATION

Support Groups:

Metairie, Louisiana. "Friends of Hep C Support Group" East Jefferson General Hospital. 1st Floor Auditorium. Meets on 1st Thursday of the month. 7-9pm. Contact person: Bridget. (504) 737-2429.

New Orleans, Louisiana. "Hepatitis C Support Group Meeting" At the office of Dr. Ellis Williams. 3239 Bienville St. Meets on 3rd Tuesday of the month. 7-9pm. Call (504) 943-6365 or toll free (866) 891-4164.
<http://www.sirentowail.org/>

Lafayette, Louisiana. "Hepatitis Support Group" 1st and 3rd Wednesday nights of each month. For more information, contact: Christine Pullum (337) 981-0220.

Hotline:

1-800-522-HEPC (4372)

"The Hepatitis Help Line Call Center at Hep C Connection, located in Denver, Colorado, operates Monday – Friday, 7:00 a.m. – 5:00 p.m. (MST). Our trained phone counselors are hepatitis C-challenged individuals, themselves, or are caregivers for hepatitis C-challenged family members. They combine personal experience with on-going research and training to provide confidential, practical help and up-to-date information about living with the virus. Frequently, that includes educating callers about hepatitis A and B, and addressing co-infection (HCV/HIV) issues, as well." <http://www.hepc-connection.org/>

Information:

<http://hepatitis-central.com/hcv/>

<http://www.focusonhepc.com/>

<http://www.epidemic.org/index2.html>

<http://www.hcvadvocate.org/>

<http://www.liverfoundation.org/>

S494: Fall 2004

Research assistantship with Alicia Suarez

This position will be to assist Alicia with the research project, "So How Did You Get That?": Experiences of Individuals Living with Hepatitis C Virus (HCV). The project involves in depth interviews, which will be collected in the summer of 2004. The Research assistant (RA) will help with the data analysis in the fall of 2004. The RA will not be expected to work any more than 10 hours a week. Here are the requirements for the position:

- Participate in informal training session on how to transcribe data.
- Read research proposal and relevant background literature to become familiar with project. (Articles will be provided to RA).
- Transcribe interviews with a *high* level of accuracy.
- Participate in first stage of data analysis through filling out Interview Outline Forms.
- Informal meetings with Alicia to discuss the first stage of data analysis. These meetings will be every other week or so depending on our schedules.
- Demonstrating an understanding and dedication to the data analysis process.

Grades will be evaluated based on completion of the above goals. The RA will earn 3 credit hours from the position.

I, _____, agree to participate as a Research Assistant for the abovementioned course. I understand what is required of me and how I will be evaluated.

Signature _____

Date _____

Interview Outline Form

Completed by:

Date:

Respondent Name:

Gender:

Age:

Race:

Class:

Employed:

Occupation:

Spouse/Partner occupation:

Household Income:

Evaluation of income:

Education:

Religion:

How often meditate/pray:

Marital Status:

Description

- 1) Illness concept

2) Disclosure

3) Social Support

4) Stigmatization

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POSITIONS HELD

2006-Now Assistant Professor of Sociology, Pacific Lutheran University
2004-2006 Pre-Doctoral Scholar and Instructor, Department of Sociology and
 Anthropology, DePauw University
2001-2004 Associate Instructor, Department of Sociology, Indiana University

EDUCATION

June 2006 **PhD**, Sociology, Indiana University, Bloomington
 Dissertation: "So How Did You Get That?": Experiences of
 Individuals Living with Hepatitis C Virus.
 Dissertation Committee: Brian Powell (Co-Chair), Bernice
 Pescosolido (Co-Chair), Elizabeth Armstrong, Stephanie
 Kane
 PhD Minor: Criminal Justice
 Qualifying Exam: Sociology of Deviance

2003 **Preparing Future Faculty Certificate**, Sequence in the Sociology of
 Higher Education and Scholarship of Teaching and Learning
 Indiana University, Bloomington

2002 **Master of Arts**, Sociology
 Indiana University, Bloomington
 Thesis: "Is Pornography All Bad or All Good?
 Mixed Beliefs about Pornography in the U.S."
 Committee: Brian Powell and Bernice Pescosolido (Co-Chairs)

1999 **Bachelor of Arts**, Sociology
 Indiana University, Bloomington

RESEARCH AND TEACHING INTERESTS

Medical Sociology	Deviance	Gender/Women's Studies	Social Psychology
Sexuality	Criminology	Social Inequality	

HONORS AND AWARDS

- 2004-2006 **Pre-doctoral Scholar**, Department of Sociology and Anthropology, DePauw University, Greencastle, Indiana
- 2005 **Outstanding Graduate Student Paper Award**, Society for the Study of Social Problems, Teaching Social Problems section, for “The Forbidden Chapter: Representations of Sexuality in Introductory Sociology Textbooks” (Authored with Alexandra Berkowitz)
- 2005 **Lieber Associate Instructor Award**, University-wide Outstanding Graduate Student Instructor Award, Indiana University
- 2005 **Dyad Grant from the Andrew W. Mellon Foundation**, Category 1: “Fostering Community, Furthering Fellows”, Strengthening Intellectual Communities, DePauw University
- 2004 **Stuart Simon Dissertation Fellowship**, For outstanding contributions and commitment to teaching and research, Department of Sociology, Indiana University
- 2004 **Doctoral Student Grant-in-Aid of Research**, University Graduate School, Indiana University
- 2003-2004 **DePauw Faculty Fellow**, DePauw University, Greencastle, Indiana
- 2003 **Edward H. Sutherland Award for Outstanding Teaching**, Department of Sociology, Indiana University
- 1999-2004 **Graduate Tuition Scholarship**, Department of Sociology, Indiana University
- 1999-2004 **Dean’s Minority Fellowship**, Indiana University
- 1996 **Dean’s List**, Louisiana State University

TEACHING EXPERIENCE

- 2004-2006 **Instructor**
Department of Sociology and Anthropology, DePauw University
Full responsibility for all aspects of course design, preparation, implementation, and grading.
- Courses Taught:**
Contemporary Society (One semester of 30 students)
Medical Sociology (One semester of 20 students)
- 2001- 2004 **Instructor**
Department of Sociology, Indiana University
Full responsibility for all aspects of course design, preparation, implementation, and grading.
- Courses Taught:**
Deviant Behavior and Social Control (Five semesters of 22-68 students)
Field Experience in Sociology (Six semesters of 1-6 students)
Introduction to Sociology (Two semesters of 63 to 71 students)
Sexual Diversity (Two semesters of 65-71 students)
- 1999-2001 **Teaching Assistant**
Sociology Department, Indiana University
Sexual Diversity, Sociology of the Family, Social Problems and Policies, Constructing Sexuality
Assisted in grading exams, papers and assignments, advised and tutored students, wrote examination questions, held review sessions, and maintained gradebooks.

TEACHING PUBLICATION

- 2003 Suarez, Alicia. "Deviant Behavior and Social Control Syllabus." In *Teaching the Sociology of Deviance*, 5th ed. Martin Schwartz and Michael Maume, Editors. Washington D.C.: Teaching Services Program. American Sociological Association.

PAPERS IN PROGRESS

- "The Forbidden Chapter: Representations of Sexuality in Introductory Sociology Textbooks"
Under review.
- "Varying Levels of Disclosure Among People with Hepatitis C Virus (HCV) and the Significance of Race"

PRESENTATIONS AT PROFESSIONAL MEETINGS

- 2005 Suarez, Alicia and Alexandra Berkowitz. "The Forbidden Chapter: Representations of Sexuality in Introductory Sociology Textbooks." Presented at the annual meeting of the American Sociological Association in Philadelphia, PA and at the annual meetings of the Society for the Study of Social Problems awards session in Philadelphia, PA.
- 2005 Suarez, Alicia. "So How Did You Get That?": Experiences of Individuals Living with Hepatitis C Virus. Presented at the annual meeting of the Pacific Sociological Association in Portland, Oregon.
- 2002 Suarez, Alicia. "Is Pornography All Bad or All Good? Mixed Beliefs about Pornography in the U.S." Presented at the annual meeting of the American Sociological Association, Chicago, IL.
- 2002 Suarez, Alicia. "All Bad or All Good? Using Feminist Frameworks to Explore the American Public's Scorn of Porn". Presented at the annual meeting of the Midwest Sociological Society, Milwaukee, WI.

SERVICE

Professional

- 2002-2005 **Guest Lecturer**, Indiana University and DePauw University, Lectures on body modification, in-depth interviewing, and pornography
- 2004-2005 **Honors Thesis Committee Member**, DePauw University
- 2004-2005 **Participant**, Committee for Latino Concerns, DePauw University
- 2003-2004 **Graduate Affairs Committee**, Department of Sociology, Indiana University
- 2003 **Panelist**, Graduate and Professional Student Organization Orientation Program and McNair Scholar's Program, Indiana University
- 1999-2000 **Social Committee**, Sociology Graduate Student Organization, Indiana University

Community

- 2005 **Invited Speaker**, Presentation on Hepatitis C Virus at Johnson County Juvenile Detention Center

- 2005 **Faculty Liaison**, Vagina Monologues in association with the V-Day College Campaign, DePauw University
- 2002, 2001 **Actress**, Vagina Monologues in association with the V-Day College Campaign, Indiana University.

PROFESSIONAL ASSOCIATIONS

American Sociological Association
Sections: Crime, Law, and Deviance;
Sociology of Sexualities;
Medical Sociology
Midwest Sociological Society
Pacific Sociological Association

Society for the Study of Social Problems
Sections: Sexual Behavior, Politics
and Communities; Health, Health
Policy, and Health Services;
Teaching Social Problems
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REFERENCES

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