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2008-02-25

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Challenges & Struggles: Lived Experiences of Individuals with Mental Illness,
Substance Abuse and General Medical Conditions

by

Anna Liza D. Villena

DISSERTATION

Submitted in partial satisfaction of the requirements for the degree of

DOCTOR OF PHILOSOPHY

in

Nursing

in the

GRADUATE DIVISION

of the

UNIVERSITY OF CALIFORNIA, SAN FRANCISCO

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Acknowledgement

The road to accomplishing my dissertation was certainly lengthy yet by no means driven alone. Along my journey, there were many individuals who offered assistance and advice as I wrote my dissertation. I am deeply indebted and thankful to my dissertation chair and mentor, Dr. Kit Chesla, and the members of my committee, Dr. Catherine Waters and Dr. Bethany Phoenix. Dr. Chesla's insights and advice were invaluable. Without the committee's support, it would have been impossible to complete my dissertation.

I would like to thank Dr. Gary and the SAMHSA/ANA Minority Fellowship Program (MFP). Dr. Gary's guidance and constant beacon of support proved to be invaluable through my dissertation process. I would like to express my thanks to Dr. Robert Ratner and Rick Crispino. In the last eight years, they shared my passion and vision for working with individuals who suffered from co-occurring disorders.

I am grateful to all of the informants who participated in this study. I thank them for sharing their stories and allowing me to enter into their world. I am eternally indebted to my parents and family for all of their help. Lastly, I dedicate this study to Cate, who struggled and overcame her addiction yet only to succumb to breast cancer two months after our interview.

ABSTRACT

THE CHALLENGES AND STRUGGLES OF LIVING WITH
MENTAL ILLNESS, SUBSTANCE ABUSE, AND GENERAL MEDICAL
CONDITIONS

Anna Liza D. Villena

Approximately 20 million people suffer from substance abuse disorder in a given year and approximately 7-10 million of them will have co-occurring disorders (COD) of both mental illness and substance abuse. Moreover, 61 percent of those who have COD have not received treatment for either illness. To complicate matters, individuals with COD have higher rates of other chronic health problems (i.e. diabetes), multiple re-hospitalizations and over utilize emergent services. Despite their elevated risk for physical morbidities, there is a dearth of literature that focuses on the impact for those with COD of having multiple physical health disorders. Of concern is how this population copes with medical health issues while at the same time living with a psychiatric illness and substance abuse or dependence.

The purpose of this interpretive study was to understand: (a) the social and structural barriers that individuals with COD encounter in regards to their healthcare; and, (b) how individuals with co-occurring disorders of mental illness, substance abuse, and other chronic medical illnesses manage their illnesses. A purposive sampling of twenty individuals with COD (11 males; 9 females; 65% African American) were recruited from community treatment centers and

supportive housing sites. Participants were interviewed for one hour on two occasions. Narrative interviews focused on meanings of health, management of illness and experiences with the healthcare system, were conducted. Thematic and paradigm case analyses were conducted on two occasions. Narrative interviews focused on meanings of health, management of illness and experiences with the healthcare system, were conducted. Thematic and paradigm case analyses were conducted.

Social and structural barriers to improving health included difficulties with interpersonal relationships with healthcare providers. Participants felt they were not heard and/or understood by providers. Additionally, informants described that limited or missing health insurance coverage, support, limited access to mental health services, frequent changes in Medicaid regulations, and increases in share of cost for medications as impediments to their health management. Unstable, unkempt, and crime-ridden housing and neighborhoods were barriers to improving and/or maintaining their health.

Additionally, three distinct patterns of coping with mental illnesses, drug and/or alcohol addiction, and physical chronic illnesses were observed, which included (a) interconnectedness, (b) ambivalence, and (c) waiting in defeat. The three patterns of coping describe the commonalities and differences in individuals' responses to living with COD. Implications for clinical care and social policies are included.

Catherine A Chesla

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CHAPTER ONE

INTRODUCTION

The purpose of this hermeneutic interpretive study is to discover the meanings of health, health beliefs and practices and health management of individuals with co-occurring disorders of mental illness, substance abuse and chronic diseases. The specific research question of this interpretive study is “How do individuals with co-occurring disorders of mental illness, substance abuse and chronic diseases (i.e. HIV, diabetes, hypertension and hepatitis C) perceive and manage their health?”

The dearth of literature on health beliefs and practices within individuals who have co-occurring disorders of mental illness, substance abuse and chronic illnesses has played a vital role in society’s fragmented healthcare delivery to this vulnerable and disenfranchised population. Health providers have limited insights as to how this population’s health beliefs impact their health maintenance. As a consequence, we often see this population frequently return to the emergency department seeking medical treatments, often times when the disease severity has worsened. Clients’ perceptions of their health have a major impact on their use of health services (Kinzel, 1991). This research study will provide a foundation that can serve as a guide for further and larger research studies. Additionally, the findings can also serve as an underpinning for improvement in healthcare delivery to a complex population

Since the majority of studies have traditionally focused on either substance abuse or mental health problems, the current research examines the impact of

both diseases as well as other chronic diseases on the lives of the participants. The research approach focuses on the participants' lives holistically and of their disease experiences in view of understanding how they manage the multiple layers of their chronic illnesses.

Background & Significance

Approximately 33.2 million adults age 18 and older have a serious mental illness or a substance use disorder. Of these adults, 40.4 percent (13.4 million) have only a serious mental illness while 47.4 percent (15.7 million) have only a substance use disorder; and 12.2 percent (4.0 million) have both serious mental illness and a substance use disorder. Furthermore, 61 percent of those who have co-occurring disorders of both serious mental illness and a substance use disorder have not received treatment for either illnesses (Substance Abuse Mental Health Services Administration, 2002). To complicate matters, individuals with co-occurring disorders (COD) of mental illness and substance abuse have higher rates of chronic health problems (Dickey, Normand, Weiss, Drake, & Azeni, 2002), have multiple re-hospitalizations, frequently over utilize emergency services (Curran et al., 2003) and frequently present for care within the primary health care context (Gournay, Sandford, Johnson, & Thornicroft, 1997). Individuals with COD have increased prevalence of cardiovascular disease, high blood pressure, diabetes, arthritis, digestive disorders, and asthma (De Alba et al., 2004; Mertens, Lu, Parthasarathy, Moore, & Weisner, 2003; Miller, Druss, Dombrowski, & Rosenheck, 2003; Sokol et al., 2004; Upshur, 2005). Additionally, individuals with severe mental illnesses have much higher rates of HIV and hepatitis C than those

found in the general population (Brunette, Drake, Marsh, Torrey & Rosenberg, 2003; Rosenberg et al., 2001; Sullivan et al., 1999). Moreover, specific mental or substance-use diagnoses place individuals at higher risk for certain general medical conditions. For example, those in treatment for schizophrenia, depression, and bipolar illness are more likely than the general population to have asthma, chronic bronchitis, and emphysema (Sokol et al., 2004). Persons with anxiety disorders have higher rates of cardiac problems, hypertension, gastrointestinal problems, genitourinary disorders, and migraine (Harter, Conway, & Merikangas, 2003). Individuals with schizophrenia are at increased risk for obesity, heart disease, diabetes, hyperlipidemia, hepatitis, and osteoporosis (American Diabetes Association et al., 2004; Goff et al., 2005; Green, Canuso, Brenner, & Wojcik, 2003). Chronic heavy alcohol use is associated with liver disease, immune system disorders, cardiovascular diseases, and diabetes (Carlsson et al., 2000; Corrao, Rubbiati, Bagnardi, Zanbon, & Poikolainen, 2000; NIAAA, 2000). Furthermore, they have higher morbidity and mortality rates when compared to the general population (Chafetz, White, Collins-Bride, & Nickens, 2005). For the purpose of this research study, co-occurring disorder is defined as the co-occurrence of substance abuse or dependence and any psychiatric illness. COD exists when at least one disorder of each type can be established independently of the other and is not simply a cluster of symptoms resulting from a single disorder (Co-Occurring Center for Excellence, 2003).

Despite their elevated risk for physical morbidities, there is a dearth of literature that focuses on the impact for those with COD of having multiple physical

health disorders. Of particular concern is how this population copes with medical health issues while at the same time living with a psychiatric illness and substance abuse or dependence. Current studies on COD focus on recovery (Laudet, Magura, Vogel, & Knight, 2000a, 2000b; Magura et al., 2003; Moggi, Ouimette, Moos, & Finney, 1999); housing (Bebout, Drake, Xie, McHugo, & Harris, 1997; Metraux, Marcus, & Culhane, 2003; Tsemberis & Eisenberg, 2000) and clinicians' perspectives when working with COD individuals (K. Carey, Purnine, Maisto, Carey, & Simons, 2000; Maisto, Carey, Carey, Purnine, & Barnes, 1999). Gaining a better understanding of the complexities of participants' mental health, substance abuse or dependence and physical health issues will improve healthcare providers approach and care when engaging with this population.

Specific Aims

The specific aims for this study are:

- 1) To describe and understand how individuals with COD construct the meanings of health and illnesses.
- 2) To describe and understand how individuals with COD manage their illnesses.
- 3) To describe and understand the perceived impact of multiple illnesses within the lives of individuals with COD.
- 4) To describe and understand the support network that individuals with COD utilize.
- 5) To describe and understand social and structural barriers that individuals with COD encounter in regards to their healthcare.

CHAPTER TWO

LITERATURE OF REVIEW

Introduction

Co-occurring disorder (COD) of mental illness and substance abuse is highly insidious, transcending “differential types of psychiatric diagnosis, and drug of abuse, and is encountered regularly in psychiatric and medical emergency rooms, clinics and hospitals” (Chambers, 2007, p.4). Additionally, individuals with COD have higher rates of chronic health problems (Dickey, Normand, Weiss, Drake, & Azeni, 2002) and multiple re-hospitalizations, frequently overutilize emergency services (Curran et al., 2003) and often present for care within the primary health care context (Gournay, Sandford, Johnson, & Thornicroft, 1997). As a result, they have higher morbidity and mortality rates when compared to the general population (Chafetz, White & Collins-McBride, & Nickens, 2005).

In the hope of ameliorating the increasing health problems and improving health management among individuals with COD, it is important to understand this population’s health status, health risks, health behaviors, health perception, and health management not only of mental illness, but also of physical health. To date, there is a dearth of literature that focuses on various physical health aspects of the COD population, specifically on how they cope with multiple medical health issues in addition to mental illness and, often, substance use and dependence. Current studies on COD focus on recovery (Laudet, Magura, Vogel, & Knight, 2000a, 2000b; Magura et al., 2003; Moggi, Ouimette, Moos, & Finney, 1999), housing (Bebout, Drake, Xie, McHugo, & Harris, 1997; Metraux, Marcus, & Culhane, 2003;

Tsemberis, & Eisenberg, 2000), and clinicians' perspectives when working with COD individuals (Carey, Purnine, Maisto, Carey, & Simons, 2000; Maisto, Carey, Carey, Purnine, & Barnes, 1999).

This chapter reviews chronic physical health problems of the COD population, specifically focusing on individuals with severe mental illness (i.e., schizophrenia, bipolar disorder, and schizoaffective disorder), substance abuse/dependence, and with a diagnosis of the human immunodeficiency virus (HIV) or acquired immunodeficiency syndrome (AIDS). I use this subpopulation of individuals with co-occurring disorders as a springboard for understanding their health, health risks, health behaviors, and health perceptions.

The first section examines the preponderance and severity of chronic physical health conditions endured by persons with CODs. The second focuses on medical sequelae to substance use and dependence in the COD population. The third section reviews factors that influence health behaviors in the COD population. Lastly, I address lacunae in the literature as well as future directions for research designed to improve clinical practice with the COD population.

The literature search was conducted using PSYCINFO, CINAHL, and PUBMED. The following search terms were used: "co-occurring disorders"; "dual diagnosis"; "health perceptions"; "health beliefs"; "substance abuse and mental illness"; "chronic illness"; "dual diagnosis and health"; "health management"; and "health values". Combinations of terms, such as "co-occurring disorders AND health beliefs or perceptions" or "dual diagnosis AND health beliefs or perceptions" were also explored, but these keywords did not provide any matches. Hence, the

search was narrowed by using terms like “mental illness AND health beliefs” or “substance use AND health perceptions,” which provided several articles.

Thereafter, references within these retrieved articles were used to broaden the search.

Co-occurring Disorders and Physical Health Issues

Human Immunodeficiency Virus and Hepatitis C

Individuals with CODs have an increased risk for HIV due to particularly higher HIV risk behaviors, such as injection drug use and unsafe sex, as well as impaired judgment associated with their psychiatric disabilities and drug use (Dausey & Desai, 2003). Individuals with CODs are at considerably higher risk for HIV infection than patients with a single psychiatric diagnosis (Hoff, Beam-Goulet, & Rosenheck, 1997; King, Kirdorf, Stoller, & Brooner, 2000; McKinnon, Cournos, & Herman, 2002; Stoskopf, Kim, & Glover, 2001). Within the COD population, the percentage of patients with HIV infection range from 3.4% to 48.3% (Douaihy, Jou, Gorske, & Salloum, 2003), which is considerably higher than comparable estimates in the United States population of approximately 0.3% to 0.4% (McQuillan et al., 1997).

Rosenberg et al. (2001) examined the prevalence of HIV, Hepatitis B (HBV), and Hepatitis C among the mentally ill population. A convenient sample of 323 inpatient and 608 outpatient individuals between 18 and 60 years of age was recruited from the public health systems of Connecticut, Maryland, New Hampshire, and North Carolina. Results indicated that individuals with mental illness and substance use were more likely to have an increased risk for HIV, HBV,

and Hepatitis C, as compared to patients who did not have these diagnoses. The odds ratio (OR) for a person with COD to develop: (1) HIV was 2.93; (2) Hepatitis C was 2.42; and (3) Hepatitis B was 1.74. Furthermore, the results demonstrated a tremendous increase in risk for these infectious diseases when participants used intravenous drugs. The OR for contracting HIV increased to 6.49; for Hepatitis B, it rose to 4.76. In regard to Hepatitis C, researchers documented an alarming increase in risk for individuals who used intravenous drugs (OR 31.25). The generalization of this study's findings was limited to the East Coast region of the United States. The prevalence of HIV, HBV, and Hepatitis C could vary by geographic locations. Further limitations included a convenient sample, which raised the question of the representativeness of the study and, hence, threatened its external validity. Despite such limitations, a more recent study by Dausey and Desai (2003) replicated these findings.

Dausey and Desai (2003) conducted a cross-sectional study by comparing the differences in HIV prevalence and risk behaviors in 6,593 patients with substance abuse problems and patients diagnosed with both psychiatric and substance abuse problems. Participants were selected from a larger national study. Hierarchical linear modeling was utilized to compare risk behaviors between the two groups. Results showed that, in contrast to participants with substance abuse problems, patients with both disorders were more likely to share a needle (OR 1.47), have sex for money or gifts (OR 1.76), have sex with an intravenous drug user (OR 1.59), and be forced to engage in sexual behavior (OR 2.51). Several limitations to the study were noted: (a) psychiatric clinical

diagnoses were not based on the Diagnostic Statistical Manual IV criteria or the International Classification Diseases coding; and, (b) self report of HIV status and the lack of medical records to confirm the diagnosis could lead to underreporting, so that HIV rates could be higher. Despite its limitations, this study supported Rosenberg's findings that individuals with COD were at higher risk for acquiring HIV due to high-risk behaviors.

Klinkenberg et al. (2003) estimated the prevalence of HIV, HBV, and Hepatitis C in St. Louis among homeless individuals with CODs and assessed which variables were associated with exposure to these infectious diseases. A convenient sample size (n=204) was obtained from an ongoing assertive community treatment study. Participants were diagnosed with both mental illness and substance abuse, but were not currently engaged in treatment for either condition. HIV status was evaluated at baseline and 24 months. At baseline: (1) 6.2% of participants were HIV-positive; (2) nearly one-third of them offered evidence of prior exposure to HBV; (3) 30% were antibody positive for Hepatitis C; and, (4) about 44% had a reactive test for either HBV or Hepatitis C. A reactive test for HBV or Hepatitis C was strongly associated with substance use, especially when there was a history of intravenous drug use. The small number of participants who were HIV positive limited the authors' capability to conduct a predictive analysis for HIV. At 24 months, participants who were HIV negative at baseline remained negative, but results for Hepatitis C and HBV at 24 months were not reported.

The prevalence rates for HIV, HBV, and Hepatitis C at baseline were significantly higher when compared to the findings of Rosenberg et al. (2001). These findings can be explained based on the difference between the characteristics of the studies' samples. In contrast to the sample used by Klinkenberg et al. (2003), the population used by Rosenberg et al. (2001) was more urbanized, had less substance abuse disorders, and had a lower proportion of homeless individuals (16%). Despite the differences between the samples, the risk factors (i.e., substance use and high risk sexual behavior, e.g., commercial sex) among those with HIV, HBV and Hepatitis C were found to be similar across the studies.

In addition to HIV, Hepatitis C has gradually increased due to drug activity and use of contaminated equipment. Osher et al. (2003) investigated the relationship between substance abuse and increased rates of Hepatitis C transmission among persons with severe mental illness. Participants (n=777) were tested for Hepatitis C in the course of 18 months. HIV or HBV positive individuals were eliminated from the final analysis to focus solely on Hepatitis C. Out of 668 participants, 546 were Hepatitis C negative. A stepwise regression was conducted to identify predictors for Hepatitis C. The results indicated that increased Hepatitis transmission was related to drug use. Crack was identified as a mediator for Hepatitis C transmission through sharing contaminated equipment. Limitations of the study included a retrospective design and self report of behavioral risk factors.

To summarize, from the research reviewed, it would seem that drug use, specifically crack, increased the risk for Hepatitis C. Additionally, route of

administration, such as intravenous, further increased an individual's risk of contracting Hepatitis C. Risky behaviors, like unprotected sex or sharing equipment, further increased exposure to HIV, HBV, and Hepatitis C. These high rates are of great concern, especially in the public health sector.

Medical Sequelae to Substance Use and Dependence

Alcohol and drug use/dependence and psychiatric impairments can contribute in various ways to the prevalence and experience of serious illnesses, medical complications, and chronic conditions (Leonard et al., 2001; Zavala & French, 2003). Salloum, Douiahy, Ndimbie, and Kirisci (2004) examined whether concurrent dependence on alcohol and cocaine use was associated with increased impact on physical health, as compared to individuals with mental illness who use only cocaine or only alcohol. Three distinct groups were examined: (a) 38 psychiatric patients with alcohol dependence; (b) 25 psychiatric patients with cocaine dependence; and (c) 25 psychiatric patients with both cocaine and alcohol dependence. Those who utilized other forms of illicit drugs were excluded. Logistic regression and odds ratio were utilized for statistical analyses. Results indicated that psychiatric patients with concomitant alcohol and cocaine use had higher rates of physical (OR 8.3) and hepatic (OR 2.3) disorders when compared with the cocaine dependence group. When compared to the alcohol dependence group, the rate for physical disorders was much lower (OR 2.9). However, the rate for hepatic disorders was very similar (OR 2.4). This study was limited by its small sample size and its cross-sectional design. Moreover, this study only showed association and not causality. The study demonstrated that a preponderance of

the sample alcohol and drug dependence increased the risk for serious physical ailments. This suggests that increased variability in drug use compounded health risks for those with COD.

In addition to liver diseases, illicit drugs can lead to cardiovascular disease. Substance abuse with cocaine is associated with multiple cardiovascular conditions, including myocardial infarction, dissection, left ventricular hypertrophy, arrhythmias, sudden death, and cardiomyopathy (Frishman, Del Vecchio, Sanal, & Ismail, 2003; Pozner, Levine, & Zane, 2005). Lange and Hillis (2001) found that cocaine use accounted for up to 25% of heart attacks in patients between the ages of 18 and 45.

As well as illicit drugs, licit drug use, such as nicotine, is quite prevalent among those with severe mental illness. The psychiatrically ill in the U.S. consume about 70% of all cigarettes smoked (Grant, Hasin, Chou, Stinson, & Dawson, 2004; Leonard et al., 2001). Moreover, many people with mental health problems, in particular schizophrenia, die from smoking related diseases, such as cardiovascular and respiratory diseases, at rates twice those of age-matched control populations (Brown, Barraclough, & Inskip, 2000).

Jung and Irwin (1999) found that depressed smokers had lower natural killer cell activity than non-depressed smokers and depressed non-smokers. They hypothesized that dysfunctional natural killer cell activity contributed to primary tumor development and metastatic cancer risk. Dalack and his colleagues (1998) commented that recent data indicated smoking as a risk factor for tardive dyskinesia, independent of medication exposure. Tardive dyskinesia, a movement

disorder that may become apparent only after long-term treatment, has been linked to increased morbidity and mortality in those with chronic schizophrenia (Dalack, Healy, & Meador-Woodruff, 1998). The burden of smoking-related illnesses in addition to mental health problems is significant. Boyd and Lasser (2001) commented that individuals with mental illness were often the least capable of coping with the devastating medical illnesses caused by smoking.

Other Chronic Health Conditions

With the advent of new atypical antipsychotics like Zyprexa, diabetes is now commonly seen among individuals with CODs (Dickey, Normand, Weiss, Drake, & Azeni, 2002). Antipsychotic agents may increase the risk for diabetes by causing increased insulin resistance, decreased insulin secretion, or a combination of both. Hence, persons with schizophrenia are at higher risk for developing diabetes (Clark & Burge, 2003). In addition, these new medications can lead to obesity (Hennen, Perlis, Sachs, Tohen, & Baldessarini, 2004), which, in turn, can further increase one's risk for cardiovascular diseases (Dickey et al., 2002).

Dickey, Normand, Weiss, Drake, and Azeni (2002) conducted a cross-sectional study to examine whether certain medical disorders were more prevalent among adults with severe mental illness and whether a co-morbid substance use disorder increased prevalence beyond the effect of severe mental illness alone. The study sample consisted of 26,332 Medicaid beneficiaries between the ages of 18 and 64. Of these, 11,185 were treated for severe mental illness. The results demonstrated that individuals with severe mental illness posed a significantly

higher risk for general medical disorders when compared to individuals without severe mental illness.

As compared with the control group, individuals who had co-morbid disorders of substance abuse and schizophrenia or bipolar had increased odds of suffering from eight different medical conditions: diabetes, hypertension, heart disease, asthma, gastrointestinal disorders, skin infections, malignant neoplasm, and acute respiratory disorders. Moreover, in comparison with the control group, they had greater probability for developing five of the eight medical conditions: heart disease (OR, 4.24); asthma (OR, 3.29), gastrointestinal disorders (OR, 2.82); respiratory disorders (OR, 2.02); and skin infections (OR, 1.97). This study was limited in that it relied on insurance claims data as the sole source for treated or formally diagnosed conditions. Given that the previous studies illustrated how cocaine, ethanol (Salloum et al., 2004), and smoking cigarettes (Jung & Irwin, 1999) impact the body's physiology, the study by Dickey et al. (2002) underscored the severity of general medical illnesses within the co-occurring disorder population.

Summary

To summarize, the aforementioned studies elucidated that physical health conditions, such as HIV, Hepatitis C, and other chronic health conditions (e.g., diabetes, hypertension, and cardiovascular diseases) are significant and growing problems among the COD population as compared with the general population (Cournos & McKinnon, 1997; Silberstein, Galanter, Marmor, Lifshutz, & Krasinski, 1994; Susser, Valencia, & Conover, 1993). The research cited significant

variables, such as unsafe sex, impaired judgment, types of substance use, and route of drug administration, that could increase risk and rates for infectious diseases. Additionally, simultaneous use of illicit drugs, smoking, and alcohol abuse significantly increased rates of general medical illnesses (e.g., cardiovascular and emphysema) among the COD population.

Individuals with CODs are afflicted with other chronic illnesses beyond mental illness and substance abuse alone. The amalgam of these diseases, coupled with mental illness and substance use/abuse, further threatens the COD population's overall health. Moreover, societal issues experienced by this population exacerbate their vulnerability, which, in turn, leads to poor health. The following section describes factors influencing health behaviors in this population.

Factors Influencing Health Behaviors Among Individuals with Severe Mental Illness, Substance Disorder and HIV

A multitude of factors influences a person's behavior *vis a vis* health. Poverty, low socioeconomic status (SES), race/ethnicity, knowledge deficit, stigma, lack of health insurance, access to healthcare, and lack of interpersonal relationships are some examples of barriers to optimal care. They are also the factors that increase one's vulnerability to many health threats. The social consequences of severe mental illness can lead to increased high-risk behavior. Moreover, these factors create competing concerns that often lead an individual with COD to neglect his/her health. The most prominent of these influencing factors on the health behaviors of the COD population are: (1) social (poverty/low

SES, stigma, and housing);(2) racial/ethnic; (3) cognitive impairments; (4) motivational; and, (5) lack of social skills.

Social Factors

Poverty/low socioeconomic status. People who are impoverished or are in chaotic situations constantly struggle to secure the necessities of life, such as food and shelter and care for their dependents. When people are placed in such circumstances, the connection to medical care is often tenuous. They may often delay seeking medical attention until their illness becomes debilitating (Larson et al., 2005). Furthermore, if they are able to obtain medical care, they may find it difficult to keep scheduled appointments—due to lack of childcare, money, or transportation. The consequences of poverty, such as poor housing and inadequate diet, may complicate adherence to complex regimens and compromise the effectiveness of medications among the COD population (Messerli, 2002).

Individuals with severe mental illness often live below the poverty line, reside in substandard housing, are frequently homeless, and receive poor or no medical care (Calsyn et al., 2004). Such dire circumstances lead to competing concerns and the need to prioritize. For example, for a person with HIV/AIDS, the diagnosis may not be viewed as a pressing concern if survival related to food is the primary need (Weinhardt, Carey, & Carey, 1998). Thus, taking protective actions, like purchasing condoms or obtaining the privacy needed to negotiate safer sex, is secondary to more basic survival needs (Weinhardt et al., 1998). Since many individuals with severe mental illness live in geographical areas where there are high rates of HIV and other sexually transmitted disease, such behaviors increase

their chances of coming into contact with the virus (Calsyn et al., 2004; Carey, Carey, & Kalichman, 1997).

Weinhardt, Carey, and Carey (1998) conducted a survey of HIV risk behavior and public health among 61 women with severe mental illness, participating in an outpatient program in New York. In this study, the researchers assessed the participants' knowledge about HIV/AIDS. According to their findings, poverty and unemployment directly increased risk behavior among women living with severe mental illness. Impoverished women were more likely to depend financially on a partner and had to exchange sex for housing, food, or to meet other basic needs. Hence, a woman's efforts to reduce her risk behavior were inextricably bound to her limited resources and opportunities, making HIV/AIDS a lesser concern in her life. Results further indicated that women with severe mental illness were at greatest risk for HIV infection, with 38% reporting at least one type of risky behavior, 23% reporting two or more risk factors, and 16% reporting three or more risk factors during the previous two months. Examples of risky behaviors were having more than one male partner; engaging in sex with anonymous male partner; and having intercourse without a condom with a known or suspected non-monogamous partner. Thirteen percent of the women also reported sexual coercion placed them in a risky situation. Other researchers documented that sexual coercion placed individuals with severe mental illness at further risk for HIV (Mckinnon, Cournos, & Herman, 2002).

Although this study's findings provided certain insights into how poverty and low SES were intricately interwoven with risky health behaviors, several limitations

threatened the study's internal and external validity. First, the sample was homogenous, and it consisted of mostly Caucasian women with a diagnosis of schizophrenia. Thus, these findings may not be generalizable to men, other races/ethnicities, and other psychiatric diagnoses. Second, the small sample size decreased the study's statistical power, affecting statistical conclusion validity. Third, the study used a cross-sectional design, which presented findings at only one point in time.

Stigma. In addition to poverty, stigma is a social factor that shapes a person's health behavior. HIV, mental illness, and substance abuse in particular are stigmatized illnesses. The stigma associated with mental illness harms the self-esteem of many individuals with mental illness. It, in turn, serves as a barrier to one's health and recovery (Link, Struening, Neese-Todd, Asmussen, & Phelan, 2001; Snowden & Pingitore, 2002; Teh-Wei, Snowden, Jerrell, & Nguyen, 1991). One study found that the proportion of African Americans who feared mental health treatment was 2.5 times greater than the proportion of whites. African Americans cited fears of hospitalization as a primary reason for not seeking care (Sussman, Robins, & Earls, 1987). Moreover, HIV positive individuals may be hesitant to disclose their illness because of shame and/or skip medications to keep their HIV status a secret. This, in turn, would further delay the needed treatment (Herek, Capitano, & Widaman, 2003).

Housing. Another significant social barrier to one's health maintenance is lack of housing. Deinstitutionalization in the mental health care system has led a move from institutional to community care. Inevitably, this led to more individuals

with mental illness and with CODs housing themselves on the streets. Research has shown that lack of housing or unstable housing significantly affects one's health status. This was evident in a study by Masson, Sorensen, Phibbs, & Orkin (2004), whose sample consisted of primarily homeless individuals.

Masson et al. (2004) conducted a two-year longitudinal study examining factors affecting medical service use among HIV-infected persons with a substance abuse disorder. The sample was comprised of 190 participants enrolled in a randomized trial of a case management intervention. Independent variables were categorized as: (1) predisposing factors (ethnicity); (2) enabling factors (housing); and, (3) need factors (alcohol use and health problems). Poisson regression models were used to examine the relationship between the factors and frequency of emergency department visits, in-patient admissions, and ambulatory care visits. During a two-year period, 71% of the sample was treated in the emergency department, 64% was hospitalized, and the average number of ambulatory care visits was 12.9. Ninety-two percent of the sample was homeless and had a statistically significant association with higher utilization of emergency department and inpatient services ($p < 0.001$). Individuals who were homeless had 113% more in-patient admissions than those who were not homeless. Drug use was associated with higher inpatient (28%) and ambulatory care service use (17%), and alcohol use severity was associated with greater use of emergency medical services. Homelessness and substance abuse exacerbated the health care needs of HIV-infected persons and resulted in increased use of emergency department and in-patient services.

Racial/Ethnic Factors

Although the study findings of Masson et al. (2004) indicated that predisposing factors, (i.e., ethnicity, age and education) were not statistically significant, research on health disparities in medical service use among individuals with severe mental illness, substance use, and HIV indicated otherwise. For instance, Burnam et al. (2001) noted several disparities in treatment access: (a) outpatient mental health service use was less likely for members of ethnic minority groups and persons with low income and low education; (b) African Americans were more likely than other racial/ethnic groups to receive formal substance abuse treatment; and (c) persons with low income and low education were more likely to have their substance abuse treated in lower-cost outpatient settings or self-help groups.

Information and Information Processing

In addition to social factors, knowledge gaps, coupled with cognitive deficits due to mental illness, place individuals with severe mental illness at greater risk for unresolved health problems. Specifically, individuals with mental illness have increased HIV/AIDS susceptibility because they are poorly informed (Carey, Carey, Weinhardt, & Gordon, 1997; Cournois & McKinnon, 1997). In comparison to the general population, those with severe mental illness lack key information about disease transmission and prevention of HIV/AIDS (Carey, et al., 1997).

Carey, Carey, Weinhardt, and Gordon (1997) conducted a survey to examine behaviors associated with HIV transmission among 33 men and 27 women affiliated in a state psychiatric hospital. Results indicated that participants

in this sample misperceived information about HIV transmission, risk reduction, and risk factors. Thirty percent did not know that a person could be infected but asymptomatic. Additionally, 35% thought that HIV could be transmitted from a toilet seat, and 58% thought HIV could be acquired from donating blood.

Information about condom use was often inaccurate as well. Many participants believed that practices such as douching (45%), oral contraception (23%), or use of a diaphragm (48%) would protect against HIV transmission. No gender differences regarding HIV transmission knowledge were found. Despite its statistically significant findings, several limitations were noted. The sample was homogenous, consisting of mostly Caucasians with a primary diagnosis of affective disorder, which could limit the findings' generalizability to other racial/ethnic groups. Moreover, the predominance of affective disorders could limit the generalizability of this study to individuals with other psychiatric diagnoses (Carey et al., 1997). These findings were replicated by Otto-Salaj et al (1998), who conducted a survey of 68 men and 66 women with severe mental illness to assess their knowledge about risk behavior and risk reduction. Their findings demonstrated that participants had misperceptions about HIV/AIDS. For example, 48% erroneously believed that careful cleansing after sex would provide protection; 42% did not know that latex condoms should be used for protection against the AIDS virus. Unlike the study performed by Carey et al. (1997), Otto-Salaj and colleagues found gender differences: women were less informed than men. Again, this study had several limitations—namely, the sample was comprised of

predominantly Caucasians (54%) with a primary diagnosis of schizophrenia (46%) or affective disorders (28%), possibly limiting the findings' generalizability.

Gordon et al. (1999) conducted 16 same-gendered focus groups among 36 individuals suffering from severe mental illness to investigate the social context of their intimate relationships and the psychological antecedents of their sexual decision-making. Five themes were extrapolated from the qualitative analysis: (a) HIV knowledge was superficial and insufficient, placing them at higher risk for HIV; (b) the contexts for sexual activity were inconsistent and unpredictable, and often occurred in social networks where HIV risk may be elevated; (c) partner sexual selection increased these participants' risk for HIV; (d) lack of interpersonal and communication skills inevitably led to poor HIV risk reduction; (e) there was low motivation for sexual risk reduction; and, (f) these participants were often unmotivated to discuss safe sex prior to sexual activity (Gordon, Carey, Carey, & Weinhardt, 1999). This study was limited, in that most of the participants were Caucasians with a diagnosis of schizophrenia. This compromised the study's generalizability. Despite the study's limitations, its findings provides insights into how individuals perceived knowledge about HIV and their risky behaviors. Additionally, it would seem that insufficient knowledge placed these individuals at increased risk for contracting HIV.

Cognitive Impairments

Although lack of information may pose a barrier to health and health behaviors, certain cognitive impairments impose even greater obstacles for the COD population. Individuals with COD and HIV have significant cognitive

impairments, including attention deficits, memory problems, and impaired decision-making (Calsyn et al., 2004). Moreover, impaired cognition and poor reality orientation typically characterize psychotic disorders and can lead to misperceptions about the transmission of HIV and other risk-enhancing behaviors. McKinnon, Cournos, Sugden, Guido, and Herman (1997), for example, reported that patients with schizophrenia who had greater positive symptoms (i.e., hallucinations, delusions) were nearly three times as likely to have multiple sex partners and to trade sex, as compared to patients with other diagnoses like bipolar disorder and major depression. Such cognitive deficits could also lead to difficulty in adhering to medications and treatments (Calsyn et al., 2004; Keefe & Hawkins, 2005).

Lack of Motivation

Lack of motivation among individuals with severe mental illness is a crucial barrier to health since it can lead to non-compliance to treatment (Mulder, Koopmans, & Hengeveld, 2005). Severely mentally ill adults commonly experience some degree of generalized avolition and anergia as a function of disease processes (Carpenter, Heinrichs, & Wagman, 1988), medication side effects, and other biological and psychosocial factors (Strauss, Rakfeldt, Harding, & Lieberman, 1989). Findings from numerous studies demonstrated that lack of motivation placed individuals at high risk for negative health behaviors (Carey et al., 1997; Gordon et al., 1999; McKinnon, Cournos, & Herman, 2002).

The results of the study by Carey et al. (1997) also revealed that the severely mentally ill population was poorly motivated to alter sexual behaviors to

reduce risk. In their study, Carey et al. (1997) examined HIV-related risk behavior among 33 men and 27 women with severe mental illness who were receiving outpatient treatment. A self-administered, self-report survey measured HIV-related risk behaviors, information, motivational beliefs, and skills. Although motivational indices indicated that patients were not opposed to condom use, they perceived themselves to be at low risk for infection and, therefore, were less motivated to conduct safe sexual practices.

The study had several limitations. First, the sample was homogenous, consisting mostly of Caucasians (73%) who were primarily diagnosed with affective (32.3%) or schizoaffective (35%) disorders. That could limit the study's external validity. Self-report often creates recall bias, which could also affect the study's findings. Despite its limitations, this study's findings provided insights into this population's risky health behaviors. Similar findings were found in a more recent qualitative study by Gordon et al. (1999), who found that individuals with severe mental illness possessed low motivation for sexual risk reduction and were often unmotivated to discuss safe sex prior to sexual activity.

Individuals with severe mental illness may lack motivation to reduce sexual risk because sexual behavior often serves multiple short-term needs that might otherwise go unmet due to their inadequate interpersonal, social, and financial resources. Hence, they may be less likely to insist on condom use lest it endanger relationships that provide essential social and economic support. Alternatively, partners may be selected for the tangible benefits they offer in exchange for sex, money, shelter, and protection (Carey et al., 1997).

Lack of Social and Interpersonal Skills

Individuals with severe mental illness lack strong social networks that can help to exert a positive, normative influence in the pursuit of healthier behavior. Individuals with severe mental illness often lack interpersonal and social skills, including conversational ability and assertiveness, needed to negotiate safer sexual relationships. Such deficits limit their ability to navigate complex social transactions, including intimacy. Numerous researchers have documented a lack of interpersonal and instrumental skills needed to navigate the most basic of social transactions, including sexual intimacy needs (Gordon, 1999; Caslyn, 2004) among persons with schizophrenia, bipolar disorder, major depression, and schizoaffective disorders. Such limitations can be pervasive and enduring unless altered through structured and focused skills training (Bellack & Mueser, 1986).

Substance Use Influence

The Epidemiologic Catchment Area Study (U.S. Department of Health & Human Services, 1992) data demonstrated that individuals with mental illness have a considerable risk for substance abuse disorder, at least 27.5% for lifetime prevalence and 44% at point prevalence. Substance use certainly influences and can deleteriously affect a person's health. The presence or use of drugs predisposes one to risky behavior. Several researchers found that risky sexual behaviors were usually preceded by the use of alcohol and illicit drugs (Calsyn et al., 2004; Carey et al., 1997; Gordon et al., 1999). Moreover, among patients treated on dual diagnosis units, HIV seroprevalence was significantly related to the type of substance used, with injection drugs conferring the highest risk. But, even

use of non-injected drugs or alcohol alone resulted in rates of HIV infection substantially higher than the average rate. Patients with substance use disorders were likely to be members of social networks in which the likelihood of exposure to HIV, either through injection drug use or through sexual risk behavior with infected drug users, was elevated (McKinnon, Cournois, & Herman, 2002).

Summary and Lacunae

Individuals afflicted with HIV, mental illness, and substance abuse face a multitude of barriers that influence their health behavior and health seeking decisions. The literature on this population provides a framework for future studies of the COD population. Moreover, they impart a foundational knowledge about the barriers encountered by individuals who have mental illness, substance abuse, and HIV/AIDS. However, given that individuals with co-occurring disorders have an increased risk for more than one medical illness (Otto-Salaj, 1998; Salloum, 2001) as well as infectious diseases (Klinkenberg, 2003; Rosenberg, 2001), there is a need for broader studies to be conducted beyond COD and HIV. Specifically, there is a need to incorporate in future research how individuals perceive and manage a multitude of illnesses (e.g., hypertension, diabetes) in light of their mental illness, substance disorder, poverty, stigma, lack of housing, and lack of interpersonal skills. There is a paucity of literature on how the layers of multiple medical health issues impact individuals suffering from mental illness and substance abuse. Inquiry and exploration are called for

regarding how substance abuse, HIV, Hepatitis C, diabetes, and other chronic health conditions affect the overall health and health management of individuals with mental illness. Additionally, since individuals with co-occurring disorders have increased rates of trauma and abandonment (COCE, 2003), an examination of how past experiences impact their coping skills is essential to understand this population.

Although the studies selected for this literature review provided solid foundations for future experiment, two significant limitations should be noted. First, most of the study samples were composed predominantly of Caucasians diagnosed with schizophrenia, which limited the generalizability of the studies' findings to other ethnic/racial groups and to individuals with other psychiatric diagnoses. Furthermore, these studies failed to include cultural differences that can affect health behaviors. Future research must account for the manner in which culture molds an individual's beliefs and practices. Given that U.S. society is experiencing increase in numbers of multi-ethnic/racial groups, attempts should be made to include members of these groups in scientific inquiry. African Americans, who account for 12% of the U.S. population, have high rates of psychiatric disorders (Surgeon's General's Report, 2001). Ethnic disparity in health-related services is apparent in persons with co-occurring disorders, because increased stress is associated with increased psychosomatic complaints, more often reported in African American and Hispanic populations than in Caucasian

populations.

African American and Hispanic persons with co-occurring disorders are often underrepresented in these studies (Nejtek, in progress). Although significant progress has been made in improving the nation's overall health, health disparities continue to exist among African Americans and Hispanics relative to the general U.S. population. African American and Hispanic populations are expected to expand by approximately 24% over the next decade (Center for Mental Health, 1998). Thus, including minority persons with co-occurring disorders in scientific inquiry is clinically and culturally necessary.

Second, with the exception of the study authored by Gordon et al. (1999), the methodological designs used in these selected studies were predominantly quantitative in nature. Although they provided significant information about the state of the science, these methodological forms limit researchers' ability to gain insight into lifestyle, culture, motivations, behaviors, and preferences of individuals with COD's. To further expand the field and to ascertain the reasons behind the results of these quantitative studies, it would be important to conduct a study utilizing qualitative methodologies. Furthermore, to be able to modify and/or change high-risk behaviors among this population, it is important first to identify their points of view, beliefs, and practices about their illnesses. According to Reis (1988), individuals construct subjective meanings of health that are varied and

different than those of medical professionals. As a consequence, adherence/non-adherence to medical prescriptions and recommendations as well as preventive programs depends largely on the way one conceptualizes health and disease processes.

Present Study

The objective of this hermeneutic interpretive study is to discover the health beliefs and practices and health management of individuals with co-occurring disorders of mental illness, substance abuse, and chronic disease. Given that the preponderance of the existing literature on the COD population focuses on those with HIV, this study seeks to broaden the field by including individuals with COD who suffer other chronic illnesses, such as cardiovascular diseases, metabolic disorders, and joint disorders. To address health disparities and under-representation of minorities within the COD investigations, the researcher obtained participants from a diverse multiethnic community. The majority (65%) of the participants for this study are African Americans. This study utilizes interpretive phenomenology and narratives, a qualitative methodology, to elicit participants' views and beliefs about their health management, health behaviors, and coping patterns.

Interpretive phenomenology allowed the researcher to examine the lived experiences of individuals with COD. Additionally, utilizing this methodology enabled the researcher to investigate how the participants' socio-cultural experiences impacted their illnesses and behaviors. The

findings in this study add to and expand on the current body of research on the individuals with co-occurring disorders.

CHAPTER THREE

METHODOLOGY

Introduction

This chapter aims to understand the health perceptions and practical engagement of individuals who suffer from co-occurring disorders (COD). Prior to a discussion of the application of a hermeneutical approach toward individuals with COD, I provide a brief overview of the philosophical underpinnings of this investigation. The first section reviews the Cartesian model of the self (Descartes' mind and body split). This is followed by a discussion of the emergence of Husserl's phenomenology and how that led to Heidegger's concept of a person. Finally, an overview of the conception of the hermeneutical self is presented.

The second major section of this paper explicates how an interpretive phenomenological hermeneutics as a method can help guide researchers and clinicians toward a deeper, more complex understanding of those who suffer from COD. Indeed, I contend that such an interpretive phenomenology can provide a foundation and methodological framework for this research study to break with more restrictive conceptions about those who suffer from COD. With a primary focus on engaged practices and everyday coping skills, interpretive phenomenology allows for a more complex understanding of the formulation of such selves. The third section explains the research design of this study. Inclusion and exclusion criteria, recruitment, and data analyses are discussed.

Split Self: A *Dis*-Embodied Being

The modern metaphysical formulation of the self rests on the Cartesian Logic or Reason— that the mind can doubt all that exists but never doubt that it is a mind doubting; thus, this mind or Cartesian self provides the foundation for knowledge and medical science. Since Descartes there has been a tradition of conceiving the self as split from the body, not only in Western metaphysics, but also in the production of knowledge in Western medicine. Descartes held that the mind (*res cogito*) and the body (*res extensa*) are two separate and distinct substances (Benner & Wrubel, 1989; Modell, 2003). The mind exists only in time, while the body is physical and has extension in space and environment (Benner & Wrubel, 1989). The mind interacts with the body but remains nevertheless distinct from it. It is through this interaction with the body that the mind is able to obtain knowledge of the world as representations of things or copies of ideas as experienced by the body through its senses. Thus, the mind becomes self-contained, standing outside the world and without a relationship to it, becoming something conceivable apart and separate from this relation. The self can acquire knowledge of the world, then, only through its senses and the representations it produces (Benner & Wrubel, 1989; Visnovsky & Popper, 1996).

Another of Descartes' notions is that the self is atomized, ahistorical, atemporal, and decontextualized. This view of the self suggests that researchers and clinicians are blinded from being able to understand how such selves exist in time and space. The Cartesian notion is limited in assisting us to understand how a self has the capacity to shape time (history) and space (specific locations, such

as in Oakland) as human beings living among other human beings who transform constantly the world they inhabit. Because the Cartesian model fails to recognize that such selves are constituted in and by the lifeworld, it will always be an inadequate model for understanding individuals, especially those afflicted with COD. Moreover, the Cartesian notion of the self fails to recognize how an individual contributes to his/her own world in both reasoned and irrational and healthy or unhealthy ways within local and global collectives and in so doing, continuously transforms one's self.

Descartes' view manifests in all forms of society, including the mental health field. Historically, the understanding of and treatments for mental illness fall into two broad strands: (1) focusing primarily upon the body, and (2) focusing primarily on the mind. Models of mental illness typically locate causality either in the mind or in the body/brain (e.g., psychiatric explanations of depression as resulting from low levels of serotonin, dopamine, or noradrenaline). These types of models neglect the self's lifeworld. Hence, when choosing to follow this type of approach, researchers and clinicians will ultimately have a limited view of an individual with co-occurring disorder, which may lead to poor and incomplete nursing care.

Ms. J., for example, suffers from depression and cocaine addiction. According to the Cartesian notion of the self, her symptoms are embedded in the brain (i.e., decreased serotonin secretion). Descartes' view fails to recognize that her depression and addiction may be associated with or due to her multitude of physical ills and the social wounds of homelessness. Furthermore, since Descartes' notion of the self is atemporal and ahistorical, researchers and

clinicians can then take the position that Ms. J, possesses no history and, therefore, has no story to tell. If a clinician follows this path, then he/she may not understand Ms. J. Perhaps, Ms. J's depression is related to a past event or incident rather than simply a chemical imbalance. In short, Descartes' ideas fail to recognize a sense of self as it is formed in and through time, space, society, history, and an embodied physio-biology.

Despite its limitations, the Cartesian model does offer some insight and utility. Cartesian logic provides a framework for philosophers in the construction of knowledge, moving decisively away from a theological notion of existence and toward a basis for building scientific knowledge. However, we must move beyond Descartes by taking a more pragmatic approach to how the self is an absolute indivisible mind and body, engaged with and shaped by the social, which in turn and over time shapes the social, which then shapes its mind and body configuration (Benner, 2001). It is precisely for this reason that it is important to understand the self as constituted uniformly by both a mind (consciousness) and body (biological/chemical/physical) acting in the world and acted on by the world. Hence, it is important for researchers to carry with them the insights offered by the Cartesian model, yet seek to broaden and complicate such logic.

Clearly, the Cartesian notion of the self leads to an impasse in COD research. One cannot separate the mind from the body; neither can one separate reason from unreason, nor separate the mind/body as a composite whole from the world when comprehending the formation of the healthy and the "unhealthy" subject. I turn to interpretive phenomenology, a holistic notion of the self, as a

platform for gaining a broader, more comprehensive insight into understanding an individual suffering from co-occurring disorders (COD).

Echoes of Descartes' Dualistic Approach

Phenomenology's basic tenet is that consciousness is always directed at something, exploring not merely the essential structures of all conscious experiences and their intentional objects, but the grounding of these essences and objects in a transcendental realm and in the transcendental ego as their absolute source (Koch, 1995; Lavery, 2003). It is an investigation into how meanings are constituted in and for consciousness (Benner & Wrubel, 1989).

The work of Edmund Gustav Husserl (1859-1938), grandfather of Phenomenology, extended the Cartesian model by examining man's relationship to the world in terms of subjects knowing objects (Magee & Dreyfus, 1987). He made an important departure from Descartes by focusing on subjectivity. Husserl's subjective-based phenomenology expanded on the Cartesian model by emphasizing the lived experiences of the person, focusing on the world as lived by the person (Lavery, 2003). Husserlian phenomenology identified three elements that systematized a conception of consciousness: (a) intentionality, (b) essences, and (c) bracketing (Koch, 1995). Such a model analyzed whatever it is that is experienced, regardless of whether there is any sense in which matters objectively are as we experience them (Magee & Dreyfus, 1987)

Briefly, intentionality, borrowed from Brentano (1874), is the system that explains the intentional structure of all consciousness: how a person grasps the phenomena. The "intentionality" is the mind's "directedness" toward objects

(Koch, 1995), whereby the intentional content captures our perceptions, beliefs, desires, intentions, and so on. Such an act can be directed toward the same object under the same aspect. For example, I can perceive that I am singing, believe that I am singing, desire that I be singing, and so on (Dreyfus, 1991a). Directedness is based on the assumption that our own conscious awareness is what gave us absolute certainty (Koch, 1995). By intentionality Husserl posits that all our thinking, feeling, and acting are always about things in the world.

Briefly, universal essences (or "eidetic structures"), according to Husserl, refer to those lived experiences that are common to all persons (Lopez & Willis, 2004). These essences are considered to represent the true nature of the phenomenon being studied, whereby reality is something "out there to be grasped" in our acts of thinking. Husserlian phenomenology is based on a model of immanence and does not consider what lies outside the bracket—the lifeworld and human experience as it is lived (Lavery, 2003). It accounts only for a consciousness formed in the immediate and direct perception of objects within the bracketed-off.

Husserlian phenomenology (or "Transcendental Phenomenology") aims at arriving at the purest objects of consciousness that are assumed to be the building blocks of all psychic activity. To reach such pure phenomenology, Husserl offered a system of "bracketing the world" (more technically as the "phenomenological reduction" or "*epoche*"), shedding light on how the pure essence of the object of which one is conscious occurs when we place all else outside of its frame; hence, allowing us to see how such a bracketing opens to the pure perception ("intuition")

of most elemental building blocks of consciousness. It is through bracketing that we “can describe the fundamental structure of our lifeworld and the world of the lived experiences” (Draucker, 1999). To clarify, there is always a consciousness of something. For example, when studying individuals who suffer from co-occurring disorders, I must withhold any presuppositions about the nature and progression of the interaction process being described. I do not deny that such presuppositions exist. But to get at the essence of individuals who have COD, in this process of *epoche*, all other elements must be placed outside the frame of pure perception.

Husserlian phenomenology identifies a system that reveals how consciousness works and how we perceive pure essences as a system that is entirely self-contained within the absolute realm of that which consciousness brackets off. All that is contingent (i.e., my 12 years of nursing experience) and other contextual features remain outside the frame in order to isolate what is essential to the object of our perception. As such, Husserlian phenomenology directs us to understand the pure objects of consciousness as isolated and immanent; thus, to disregard its actuality (Smith & McIntyre, 1982).

For Husserl the subject-matter of phenomenology is consciousness and the intentionality of consciousness. Husserlian phenomenology, thus understood, describes the essential structures of consciousness independent of questions of the reality of its objects. He postulated that consciousness should not be viewed naturalistically as part of the world. Hence, consciousness is precisely the reason why there is a world there for us in the first place. World, according to Husserl, is opened up, made meaningful, and disclosed through consciousness. Both

Descartes' and Husserl's concepts of a person provided a representational view of a person. Such a notion of a person does not fully explicate daily human activities (Benner & Wrubel, 1989); hence, one must turn to an ontological stance rather than an epistemological one to fully understand a person.

Transcending Cartesian and Husserlian Ideologies:

A Holistic Self

Martin Heidegger (1889-1976), a German philosopher widely regarded as the most original 20th century philosopher (Sheehan, 1998), developed existential phenomenology. He believed that to conduct human science we should look at the world or human experiences as they are lived by considering the taken for granted in our lives. Heidegger separated himself from Husserl's transcendental phenomenology (Magee & Dreyfus, 1987), asserting that the central problem with the ontology of scientific reason is the status of the subject (Çüçen, 1998). The status of the subject has been a pervasive problem since Plato and Aristotle, but became more clearly visible with Descartes' dualism of mind and matter (Sheehan). Thus, it is necessary to overcome the *dis*-embodied and isolative view. Subjectivism and objectivism are contrasting symptoms of the same underlying disorder of Western thought. Heidegger stated that to simply reassert the subjectivity of life or existence as a distinct order of being opposite the objectivity of the being of physical things in space and time is not a strong framework. He clearly believed that what is needed is an ontic of the fundamental question of Being (Dreyfus, 1991a; Sheehan)

Heidegger further challenged both the Cartesian model and Husserlian phenomenology by moving from an epistemological identification of being to an ontological explanation of Being (i.e., what it means to be a person and how the world is made intelligible (Çüçen, 1998; Dreyfus, 1991a; Çüçen, 1998). *Being* for Heidegger was the essence of all things and all beings. However, we cannot positively define this *Being*, for to do so would demote Being to an entity or *being*. Thus, we must open ourselves to Dasein, or that which characterizes getting at Being.

Dasein

For early Heidegger, in *Being and Time* the subject matter of phenomenology was *Dasein*, or the understanding of being (Dreyfus, 1991a; Sheehan, 1998). For Heidegger, to be human was to be a self in the world. Moreover, he believed that the content of this understanding was manifested through human existence of *Dasein*, a scholastic term for “existence,” as opposed to essence or “being-thus.” His use of the term *Dasein* built on the idea already articulated by Kierkegaard, that human existence is something radically different from the mere subsistence of ordinary things (Todres & Wheeler, 2001). *Dasein* focuses on our individual possession of our existence.

Heidegger’s concept of “being-in-the world,” or *Dasein*, offers a necessary step toward the sense of an integrated, holistic self (mind and body) in the world, in the hopes of providing a better understanding of those subjects who suffer from mental illness and addiction. It moves us towards understanding that the subject is in the world and the world is in the subject. Existence is always in the world.

Dasein is existence (Dreyfus, 1991a; Sheehan, 1998). Heidegger posited that beings are defined by how they live. That is, as “beings in the world” we experience the world we inhabit as an engaged agency—always already in context (Benner, Tanner, & Chesla, 1996). The agency has a non-reflective understanding of the world because the individual is always situated in a meaningful context, enabling the self to grasp meanings directly (Benner & Wrubel, 1989) Heidegger described four facets of a human being: (a) dwelling in a world; (b) as embodied being; (c) as self-interpreting beings; and (d) as being in time.

Dwelling in a World

"World" for Heidegger is not a purely intentional cognitive set of beliefs--a definition that would necessarily collapse back into the Cartesian notion of the conscious subject (Leonard, 1994). And, departing from Husserl, the world is neither "out there" to be grasped, nor held in the mind. Rather, world, according to Heidegger, is “a dynamic set of relations, ultimately ordered to human possibilities which lend meanings or significance to things that one deals with” (Sheehan, 1998, p. 316). This conception of world situates practical experience at the center of understanding of being (Sheehan, 1998) and, thus, provides access to what is possible and can be expanded in relation to existing concerns and possibilities (Leonard, 1994).

Accordingly, world is *a priori*. That is, we exist in the world and of the world we have created through language, thought, and action. Language allows for things to be articulated and makes things show up for us. Moreover, language acts as a vehicle for individuals to relate that make sense in a particular culture

(Leonard, 1994). As agents we become capable of thinking, creating language, and self-reflexivity, all of which allow us to understand ourselves. As humans we exist and relate to the world in a uniquely human way, that is, in a social manner that is open to all things, including our own selves, and capable of acts of disclosing and "discovering" (or Heidegger's technical term, "*lichtung*") (Bracken, 2000).

Disclosing and discovering are two modes of revealing. According to Heidegger, disclosing is a necessity for *Dasein*'s discovering of entities. That is, we understand things that show up for us through background familiarity (disclosing). And, in this holistic background familiarity (disclosing), it makes it possible for us to deal with particular circumstances (discovering). *Dasein* is absorbed in the background familiarity that discloses the world as familiar in such a way that there is no separation between *Dasein*'s disclosing comportment and the world disclosed. As a discovering or disclosed agency, we define the world, being drawn in by it (Dreyfus, 1991a); thus, accounting for the self's unique capacity for disclosedness, or the act of letting be seen and/or unveiling things in the world.

Human agency exists in multiple worlds that often overlap. However, what constitutes their core—what Heidegger calls "worldhood" possibilities (Sheehan, 1998, p. 317)—is the salience that accrues to things by their relatedness to human interest. The worldhood of the world is woven through an intricate web of purposes and meanings, terminating in a possibility of a getting-at-Being, or *Dasein* (Conroy, 2003). Through this nexus, our activities and our identity allow entities to make sense or show up for us. For example, when I encounter a patient

suffering from bipolar disorder, I do not simply see an individual with psychiatric disorder. I also view this individual as an African American homeless man who has been battling cocaine addiction. Thus, as clinicians we must try to direct an understanding of how the patient is in the world, recognizing that he/she is both an individual and social, simultaneously shaping and reflective of the world he/she inhabits. The subjective/objective Cartesian dualism that forces us into idealism/subjectivism or realism/objectivism is replaced by a Heideggerian understanding person-in-world. This is to say that this model of self-as-mind and body has the capacity to bring about a 'discovering' of the world. Hence, the opening up of a space of unconcealment or exposure can usefully inform our understanding of the many who suffer from substance abuse disorder and/or mental illness.

Modes of engagement: how a being relates to his/her world. Heidegger postulated three interrelated ways of how a being relates to his/her world: (a) ready to hand, (b) unready to hand, and (c) present at hand. Ready at hand is the primordial way of how a being engages in the world, providing the primordial, direct access to human phenomena. In this mode the practical of everyday activity is the primary focus. "The ready to hand is not grasped theoretically at all" (Heidegger, 1962). This act refers to "equipment" (Benner & Wrubel, 1989) that is transparent, unnoticed, and experienced as an extension of the body because of the way a person is actively involved in the situation. We are actively engaged in practical projects in the world in such away that we become unaware of our actions. These actions are so deeply embedded in our lives that we do not even think about the

steps that we take to complete them, such as mailing a letter, driving a car, or talking to a friend. There are no deliberate means-ends planning in this mode. Our actions become so contextualized as a part of who we are that any possibility of objectification is erased. Hence, in this mode of engagement, human actions are so taken for granted that we are incapable of a self-reflexive accounting of their existence. We act within them, and they rarely become problematic. However, reflection on our actions is usually prompted by confronting a problem with our equipment. Hence, this leads to the unready to hand mode (Dreyfus, 1991a; Packer, 1985).

The unready to hand mode is when breakdown occurs based on our inability to work with the equipmental context smoothly. In this mode, the realization of the problem is experienced as part of the situation because it stands out and becomes problematic. The source of the breakdown becomes salient in a way that it was not in the ready to hand mode (Packer, 1985).

We enter the present-at-hand engagement when we detach ourselves from ongoing practical involvement in a project at hand. This occurs because we have been unable to find a direct and circumspect way of dealing with a problem that arose. In this mode we step back, reflect, and turn to a more general, abstract mode to understand human actions. This engagement is seen more as a detached and objectified view (Dreyfus, 1991b; Packer, 1985). In this mode *Dasein* takes a detached, disengaged attitude towards things or, as Heidegger stated, it is a stance that “*deworlds*” or is “*deworld-ing*” (Dreyfus, 1991b).

Embodied Being

In contrast to Descartes' concept of *res extensa*, Heidegger's being is not merely a *body*; rather it is *embodied*. Simply put, our bodies are the vehicles that provide the possibility for the concrete action of the self in the world. It is through our bodies that we first grasp the world and move with intention in that meaningful world. Our practices embody our skilled understanding of our culture. An assumption is that common practices are based on shared, embodied, perceptual capacities (Leonard, 1994). We are shaped temporally and spatially through praxis, historicity, and the culture in which we find ourselves (Benner, Tanner, & Chesla, 1996). Thus, as opposed to the Cartesian model, the existence of Heidegger's subject in the world is a set of interdependent relationships between self and world (Conroy, 2003).

For example, some African Americans who suffer from mental illness believe that the disease is called "one's blood being thick or thin and heat or cool bringing about physical or emotional distress" (Snowden, 1999, p.365). Concerns regarding blood issues and health symptoms have been found among African Americans in the United States, in South America, and in regions of the Caribbean. Numerous anthropologic studies have documented how cultural beliefs have influenced individuals' views about their health. Hence, as an embodied agency one must understand not only the biological causes, but also how psycho-social embodiment impacts and shapes such an agency in this world.

Self-interpreting Beings

As beings we are thinking and interpretive entities, but always in-the-world and of-the-world. We do not enter this world to be pre-defined, but become defined in the course of living (Benner & Wrubel, 1989). We are self-interpreting in a non-theoretical or non-cognitive way. We are engaged and constituted beings by virtue of our interpretive understandings (Leonard, 1994; Taylor 1989). Heidegger claimed that these interpretations are not generated in individual consciousness as subjects related to objects, but rather are given in our linguistic and cultural traditions and make sense only against a background of significance. Examples are studies conducted about varying degrees of family risk and protective factors in mental illness. One of the most developed lines of research on family factors and mental illness deals with relapse in schizophrenia. A study comparing Mexican American and Caucasian families found that different types of interactions predicted relapse. For the Mexican American families, interactions featuring distance or lack of warmth predicted relapse for the individual with schizophrenia better than did interactions featuring criticism. For whites, the converse was true (Lopez et al., 1998).

Being in Time: Temporality/Spatiality (Thrownness)

Temporality means to “exist” toward the future. It is to understand our finitude and mortal becoming. It is not simply concerned with natural time; rather, it is the span of one’s life. For Heidegger, the meaning of being is time (Sheehan, 1998). Time, according to Heidegger, is also the future. That is, the future moves not from the past through present to future, but out of the future through the past to

the present. Temporality is viewed as connectedness rather than as linear time. Hence, in Heidegger's view, to fully comprehend the "being" we must understand that the being is constitutive of its past and future, of having been-ness and being expectant (Leonard, 1988). Simply put, past penetrates and shapes the experience of the present, almost like a template, and past experience is always understood and reinterpreted in the light of what comes later (Orange, 2000). The individual is never seen as a "snapshot," but always a circular picture of past, present, and future.

Related to temporality is the issue of "thrownness." Heidegger postulated that human beings are thrown into a world that they have not made but that consists of potentially useful things, including cultural as well as natural objects (Dreyfus, 1991a; Sheehan, 1998). Because these objects and artifacts come to humanity from the past and are used in the present for the sake of future goals, Heidegger posited a fundamental relation between the mode of being of objects and of humanity and the structure of time (Sheehan, 1998). When we are born, we are situated in a place already marked by previous human purposes, cares, and interests. In other words, this notion of thrownness means that we find ourselves in a particular nexus of cultural, familial, and situational practices and meanings, and out of this thrownness we take a stand about ourselves (Leonard, 1998). To use Gadamer's (1997) (and Heidegger's) expression, the human being as such is always thrown into the world--is spatially and chronologically situated, so every act of consciousness (every act of intentionality) is inescapably tied to the particular location and epoch into which the subject has been thrown.

An example is a recent study conducted by Nehls and Sallman (2005) of women with co-occurring disorders and sexual abuse. This study elucidated how each of the participants were thrown into a world of violence as children and continued towards adult life. Each of the women was abused as a child, as an adolescent, and also as an adult. This finding was significant because it illuminated the context of women's lives, a context that has both created and limited their possibilities. The notion of being thrown into a cycle of abuse provided the lens through which one could view abuse, mental health, and substance abuse as cultural issues and not merely an individual's mental health or substance abuse problem. Draucker (1999) suggested that interpreting the women's life histories with the Heideggerian concept of thrownness provoked an investigation of all familial, social, and cultural factors that limit women's possibilities (Nehls & Sallmann, 2005)

Hermeneutic (Interpretive) Phenomenology: An Approach

To the Study of Individuals with Co-Occurring Disorders

Definition of Hermeneutic Phenomenology

Philosophical hermeneutics stems from the tradition of the human sciences' reactions against the neo-Kantian philosophy of positivism (and, later, logical positivism), which posits the objective measurability of things (Schwandt, 2000). Hermeneutics challenges the positivist metaphysics that separated epistemology from ontology, and which claimed the absolute measurability of existence as a way to understand the self and world. Hermeneutic-phenomenology provides both interpretive and descriptive elements (Heidegger 1962; Husserl, 1965, as cited in

Van der Zalm & Bergum, 2000). The primary objective of hermeneutic phenomenology is the direct investigation and description of phenomena as experienced in life by using the practice of phenomenological reflection and writing to understand the forms of life (van Manen, 1990).

Hermeneutical Goal

Joining Hans-Georg Gadamer (a pupil of Heidegger's), Charles Taylor argued that the sole purpose of hermeneutics is to construct a methodological foundation for science (Schwandt, 2000). It is predicated on the assumption that "understanding" (*verstehen*) is not governed by rules or a set of procedures (Schwandt, 2000). Both Gadamer and Taylor asserted that understanding is the mode of being, which is existence (Schwandt, 2000). Hermeneutics looks for ways to understand the social practical world, the embodied self, and others through everyday skills, practices, and experiences, searching for commonalities in meanings, skill, practices, and embodied experiences (Benner, 1994). The hermeneutic approach seeks to elucidate and make explicit our practical understanding of human actions by providing an interpretation of them. Hence, when we adopt a hermeneutic approach to human action, we essentially treat the action as though it has a semantic and textual structure (Packer, 1985). Through hermeneutics the researcher unveils the underlying coherence or sense of the phenomena (Plager, 1994). Interpreters seek to unveil commonalities, differences, and what makes these possible. Researchers do not look for private idiosyncratic events or understandings. However, interpreters do attempt to disclose what is at stake for the individual, his or her issues and concerns in everyday life. The

interpreter seeks to hear and understand, and strives accurately to represent the voice of the participant. The use of probes and clarification during multiple interviews can lead to greater understanding and decrease misunderstanding of the phenomenon being studied. The interpreter must clearly describe and articulate the participant's voice, thereby providing a venue for the audience to notice meanings and qualitative distinctions within the texts about the phenomenon in question (Benner, 1994b).

Heidegger's notion of the hermeneutic principle, however, pointed towards an understanding not based on measurability, but rather on "the power to grasp one's own possibilities for being in the world in certain ways" (van Manen, 1990, p. 180). Hans-Georg Gadamer significantly extended this definition by adding that, when "interpreting a text we cannot separate ourselves from the meaning of the text." (van Manen, 1990, p. 180). That is, the researcher brings his/her own prejudices to the research study and becomes part of the interpretation of the text.

Understanding is more powerful than explaining as a model to advance our understanding of health care because it stands more fully in the human world of self-understandings, meanings, skills, and tradition (Benner, 1994a). Historicity, transformations, gains, losses, temporality, and content are sought with understanding (Benner, 1994a).

Ethically, the researcher/interpreter must respect the voice and experiences of the described text. The interpretations must challenge the interpreter's own views. If not, then there is a danger of reading/writing one's own pre-conceptions (Benner, 1994b)

Entering the Hermeneutic Circle and Fore-structures

In hermeneutics, the researcher's role is to critically analyze or explain the text (or some human action). Utilizing the hermeneutic circle proposed by Heidegger (1927/1962), the researcher will approach an understanding and interpretation of the subject in a circular manner between persons in their interactions with one another and in the world, constantly moving dialectically between the parts and the wholes. To enter the circle, Heidegger asserted that it is the researchers' task never to allow our fore-having, fore-sight, and fore-conception to be presented to us by popular conceptions. Rather, it is the researcher's responsibility to make the scientific themes secure by working out these fore-structures. Fore-structures, our pre-understanding of a phenomenon, consist of (a) forehaving, the background understanding that provides the structure in terms of which one approaches the thing to be interpreted (Geanellos, 1998); (b) foresight, the researcher's point of view, allowing him/her to make an interpretation of the phenomena (Leonard, 1994; Plager, 1994); and (c) preconceptions, the theoretical conceptualization and ideas about the phenomenon (Geaneallos, 1998; Plager, 1994). The researcher enters the circle with the understanding that there is no foundational view of the world as atemporal and ahistorical (Conroy, 2003). The metaphor of the circle, however, should not suggest that it is like a closed system between the fore-structure and the object being interpreted. Both object and fore-structure may require radical alterations, even transformations. And the process of interpretation may cause the interpreter to go far afield from his or her

own early fore-structure and from the first simple perception of the object of interpretation.

Researcher's Social Responsibility in a Postmodern World

Postmodernism situates a study within a particular context, historical framework, or social-political perspective, and empowers study participants. In a postmodern view there is never a single unitary explanation. Similarly, in a hermeneutic description no single interpretation of the human experience will exhaust the possibility of yet another "complementary or even potentially richer or deeper description (van Manen, 1990, p. 31).

In light of the multiple representations and interpretations, the questions remain: As a novice researcher, how does one represent the participants' "stories" to enable the audience to visualize and comprehend the intricacies of this population? How can one articulate the complexities of the lives of individuals with mental illness, substance abuse, and chronic physical morbidities? How can a novice write about a research population without subjugating, demeaning, sexualizing, or racializing it? How can one critically view the phenomena that inform the everyday existence of such subjects without reducing the participants to categories that risk essentializing identity and/or simplifying experience? To circumvent slipping into essentialist and/or exoticist categories of patients as Other, I will use critical theories of critical alterity (or "Other") and race.

Alterity refers to the "alter ego category of otherness that is specific to each culture's metaphor of the self" (Ladson-Billings, 2000, p.262). While the issue of alterity navigates back to the concept of the insider versus outsider or the "emic

versus etic” perspectives, it moves beyond the self/other conception (Ladson-Billings, 2000). It focuses on the racial/cultural viewpoint of the other. King (1995) stated that this is more than a dualities point of view; rather it recognizes that the alterity perspective does not essentialize other perspectives (Ladson-Billings, 2000). Edward Said (1978) understood this in terms of the West's gaze upon the Middle Eastern or Indian subject as Other. He wrote in *Orientalism* that alterity divides the world into manageable parts that deem the non-Westerner as a dark, ahistorical, and primitive Other, and the Westerner as a light, civilized, Self. It transforms an imagined space of Otherness as real. Gayatri Spivak (1988) further extended this concept of alterity, referring to the "subaltern" as the subject that is denied a voice and subjectivity within this Orientalist process of othering of Third World individuals. Said and Spivak spoke to the Othering dynamics of a different nation-state space than the U.S. However, it is important to keep such insights in mind when analyzing the process by which subjects such as those from whom I gathered testimony are racialized, exoticized, even Orientalized within the U.S. The words of bell hooks offer insight here: "when we write of the Other we subsequently destroy, expunge: no need to hear your voice when I can talk about you better than you can speak about yourself" (Fine, 1994, p. 70).

Mindful of such processes of Othering, I aim not only to give voice to the subaltern, but also to untangle a long tradition of the Westernized construction of racialized hierarchies of difference. The goal is to give voice to and humanize those African Americans who are the focus of this study by allowing them to speak about their experiences and histories of violence and criminality, as well as their

identity as racialized subjects suffering from mental and/or other forms of instability spinning out of family and/or home social environments, always taking into account when conducting the study the writer's positionality as an outsider. The researcher's participant-observer status is mentioned not only to self-reflexively foreground the different psycho-social positionality that she inhabits, but to highlight what Martin Heidegger identified as "forestructures." For example, as I begin to analyze the narratives of such subjects, I voice my stance. I am a woman, of Filipino descent, born in the Philippines and raised in the inner city of San Francisco. I was a welfare and food stamp recipient as a child. Along with the participants, I occupy the same "non-dominant" space in society. That is, I am also "Othered" or can be identified as the alterity. In regard to the gendered self, I can identify with the female participants, yet remain separated from the other male counterparts. Finally, I am a nurse practitioner who has worked with persons with co-occurring disorders in the heart of Oakland and Berkeley.

In this research study, I maintained a constant awareness of the significant histories of subjects so as to contextualize their current narratives, and "understand" their selves in and of the world. As a researcher, I continued to foreground the hermeneutic frame through which I approached an "understanding" of such subjects within a historical, political, and social context.

In addition to acknowledging my positionality, I adhered to Highwater's (1981) emphasis on the fact that as scholars we must be challenged to ask not only about who is the research, but also for whom. The latter question is not simply about advocacy, but rather about who is capable to act and demonstrate

agency. Agency is enacted through both epistemological and discursive forms (Ladson-Billings, 2000). When I started this journey, my goal was to create a platform of greater understanding of the complexities of individuals with co-occurring disorders for clinicians and academics like myself. However, as I have been traveling this road for quite some time, I realized that my program of research was not only for the clinicians and academics. Rather, it was also for the general public and for policy makers. I undertook this journey to provide a venue for informants to voice their struggles, to create greater understanding that might lead to improved health care delivery and laws that would provide access to health care, shelter, insurance, and so forth. I conducted this study with the foreknowledge of critical race theory that contains within it the hegemonic structures and symbols that keep injustice and inequity in place. Equity and justice are the very notions researchers must bear in my mind so as not to act as colonizers.

Although researchers write in their own voice, as Fine, Weiss, WeSeen, and Wong (2002) suggest, “we [must] present the long narrative, colorful and edited drawn with/from informants” (p.194). In this postmodern era, we as researchers must “work the hyphen” (Fine, 1994, p.194) by probing and investigating how we are in relation with the context we study and with our informants, understanding that we are all multiple in those relations. We must listen to the plurality of voices. Finally, in our research we must be not only the instruments/tools, but also the co-constructors of the selves-others.

Research Design

In an interpretive study, the utmost consideration is to find individuals who have experienced the phenomenon being explored and can articulate their experiences (Creswell, 1998). The aim of interpretive phenomenology is to take into account the context in which human beings live, their histories, and to illuminate common or distinct patterns of meanings and action in the lives of those studied.

Inclusion and Exclusion Criteria

Using purposive sampling, 20 participants who were at least 18 years old, spoke English, had an Axis I diagnosis, had a diagnosis of current or past substance abuse or dependence, and had at least one chronic medical health issue, such as hypertension, were recruited (Table 1).

Informed Consent

Approval from a Committee on Human Research was obtained for the study at UCSF (#h2269-25528-04). The study was initially explained to the participants over the telephone, and again, before the interview, at which time the consent form was read and signed by the participant(s) (Appendix I). It was anticipated that the interview(s) would cause emotional distress for the participants. The participants were reminded that they could stop the interview at any time and were free to not answer any question(s). Although we anticipated this vulnerability in the population, none of the participants expressed suicidal thoughts or ideations during the study. The researcher provided emotional support

and crisis intervention when necessary. Participants were advised to speak with their social worker if difficult feelings arose after the interview and a list of community mental health services were provided for additional counseling if necessary.

Once the participants consented, an open-ended interview was conducted for approximately 60 minutes. A payment in the form of a \$10.00 Safeway food voucher was given to each participant at the end of each interview. The interviews were tape-recorded and transcribed verbatim and data were identified with the use of codes instead of names.

Sites

Participants were recruited from Supportive Housing (SH) and Charter House (CH). Supportive Housing consisted of eight single residency occupancy hotels. CH consisted of three treatment housing programs.

Supportive Housing. Supportive housing combined affordable subsidized housing with support services to enable individuals who were homeless or at risk of homelessness—especially individuals coping with mental illness, substance abuse, HIV/AIDS, and/or other special needs—to live independently in the community rather than in institutional settings (such as mental institutions, hospitals, or jails). Funds for supportive housing were obtained from a variety of sources, including federal programs (e.g., HUD's Supportive Housing Program and Shelter Plus Care program), state and local sources (e.g., departments of health, mental health, or substance abuse treatment), as well as private foundations and philanthropy. Typically, each of the housing sites had an integrated team service,

which could include one or two case managers, a social worker, and a mobile medical team who conducted weekly visits to each housing sites. However, due to budget constraints and decreased funding, some of the housing sites did not have a service team available. Each team could oversee between 50-75 individuals residing at each hotel. Individuals who resided at SH's housing sites were not mandated to attend the drug treatment programs.

Charter House. Charter House was a non-profit provider founded in 1971 that specialized in providing integrated mental health and substance use counseling and treatment services. CH programs included: 1) the Dual Diagnosis Residential Treatment Program that provided 24-hour service for 15 residents at a time; 2) the Supported Independent Living Program that provided 19 beds of transitional housing, four beds in permanent housing, and supportive services, case management and counseling for 120 individuals; and, 3) the Charter Creative Living Center, a day socialization program serving 150 mentally disabled adults two days a week. Recent federal funding enabled CH to contract for a mobile nurse practitioner to help with medical management for participants at each sites.

Recruitment

The goal of the study was to recruit from Charter House and Supportive Housing. The research study was discussed with case managers, case coordinators, program directors, physicians, nurse practitioners, physician assistant and service coordinators at each agency. A request was made that they refer participants whom they knew meet the inclusion criteria and who could articulate their experiences. Twenty-four participants were referred for the study

and, only twenty participants were enrolled. Two individuals refused to be interviewed due to fear of confidentiality issues. One participant was actively psychotic during the telephone screening, and one participant had difficulty speaking English.

Data Collection

Interviews. All interviews took place at the participants' apartments. Data collection was primarily through in-depth interviews with open-ended questions, encouraging participants to articulate their experiences. Participants were interviewed twice for approximately 60 minutes. Four participants only had one interview. One participant left the program and the researcher was unable to locate him within the community. Two participants did not have time for a second interview. A second interview was attempted three times with one participant; however, during each encounter she was intoxicated.

Interviews were tape recorded and transcribed verbatim. At the end of the interview, demographic information was obtained using a self-report demographic questionnaire (Appendix II). Using a 'yes/no' format, the questionnaire determined whether participants had existing case managers, primary care doctors, psychiatrists, and, health insurance coverage. Additionally, the questionnaire was utilized to assess gender status, racial/ethnicity background, current drug use and type of drugs used. The first interview focused on narratives about health beliefs, practices and health management experiences (Appendix III). The second interview was a follow-up on preliminary findings and was used to explore topics in greater depth, and verify preliminary analysis. The goal for each interview was to

elicit clear and concrete narrative accounts about the participant's current experience and reflection on that experience.

Narrative acts are meaningful accounts that point to what is perceived, what is worth noticing, and what concerns the participant. Narratives are stories of everyday experiences that reveal the participant's situated understanding organized by the social world they inhabit. Narratives provide closer access to practice and practical knowledge of individuals with co-occurring disorders. Through these narratives the researcher analyzed and reflected, searching for themes and common meanings. The researcher utilized the narrative as a tool to elicit deeper understanding of the phenomena studied (Parker & Wiltshire, 2003). Examples of narrative questions that allowed participants to narrate their current experiences were, "Tell me the story about when you first realized you had some health problems? How did you feel? What was most important to you during all of this? How did you think about yourself and your health change during this time?" Probes were used to elicit more details about the narrative.

Approximately three to four weeks, the amount of time needed to transcribe an interview and do a first cut analysis of data, were allotted between interviews. Along with conducting interviews, the researcher kept field notes about the interview recording. The researcher wrote notes about her observation during the interview (e.g. the apartment, participant's verbal and nonverbal expressions). Additionally, the researcher wrote notes about her feelings regarding the interview and its context (e.g. feelings about what was said and her reactions towards the participant). Field notes generated different forms of experiential material than was

available in the interviews. Moreover, through the act of writing field notes, the researcher was triggered to recall the setting of the interview and the emotions elicited while the interview proceeded. Field notes were used to reflect on the purpose of the project, commitments to the informants, and process the interpretation in an ongoing manner. (Emerson, Frets, & Shaw, 2001).

Data Analysis

Transcribed interviews and field notes were sources of data in this study. Interpretive and hermeneutic phenomenology was used to analyze the data. The goal was to uncover the lived experiences through the window of language in order to understand the world, the self and others (Benner, 1994). Through the participants' narratives, the researcher engaged, reflected, synthesized and analyzed the transcribed texts to generate interpretative commentary and to articulate meaning (Benner, 1994). Analysis in hermeneutic phenomenology approach involves moving from the field text, created by data collection to a narrative text that is meant to stand alone for other readers (Recover 1981 as cited in Cohen, Kahn, & Steeves, 2000).

The interpretive analyses began during the interview when the researcher was actively listening, thinking and interpreting the meanings of what was being said. The ongoing process of interpretation paralleled further data collection and continued throughout the final interpretation and articulation. The researcher immersed herself in the data by simply reading through the text multiple times. The aim of this immersion was to establish some initial interpretation of the data that would drive later analysis of the data in subsequent phases of analysis

(Cohen, Kahn, & Steeves, 2000). Moreover, multiple readings of the data continued with writing and rewriting of the narrative text that occurred.

Interpretive analysis involved four strategies: (a) case analysis; (b) thematic analysis; (c) paradigm cases; and, (d) exemplars (Benner, 1994). The text was initially analyzed using a case by case analysis. Each text was read carefully to understand its meaning. With every case, the researcher wrote interpretive notes and questions. Once all of the cases were analyzed, a cross-case analysis was utilized. A thematic analysis was done across cases to clarify distinctions and similarities. A theme is an abstract entity that brings meaning and identity to a recurrent experience and its variant manifestations. A theme captures and unifies that nature or basis of the experience into a meaningful whole. The researcher acted as an instrument in the interpretation of the text and developed clearer understanding of the everyday lives of individuals with COD. At this phase, the researcher labeled themes and extracted passages that had similar themes. Thereafter, the researcher examined the themes together and alongside passages that had the same label but were separated from the rest of the text (Benner, 1994; Cohen, Kahn, & Steeves. 2000).

Paradigm cases are whole texts that “stand out,” revealing patterns and meanings that are puzzling or unsettling. First the whole interview text was read for an overall understanding of the story. Then topics, issues and concerns were selected for more detailed analysis. A systematic moving from the parts back to the whole allowed the researcher to check for puzzling incongruencies and mysteries (Benner, 1994). These texts were not broken into parts because their

meanings would be lost. Moreover, paradigm cases allowed us to understand the transition as it unfolded or a particular way of being in the world emerged. The goal was to identify puzzling incongruencies and mysteries (Benner, 1994).

Once meanings, common situations, and embodied experiences were identified, exemplars were extracted from the text to demonstrate the similarities or contrasts. These were salient excerpts that characterized common themes or meanings across informants. They were parts of stories or instances that had similar meanings within informants' stories (Crist & Tanner, 2003). They conveyed aspects of a paradigm case or thematic analyses. A range of exemplars allowed for the ability to transcend traditional clinical boundaries, add nuances, and qualitative distinctions to the understanding of the phenomenon (Benner, 1994).

The project generated a tremendous amount of data. Atlas Ti, a qualitative software program was used to manage and track data. All interviews were entered into a database. Exemplars and narratives were tracked by using the software. SPSS, a statistical software, was utilized to manage the demographic database. Entries from the questionnaire were categorized using SPSS statistical software.

Finally, the process of writing and rewriting was crucial to hermeneutic phenomenology (van Manen, 1990). The movement from identification and comparison of themes to a coherent picture of the whole occurred through this reflective process of writing and rewriting. Such a process led to gaining more insight and a tentative understanding of the meaning of the informant's experiences as conveyed through the exemplars and themes. These interpretations and understandings were summarized in interpretive notes that

were circulated between the researcher, her advisor and peers. The overall goal of the analysis was to detect and describe themes and narratives that explained the categories providing a coherent and detailed description of lives of the individuals with COD.

Methodological Rigor

In quantitative studies, statistical standards exist for drawing a sample population that is representative and unbiased. Moreover, there are instruments designed to be objective and that are standardized for repeated, reliable, and valid use. These standardized procedures do not and cannot work for qualitative studies; however, different methodological criteria are utilized. Lincoln and Guba (1985; 1994) developed five criteria to assess quality of qualitative research, which include credibility, confirmability, transferability, dependability and authenticity. Credibility, comparable to internal validity, addresses the issue of 'fit' between respondents' views and researcher's representation. It poses the question whether the explanation fits the description. The researcher met this criterion through member checking. The researcher asked the informants if the interpretation of the data made sense to them and if it reflected their experiences. Additionally, to ensure credibility, the researcher provided 'thick' description of the data that included the complexities and variabilities as well as commonalities. Transferability, comparable to external validity, refers to the degree to which the results of qualitative research could be generalized or transferred to other contexts or settings. The qualitative researcher met this criterion by describing the research context and the assumptions that were central to the research. Dependability,

comparable to reliability, is achieved through a process of auditing. Use of field notes and journals ensured that the process of research was logical, traceable, and clearly documented. Reflexivity was central to the audit trail in which the researcher kept a self-critical account of the process, including internal and external dialogue. Reflexivity demands that we interrogate ourselves regarding the ways in which the research efforts are shaped around the binaries, contradictions, and paradoxes that form our own lives (Gergen & Gergen, 2000). Confirmability is concerned with establishing that the data and interpretations of the findings were not figments of the inquirer's imagination but were clearly derived from the data. To meet this criterion, the researcher consulted with other qualitative researchers, such as other doctoral students as well as her advisor on interpretive analyses. Authenticity is demonstrated by illuminating a range of different realities (fairness) with depictions of their associated concerns, issues and underlying values. The researcher strove to represent all participants' views, perspectives claims, concerns and voices in the text. These criteria served as a guide in an ongoing evaluative process throughout the investigation.

Limitations

Interpretive hermeneutic phenomenology is best suited to answer how various processes work and the important content of people's lives and commitments. While this method cannot aid in predictions, it can improve our understanding of issues and concerns. Fore-structures must be acknowledged as clearly as possible. When an interpretive account loses its contextuality and temporality and operates beyond its original context, it may be reduced to what

Dreyfus referred to a leveling to banality, and then become mere assertion. This project is limited by the fact that all informants were drawn from two treatment programs in the Greater Bay Area. To the extent that informant's processes of living with COD were structured by these resources, the findings are restricted to others with COD who live in similar circumstances. Insights derived from the informants' own perspectives are strengths; a broader perspective using insights from patients and staff would have strengthened the findings.

Sample Description

Twenty participants participated in the study. Ten participants were recruited from each facility. The sample comprised of 11 males (55%) and 9 females (45%) with a mean age of 51 years. Racial/ethnic identification of 65% of the participants was African Americans. Depression (65%) was the prevalent psychiatric disorder. Alcohol (45%) was the most common drug of choice. Hypertension (50%) followed by diabetes mellitus Type II ((25%) were the most common medical conditions. Only three participants (15%) were currently using illicit drugs and/or abusing alcohol. Three informants (15%) did not have insurance while 16 informants (80%) had Medi-Cal.

Table 1: Descriptive Statistics

AGE

	N	Minimum	Maximum	Mean
AGE (years)	20	39	64	51.25

ETHNICITY

	Frequency	Percent
African American	13	65
American Indian	1	5
Caucasian	5	25
Latino	1	5
Total	20	100

GENDER

	Frequency	Percent
Female	9	45
Male	11	55
Total	20	100

PSYCHIATRIC DIAGNOSIS

	Frequency	Percent
Bipolar	3	15
Depression	13	65
Schizoaffective	2	10
Schizophrenia	2	10
Total	20	100

MEDICAL CONDITIONS

	Frequency	Percent
Diabetes	5	25
Degenerative Joint Disease	5	25
Hypertension	10	50
Hepatitis C	4	20
Obesity	5	25
More than one medical condition	12	60
More than two medical conditions	8	40
More than three medical conditions	7	35

INSURANCE

	Frequency	Percent
CMSP_County Uninsured	3	15
Medi-Cal (Medicaid)	16	80
Other	1	5
Total	20	100

PRIMARY CARE DOCTOR

	Frequency	Percent
Yes	19	95
No	1	5
Total	20	100

PSYCHIATRIST

	Frequency	Percent
Yes	12	60
No	8	40
Total	20	100

CASE MANAGER

	Frequency	Percent
Yes	16	80
No	4	20
Total	20	100

CURRENTLY USING ILLICIT DRUGS

	Frequency	Percent
Yes	3	15
No	17	85

TYPES OF SUBSTANCE USE

	Frequency	Percent
Alcohol	9	45
Cocaine	1	5
Crack	6	30
Marijuana	1	5
Methamphetamines	2	10

More than one type of drug	1	5
Total	20	100

CHAPTER FOUR

"IT'S A STRUGGLE, IT'S A CHALLENGE": COPING WITH CO-OCCURRING DISORDERS

Introduction

The disturbingly steady increase of individuals with co-occurring disorders (COD) cannot be ignored. Such a growing population in today's social, racial, and gendered contexts necessarily presents healthcare providers with new puzzles to solve and obstacles to overcome. Co-occurring disorder is not a new health phenomenon. Historically, individuals with COD have been marginalized and excluded from mainstream society. These people share a history of stigma, discrimination, isolation, segregation, mistreatment, and abuse. Furthermore, they often live below the poverty line and, thus, constantly struggle to secure the necessities of life—e.g., food and shelter. They either reside in substandard housing, are homeless, and receive poor or no medical care (Calsyn et al., 2004).

The aim of this chapter is to describe the lived experiences of persons with COD in managing their health. Special emphasis is placed on how they experience health challenges in the face of everyday stressors, including tenuous habitation, social stigma, low income, and unsupportive physical and policy environments. This chapter also focuses on the challenges and difficulties these individuals encounter when coping with co-occurring disorders complicated by their biological, psychological, and psychosocial vulnerabilities. The first section illuminates the intricacies of their interpersonal relationships with healthcare providers, and the second section articulates how they must negotiate and

navigate an arduous healthcare system. The third section discusses how an individual's living situation can severely impact his or her health. For the purpose of confidentiality, I have fictionalized the names of participants, providers, programs, and geographic locations.

I

Intricacies of Interpersonal Encounters with Providers

As the number of individuals with COD continues to increase, primary healthcare providers will be faced with the challenges of managing this population's multiple illnesses. Individuals with co-occurring disorders of mental illness and substance abuse have higher rates of chronic health problems (Dickey, Normand, Weiss, Drake, & Azeni, 2002), experience multiple re-hospitalizations, frequently over-utilize emergency services (Curran et al., 2003), and often present for care within the primary healthcare context (Gournay, Sandford, Johnson, & Thornicroft, 1997). Furthermore, they have higher morbidity and mortality rates compared to the general population (Chafetz, White, Collins-McBride, & Nickens, 2005). Physical health conditions such as HIV and Hepatitis C (HCV), along with other chronic health conditions like diabetes, hypertension, and cardiovascular diseases, are on the rapid rise among the COD population (Cournos & McKinnon, 1997; Silberstein, Galanter, Marmor, Lifshutz, & Krasinski, 1994; Susser, Valencia, & Conover, 1993). This is only exacerbated by a dependence on alcohol and drugs (psychiatric or otherwise), contributing to an increased prevalence of serious illnesses, medical complications, and chronic conditions (Leonard et al., 2001; Zavala & French, 2003).

In the era of managed care, dramatic changes in the healthcare delivery and financial crisis have occurred. Society is now faced with “moving away from fee for service to capitation and risk sharing between payers and providers” (IOM, 1996). Managed care emphasizes providers’ productivity and clinic capacities. Health providers are caught in a web of attempting to provide comprehensive effective care while at the same time treating a higher volume of patients in any given day. Therefore, providers must swiftly diagnose and treat health problems, leaving little or no room for patients’ narratives. This brief encounter is further complicated by a set of invisible barriers: the providers are immersed in evidence based medicine practice, and the individual with COD is working with scenarios of prior healthcare contacts and lived world experiences. Evidence based medicine practice is at times problematic because clinical encounters can be condensed to one-dimensional problems that are neatly solved by recourse to research trials and the hierarchy of evidence. However, this type of encounter often leaves little attention to patients’ values and preferences (Tracy, Dantas, Moineddin, & Upshur, 2005). Patients’ interpretations of clinical encounters further deepen their perceptions that (1) they are not heard or listened to, and (2) they are not understood. These two perceptions prevent the possibility for communication and trust, and ultimately have a lasting and damaging impact on the health of individuals with COD.

Not being heard or listened to. Participants in this study described the impasse they faced when coping with their illnesses. Most were knowledgeable about their illness and cognizant of recent changes in both their symptoms and

their bodily experience. Yet they voiced that their utmost challenge in attempting to cope with their illnesses was convincing providers of their needs, that is, to be able to articulate and have acknowledged their own narrative about their body and psyche. They struggled to have their personal account be attended to rather than have a provider listen quickly and selectively to their story and form an overdetermined conclusion. Not surprisingly, most participants expected providers to understand the complexities of their illness and to step into their shoes to understand better their total lived context. What they were searching for from their healthcare providers was not only the medical knowledge to diagnose and manage their illnesses, but for a social-contextual understanding that broadened providers' practical and empathic reach. In other words, individuals with COD articulated a need for providers to combine medical knowledge with an understanding of the patient's entire social and lived-world context. "Lived-world" is a shorthand expression used in the remainder of this chapter that refers to the fact that the participants in this study have histories and present lives that are often complicated by social inequities, stigma, racism, and poverty, which constitute their "lived world."

Sheila, a 52-year-old African American woman, had Hepatitis C, diabetes, hypertension, and a 30-year history of major depressive disorder. She began using drugs at age 14 to make herself feel better. During her early 20's, she experienced multiple psychiatric admissions. In spite of her psychiatric illness and substance abuse, she was able to continue to work intermittently. At 47, Sheila underwent carpal tunnel surgery on both her wrists. Immediately thereafter she

returned to work, but began experiencing severe pain in both wrists. She also began to feel fatigue and to lack the energy to return to work after weekends. Sheila's 40-hour work-week took a toll on her mental and physical health. In 2002, at age 48, her depression worsened when her sister suffered an aneurysm. Her sister's illness triggered memories of her mother's death in 1994, and her grandmother's death in 1995. She continuously missed work and could not pay her bills. Unable to cope with her depression, she turned to alcohol, crack, and heroin for the next three years, culminating in a downward spiral.

Thirteen months prior to the interview, with the mounting stress of taking insulin, inability to care for her mental health, and lack of income and support, Sheila attempted suicide by discontinuing her insulin and taking an overdose of crack. Fortunately, a neighbor called 911. Sheila was taken to the ER, where she was revived and eventually admitted to a psychiatric facility. Thereafter she was remanded to enter drug treatment through Proposition 36, a California State initiative to enhance public safety by reducing drug-related crime and preserving jail and prison space for violent offenders. The initiative provided community based substance abuse treatment programs for non-violent defendants, probationers, and parolees charged with simple drug possession or drug use offenses.

After being treated unsuccessfully in several drug treatment programs, Sheila entered the dual diagnosis program at Charter House. For six months she lived at one of Charter House's (CH) shelter plus care homes, where her rent was \$25.00 a month plus a \$58.00 program fee. While at CH she was required to

attend a drug program, was assigned a case manager, and underwent mental health treatment from CH's in-house psychiatrist. According to Sheila, that this was not enough.

Sheila desperately needed and wanted help for her depression. She no longer desired to use drugs or alcohol to suppress her emotions. However, the lack of holistic therapy that combined medical knowledge with an appreciation of her history and the whole of her life experiences made her feel helpless, trapped, and paralyzed by her emotions. For Sheila, being clean and sober did not lead to a place of psychological strength, but rather heightened her sense of emotional pain.

In the following narrative, Sheila described her desperate attempt to obtain psychiatric medications that relieved her depression and her difficulty in finding what I have identified above as a holistic therapist. Although she was enrolled in a dual diagnosis program that did not necessarily mean that her access to the psychiatrist and a therapist was easier. As a consequence, she had to find other programs during her mental health crisis. When she finally saw her psychiatrist, he did not listen to her and did not incorporate her lived-world experience with his medical knowledge. To get the psychiatrist to listen and act on her concerns, she was forced to exaggerate her symptoms, to perform a narrative of self with histrionic hyperbole:

Sheila: I'll ask Dr. Black if there's something not working right, "Could you help me with my medication," or "Is it me, or what?" I'll talk to him or I'll talk to my counselor. And sometimes it is the medication and sometimes it's just me. But I need to hear it or to talk about it. With Dr. Black I feel like – I started on 10 mg of Lexapro. Well, I started on Zoloft when I first came. I came to Bonita House on

Zoloft but it wasn't working. And I just felt terrible, so I went to River Creek (drop in crisis center). River Creek started me on Lexapro at 10, so I'm up to 40. But every time I've gotten a raise from Dr. Black, I've had to cry, and, just be a lunatic before he would give me a milligram raise. I'd like tell him, "I just don't feel right. Something's not working." And then he'll give me a milligram raise. I'm hoping that this 40 works because I went through so much to get this 40 from 30, it's hard.

I: When you said you went through so much to just get your medication changed, can you explain that to me a little bit more?

Sheila: I have to be damned near jumping off the Bridge, you know, and damned near feeling suicidal, and then he'll say, "Well, do you want me to call 911?" He has to visibly – at least for me he has to visibly see me just upset and crying.

I: What did you do to get that increase in medication?

Sheila: I tried to let him know that there's something wrong. Somebody's gotta do something. And then I'm afraid of him sending me to Pavilion (a psychiatric hospital).

Sheila was infuriated with the psychiatrist, whom she perceived to be completely inattentive. So the encounter became a dangerous balancing act—to hyperbolize self-destructiveness yet not so much so that it led to a referral to a psychiatric hospital, where she had previously been traumatized. Sheila's experiences with the healthcare system and providers continued to be filled with frustrations and obstacles.

The lack of empathy or ability to understand her problems extended to her relationship with her case manager. The case manager was supposed to be sensitive to the lived-world experiences of individuals like Sheila. And yet Sheila did not experience this understanding. Indeed, as her narrative illustrated, the case manager's treatment was not sensitive to Sheila's personal suffering. Just as

with the psychiatrist, when Sheila attempted to disclose her concerns and worries to her case manager, her lived-world narratives of mind and body went unheard:

Sheila: “So when I heard I was [going to] have Malcolm, and, you know, he ke[pt] emphasizing Senior Caseworker, but I found out that Senior Caseworker mean[t], I thought it meant more schooling. But it seem[ed] the, where it’s came out that Senior Caseworker just meant you’ve been there longer. So I was, I was enthusiastic at first until every time I go, I tell him a problem I have, and he gave me a parable to one of his other clients, or something he’s went through.”

I: Can you tell me the last time you told him a problem and this happened?

Sheila: Yes, I told him I have degenerative joint disease on my knees. So I was telling him that, sometimes I just get boggled down, it’s just too much. He always wants to have the appointment at 3:00 o’clock. This was when I was going to my program every day. And so I was telling him that that riding the bus, you know, here and there, I have things I need to take care of. I need to shop, and then I have to come here. And I say, “You know what? The bus is just killing me.” It was, “Well, when I first came to the country, me and my daughter,” you know what I’m saying? “Me and my daughter rode the bus all the time.” And, and that was that. I mean that was just the last one, but it’s always something. Like I told you, when I tell him about Prop 36, I’m worried about it, he tells me about, “Yeah, I’ve been to court before with one of my clients, and he had two open containers.” And I’m thinking to myself – and that’s where the poor person thing comes in.”

Instead of hearing Sheila’s difficulty keeping a 3:00 o’clock due to public transportation and increasing knee pain from her arthritis, her case manager focused on a completely unrelated issue, the previous client’s court appointment. Rather than obtaining help from her case manager, she felt increased estrangement due to his inability to grasp and empathize with her live-world issues. Thus, Sheila felt like a social pariah, and even more “alone” with her problems. The case manager, whose particular skill should be to assist persons with COD to manage their multiple needs, seemed unable to attend to Sheila’s particular story.

This experience with her case manager destabilized Sheila's sense of self, to a destructive degree. The incongruence of the two people's concerns— (a) the case manager's attention to civil disobedience and his use of a parable, which might be culturally driven given that Malcolm was from Africa; and (b) Sheila's concern about her material lived-world—led to a fundamental breakdown in communication.

Sheila's story highlights the need to enrich the clinical practice of psychiatrists, healthcare providers, and case managers who work with individuals with COD with an appreciation of their particular and unique needs. Clinicians working with this population must have the skill to see beyond two-dimensional types. In their clinical encounters they must create a space for an open dialogue for patients like Sheila so that they will be able to find an emotional place for a holistic healing.

Sheila's struggles with interpersonal relationships with her healthcare workers extended to her physician and played out most forcefully in the management of her diabetes. In the past and in the present, managing her glucose was a constant source of stress for Sheila. She thought she had escaped this debilitating disease, from which both her mother and aunt died. But a diagnosis of Type 2 diabetes at age 47 raised fears of her own mortality, that she, too, would succumb to death by diabetes. Her mother's and aunt's deaths had felt like abandonment by those family members who mattered most to her. These deaths further solidified her feelings of "being alone" in this world.

Frightened, helpless, and unable to control her diabetes, Sheila was faced not only with her sense of loss, but also her own mortality. Her dilemma: if she

checked her sugar and it was high, her stress level would escalate, which, in turn, would increase her blood sugar. Perhaps not checking her sugar signified a partial denial of her illness. Even when she felt ill, her first instinct was not always to consider diabetes as the source, although she said it almost always was. To ease her stress, at times, Sheila relied on her nurse practitioner, Lex, to check her blood sugar rather than doing it herself. She felt safe and comforted when Lex checked it. Since Lex's scope of practice was limited, Sheila still required a physician to manage her diabetes. During one of her clinic visits, she advocated her need for insulin to her physician but did not obtain the care she wanted.

Sheila: It just so happens that I've been on insulin. I struggled for about a year not to go on it. 'Cause I've always had insulin from the time I was first diagnosed. But this year, since I had lost so much weight, when I was at the Pavilion, I tried to do without insulin anyway. It didn't work. So I was starting to feel better because I had the right insulin, and my blood sugars are going down. But –I don't know if it's just my luck or it's me feeling sorry for myself or what, but [sighs] I go to the clinic a week before last. Last week. For a scheduled appointment. Somehow or another, I mean it's never quick, but somehow or another it's extra long. And come to find out, the reason **it's extra long** is because they took what – what they were scheduled was it was the wife should have been before me, then me, and then the husband. But what they ended up doing was taking the wife and husband together in an appointment before me, so I ended up waiting longer than usual. So, and then come to find out, *I'm so exhausted when I get out of there*, and I had my prescription in. I'm taking 70/30, right? So that my blood sugars will be low in the morning. That's what the 70 is and I look at the prescription and I see, but, you know, it's a doctor. So I give the prescription, I bring it home, and I've been using it. And then I was ecstatic because they gave me three bottles. The one bottle – and that's still good for 3 bucks. On my prescriptions, no matter how many they issue you, it's still 3 bucks. But I was ecstatic because the first time they only gave me one for 3 dollars. So I was ecstatic when I saw 3 vials for 3 dollars, you know? So –come to find out, *the lady gave me the wrong insulin*. [Laughs] I called her, I had her voice mail. She checked Monday, Wednesday and Friday. She happened to be on vacation, but I knew that she would pick it up Monday. And

she called, and she says, “Oh, yes, I did give you the wrong,” ‘cause I said, “Well, did you give me the wrong insulin, or did you just change it and not remember to tell me?” So she calls me Monday. She says, “Yeah, I gave you the wrong,” so she’s trying to make all these things to try to correct it, and I said, “You know what? I have an appointment Saturday. And you can just do what you need to do and we can figure it out then.” Because now I got two bottles of insulin that I don’t need, that it’s perfectly good insulin, and it would be nice if they would take it back and give me what I need *so I won’t have to pay again*. But that – it’s – it wouldn’t be that easy. So I’ll see her on Saturday. Since she’s been on vacation, she has a Saturday appointment, so – and I just left it at that because like maybe it was the wrong thing to do, but, you know, and whatever it was doing to me, you know, I’m not dead yet. You know, all that running around, trying to correct your mistake, when I don’t have a car, and I’m on the bus, and it’s hard to – you know, like when you go to the pharmacy, they have this number at the clinic that nobody ever answers. Nobody ever answers. But that’s why I have her voice mail, which she checks a couple times a week. So it didn’t make any sense for me going down there and getting all riled up, not being able to get what I need, *don’t have the money to get it*, and, and expecting them to fix it in the machine, in the computer, where I can get it for free. So I don’t know.

I: So you’ll find out Saturday.

Sheila: Well, yeah, it, she says it, *hurries me, but what she tried to do, she says, “Just go get it – I’ll write you out a prescription for, for R, which is Regular,” because what she had did, she had gave me NPH, which is, you know, and 70/30 is NPH and R. But, you know, you can mix it.* But what she had given me with the 70/30 is I woulda just had one bottle. But to correct her mistake, she says, “Well, since you have N’s, come get a prescription for R.” No, I don’t wanna pay again. That’s not the point. The point is you fix it. And, hopefully, it’ll be fixed.

I: How did your body react to that?

Sheila: Well, the reason I called her is because I noticed that when my sugars were kinda high in the morning when they shouldn’t have been. So then that’s when I realized, oh, this is N, and, not 70/30, and so I called and put it on her voice mail. I don’t know. I try not to get upset. That’s why I try to come in here and just go through it, and what’s mine is mine, and if it’s not, I just try not - to leave it alone. I try. But maybe it’s not working as well as I think. But I try not to get upset because of the diabetes. I don’t know. But it didn’t really

react. It's just my sugars are high in the morning and they shouldn't be, and that was the whole idea of doing what we're trying to do, so that it can get regulated.

I: Well, it seemed as though you did the right thing by calling and figuring it out. It also seemed as though you had another barrier that you had to jump through.

Sheila: Yeah. Yeah, she wanted me to jump through that barrier on Monday when she, "Oh, yes, I did do it. I did write it wrong." It was her fault. It was also mine for not rechecking. But you figure, I don't know.

I: So this Saturday you're seeing the doctor?

Sheila: Yeah. And, hopefully, she's figured it out. Hopefully, I won't have to wait for another prescription to be filled and pay another 3 dollars, because I got two perfectly good bottles of insulin that I don't need. I'm not gonna need if you write the right prescription.

Sheila's visit to her doctor demonstrated how small issues in care, a mistaken prescription, can create major impediments for self-management in patients struggling with limited personal resources. Frustrated and exhausted after waiting for quite some time to see her physician, Sheila, who must survive on \$238 dollars a month, was elated when she realized that she was able to save some money after obtaining her three vials of medication for only \$3 dollars. However, her joy did not last long; she soon realized that the physician had given her the wrong medication. Sheila advocated for herself by calling the physician and informing her of the mistake. Sheila took responsibility for not checking the prescriptions more thoroughly but she hadn't done so because a "physician had written it." Her frustrations intensified when the physician simply wanted her to pick up an additional prescription, an action that demonstrated to Sheila the physicians lack of care or grasp of her real life constraints. This narrative provides

another example of providers' insensitivity to the patient's lived-world context. Sheila felt the physician did not comprehend the complexities of trekking to the clinic and, more importantly, the fact that she was living on a limited income. Sheila felt it unfair that she should spend more money and time to correct the provider's mistake, and she had to further negotiate with the healthcare system to achieve this understanding.

Sheila's experience with her primary care provider was marginally better than with her psychiatrist and case manager. The provider had accommodated Sheila's need for access by giving her a special number to reach her and a specified schedule of times the doctor would check messages. Additionally, the physician admitted error. Although there may not have been a simple solution, the physician attempted to correct the mistake in her own way. However, Sheila's financial and personal strains made a "simple" medication error particularly burdensome.

Sheila's narratives illustrated that coping with multiple illnesses presented significant challenges. Although she learned to voice her concerns, Sheila's experiences demonstrated that providers—physicians, psychiatrists, and case managers—frequently did not listen to or acted upon what she drastically needed. She perceived that she may have been shunned because she was "poor" and did not have the means to pay for such services.

Sheila: And I've been here all this time, and I just feel like – whatever help I'm getting, sometimes, a lotta times I feel like whatever help I'm getting is like, you know, the poor indigent Shelly. You know what I'm saying? I just – I don't know lotta things that I could be having or should be having, I don't have any medical

coverage, so I don't get, and they can't seem to get it for me. I have no medical coverage. Nothing.

Stephanie, a 36-year-old Caucasian single mother, suffered from chronic abdominal pain and bipolar disorder, and was recovering from methamphetamine (speed) addiction. Six years prior to the interview, Stephanie endured severely low self-esteem and insecurities, and wanted to be accepted by society. As she searched for acceptance from social cliques, she succumbed to "speed." She wandered the bar scene and eventually met people who used drugs. Her addiction led her to a place to which she referred as "hell." She became paranoid, thinking everyone wanted to hurt her. For the following three years, "speed" controlled her mind and body. Although she was afraid to quit, an unexpected event changed her life. Three years prior to the interview, Stephanie became pregnant, at which point her main concern became her unborn child. To protect the fetus, she left her social cliques, entered treatment, and vowed never to touch drugs again.

Stephanie's identity and life were shaped by one solitary force, her two-year-old daughter, Lily.

Stephanie: I never touched it again. And it was even handed to me by so-called friends: "Oh, here. You want some?" And I just got done telling him I was pregnant and I wasn't gonna do it anymore. They still and try to get you to do it. They don't want anyone to get out of it because they can't. And so I didn't find [laughing] very much help or support amongst the people that I knew. So I just stayed away. I forced myself into a homeless shelter, where I had to be home at 7:00 o'clock. I had to be inside; otherwise I got kicked out. I was pregnant. And I would never hurt my baby. So there was not coping mechanism. There just wasn't an option to do it again.

At the time of the interview, Stephanie had not used "speed" for three years. She was also enrolled in finance classes at a community college. She

continued to seek therapy for her mental health issues. Stephanie's primary issue was coping with her chronic abdominal pain, which interfered with her ability to eat. Although she had had recurrent bouts of abdominal cramping and diarrhea, her primary care doctor was unable to diagnose her illness. She had been tested for multiple illnesses, yet the results were always normal. As a result, her primary doctor referred her to a gastroenterologist, a consult she characterized as a "horrible experience". In the following narrative, she shared an incident where her gastroenterologist and his staff demonstrated inattentiveness and lack of concern for her health.

"He [primary care doctor] then sent me to a gastroenterologist, who turned out to be the jerk. They did an endoscopy, which is, you know, they put a scope down your esophagus and go all the way down into your stomach and through your stomach, out the back. And found out – well, first, I woke up. Nobody was there. Nobody could tell me what happened, what they found, what went on. Then I called several days later 'cause nobody ever called me to tell me what was going on – all they did was give me a prescription, said, "Take this." I said, "Why?" "Oh, I don't know. It's because it's there." And so I finally called, you know, after maybe a few days or a week or something, to ask to speak to the doctor, and never got to him, got to the nurse. I said, "Well, can you tell me what they found?" "Well, you don't have cancer." I said, "Well, that's nice" [laughs], "Thank you." Yoo hoo! I said, "Well, do I have an ulcer? Why am I taking this Prevacid," or back then it was Nexium. "Oh, well, you have a slightly inflamed stomach lining due to some heavy acids in your stomach, so we're giving you that for the acid."

Stephanie's experience after her procedure illustrated two issues: her fear of being alone after the procedure and the dismissive way things were explained post-procedure. The staff was incommunicative and shared limited information about the findings. When she attempted to call the doctor's office a few days later,

she was simply informed to take the Prevacid and to follow up in a month for another procedure.

The following encounter, her colonoscopy with the same physician, was in no means better than the previous experience. Stephanie, who was supposed to be seen in a month, was not seen for another few months.

Stephanie: No mention until the day of my colonoscopy, when they finally got me in there for that, which was months later, by the way. They – the doctor came in, “So, how you doin’ with the swallowing?” I was like, swallowing? He said, “Well, you’ve got a pretty big hiatal hernia and an ulcer in your esophagus.” I said, “What?” I said, “Well, why didn’t they tell me that? Nobody was here to tell me after the procedure what had happened. And when I called your office, they gave me the wrong information.” “Oh, I’m sorry about that. Well, this is what you have.” And then they went to do the procedure, and it hurt so badly that I screamed the whole house down, apparently swore at him and everyone else that was in there. I don’t remember that part. All I remember is that it really hurt, and the last thing I remember was saying, “Please, please, please make it stop.” And yelling, screaming, because it hurt, and screaming in pain, not yelling like, “You sonofabitch,” but in pain, and so apparently they had to stop the procedure, and then he was just gonna scoot right on outta there. I told him my mom was in the waiting room and to please tell my mom anything that was going on. He went in – my mom grabbed him on his way, and said, “So what’s going on?” He said, “Well, we gave her enough stuff to put down a horse, but she still screamed the whole house down and yelled at, nobody wants to hear her yell.” [Laughs] “We’re gonna have to do it under local anesthetic if,” you know, bla bla bla. And then I waited – well, first, I tried to call even the same day, his office, to find out what was going on. I never got a human being. All I got was an answering machine saying, “Please don’t leave a message” on it. Then I finally got the nurse, like, I don’t know, a week later, to try and make the appointment for the other colonoscopy with general anesthetic or see what my next move was, or what the hell happened even. “Well, it’s gonna take quite a while. We’ll call you back with the appointment.” I haven’t heard from him yet.

I: How long has that been now?

R: It's been like three weeks. So I finally went to Adult Primary Care, totally complained, saying, and this is just absurd, and my mom's doctor luckily takes MediCal. She's got a gastroenterologist

This is an especially telling event. The physician's language objectified and diminished Stephanie by likening her to an animal; thus, marking her as other than human. The doctor's declaration, "nobody wants to hear her yell," revealed his sense of being inconvenienced, yet, functioned to primitivize. According to him, she was not "crying" out of pain, but "yelling," a behavior that carries with it stronger associations of socially unsanctioned aggression and lack of civility.

Stephanie's experience revealed how perceptions of the underclass, white, black, or brown scenarios could lead to patients being kept in the dark about important healthcare conditions. It was only by insisting as well as slips of the tongue when the doctor asked about her throat, that she found out the full extent of her condition. Furthermore, it illuminated how race took a secondary position to class. It mattered little that Stephanie was white. More importantly, the experience illustrated that members of the underclass and their narratives were automatically clicked into a place that objectified and dehumanized them. Surprisingly, Stephanie's experience with this particular provider did not deter her from seeking care for her illness from another healthcare provider. However, an encounter like the one she experienced might hinder other participants from seeking further care.

Although many informants in this study had experiences that paralleled those of Sheila and Stephanie, there were also instances where persons with COD successfully established relationships with providers that took into account their own real-life constraints. Cate, whose biographical experience in many ways

mirrored Sheila's, demonstrated that through perseverance and persistence one can overcome this impasse.

Cate was a 52-year-old Native American woman who was chronically homeless for over 5 years during her early 20s and eventually lived in multiple single residency occupancy homes. While homeless she continued to use heroin and crack, a habit she started as a teenager that lasted almost 20 years. During that period she was forced to give up custody of her son and daughter. Although she lost her children, she was able to form a long lasting relationship with another homeless man, Dennis, who became integral in her recovery process.

Cate's life continually presented a multitude of challenges, struggles, and seemingly insurmountable obstacles. According to Cate, her health went from "sugar to shit." She suffered from diabetes, diabetic neuropathy, hypertension, emphysema, major depressive disorder, and post-traumatic stress disorder. Five years prior to the interview, she was diagnosed with breast cancer and subsequently had a mastectomy. One year prior to the interview, Cate's acute sense of internal biological workings and general intuitiveness led her to believe and confirm that the cancer had returned.

I knew something was wrong with my breast. But everyone told me, "Oh, no, ain't nothin' wrong with it," I had a leakage coming out of the nipple. That told me something [was] wrong.

Through persistence and a firm belief of her health, Cate convinced the doctor to thoroughly evaluate her condition. She sought help from the mobile medical team, comprised of a physician and her assistant, which provided free primary care clinics to tenants living at her housing site. Unlike Sheila, Cate's

physicians listened to and acted on what she strongly believed was wrong with her body. The doctor's validation and acknowledgement of Cate's concerns enabled her to trust and to continue her medical care with the mobile team.

Dr. Ross is the lady that really saved my life. [Coughs] She sent me for all these tests. [She] believed me. She believed in me, that I knew something was wrong. And so after all the tests, my breast swole up about two times the size of a grapefruit, maybe a small watermelon. And they had all these pock marks in it. And it was beet red, and it hurt. So she sent me to this lady called Dr. Concheta, and Dr. Concheta took this long thing, about this long, and poked holes in it, and pulled out pieces for biopsy. Well, the first biopsy showed wasn't nothin' wrong with it.

Although the breast appeared abnormal, which warranted the doctors to investigate, the biopsy result was normal. Upon hearing the results, Cate strongly stood her ground and insisted that it was a mistake. She instinctively knew that something was wrong. She was neither intimidated nor afraid to voice her concerns. Furthermore, she advocated for herself and was adamant that Dr. Concheta investigate further.

And I'm like, "You cannot tell me something isn't wrong here." So the second one she did, she went – 'cause I kept telling them, "It ain't on top. It's underneath." And she went underneath and took the biopsies, and it was full of cancer. So they – she told Dr. Concheta, and Dr. Concheta – I mean Dr. Concheta told Dr. Ross, and Dr. Ross and Dr. Concheta agreed that the breast had to come off."

Cate's perseverance was fundamental to her obtaining the diagnosis. Although the biopsy was normal, the doctors paid attention and seriously investigated her complaints and needs. They were not dismissive; rather, with a seemingly greater lived-world sensibility, they took the time to examine and probe deeper into her concerns.

What Sheila and Cate asked for was a meeting of minds. They wanted more than simple attention to their ailment. They wanted an understanding on the part of the provider of their lived-world circumstances and contexts. They expressed considerable *need for understanding*.

Leila, a 43-year-old Caucasian woman who lived at CH's intense dual diagnosis program for eight months prior to the interview, perceived her appearance, her mental health history, and alcohol addiction as attributes contributing to difficulties in her attempts to care for her health. Leila suffered from hypertension, bipolar disorder, post-traumatic stress disorder, and alcoholism. She started drinking at 12 years of age and was an alcoholic by age 15. Both her parents and three sisters were recovering alcoholics. Leila had obtained help for her addiction in the past but had relapsed several times. At the time of the study, she had been sober for seven months but had relapsed for two days a month prior while visiting a friend. While living on the streets, Leila had endured rape and both mental and physical abuse. Consequently, she was cautious with anyone she encountered. She desperately wanted help for her bipolar disorder, but the help she received was often distant and tenuous, leaving her fearful of healthcare providers. She thought that health providers did not have a full understanding of the complexities associated with having mental illness and substance abuse disorder. Oftentimes substance use can mimic and mask other symptoms, thus making it difficult to discern what is truly happening.

Leila: I've been in many hospitals, and – because of my Bipolar Disorder – but I really feel that a lot of them misdiagnose you, put you on medicines that don't work, put you on medicines just to keep you

sedated and quiet, and right now I'm on a really mild amount of medicine, and I'm doing really well with it.

I: Can you tell me more about these times when you've been just given medications and they don't work for you?

Leila: Yeah, I think it's because I'm dually diagnosed. I have alcoholism and drug past history, plus I'm diagnosed with Bipolar Disorder. So oftentimes you can – when you're coming off of alcohol or drugs, that can be looked upon as a different – an entirely different entity. You can be looked upon as schizophrenic. You can be looked upon – because you are coming – you are literally going into DT's or something, and they just label you 5150 and throw you in a hospital, and have no clue. As much as you tell them, they don't – they usually don't listen because the way you look when – I mean I got so bad with drinking that I would just have urine on me and be literally on the street and just people don't – I hate to say it but people d[on't care] and I was homeless for a while. And people don't give you the adequate treatment that I believe is deserved. I've been strapped, strapped down a few times in hospitals and been injected with medicines because I was going through DT's, in fact.

I: Can you recall that time or tell me that story when this happened to you?

Leila: Sure. I had been drinking heavy for a long, long time, meaning months, without eating and things like that. I was just way far into my disease and probably getting into other drugs, and I was coming off of alcohol, not on my own accord. I just didn't have any money, and I couldn't get any. And I started going into DT's, and an ambulance picked me up and strapped me down, and took me to Pavilion, and threw me in a room, and fed me Haldol with a needle, and it's very scary. Very petrifying. That's happened many times to me. Until they finally got to know me.

Leila: I had one guy, one so-called doctor, quote/unquote, walk in to me when I was half out of it and say, "Have you had sex lately?" And I'm just going through withdrawal and stuff. But he put on a pair of gloves. And, he asked, "Do you care if this guy's with me?" He goes, "I'm gonna do a checkup on you." And he put on a rubber glove and stuck his finger up my anus. Yes, that happened to me. I've been like raped in hospitals basically. I have such bad phobias against going to any hospitals, against going to any – now my dentist and me have a good rapport and that's OK. I'm very careful with who I allow touching my body.

Leila's narrative demonstrates several clinical dilemmas. First, that multiple, competing symptoms in a patient who is uncommunicative and unknown to a provider presents risks for misdiagnosis. Repeatedly Leila's clinical presentation led her to be treated as if she were psychotic when, in fact, she was in severe withdrawal and delirium tremens (DT). Secondly, her narrative demonstrates that the clinical environment in which extremely vulnerable patients are treated can be harsh and demeaning. Leila was able to recall such treatment by healthcare providers even when she was in a severely impaired mental state. These past experiences left her fearful and resentful about healthcare.

To trust or not trust. Participants articulated that "trust" was integral to the formation of any type of relationship, especially with their healthcare providers. Many participants observed from a distance prior to any type of engagement with their providers. Many individuals with COD have a history of trauma, abuse, and abandonment (Rachbeisel, Dixon, & Scott, 1999). Trusting another human places one in the vulnerable position of relying on others and may lead to disappointment and hurt. For this population, building and creating trusting relationships with healthcare providers is a guarded and carefully crafted act. The ever-changing assignments of healthcare providers and their inconsistent presence created fragmented relationships, thereby making it more difficult for individuals with COD to trust them.

Within the last six years, Patrick, a 45-year-old morbidly obese Hispanic male who lived at one of Supportive Housing (SH) SRO buildings, suffered from major depression, substance abuse, morbid obesity, hypertension, severe arthritis

and attending chronic pain. He relied on his electric wheelchair as his means of mobility. At the time of the study, Patrick had been clean and sober for six years. His present consciousness was constantly infused with thoughts about past sexual and physical abuse he had endured. His identity was shaped by what had transpired in the past; thus, he exhibited cautiousness with people around him. He observed at a distance prior to wading into any health or community services, thus protecting himself from potential emotional harm. When we met, he was overwhelmed with a past trauma, the death of the person who had molested him as a child. The 30th anniversary of his abuser's death filled his current thoughts.

So for 30 years I've been dealing with this. It's been longer than that since the molestation took place, but it's been 30 years – two days ago it's been 30 years since he was killed, and there was no closure as far as what he did to me. So recently that day was coming up.

Patrick's history of abandonment impacted his ability to trust people. Thus, finding healthcare providers to work with was often tenuous. In this narrative, Patrick shared his trials and tribulations involved with finding a therapist with whom to work:

Patrick: I've gone through a lot of therapists, a lot of doctors. What's hard for me is when a doctor or a therapist says they have to move on. So I have to get another provider. Abandonment issues start to come up. And not only that; I start thinking, oh, they're moving on and I'm still stuck here. As far as getting somebody that understands and really shows a genuine care, sometimes that's an issue.

I: Tell me more about this story about the therapist leaving and your issues of abandonment comes up.

Patrick: Well, I was involved in a program called the East Bay Community Recovery Project. And this is while I was doing the volunteer work in the alcohol and drug program. So I got some therapy through interns at this program. And the interns would only be there like eight months. And so they would work with me, I would

work with them. And that's how I looked at it. They didn't only work with me; I worked with them. And after getting a good feeling with this person, as far as them understanding where I'm at, what I'm trying to do, all of a sudden their internship was over. Somebody else is going to come in next week. I felt like I'm being abandoned by this person, who had just started to get to know me, who I had just started to feel comfortable with, because there's also trust issues involved. And now somebody else's new is gonna come in. If I want to continue getting therapy at this particular place, I have to start over. That's how I felt. Because this person's going to come in, not knowing me, and wants to know about me. So here I am, gonna have to rehash or dig back stuff up that I worked with the last therapist with. After eight months, that therapist left. So it started, you know, the abandonment issue was there. They're abandoning me. I'm just getting comfortable, you know? I'm talking with this person. Things are coming out. And all of a sudden they have to leave.

Patrick's traumatic history influenced his ability to build trust and rapport with providers. Moreover, the constant shift in his mental health care providers proved to be arduous for him in developing a trusting and long-term relationship. The constant changes in his therapeutic relationships simply had him repeating his stories, which meant reliving the pain and agony without ever reaching any type of closure. Hence, rather than moving forward with his treatment, he simply experienced what could be likened to a version of the film *Groundhog Day*—repeating itself over and over again.

Patrick further elaborated that when he finally found someone he could trust who was not an intern, namely, his psychotherapist, Dr. Sprigg, that relationship ended because Dr. Sprigg, who had worked at SH for over four years, was dismissed due to conflicts with other patients and staff. When Patrick was told “she no longer work[ed] [there], he felt “like the rug was pulled out from under me.” Dr. Sprigg's departure was a “loss of a support system,” a severe disruption, and an interruption in his mental health progress. Patrick was cognizant that this event

triggered his abandonment and trust issues. Moreover, the 'unknown' or 'uncertainty' of his therapy and mental health progress frustrated him. His relationship with Dr. Sprigg, which had taken three years to build, had resulted in positive outcomes.

It took long for Dr. Sprigg and I to get the relationship where we were at. You know? Disagreements and everything else. But all that, we were able to remedy. And we moved on. With the work Dr. Sprigg and I had been doing, my depression periods have been short.

Dr. Sprigg's sudden departure meant it was necessary to find another therapist and build a new relationship—a significant stressor for Patrick. The day after he was informed that Dr. Sprigg no longer worked at the clinic, he had difficulty sleeping.

Finally got to sleep around 12:00 o'clock. But then, again, I stood in bed all day yesterday till 2:00 o'clock. But then, again, I was awake at 3:30 this morning. Since Dr. Sprigg hasn't been here, my sleeping pattern has changed, because there's a lot more stuff messing with me. But that's something that, again, the psychiatrist working with me, because he was talking about increasing the sleep medication, when I seen him in June.

Patrick's frustrating and fragmented relationships with his providers were barriers in his mental health progress. Tainted and scarred by his past vulnerabilities, Patrick engaged with healthcare providers with severe cautiousness. Unfortunately, once he found someone he trusted, that relationship was severed by a third party, which left him severely depressed.

Participants like Patrick articulated that length of time is central in developing the level of trust that leads to a solid relationship. Once they were able to form a trusting relationship, this opened a window of opportunity for change.

Dan, a 36-year-old, 360 pound Caucasian male covered with tattoos, resided at CH's shelter plus care housing unit, suffering from hypertension, morbid obesity, and schizoaffective disorder, and recovering from methamphetamine ("speed") addiction. While in high school, Dan used methamphetamine and alcohol as means of coping with his life stressors. During these formative years, Dan made multiple suicide attempts. However, it was not until he was 22 years of age, after his mother's suicide and after his father forced him to see a psychiatrist, that he was diagnosed with schizoaffective disorder and major depression. At that time, Dan was assigned several case managers from the county mental health offices. In his 20's he worked as a plumber, and the majority of his earnings fed his "speed" addiction. The drug and alcohol shielded him from thinking about his mother's suicide and from his tumultuous relationship with his father. Furthermore, "speed" made him feel normal in a sense and suppressed his self-imposed stigma about his mental illness.

Dan was not ready to accept any type of help, either from his case manager, Marvin, or from family members. Marvin attempted to help Dan, yet it was not until four years ago, at age 32, that Dan decided he needed help. At that time, Dan was accosted at knifepoint while purchasing methamphetamine. He marked this incident as dangerous and life threatening, a turning point in his life that made him realize this was not how he wanted to live. The following day, he contacted his case manager and asked for help. Since then he has been enrolled at CH's dual diagnosis program.

Although he had been clean and sober for the last three years, it was only within the past six months that he had realized a change needed to happen for him to move forward with his treatment. As part of the requirement during his treatment, Dan had to work a total of 15 hours a week. However, because of his “laziness,” he worked only a few hours a week. Dan’s case manager, Marvin, caught him lying about his work a few times, at which point Dan could no longer cover a lie with another lie. This was a momentous turning point in Dan’s treatment progress. At that moment, he realized he needed help with what he called his “laziness,” which, in fact, was anxiety. He struggled with socializing with those he called “normies.” A confrontation with Marvin allowed him to reflect on the need to be honest with himself through his recovery. Marvin was one of the core supports to whom he turned within the last three years to help him manage his mental health.

Dan: That was embarrassing more than anything, it was embarrassing, and I felt – I had these feelings before, when I wasn’t doing what I was supposed to be doing. I would lay upstairs in my bed, and I’d realize that I wasn’t accomplishing anything and, you know, in the context of what you’re supposed to be doing, and what you, you know, feel responsible for yourself. And I really noticed that I was ashamed more than anything.

Marvin did not put me on a 30-day probation, which is what they normally do, but that he was going to help me turn over a new leaf, to go from dishonesty to honesty. And he did that by giving me a form that I have to fill out...the places I work. They also have to fill out their name and their phone number and how many hours I work. So that really helped me, having a, you know, a little something extra to help me complete what I did.

I: Were you readily willing to accept the changes or what his suggestions were?

Dan: Yeah, I think that – when I realized, you know – he says I was one of those guys that kinda wears a sign on my back that says, you know.

I: How was that process for you, from changing yourself from being dishonest to being honest to yourself?

Dan: Well, I figure if I plan to make any moves from where I'm at to where I want to be, that I'll have to take some advice and some suggestions from other people, because I wasn't getting there on my own, and when those people appeared at first to be people that were just telling me what to do because they were getting a paycheck for it, and then I decided to try a new way of thinking, that maybe they actually do care. And when I looked at it with that, you know, change of life, I realized that it was something that I needed to do for myself.

Rather than placing him in a 30-day probation, Marvin gave Dan a second chance, which demonstrated to Dan that his case manager really cared about his progress. This made Dan willing to work at his treatment. His relationship with Marvin was integral to Dan's progress and his commitment to move forward. Marvin's confrontation forced Dan to reflect and to realize he was not working on himself. Dan's long-term relationship with his case manager created a solid and trusting foundation for his recovery. He emphasized the importance of trust and how "trust" allowed him to open up to his psychiatrist and case manager.

I: You talk a lot about that trust, that issue of trust, trusting your doctor, trusting your psychiatrist, trusting Marvin. Give me an example of the time you finally realized that these were people that you could actually trust with your self.

Dan: Well, I guess at times when, when I felt the most paranoid about hearing voices and thinking people can read my thoughts and those situations, and the fact that they were able to talk me through, you know, the problem, and get me on the correct medications and, you know, let me know that if my state of mental being isn't well enough to go to work, then go ahead and take the day off, instead of him pushing me into doing something that I don't want to do. And it kinda – I guess – that's why I started finding trust with him, you know, that, you know, if it wasn't right for me, then it wasn't right.

I: Give me the time when you distrusted your case manager or your psychiatrist.

Dan: Well, I only had trust issues, I think, mostly back when I was using because I believed that the system was geared up to just, you know, make money and milk their clients, you know, like they didn't really want you to get better because how is he gonna get his, you know, 40 or 50 dollars an hour or whatever he makes, the psychiatrist? How is he gonna continue to make that money unless he has people who have problems?

I: Tell me the time when you finally shifted that point of view.

Dan: Well, I guess it took – it was about two years after getting clean and sober that I started seeing that these people were here to help me, and it was like – I don't know. Just they didn't open any new doors. They just kept offering the same thing over and over again, until I had a better understanding of what they were getting at. They were telling me that there was no cure for schizophrenia and things like that. And I thought no way, there has to be a cure. I can't go on forever like this. And when things started getting better, you know, like a lot of my problems, my doctor said, was due to drug induced psychosis, that the drugs had affected my brain so badly that I was having a hard time getting in touch with reality, and I think once I started getting a grip of what's going on, that's when I started feeling better.

I: You said you started getting a grip. When was this? Can you remember that time?

Dan: Yeah, it's about a year ago, just before I moved into this house. Some of the, like the – the ability to wake up in the morning, you know, without an alarm clock, to wake up at the same time every morning, and the ability to make it through a day, not thinking I needed a bag of speed because normally I was lazy or depressed or whatever it was, you know, in the past. And some of those things just started becoming a little bit easier. You know? Daily expectations.

I: How do you maintain the relationship or the trust issue?

Dan: Well, I try to – when they do something, like what Marvin did for the Alameda County Vocational Program, getting me this job, just being responsible enough to show up on time every day and to do what I'm supposed to do, so that, you know, when somebody helps

you to build a bridge, that you don't sit there and destroy it yourself. That's about the, you know, the extent of keeping the relationship honest and keeping things good, is, you know, doing what I'm supposed to do.

The providers' persistence and support were a stronghold for Dan. These actions and their long-term relationships provided the solid foundation for their rapport, which eventually enabled Dan to seek their help when he was ready. Furthermore, Dan's understanding of his own mental illness and its course enabled him to engage with his case manager and psychiatrist. The fact that both Dan and his healthcare providers were finally able to reach a point of common understanding enabled them to be able to work together.

Although Dan built a substantial relationship with his psychiatrist and case manager, this has yet to happen with his medical providers. Dan's difficulty in engaging with his medical doctors served as an impasse in his caring for his blood pressure.

Dan: I'd say the only other barrier is, is that I still, for some reason or another, distrust doctors. I feel that they're there to make money, and that every little problem that they find they, they blow it up tenfold. Like if you have a little bit of high blood pressure, oh, it's terrible, you know? Next thing is that you go there and he says, "You're 360 pounds, Dan," and the guy who's telling you this weighs 325, you know? The doctor's a big, heavy guy too, and he's telling me, "You'd better worry about diabetes." And I'm thinking in my head, "Well, you'd better think about diabetes too, chubby. [Laughs] You're not exactly too healthy yourself." You know? And when a doctor is big and overweight and wears glasses and, you know, you think this guy is in terrible shape, you know? Who is he to be telling me what to do? I've never had much trust for doctors. My biggest obstacles, is finding trust in somebody who's supposed to be there to help you, not just to collect a big check.

With his healthcare provider Dan does not experience the empathic reach and engagement between patient and provider. This is a reversal of the earlier

examples above: the "chubby" body of the provider makes it impossible for Dan to trust or accept the advice from his physician. The provider's unhealthy image, which mirrored Dan's body image, was a barrier to trust and engagement. How could Dan trust a doctor's word about weight loss when the physician, himself, was overweight? Dan could not and would not listen to the doctor's advice since he felt that the doctor, himself, did not follow his own recommendation. Dan's history of overcoming his distrust of a psychiatrist and case manager bode well for his eventual capacity to engage with a variety of people in his life. Perhaps with time, and perhaps a change of provider, he will similarly find trust with a healthcare provider.

Individuals are embodied and self-interpreting beings shaped by history, biology, and social context. As mentioned above, the participants in this study have histories and present lives that are often complicated by social inequities, stigma, racism, and poverty—what I have identified in shorthand as *lived-world*. Furthermore, living with a chronic or recurrent physical and/or mental illness deepened their psychosocial vulnerability. In interviews informants illuminated the difficulties they had in developing strong, solid, and trusting relationships with their healthcare providers. They narrated examples of not being heard or understood by their providers. They discussed issues surrounding trust as an impasse in developing a working relationship. Given that individuals with COD have multiple physical and mental health issues, it is imperative that they form connections with their healthcare providers, who are at the frontline in engaging with this population. For this connection to be established, providers must be attuned to the complex

lived-world contexts of their COD patients.

To address the issue of “not being heard or understood” requires a level of shared understanding, including the complex processes of negotiation and collaborative, through which both lived-world contexts and medical knowledge are fashioned anew. The balance of lived-world knowledge of the patient and the medical knowledge of the physician must be properly calibrated, which requires listening and hearing, constant narrative understanding, and emphatic connection.

Participants’ narratives expressed the need for providers to have a certain sensitivity and a caring, compassionate demeanor to begin building a trusting relationship. Moreover, the experiences reflected by these participants with healthcare providers resonated a need to have understood their vulnerabilities and competing needs in order to provide a stronger support for their illnesses. The behavior healthcare providers exhibited impacted how they were perceived. Thus, understanding the complexities of the medical diagnoses of persons with COD, as well as their social inequities, and past and present traumatic experiences, were essential to effective practice with this population. These findings have severe clinical implications; however, it is also important to bear in mind that individuals with COD may be particularly sensitive to nuances of social interactions; thus, they may highlight these interactions more than individuals who do not suffer from COD.

Participants in this study found that inconsistency and lack of continuity with providers proved to be a barrier to quality health care. It is understandable that providers often have to leave their jobs due to the demands in their lives, but steps might be taken to buffer this population from acute abandonment or rejection. One

participant suggested that a simple introduction to the new healthcare provider by his old doctor made him feel more at ease and comfortable with the changes. Additionally, planning services that provide for increased continuity of care are an important health policy issue for care of this population. Services that use trainees, which demand frequent provider changes, are not advisable for this extremely sensitive patient group.

II

“Health care is becoming a commodity that is scarcer and scarcer for the poor.” (Peter, 2006, p.24)

Negotiating and Navigating an Arduous Healthcare System

The United States is the only major industrialized nation that does not provide universal health coverage (Institute of Medicine, 2004). Individuals with COD frequently depend on the government for their health insurance (e.g., Medicaid). The U.S. mental health system is badly fragmented and contributes to the undertreatment of mental illness. Accessing and navigating the healthcare system is a challenge for anyone, especially for those afflicted with mental illness and substance abuse. Participants in this study articulated the difficulties they have working with the healthcare systems as a barrier in coping with their health.

Uninsured and waiting for approval. Participants listed lack of insurance, being underinsured, and/or waiting for approval from the government for state disability as barriers to improving their mental and physical health. The American College of Physicians and the Institute of Medicine (IOM) have recorded a significant link between health insurance and health status. Their reports support

the conclusion that lower use of medical care by the uninsured often results in poorer health status for these individuals. Furthermore, the IOM found that the uninsured received substandard acute care and often went without the necessary care to manage chronic conditions (IOM, 2004).

Peter, an obese, 60-year-old African American male, lived at one of SH's SRO apartments. In his mid-40s, Peter was a successful businessman, happily married, with an above average income. In his family he had always played the caregiver role—to his sister with cerebral palsy and to his ailing grandmother. Thus, when his stepfather died and his mother suffered from a stroke, Peter took the caregiver role once more. Thinking his mother would live only six months, he left his family in Los Angeles and moved to Berkeley to care for her. However, six months turned into six years, during which he turned to alcohol to deal with the stress of caring for his mother, his divorce, and his failing business. This inevitably led to a downward spiral, and Peter ultimately suffered from alcohol psychosis and severe depression. After his mother's death, his alcohol induced psychosis worsened. During one of his psychotic episodes, Peter locked himself in his house armed with shotguns. After a showdown with the police, the city eventually placed him in a psychiatric hospital.

For the past eight years leading up to the interview Peter was uninsured and experienced difficulty obtaining care for his mental and physical health. He suffered from hepatitis C, severe arthritis in his arms, hands, and elbows, hypertension, alcoholism, depression, glaucoma, and had a glass lens on one eye. He felt fortunate to be able to see a doctor at one of the county clinics, but he

continued to live with severe pain in his elbow because he was unable to obtain surgery. Peter's attempt to apply for disability was denied twice. Although his depression and physical pain were disabling to a point where he could not work, the State informed him that he was not physically or mentally disabled. Since Peter needed healthcare, he attempted to work, but his severe pain prevented him from continuing with the job.

Peter: They turned me down.

I: For what reasons, I'm curious?

Peter: I wasn't disabled. [Laughs] Yeah, I know the word. Back in 1999.

I: Tell me more about that.

Peter: I had just gotten out of the hospital. We tried to go ahead and get me Disability. The State, tried to get me Disability. They turned me down. So I had to go ahead and eventually I was in a board and care for a little while, and I had to go ahead and start paying for that. I got a job, worked for a while. That's why my feet are so bad now. 'Cause I was in sales. I haven't worked since. And I went to job fairs and this and that. And I have not worked since.

Peter did not want to live on welfare and, therefore, tried to work several times. However, his pain severely impacted his ability to work. Eight years later, Peter continued to be uninsured and, consequently, maneuvered his healthcare through the county free clinics. Having been denied twice, Peter resigned any hopes of obtaining State Disability. Although he felt relieved that the county clinics existed for the uninsured, he perceived them as "substandard" and "overcrowded." The ten or 15 minutes his doctor spent with him were not enough to address his health problems. He believed that if he had insurance or was on the "Kaiser Plan,"

he would be able to “address all of [his] health problems” and see his physician more frequently rather than “every four to five months.”

He’s so rushed, and there’s so little time, and I have so many problems that things get overlooked, and he doesn’t have time to do and deal with them all. Now, if I were in a Kaiser plan, I could go to him once a month. Well, they won’t let you do that. Once every three months. And it’d be fine. But my doctor’s every four months to five months because he doesn’t have that much time.

Peter’s inability to obtain health insurance proved to be a hindrance to his care. Moreover, his story illustrated the need not merely for health insurance, but also for issues associated with accessing providers. According to Peter, waited four to five months to see his provider, which was indicative of the overcrowding and/or the understaffing at county clinics. For individuals like Peter, who suffer from multiple health issues, monthly access to healthcare providers would certainly promote health maintenance. Also, lack of ready access led to over-use of expensive healthcare options. For example, Peter experienced a flare up of gout on his hands and finger, rendering him in severe pain. Since he was unable to see his regular physician, he went to the emergency room. Lack of appropriate access to care is a healthcare system issue, as this type of coping adds to inappropriate utilization and overcrowding of the emergency department services.

Sheila, the 52-year-old African American woman presented earlier, applied for State disability two years prior to the interview based on her diagnosis of Hepatitis C, diabetes, hypertension, and major depressive disorder. During our interview, her paperwork was still at the Appeals Court waiting for review. This was a significant barrier for Sheila, as obtaining her insurance was the “magical access key” she desperately wanted and needed in hopes of obtaining a therapist.

Although she was enrolled in a dual diagnoses program at CH, she did not have a therapist; rather, she had only a case manager, who was not trained to help her with her mental health issues.

I'm trying to get a therapist. Charter House is trying to get me a therapist, but I gotta wait until the program starts or somebody's doing a nine-month program to just to study [inaudible] so that I can get it free. It's [sighs]. I've been all this time without a therapist. I need some mental help, first of all. I need some support. And that mental health and support could be the same thing for, until I can, I don't know.

Her difficulty obtaining health insurance meant that she would have to wait for approval before a therapist would see her. Her other option was to wait for some type of free program where she could be seen by students. Without health insurance participants were unable to obtain necessary medical care. Peter was forced to wait for his surgery, and Sheila continued to wait for some type of free program for her therapy.

Navigating the unfriendly, unhelpful and inflexible social system. Though most participants were fortunate to have health insurance, understanding the health system continued to be difficult. Cate, the 52-year-old Native American woman presented earlier, had chronic illnesses, including breast cancer. On the day of a surgical evaluation for a recurrence of her breast cancer, she was informed that her Medi-Cal (Medicaid) coverage had been discontinued; hence, her surgery and chemotherapy were initially delayed. Cate was furious, which fueled her determination to solve this problem.

I have a book in there with about a hundred different phone numbers to people who, who I tried to get help from. And everybody – I had to fight the State. The State say I'm not eligible for MediCal. OK, but we have a diagnosis of diabetes, emphysema, cancer now. Why am

I not eligible for MediCal? Because I worked. I had to give up my job and get treatment. Well, I was gonna have to give up my job anyway in order to get the treatment. So I gave up my job and I still didn't get the MediCal. From April till July I had no medical insurance. They didn't give me any. I had to fight them. I had to go get a lawyer. I went downtown to Legal Aid, and I'm still going through chemotherapy and everything, and being sick, and still going, doing what I have to do. I had to go downtown, see a lawyer, and her name was Miss Rebecca. Miss Rebecca fought for me. And then they tried to say I welfare frauded them. Because I worked. I reported everything like I was supposed to. And Miss Rebecca showed them where they were wrong, and that they couldn't prosecute me, and that they were wrong. So they dropped that. And I finally got my MediCal in July. But I had to go to hearings and stuff. And I did that. I got the energy and got up and went. And fought these people, and their red tape, because I needed it. I needed the MediCal or what was I gonna do? Just die? No. I'm a fighter. I'm not gonna allow this to happen. So they finally gave me the MediCal. And as it stands now, I owe \$182,000 worth of medical bills. From May through June.

Cate worked at a non-profit without any benefits and made barely enough to provide for her family. Hence, from Cate's perspective, the system "punished" her for working and thereby denied her of her insurance. Weak from her chemotherapy, Cate willed herself to fight the system so that she could care for herself. Her determination, her ability to navigate the social system by knowing who and which agencies to access, and her courage to speak up were critical in overcoming these impasses.

Stephanie, the 36-year-old Caucasian single mother mentioned earlier, lived at a Section 8 housing facility. She continuously filled out paperwork to maintain her subsidies and had to be persistent and organized to keep up with the State requirements.

I: What was it like navigating the system?

Stephanie: Very difficult. You just have to be really stubborn and stick to your guns with everything, follow up on everything, get everything they want, have it in triplicate.

I: Can you give an example when you encountered that, how difficult that was, or what was difficult about it?

Stephanie: Well, because a lot of the agencies are really unorganized. I have been trying to weeks – check this out – for weeks, to get my proof of income from – and I finally called and just got their automated system twice. To get my proof of income. This is what they sent me. A blank piece of paper. With where you could fill those things in, and sign it if, were you the social services agency. Two blank pieces of paper. Also, my worker one time made a mistake, didn't put something in the computer they needed to, and they were going to cut my Cash Aid. I did nothing wrong. I had all my paperwork. I went to my appointment. I did everything I was supposed to. And they were going – they sent me a letter, "We're cutting your Cash Aid because you didn't go to your appointment." I was like excuse me! You have to stay on it. You have to stay on top of everything because they can make mistakes too. OK, yes, they are only human, or maybe that's their sneaky, scary way of sifting through the people who really are wanting help.

I: How do you stay on top of these things?

Stephanie: Just, I don't know. I just do it. I write everything down. I follow up on every single appointment. I have a daytimer organizer that tells me, you know, every single day, what I have to do, what I have, you know, planned. I write in all my appointments and go to them.

I: It seems as though, listening to you, that organization and persistence are important when you're navigating the social services.

Stephanie: Huge. It helps that I'm a little obsessive-compulsive [laughs]. It does help. Because if you don't follow up on stuff, you don't get anywhere. You're just spinning your wheels.

Stephanie possessed cognitive abilities to be able to navigate through the system. She was articulate, organized, persistent, and determined to resolve the problem. However, individuals who did not have the same cognitive abilities possessed by Stephanie and Cate were at risk for having their services denied.

Individuals with COD often have cognitive deficits due to their mental illness and/or long-term substance abuse. Hence, many of the participants in this study indicated that the system structure was an impasse in managing their health. Paul, who had dementia, explained what happens when one is unable to circumvent and/or navigate the social and health system.

Paul, a 63-year-old African American, was diagnosed with cocaine addiction, alcoholism, early onset dementia, hypertension, and coronary artery disease. He was homeless for over five years. However, in the last six months he had been living in a single residency occupancy hotel room. He suffered two strokes in the previous five years due to his chronic cocaine use, but it had been over six months since he saw a medical provider. Paul discussed the challenges he had in obtaining refills for his medication due to changes in the Veteran's Affairs Hospital (VA) system. Frustrated that he was unable to speak with someone, he trekked to the nearest VA.

I wasn't getting my medication and stuff the way I wanted it to be done. You know? Sometimes you have to get on their case and make them really do what they have to do. They said that I missed the appointment, and I couldn't have my pills. Uh. Jesus. Medication for, for the cholesterol and heart. I have to take pills – I do – I, I take pills for them all the time too. Stroke and heart. I do. Yeah. I got three medicines, plus I take iron. I went without for about almost a whole month. They told me I missed the appointment, and like what she did, she scheduled me a month later. And that irked me. It really pissed me off 'cause I coulda died within that month

Paul encountered the healthcare system's inflexibility. His inability to see another provider for an entire month placed him at risk for a possible stroke. Paul, unlike Stephanie and Cate, was unable to articulate his need and the urgency of his request. It seemed as though when he missed his appointment, the healthcare

system was punishing him for his lack of timeliness. Or perhaps the VA was simply too inundated with patients to be able to accommodate Paul. Whatever the reason, it is clear that the VA's rules were poorly constructed for a person with COD, who may not always be able to keep medical appointments. Inflexible rules, while intended to encourage patients to be responsible about keeping appointments, introduced considerable health risks for patients could not keep appointments for reasons of personal disorganization or life stressors.

Reaching the limits. Participants with health insurance described insurance limitations and/or capitations as impediments to their health management. Limits on coverage for prescription drugs can increase the use of acute mental health services among low-income patients with chronic mental illnesses, increase costs to the government, and the increase pain and suffering for patients.

Within the last six years, Patrick, the 45-year-old morbidly obese Hispanic mentioned earlier, also suffered from major depression, substance abuse, hypertension, arthritis and its painful symptoms. Patrick's multiple physical health issues required him to take medications that exceeded what his insurance, Medicaid, would cover. Thus, it was difficult to manage his medications on his limited income.

There's only so much that MediCal (Medicaid) will pay for. You know, that's a big issue at times. Like, for instance, my medications. I am on eight medications. Per month. MediCal will only pay for six. After that they have to get a TAR (treatment authorization request), which causes a delay in my medications. So there are times that I gotta make a decision, well, what can I hold off on for four days while the pharmacist gets a TAR for MediCal to pay for this.

Without his medications, Patrick risked the possibility of uncontrolled blood pressure, worsening pain, and possible psychiatric breakdown. Hence, he made decisions about what was more important for his health—physical and mental. Every month Patrick lived without one or two of his medications until the State approved them.

There has been a time where it – well, it took – one particular time it took about a week. And it was the psych meds. And it's not like – I know, I know I use them to – as far as stability, the thoughts and all that. But like it, it took about a week, and I couldn't afford to put out a hundred and something dollars for this one particular one. And whether I was going to be reimbursed or not. There's chances I wouldn't have been reimbursed. It all depends on Sacramento. So now the six that I know are gonna go through, the six that I'm allowed per month, I make sure it's the absolute necessary ones first.

To cope with such restrictions, Patrick had to negotiate with himself and his health by creating a “needs system” for his medications.

Yeah, so basically it's like I base it on the need, you know? And as long as I have two of the psych meds out of the three, and two of the blood pressure medications out of the three, then I know I – I can wait the four or five days for the TAR (treatment authorization request) to go through because there'll at least be some of it in my system. I've learned to work it that way. Unfortunately, I don't have private insurance where I don't have to have a six limit. But I've learned to deal with it. And looking forward where I don't have to take all them medications anymore.

Negotiating or bargaining with his health in this manner certainly posed a risk for his health, but Patrick had no choice. Patrick exemplified the need to establish a creative way to meet one's needs with a broken healthcare system. After years of being on Medicaid, he learned to cope with its gaps. However, there are individuals who are caught unaware by these restrictions, have not developed such coping mechanisms, and yet, like Patrick, have medical conditions that

require consistent treatment with more than six medications per month (i.e., the Medicaid's maximum). All of these patients are put at considerable risk by limits on their prescriptions and cumbersome processes that must be continuously monitored in order to obtain appropriate treatment.

Although Medicaid covers 40 million low-income people, millions more do not meet its restrictive income and eligibility criteria and are left uninsured, as experienced by some of the participants in this study. Lack of insurance certainly compromises health, as people with COD are less likely to receive preventive care and have higher mortality rates than individuals who have insurance (Hadley, 2003). Hence, patients with COD who do not possess health insurance experience considerable stress in trying to manage multitude of illnesses. State, federal, and county grants have made it possible for mobile clinics, community health vans, and dual diagnosis programs to operate, but such facilities are insufficient to alleviate the problems and sustain the health management of the COD population.

III

They had rats in [the hotel]. They had bed bugs. They had roaches. And every day somebody was pissing in the hallway or falling out, having convulsions, or being sick or dying.

Cate

Unstable Roof Over Their heads

Participants who lived in single residency occupancy (SRO) hotels perceived their unstable, unkempt, and crime-ridden housing and neighborhoods as barriers to improving and/or maintaining their health. Residents who lived in

SRO hotels typically used shared bathrooms, shared kitchenettes, and private rooms that were often 150-200 square feet in size. The eight single residency hotels that served as recruitment sites for this study were located primarily in undesirable parts of the city with the highest crime rates. Moreover, property managers had difficulty with maintenance, and there were typically liquor stores within 100-200 feet of the hotels.

Unkempt housing. For the past six years, Patrick lived in a transitional housing apartment in Oak Town, where the property posed health risks like rodent and bed bug infestations. In addition to health hazards, the police frequently raided the SRO hotel for drugs. Furthermore, in the past few years, several people, including a teenager, had been killed during drug deals. Patrick described how his current living situation, specifically the uncontrolled bed bugs, led to severe mental health distress, where it “took me on the verge of a breakdown at one time.” Patrick had complained to management about the bed bugs, but the property managers were not quick to respond. Therefore, he took the initiative to deal with the problem by purchasing bug repellents, but this incident increased his mental stress and anguish.

I went downstairs to management the very next day, and they said, “Oh. Maintenance guy’s off today. He won’t be back till Monday.” This was on a Friday. “When he comes back on Monday, I’ll have him put some foggers in your room.” So automatically that was telling me you’re stuck in there. OK. So I, in turn, went and bought pesticides, foggers and everything myself to try to combat this problem. It didn’t help. Finally, after a week of being in there, they moved me to another room. But by that time these bed bugs got in all my belongings. I ended up being moved five different times.

Constant room changes, inability to trust people, and inefficient management of the bed bugs affected Patrick psychologically.

But with the bed bugs being bitten like that, it was like a torture. And what that did was bring up memories of childhood where being abused physically and mentally, total emotional, OK? Growing up in a dysfunctional family anyway. So it brought up that feeling of childhood, a feeling of being tortured.

Although his situation was quite severe, he had no choice but to stay in transitional housing. Because Patrick's mindset that being housed, even with the bed bugs, was a better choice than being homeless, left him with no other options but to stay.

Well, one day, coming back from the store down the street, I had to stop and cry. Because I'm saying, "Oh, I, I can't handle this, but I can't be homeless. I gotta go back there. I gotta go back there."

Patrick's housing situation exacerbated his emotional distress. The condition of his living environment was intricately intertwined with his mental health. To cope with his depression, he isolated himself and often consumed large amounts of food to satiate his depressive moods. His overeating was not conducive to his health, as he had been attempting to take his weight down from 401 pounds. Thus, his bed bug infested housing created a domino effect on his health, in that it impacted both his mental and physical health.

Precarious housing. SH's SRO hotels had neither security guards nor a system in place for safety issues. Lola, a 63-year-old African American, battled alcoholism, depression, severe knee arthritis, hypertension, and dyslipidemia. Her physical illness confined her within the boundaries of her 150 square foot single residency occupancy (SRO) room located on the fifth floor, where she had lived for

seven years. Her physical disability limited her mobility, which, in turn, led her to rely on others for shopping and other errands. However, being an elderly person living in this milieu, she was often victimized. Her neighbor who bought groceries for her also stole her money, leaving her in a quandary about whom to ask for help. The unsafe environment of the SRO directly impacted her health. She was “angry” at her current environment, fearful of leaving her apartment and, therefore, frequently stayed inside watching television or drinking. Since she had been robbed more than once, Lola felt she needed protection. She relied on safety tools that she kept nearby most of the time.

So I've been looking for my other little piece of weapon. This looks like it. No. I wonder what in the world happened to it. Oh, here we go. This is a piece of steel. (Rebar) This came off the Cypress Bridge when they had the earthquake. I found it walking up to my sister's house. And then I have a box cutter I used to use at work.

Indeed, Lola lived in a place where she had to be constantly on alert for potential abuse. Living in a situation that posed this chronic threat certainly impacted her health, whether or not she was consciously aware of it. Chronic stress can worsen depression, heart disease, and high blood pressure, and it has a major effect on life expectancy (Cohen, Janicki-Deverts, & Miller, 2007).

Wet housing. Historically there are three types of housing offered to individuals with COD—wet housing (where drugs and alcohol use is tolerated), dry housing (where drug and alcohol use is not tolerated), and damp housing. According to the literature, wet or damp housing has societal and individual benefits for people who are not interested in changing their substance use while reducing morbidity and permitting the development of trusting relationships so that

residents can be persuaded to participate in treatment (Murakami, 2005; Osher, 1991). All of SH's housing sites were considered "wet housing." Although the literature indicated that this type of housing was favorable, participants in the study commented that this type of social milieu made it more difficult for them to avoid the temptations of using. Participants pointed out that the "smell" and or "the gathering" enhanced their temptations. For those individuals who were in recovery, it became easier to relapse.

Sasha, a 54-year old African American woman who lived at one of SH's SRO hotels, suffered from asthma, hypertension, alcoholism, depression, and cocaine addiction. She had undergone numerous recovery and treatment program over a period 20 years. Her recent dry spell lasted only three months and she relapsed three weeks before our interview. Sasha, who was intermittently homeless, was elated when she was housed. However, living in an unkempt and unsafe surroundings contributed to a sense of unhealthiness and increased temptations to use drugs once more.

I cannot stand people in this building. I remember when I first moved in here, I didn't stay here for five whole days. I just put all my stuff in here. The first day or two days after I stayed up in here, somebody came – 'cause I had left the door open, and I left my window open, and I was taken – what was taken from me was my CD player. Another time 200 and some odd dollars were taken from in here. I mean it seemed like you could just come in here and lay your money down. You can't do that. Not anymore. So I got to hide everything, hide my money and stuff like that, if I want to have it. I don't even trust people in this building right now today, 'cause, you know, people might just come busting in your room for no reason. I'm just – the people in here, they don't give a damn about other people's privacy. This past weekend you could smell crack all in the hallways. We just moved down here last week. You got cigarette butts on the floor, cigarette butts smashed up on the fire extinguisher. You got

cigarette butts way down there. You got crack smell all in the hallways. Can't do nothing about that. And I'm just tired.

Feeling helpless about her living situation, Sasha would rather leave the hotel room and wander the streets to evade her temptations, leaving her with a sense of being homeless and nomadic once more. Not only was her home unsafe, it was a constant reminder of her drug habits and made it more difficult for her to maintain her cleanliness. Life at the SRO was a constant challenge of her will to keep away from drugs and out of harm's way.

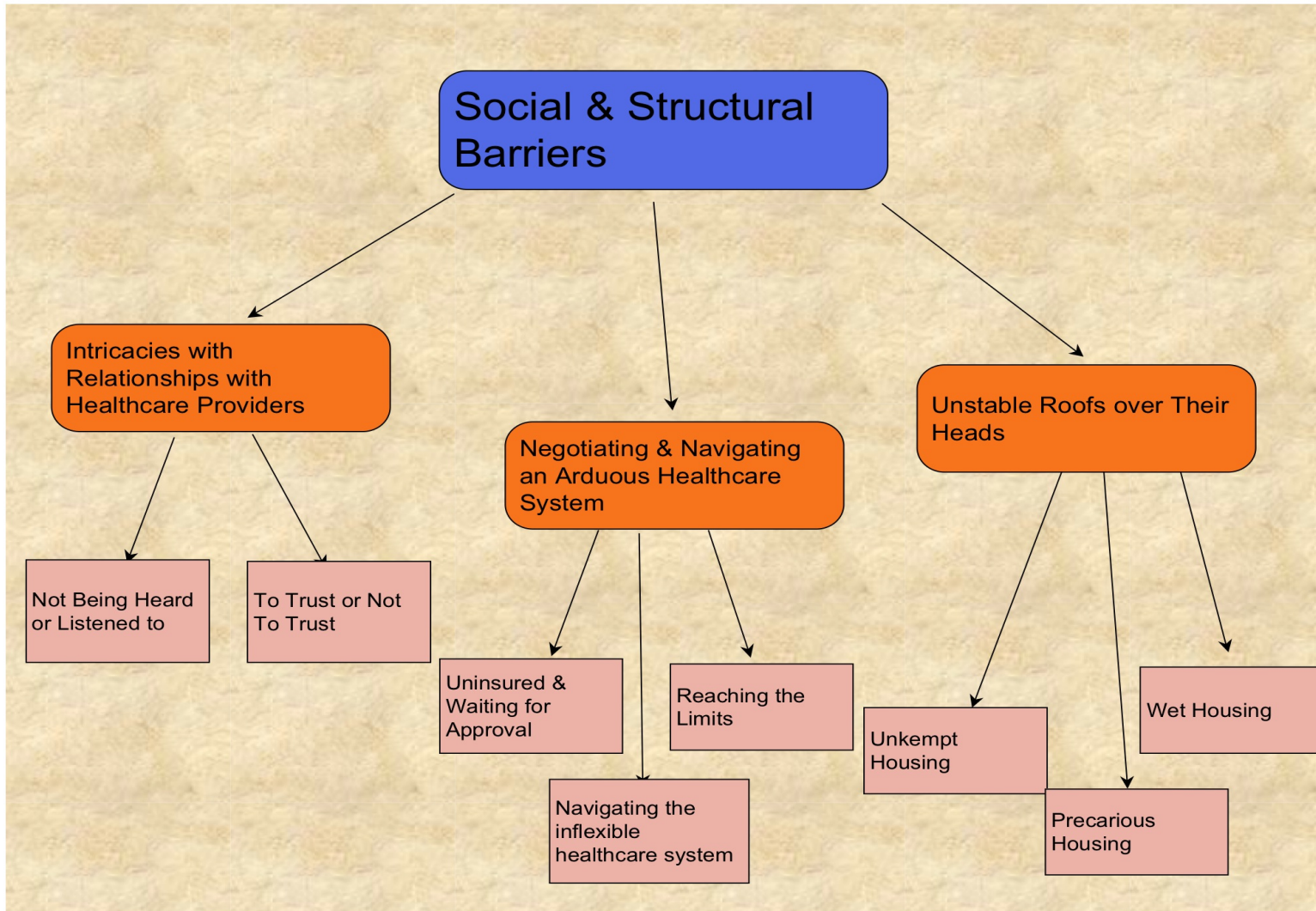
I smell it, but what I do is I leave. I go out and get some air and just leave. And hopefully the smell will be gone by the time I get back. On occasions, sometimes I come to the realization that why, why would I want that [drugs]? And I'll say no. And then I'll just leave. I'll go somewhere else. I'll go to around the lake. Going around the lake helps you build your confidence and not having to come back in here and want to go to somebody else and buy drugs.

Sasha's housing environment triggered her temptations to use. She had succumbed to temptation once and might again. Although she coped with these cravings by leaving, it was questionable if this pattern was sustainable. Although her housing provided some comfort, for example, a place to lock her possessions and a place to sleep, the constant presence of drugs was a severe test of her sobriety.

Wet housing appeared counter-therapeutic for individuals with COD who were ready for treatment. Unfortunately, all of the houses available in the study area were run as "wet" housing in order to provide the broadest range of supportive services. Participants' statements suggest that a differentiation of services might prove more efficacious for those truly committed to a non-using lifestyle.

In summary, people with health problems are disproportionately likely to occupy the least health-promoting segments of the housing stock, a factor that may exacerbate their health problems, as articulated and underscored by the participants. The social and physical characteristics of the surrounding area are vital in maintaining good health. Poor quality accommodation is often situated in impoverished surroundings with few local amenities. These sites contribute to making vulnerable individuals housebound, thereby negatively impacting their health. Due to the complex interaction between housing and health, it is important that cogent, workable, and sustainable housing accommodations be developed.

Table 1:



CHAPTER 5

COPING PATTERNS

Introduction

This chapter presents patterns of coping with the situated position of being diagnosed with co-occurring disorder (COD), and receiving treatment in the healthcare programs. The patterns described foreground the interpersonal relatedness of individuals with COD. Interpersonal relatedness refers to the need to establish close, stable, nurturing, and protective relationships (Shahar, Blatt, Henrich, Ryan, & Little, 2003) Given that individuals with COD often have difficulty forming interpersonal relationships due to several factors such as cognitive difficulties, lack of social skills, mistrust, and stigma, the participants in this study narrate their successes and failures vis-à-vis their interpersonal relationships to family, informal helpers, formal healthcare providers and the community. Theoretically, interpersonal relatedness and difficulty with attachment have been a significant issue for clients with COD.

Three distinct patterns of coping with mental illnesses, drug and/or alcohol addiction, and physical chronic illnesses were observed, which included (a) interconnectedness, (b) ambivalence, and (c) waiting in defeat. The three patterns of coping describe the commonalities and differences in individuals' responses to living with COD. Each of these patterns is discussed using paradigm cases to articulate the individuals' beliefs and practices. The informants are introduced using fictional names only, and identifying information has been altered to protect anonymity.

Interconnectedness

Interconnectedness represented the significance of interrelationships between individuals with COD and family members, friends, and healthcare providers. These connections helped individuals with COD cope with their addictions, mental illness, and physical health disorders. It was through these relationships/connections that individuals with COD were enabled to maintain their sobriety and cleanliness. Interconnectedness was also a factor that influenced and/or could subsequently lead to turning points in one's life. Often times, because of stigma or lack of knowledge, family members abandon loved ones who are afflicted with addiction and/or severe mental illness. However, in some instances, family links, such as mother-daughter dyads, can serve as incentives for changes in one's life.

Cate

Connection with her partner. Cate was a 52-year-old Native American woman who grew up on an Indian reservation with her father. However, she never had a sense of belonging. Cate lived a life filled with trauma, such as multiple rapes and emotional suffering. During her early teens, she turned to heroin and crack as means to suppress her family problems. By her 20s, she was chronically homeless, severely addicted to crack and heroin, suffered major depressive disorder, and had given birth to three children. During that period she was forced to relinquish custody of her son and two daughters, despite which she was able to form a long and lasting relationship with another homeless man, Dennis, who became integral to her recovery process. Although she was clouded by her

addiction, her salient relationship with Dennis allowed her to realize other possibilities, such as a life with her daughter without drugs. Dennis became the catalyst for change. Although Dennis suffered from drug addiction, he wanted Cate to give up drugs for the sake of her daughter.

We were sitting in People's Park, and I had just spent \$900 on drugs. And I blew all the money. I didn't have no money left. And I was depressed. And he told me that didn't nobody do this but me. You know? And why should I feel depressed? It's over. It's done. It's something I wanted to do and I did it. And I told him I was feeling guilty because that money was, you know, not just my money. It was Sabrina's money too. And I blew it. So he said, "The only way that you're gonna overcome all this stuff is to not use and get clean." And I didn't do it. So that night I snuck off. I had 20 more dollars, so I went over to this girl's house, over there by the park, and I was getting high. He kicked in the door. He said, "Your daughter's outside with me. Sleeping on the porch of the Baptist Seminary, and you up here getting high. You don't know what could happen to your daughter. You got a lotta nerve." That's what he told me. And he took and he threw a quarter and hit me in the face with it. And he told me, he said, "Now, pick up that quarter and go give it to your daughter." He said, "Cause the next time you pull some shit like that, she gonna have to call the morgue to look for you. Somebody gonna kill you." So – and it just made me think, and made me think and made me think, and, and I'm like, "God, I really do gotta do something about this." And that's when I did.

Though the drugs provided Cate with euphoric feelings, in the aftermath she was plagued by depression and guilt for having spent her daughter's money. At this point, Cate began to develop concerns for her daughter. Yet they were not strong enough to stop her from using drugs. In essence, Dennis' honesty and actions of "throwing the quarter" and "hitting my face" that woke her to reality. The physical act that she would die induced a shift in her mind and emotions. At this moment in her life a new sense of self began to emerge. Cate realized that Dennis' conduct exhibited his overwhelming love towards her. His was an act that

had never before been shown to her in her lifetime. Dennis' love and intervention precipitated a behavior shift in Cate. Perhaps without Dennis' insistence or without their relationship Cate would never have come to realize the importance of her children.

To me, that was a **true sign** that this man [Dennis] cared a whole great deal about me. I mean during the time that I was using, didn't nobody care about me. Nobody. Nobody at all.

Connection with her daughter: Unexpectedly, at the age of 27, while Cate was homeless, her daughter, Sabrina, who was 13 years of age, decided she wanted to be with her mother. Sabrina left her father's home on the East Coast to be with Cate. Sabrina's insistence on being with her mother illustrated an unconditional love towards Cate. Thereafter, Cate, who had never acted as a mother, felt obligated to give up drugs for her daughter. In this passage, Cate came to recognize how much love Sabrina had for her and that it was up to her to provide for her daughter. Morally, she understood that a mother could not place her daughter in such a precarious situation. Thus, her daughter's return meant a second chance at motherhood and solidified the importance of a life without drugs.

When my daughter came to live in the streets with us, I had told her I didn't have no home for her to come to. She came back from Philadelphia from her Daddy's, and she wanted to just be with her mom. And so I kept thinking about that, and I kept saying to myself, 'Now, if my daughter can give up a beautiful life in Philadelphia to come be with her mother, and her mother's living in the streets, that's a lotta love'. So I decided that I owed her more than that. I owed her love too. I was ashamed for leaving her in the streets like that, and being selfish to go get high. I was more ashamed than anything. And I'm like how could I do this to her?

Her daughter's return and Cate's decision to become a mother provided her with self-confidence. Sabrina's presence encouraged Cate to fight for her other

children, also taken away from her by Child Protective Services. Thereafter, Cate worked on creating and building a family unit she had heretofore never known. The notion of building a new family unit underscored a need to change her lifestyle. Thus, Cate began a transformation, becoming more confident and more expressive of what she wanted. Her experiences with Dennis and Sabrina influenced the emergence of her new self. With certainty she asserted her needs and wants:

I wanted Tenasha and Shawn back. I had lost custody of my son to his grandmother. So that was the beginning of us getting started, as I say. I worked very hard. I drug tested four times a week.

Cate found a strength of purpose in her commitment to her children. The process of detoxifying her life of drugs and staying clean was driven by a wish to reshape her mothering and to create a family unit. The driving force was her relationship with and responsibility for her three children. Cate no longer felt she needed drugs to obtain euphoric feelings. Rather, her children and her family provided her with the comfort and positive feelings she needed. Her children gave her a sense of belonging and connection in the world

I knew what I wanted. You have to have something in your heart in order to want it. You can think about it and you can act upon something else. But if you really want it in your heart, it's gonna happen. And I WANTED TO BE CLEAN because I wanted my kids back.

Mind and body connection: Cate's worst fear was relapsing. Therefore, she developed bodily skills and practices to recognize signs of potential addictive behaviors. She began to understand how her body reacted to certain chemicals. For example, while on chemotherapy she suffered severe nausea, for which she

was prescribed Lorazepam to suppress her symptoms. Unbeknownst to Cate, Lorazepam, a short acting benzodiazepine, could be addictive. After several doses, she began to feel different. Lacking “energy,” she started depending on Lorazepam “to go to sleep.” Instinctively, she felt that something was not right with her mind and body. Subsequently, she learned to look for more signs of bodily and mental changes. She noted that she “couldn’t sleep right” and her “eating was off.” After assessing the changes in her bodily functions, she realized that the Lorazepam could have been the culprit.

And I was eating these pills like it was the thing to do. Even when I wasn’t sick.

She became proactive, researched her new medication by searching the internet. After reading that Lorazepam was a highly addictive drug, she immediately threw out the drugs and removed the toxins from her body.

I flushed the rest of the Lorazepam down the toilet stool and I detoxed myself from them. And I got myself clean off of them. I flushed the pills down the toilet, got rid of them. I bought me a bottle of cranberry juice and set it on the side of the bed, and I bought a case of water. And I started flushing my body, to try to get it out of my system. Cranberry juice, it flushes your system out. And water just kinda replenishes it. I had been up for three days. I couldn’t sleep without the Lorazepam, so I stayed up for three days. And like before I went to sleep, I was just so punch sleepy, you know, like I was almost drunk, it felt like. And then when I finally did go to sleep, it was a relief. It was a relief. And I woke up that next morning, and, after I took my vitamins and stuff, I started walking around the compound and just talking to myself.

Cate became attuned to the slightest change, physical and behavioral. She “recogniz[ed] that there was a problem.” She knew she possessed a strong addictive predisposition and could fall prey easily to certain types of medications. Thus, she developed an internal alarm system as one way of combating old habits

and maintaining her cleanliness. Her capacity to cope with her addiction expanded. She developed numerous checks and balances on her sobriety, including careful monitoring of warning signs. Additionally, the passage quoted above symbolized Cate's act of cleansing and purging her body of toxins. Essentially, this process represented a rebirth and an actual sense of being reborn.

Cate's cleanliness was a state of health on which she did not want to gamble. Relapsing could mean losing her family again as well as her new life. She began to assert herself as agentic and non-destructive. She elucidated the notion of her rebirth by noting that "all of this world is still, even after 20 years, it's still new to me."

I want to be clean and sober. I choose this because it's a new life for me out here. I was so addicted for so many years, everything is new to me. And it's beautiful out here. When I was addicted to the heroin and the crack, I didn't listen to the birds. I didn't look at the greenery around me or smell the flowers or notice what a little hummingbird is.

In the past, Cate's life as an addict was isolated, filled with artificial emotions generated by drugs. However, the process of rehabilitation, relearning and living a new life provided her with positive emotions. Without the skills and techniques to recognize the potential for relapse, Cate risked a possible return to an empty existence—devoid of a sense of self and vitality. Hence, maintaining her sobriety was a central concern.

Connection with the community: From the day she decided to leave a life of drugs behind, Cate worked continuously to reconstitute a healthy way to be in her world, whether it was in relation to her addiction, to mental illness, or to physical ailments. She developed considerable skills in engaging and connecting with

others in her community. Through the years she formed and developed relationships within the community and eventually became a key community builder. While raising Sabrina, and while fighting the court system to regain custody of her other children, Cate became active in the homeless community. To maintain her cleanliness, she felt she needed to give back to the community.

Cate volunteered as a peer chaplain at Charity Church, where she searched and updated housing databases for the homeless community. Additionally, she counseled individuals who were mentally ill. She spoke of the time when a distressed mentally ill homeless man, who was recently discharged from a psychiatric facility, came to the church seeking help. He felt “no one listened to him” and that his psychiatrist just wanted to “keep him loaded on drugs.” Upon hearing this, Cate empathized with the man. She listened to him, talked with him, and told him that she had had similar experiences.

I said, “You know,” I said, “I’m here. Any time you want to talk, or we could go to a meeting if you wanted to.” And he pulled out this machete. And he said, “I want to die.” And I said, “If I have to,” and he said, “And if I have to, I will take you with me.” I said, “But why? are you doing this? To yourself?” He said, “I don’t want to live anymore.” He said, “Life ain’t worth living anymore.” I said, “Yes, it is.” I said, “I’ve been in your shoes and I know how you feel.

Cate managed temporarily to suppress the man's suicidal thoughts. Thereafter, she asked her colleagues to help him. Volunteering at Charity Church served as a constant reminder of her past experiences, a time and place she would never want to be again. Furthermore, assisting individuals with similar backgrounds helped her keep her current life in perspective and thereby maintain her sobriety.

Cate spun a web of connections in her life to manage her addiction, mental illness, and her multiple physical health issues. Like a dreamcatcher, she was at its nexus. The myriad of relationships she built created her new self and her new life. Without these links, specifically her relationships with Sabrina and Dennis, Cate would not have been able to achieve her sobriety. Both her daughter and partner supported her emotionally while battling heroin and crack addiction. Furthermore, they became her cheering section and stronghold during her recovery phase from the mild stroke she incurred during that time.

Dennis and Sabrina made me start walking. And I had a ball in my hand. And I had to squeeze it. Every time I stopped squeezing it, they would make me squeeze it. In order to get my hand back to normal. I still don't have the full use of these fingers, but because of Dennis and Sabrina I have the use of my hand.

Her family supported her cleanliness and motivated her to keep fighting for her health. Cate's family demonstrated how the basic unit of society can provide strength; it was integral to Cate's self and social development. Her family became a bulwark against her difficult times. Perhaps if Cate had not been able to rebuild her family and maintain these relationships, she might not have been able to successfully enter her recovery and rehabilitation phase. The pivotal turn in her life began when she allowed Dennis to enter her world, which, in turn, led to her realization about the importance of her children. Cate's children and Dennis provided her with the essential capacity for learning, self-confidence, and positive social interaction. Cate's transformation began and continued with the return of her family.

Stephanie

Interconnectedness involves participating in significant relationships. Although Cate's story epitomized this coping pattern, several other informants had similar experiences. Stephanie, the 36-year-old Caucasian single mother described in the previous chapter, suffered from chronic abdominal pain and bipolar disorder and was recovering from methamphetamine (speed) addiction. Like Cate, Stephanie's connection to her child and becoming a mother signified the need to quit using drugs. Stephanie and Cate were cognizant that motherhood meant protecting their children; thus, eliminating their drug habits became a central concern.

I never touched it again. I was pregnant and I wasn't going to do it anymore. I stayed away. I forced myself into a homeless shelter, where I had to be home at 7:00 o'clock. I would never hurt my baby. So there was not coping mechanism. [It] wasn't an option to do it again.

Connection with health providers: Stephanie knew that to provide for her daughter she must be able to care of herself. Stephanie, who had grown up with an absentee father, also a drug addict, wanted to provide a better life for Lily. Not wanting Lily to grow up in the same manner as she did, she soaked up as much knowledge as she could about raising a child.

I don't want her to go through that pain and agony and have to wait till she's 40 years old to get anything figured out, you know, to figure out why she's acting like she's acting or pick the wrong men all the time or, you know, be her own worst enemy. Nobody needs that. Certainly not me, and I'm trying to break the pattern there."

Therefore, she enrolled at a nearby college, took child development courses, and continued her weekly therapy sessions. During that time, Stephanie met Megan, her therapist, who became instrumental in shaping her parenting skills and helping her cope with her bipolar disorder and “speed” addiction. When Stephanie encountered difficulty with her parenting skills, she often turned to Megan for advice. For example, when Lily demonstrated crying spells while at daycare, Megan helped Stephanie troubleshoot possible causes for such behavior.

I spoke with my therapist about it, about what I could do. And I started to – I left pictures of she and I together with her so she could look at them when she was missing me. We gave her whatever security toys she particularly liked or needed to feel comfortable.

Stephanie felt comfortable with Megan, which enabled her to fully disclose her fears and concerns. When Stephanie experienced nightmares about losing Lily, which also meant losing her own self and a potentiality for relapse, Stephanie turned to Megan. Their therapeutic relationship provided her with an outlet to voice her fears and concerns.

It’s terrifying that I’m waiting for the other shoe to drop. I’m waiting for her to be taken away from me somehow, for the, you know, the lightning bolt to strike or something, and then I would like – I don’t think I’d make it through that, if anything happened to her. Which is really frightening. I’d have to, obviously, but I don’t know if I’d have the will to.

Familial links: In addition to Megan, Stephanie’s stepfather and mother provided her with the strength and support to raise Lily. Her parents’ help enabled her to organize her busy schedule and allowed her to have the time to attend groups and visit her therapist. In the past, her relationship with her parents was tumultuous. However, Lily’s birth turned their relationship in a positive direction.

As Stephanie and her mother rebuilt their strained relationship, she was able to confide in her mother about her past addiction. Rather than admonishing Stephanie, her mother became one of her main support people.

Both of them were at the delivery. They've always been helpful if I've had one appointment or another, coming over and taking care of her. While I was in summer school, one or the other or both would come over on a day when I didn't have daycare for her or something and take her. For instance, Fridays and Mondays. My mom would usually come on Fridays, and my dad would usually come on Mondays to take her while I was at school or doing my therapist appointment.

Unlike Cate, whose partner, Dennis, was influential in her life, Stephanie's partner was quite the opposite. At the time of the interview, Jack, a 36-year-old Caucasian male, was still addicted to methamphetamine. Stephanie feared Jack's influence on their daughter. Although Jack continued to use illicit drugs, Stephanie did not want to ban him from visiting Lily. She knew that Lily needed her father. Hence, she took steps to ensure that Lily would be safe around Jack. She tested his urine for methamphetamine prior to allowing him to interact with Lily. Therefore, most of their visits occurred at Stephanie's house and were always with adult supervision. Jack's addiction reminded Stephanie of the life that she did not want for herself or her daughter.

[I] don't want to take that [relationship with Jack] away from Lily. I don't want her to have abandonment issues, you know, like I did. On the other hand, I don't want her to grow up with her dad making her think it's OK to do drugs. Because my dad certainly presented that picture to me.

Both Stephanie and Cate suffered co-occurring conditions and histories of trauma. Mothering became the central purpose and defining role of their lives. For them, motherhood was a major source of both identity and self worth. Their

"mothering" became a primary motivation for quitting drugs. In short, their connection to their children and family members figured importantly into their self-esteem, behaviors, and treatment decisions.

Rick

Male informants also demonstrated that interconnectedness was a coping pattern. Rick, a 43-year-old African American male, suffered from alcoholism, major depressive disorder, chronic back pain, and hypertension. At the age of 14, Rick started drinking alcohol to escape his father's abusive behavior. At the time of the interview, Rick had been sober for six years.

My father was very violent. He beat my mom and, and us, and it was real scary, you know, and all my life, you know, being the only son, I've always hid in the bottle. I've been drinking since – I used to have blackouts at 14 years old. I've been drinking most of my life. I've drunk breakfast, lunch, and dinner

Unlike Cate and Stephanie, whose pivotal turns were influenced by their children, Rick's fear of dying became his purpose for living.

I felt like I was walking around with a cloud over me that was always raining and thundering and lightning. And it was just, you know, I was just always why me, why me. I thought about, I thought about stepping in front of a BART train at one time. You know? And, you know, the fear of killing myself, thinking of killing myself and the fear of killing myself, it forced me to start looking for answers outside of myself,

Rick was "desperate" and wanted to find help. In 2000, he entered a "homeless rehab for vets." However, it took "three times before [he] got it." Finally, on September 4, 2000, Rick stayed at the rehabilitation facility for four months. Thereafter, he attended Alcoholics Anonymous (AA) meetings, albeit skeptical that it would help with his addiction. After attending AA for "ten months," Rick was still

unclear about the tenets and the purpose of the group. It was during one of these meetings that he fortuitously met his future sponsor and friend, who guided him through the AA program. Rick's sponsor was able to penetrate his defense mechanisms. His connection with this man allowed him to accept help from others and rebuild his relationships with his family, especially his daughter.

He [sponsor] taught me how to walk through things, how to be consistent, you know? How to not bite off more than I can chew, how to be honest with myself. And so, therefore, it comes out in all I do to other people. It's not that I'm trying to impress people or things. It's that I want to do this for me now.

Rick allowed his sponsor to enter his world and help him with his addiction. His sponsor demonstrated patience and understanding in the face of Rick's anger, depression, and addiction. As with Cate and Dennis' relationship, Rick's connection with his sponsor provided him strong underpinnings for shaping his self-confidence and self-esteem.

His work with his sponsor opened new possibilities in Rick's life. His ability to work on himself and his sobriety gave him the opportunity to reconnect with his two sisters and with his daughter. These relationships further solidified the importance of his sobriety. When he was drinking, his sisters would "close the blinds and lock the door." Additionally, they walked away and did not interact with him. After six years of sobriety, his sisters now depended on him.

Today they call me when they need something. I'm one of the only males in the family. And, like I say, I'm reliable. I do what I say. I don't say anything that I will not, I'm not capable of doing. I'm just totally different person. She wants me to watch my younger niece. I'm reliable now. There's been a time when they wouldn't let me watch the children.

More importantly, Rick reconnected with his daughter, who had just turned 17 at the time of the interview. During his addiction, Rick was an absentee father. His daughter could not rely on her father for any type of assistance. Furthermore, like Rick's sisters, she was embarrassed about him. However, within the last six years, Rick had mended their relationships. He made a commitment to spend more time with her and to become more reliable.

My daughter's graduation from Antioch High School was marvelous. I was there. When they [daughter and step-daughter] were young and I was struggling with my alcoholism, you know, I had to make a lotta amends and stuff like that for that. But, you know, it was like, we were so bonded, it was amazing to me. And I guess kids forgive? My youngest daughter was showing off and running around the school, telling everybody, "This is my dad." And, it was, a very powerful experience for me.

Similar to Cate, Rick sought out relationships outside his family and his sponsor. He formed a bond with his therapist and the service team at the supportive housing program. These salient relationships enabled him to cope with his past experiences and depression.

I've got therapists in my corner. I have service team workers. I have nurse practitioners, and I'm utilizing all of these services to try to be balanced in my mental and my physical and emotional health.

Although these therapeutic relationships helped him, Rick became dependent upon and was afraid to leave them. For example, when he obtained his Section 8 voucher, a very coveted item; he continued to procrastinate in his search for an apartment and eventually decided to give up the voucher. He thought that moving out would mean leaving his comfort zone and a support system he had created and built over a three-year period. He worried that he would not be able to survive in the world without these relationships.

Since [the last interview] I have decided that I'm gonna stay here for about a year or two. So I decided to put it off on – they put me at the back of the list, so that I still have that option. But I wanted something in Berkeley. [Fear] is a major factor. That's why I really thought about it. To move now, and I was kinda fearful of moving away from my support at this time. I didn't want to go through that [moving out of SRO] at this time. [Fear] was a major factor in my decision to go to the back of the list.

Rick, like Cate, utilized his connection to the community as means of coping with his addiction. He enrolled in classes and obtained his certificate to teach a wellness program. Through these programs, not only was he able to help individuals like himself, but he was able to continue treatment for his mental health.

I'm the facilitator of this group [wellness class], and I've been drawing people – what I do is I give of myself, and in that there's the reward of making me feel like I'm worthy and I'm worthwhile and others are worthwhile, and we can help each other. It's not like I'm doing something for nothing. I'm getting a lot out of it. I'm getting a chance to work through my issues by being patient and listening to other people, and not keeping it for myself.

Additionally, these classes gave him a forum to reflect on his past addiction and to filter through his depressive symptoms. It was during one of these sessions that he realized that he was heading towards a depressive state.

When I turn off my phone and I don't start answering the phone and lock up in my room, then I'm going through a depression.

Interconnectedness, as exemplified in the above cases, is marked by engagement with relationships within and outside family networks. Additionally, parenthood prompted and solidified the importance of abdicating drugs and alcohol. Each of the informants indicated that a strong family unit helped them cope with their mental and physical illnesses. These links provided a solid foundation for individuals with COD to manage with their recovery and with their

multitude of illnesses. Interconnectedness enabled these informants to reach out beyond themselves and ask for help. To quote Cate, “It takes a tribe to raise a person.” That is, rather than fighting their illnesses alone, they utilized connections with others as sources of strength to move forward.

Ambivalence

Some individuals with COD were ambivalent about seeking care for their mental and/or physical health care. In contrast with interconnectedness, where the informants used their past to help them cope with their present lives, this coping pattern illustrates how past experiences pose a hindrance to seeking mental health care. Past traumas (e.g., abuse) created a sense of vulnerability that, in turn, led to issues of trust and mistrust.

Patrick

Patrick’s story illuminates a balancing of withdrawal and connection in forms of coping with mental illness. Through this balancing Patrick vacillated between reaching out to others and reaching within himself to manage his depression and anger. Although therapists and psychoanalysts may view isolation or withdrawal as poor coping, in Patrick’s case withdrawal helped him move towards a healthier sense of self.

Patrick, a 45-year-old Hispanic male, suffered from major depression, post-traumatic stress disorder, substance abuse, morbid obesity, hypertension, arthritis, and chronic pain. In the past, he had been incarcerated multiple times for violent behavior due to uncontrollable anger and substance abuse. Six years prior to the interview, Patrick, who was on parole, had given four positive drug tests, which

meant he would be sent back to prison for parole violation. He already had “two strikes plus a physical confrontation,” and a parole violation could mean a third strike, which would translate to “25 years to life in the state pen.” Luckily, his parole officer gave him one more chance, the option of attending a 60-day substance abuse program instead of returning to jail. Fearful of going back to prison, he opted to attend a 60-day dry out program.

It gave me enough time to get clear-headed. And to think to myself, ‘Aren’t you tired of this? You’re not getting any younger, to be locked up. You get no respect. Where are you going with this?’ So basically that’s what the 60 days did for me. And the only thing that kept me from going back to prison and just getting the 60-day dry-out, because I was continuing trying to get straight. I earned my GED in 2000. With – being clean and sober, it gave me a chance to really care about myself. And that’s being honest. All right? Under the influence, whether it be drugs or alcohol, you know, it was an escape. But it also made – didn’t give me the chance to care. About me. And so thinking clear-headedly and saying, “I’m tired of it,” “Let me see what I can do.”

As an addict he felt he was not respected or that he mattered in the world.

The parole officer’s action, however, demonstrated to Patrick that he was important. Rather than punishing him, the parole officer gave him an opportunity to attend a recovery program. During his 60-day tenure there, he realized he was “tired of going back and forth to prison,” and this offered him a different type of life. Instead of responding with anger and disdain, Patrick consciously chose to assess and reflect on his past and present life. He realized that if it had not been for the parole officer, he might not have had another chance in redeeming himself. The 60-day dry out spell thus became a symbol for his new, non-destructive and non-addictive self. Additionally, this event precipitated a behavioral change in his life.

This experience provided him with the notion of healing himself and moving into a new direction.

Withdrawing within oneself: Tired of life dominated by drugs and violence, Patrick turned a new page in his life. Unlike Cate, whose family encouraged her to quit drugs, Patrick chose this new life for himself and not for anyone else. Being clean was the first step, and managing his mental illness--his depression and anger-- constituted the second step. Patrick's anger was a significant factor in his propensity for violence. His past coping experiences with his anger only led him to jail. Thus, he knew he needed to channel this strong emotion in a non-destructive manner; to override it with a conscious behavioral change.

My anger. I'll blow up on somebody. To me that's trouble. Because if I blow up on somebody, later on, I feel bad about it because they had nothing to do with my problem. And then if I turn around and feel bad about that, that adds to my problems, because now I'm feeling emotionally bad, besides physically bad. And that causes another stressor, because I try to be conscious of my actions, because I know there's consequences for every action that I make. So, you know, I've been trying to combat this and have come a long way in doing it. The anger has, has led me to prison. I mean just overall health issues that anger tear, working on me, you know, mentally, physically, emotionally, spiritually, the whole well being. There had to be a change.

Starting from that pivotal point, Patrick learned over the next six years how to recognize mental and situational cues that exacerbated his anger. When unable to control his emotion, his anger consumed him, and his only means of coping was isolation. A spiraling effect always then ensued. Cognizant that isolation exacerbated his mental distress, he consciously chose to prevent himself from projecting his anger onto others. Patrick learned from past experiences that reacting in an angry or violent manner had severe consequences, which

underscored the need for behavioral change. Thus, he became aware of his every action . For example, as he got on the bus heading for the gym, Patrick said “Good morning” to the bus driver. When the bus driver simply ignored him and was unresponsive, Patrick, who was self-conscious, felt snubbed and “[un]acknowledge[d].” The bus driver’s behavior stirred angry thoughts in his mind.

The little devil, the anger wants to come up and say, “Oh, well, hey, you know what? I spoke to you. You can’t speak back to me?”

Patrick knew he had to suppress this nonsensical thought. So he paused and, rather than acting on these thoughts, simply let them pass.

But I end up getting off that bus saying, “Oh, well. Well, maybe it’s not a good morning for them.” So I get on my way.

Patrick employed checks and balances with his thoughts and feelings to help him control his anger. In his mind he saw a “devil” on one shoulder and an “angel” on the other. The “devil” represented poor coping and the “angel” appropriate coping. He used this balancing scale as a means for figuring out how he should deal with his depression.

And the little devil’s saying, “Don’t go outside,” you know? “You’re gonna get in trouble.” The little angel’s saying, “No, you need to go outside.” To go outside is more healthier than staying inside. But sometimes the little devil wins out. And so I don’t get in trouble, that’s what I do. I isolate.

The day of our interview marked the anniversary of the death of Patrick’s abuser. Although 30 years had passed, Patrick could not forget or cope with his past abuse. During the week of the interview. Patrick’s emotions were like a rollercoaster. There were days where his depression and anger paralyzed him

emotionally, and he withdrew, hid within his own world—his safe place. Being alone allowed him to reflect and think about this horrific event in his life.

Last week I didn't make it. Physically and mentally things got to me. So I stood in my room, stood in my bed, till 4:00 o'clock in the afternoon. I called [my psychologist] up that morning and said, left her a message: "I can't make it. Physically and mentally. I'm turning the ringer off on my phone." I needed that space, silence, and solitude. The depression level goes up, goes down. And I compared [emotions/feelings] with like a computer. You gotta turn it off and reboot. And that's what I would do in that time [isolation]. But not dealing with nothing. I try to sleep the day away to hope the next day is better. OK? But you can only sleep so long.

Isolation and sleeping enabled him to recharge and assess his current state of mind. Closing himself off and pulling away from any stimuli allowed him to be able to cope with his depression. For Patrick, interacting with others or the outside world at a time when he was unable to cope with his own emotions led to worsened depressive symptoms and an exacerbation of anger followed by violent behavior. Withdrawing became a safe form for Patrick to channel his emotions using patterns that were non-destructive for himself and others.

In addition to his "devil versus angel" thought process, Patrick developed a system to gauge his depressive moods that determined how he should proceed with the day. He modified the pain scale that health providers typically use to assess pain status and applied it to his own mental health. Based on the numbers, he then decided how to approach the day.

On a scale from zero to 10, my depression level, which I call normal, is at a 3. A 3 is being able to cope, being able to handle. When it starts getting higher than a 3, then that's where thoughts of isolation come in, not wanting to deal with nothing, wanting to sleep the day away. It's like a level 3 is normal, for me. A level seven is where I wouldn't even want to get up, I won't even get up to shower, nothing. I just say I don't want to deal with nothing. Somebody come

knocking at my door, I don't answer the door. The phone rings, I, I turn the ringer off. I've been steadfastly trying to work on feeling normal at zero. A zero to me would be peace of mind. Where my thoughts don't bother me. Where I can cope with the thoughts and deal with them rather than isolating myself, and not dealing with them on a daily basis. That would be a zero to me. Peace of mind, where I, where the thoughts don't come at me, where all different situations that come my way I could piece it or put them to the side or prioritize them. What needs to be done first. Rather than saying, ooo, holding onto myself and saying, "I don't want to deal with it. Let me just shut down." But that has been one of my safety mechanisms, is to shut down, rather than blowing up in people's faces. A ten is when the suicidal thoughts and everything come at me. I haven't been there in probably about a year and a half.

Through this system, Patrick developed the capacity to understand his mental state in various situations. In this passage, he was cognizant that isolation, though helpful at times, was not the ultimate solution to his depressive state. His ability to reflect enabled him to control his actions; in so doing, he was able also to distance himself from potentially dangerous situations and blunt his potentially destructive responses. Patrick's coping pattern was to recognize the danger and to back away from it by means of isolation. Given his history of violence, Patrick created remarkable self-management insights and skills.

Connecting with health providers: Patrick established a relationship with his therapist and medical providers to help him with his mental and physical illness, though it took years for such attachments to form. His past physical and sexual abuse made Patrick cautious about trusting anyone. He feared that full disclosure in a relationship, therapeutic or non-therapeutic, left him vulnerable to emotional trauma. Therefore, he observed at a distance prior to participating in any health or community services. Patrick's mental health was constantly infused with thoughts about his past abuse.

Despite the fact that isolation helped him cope, it was not conducive to his health. Patrick knew he needed help. From the age of 15, he tried different therapists, yet his trust and abandonment issues interfered, thereby making it difficult to sustain a therapeutic relationship. Three years prior to the interview, he met Dr. Smith. Initially their relationship was tumultuous, but after three years Patrick finally felt comfortable with and understood by Dr. Smith. At the time of the second interview, Patrick was distraught when he found out that Dr. Smith had been dismissed from the practice for misconduct. He felt that the “rug was pulled from under” him. Dr. Smith was one of the few people he had allowed into his private world. Her dismissal meant a significant loss of a support person.

By practice and habit he withdrew and retreated into his world. His self-assessed depression was at a level 5, which meant staying indoors and not interacting with anyone. After sleeping for many hours and thinking about the incident, Patrick decided to be proactive about this drastic change. Rather than yell and have an outburst with the clinic staff, he wrote a letter to the head of the department, demanding an explanation for Dr. Smith’s dismissal. In that letter, he voiced his disappointment and anger. He emphasized that his work with Dr. Smith had reduced his isolation and that they were in the process of working through his difficult problems. Writing allowed him to express his feelings without posing any threat of physical violence to anyone. Moreover, it allowed him to voice that his problems were important. Patrick wanted his concerns to be heard. In the past he would have internalized this situation and not expressed his disappointment and

anger. With Dr. Smith's help, Patrick learned skills to articulate his needs without resorting to angry behaviors.

I'm also trying to learn not to internalize it because to internalize it it's hurting me that much more. I voiced it. And I voiced it to the people who were involved in it. I had voiced it to other people. But it [did not] take away that total filling of resentment.

Additionally, Patrick established a therapeutic relationship with Dr. Ross, a family practice physician who managed the mobile clinic at his housing site. When the previous medical provider left, Patrick personalized the departure and felt offended and abandoned again. Therefore, when Dr. Ross took over the practice, he was guarded. He observed Dr. Ross's interaction with other patients. He listened and waited. When he finally decided to approach Dr. Ross, Patrick was careful. After several encounters, he realized that Dr. Ross was someone with whom he could work.

Dr. Ross's demeanor, her character itself, helped that transition be easier. I ha[d] a good rapport with her.

For the past three years, Patrick continued to see Dr. Ross, whom he trusted and valued. Through his work with Dr. Ross, he was able to obtain approval for his bariatric surgery, a surgical procedure to help promote weight loss (Torpy, Burke, & Glass, 1986). In the three years it took to be approved for the surgery, Patrick was required to: (1) demonstrate he could lose weight (40 pounds down from his current weight of 401 pounds); (2) attend dietary counseling pre- and post-surgery; and (3) undergo an extensive psychiatric evaluation before and after surgery. His morbid obesity severely impaired his mobility, requiring him to

use an electronic wheelchair. Patrick knew that this surgery would help him lose more weight, which, in turn, would help with his mobility.

Oscillating between withdrawal and connection enabled Patrick to gain control over his own behavior. He dictated to himself and others when he wanted and needed help for his mental illness. Although Cate and Patrick shared a similar abusive and traumatic past, each approached their current lives differently. Unlike Cate, who constantly engaged in and sought relationships with others to help her, Patrick was cautious and selective regarding whom he trusted to help him with his illness. Cate externalized her coping through her connectedness with people, whereas Patrick continued to be in the midst of working through his relationship with others. At times Patrick, unlike Cate, continued to withdraw from the world in order to protect himself both emotionally and physically. Patrick's story exemplifies ambivalence as a coping pattern. Another informant demonstrated a similar way of coping.

Jason

Jason, a 55-year-old Caucasian man, suffered from prostate cancer, severe depression and alcoholism. At 18 years of age he was "shooting speed," and by 21 he was arrested for illicit drug use. Like Patrick, his arrest was, in fact, a good experience. Since he was only 21, he was treated as a "youthful offender" and was sent to Nevada City to fight forest fires. Thereafter, for the next 24 years, Jason did not use drugs and was gainfully employed, in sales and management. However, through those years Jason suffered from major depression. To help him cope with his depressive symptoms and be able to function at work, he turned to

drinking alcohol. From the ages of 21 to 30 he battled alcoholism. When the alcohol took a toll on his family and his relationship with his son, he realized he needed help. He turned to AA, attending meetings for the next ten years. The people from AA became his social friends. Jason was never ashamed to admit that he was an alcoholic. However, he was embarrassed about his depression and never sought any help. In 1996, his depression worsened, and he started “slipping.” For the following nine years, Jason battled his depression without relapsing. He kept himself busy and surrounded himself with his “buddies.” However, 14 to 15 months before the interview, Jason “bottomed out.” The pressures from work and his failing relationships with his second wife and son led to his relapse. For the next three months he abused illicit drugs and alcohol and ultimately left his family. A year before the interview, Jason was admitted to a psychiatric facility and subsequently sent to a dual diagnosis program.

Hiding depression: Jason was selective as to whom he would tell about his mental illness. Primarily, he was afraid that full disclosure of his mental illness would only lead to stigmatization. His close friends were unaware of his illness, and he kept them at arms length. He kept two distinct circles of friends in two different cities. One set of friends, who knew about his illness, also suffered from other mental disorders, and the other set of friends, whom he had known for over twenty years, were kept in the dark about his psychiatric disorder.

If I were gay, I'd be in the closet. I couldn't come out and tell anybody. And that's really weird 'cause I could give a shit less about any of that stuff, right? Hi, I'm in the closet with this mental illness thing.

Although he wanted to confide in his long-time friends, Jason continued to battle both the notion of being labeled “depressed” and his own self-imposed stigmatization. Unable to fully accept his depression, Jason grappled in his mind about how to live with this illness.

I realize it's creating some difficulties in my life because I've connected with some people that I used to know, and I don't know how to bridge this gap. The mental illness thing. I can deal with being sober or not being sober. But I think in my own mind, this is not really good thinking, more accurate thinking. There are some judgments that I've made on myself. I feel a little bit less than, because of – [sighs] – the mental illness and/or being in this, quote, mental health system. And I'm struggling with how to bridge that, and where honesty comes in and where, that's probably my big struggle, because I think it's real important [inaudible], and I have to make that transition? And I'm not sure I know how to do it.

To help cope with his depression, Jason tried different medications, such as Prozac and Remeron, but eventually discontinued them on his own because “they did not work.” He visited the assigned psychiatrist once every few months but did not admit to discontinuing his medications. Jason continued to struggle with his depression. He wanted help. but he was reticent to discuss his mental illness. In essence, he isolated himself.

At the time of the interview, he had been at the dual diagnosis program for six months. Even though Jason was not mandated to stay at this program, he remained there so that he had a safe place to recuperate as opposed to being homeless.

I didn't want to have to go look for a place while I was undergoing radiation treatment, and then having the seeds. It just didn't make a lot of sense. As much as I wanted to leave.

Jason, who was cognizant that his relapse was due to his untreated depression, continued to be conflicted about obtaining mental health care. As a result, Jason did not engage with his case managers, nor was he fully attentive to the mandatory groups he attended. Mostly he found these meetings “simply a joke and [at times] incredibly patronizing.” Thus, to show proof of his attendance, he occasionally forged signatures.

I go to maybe two or three meetings a week, and tell them that I go to three, because that’s the requirement. My little meeting card is what I call creative writing sometimes.

Self-talk: Similar to Patrick’s ‘devil versus angel’ thought process, Jason utilized his “vulture versus angel” to sift through his feelings. The “vulture,” or rather “judgment,” symbolized his riskier side, while the angel represented his more conservative side. The “vulture” or judgment represented his thoughts that continuously told him that being depressed was bad and unacceptable. Jason, like Patrick, needed to pull the reins on his “vulture.”

I still make judgments on depression and on my mental illness. One percent of the time my evil twin, which is judgment, creeps in, and that’s what I was talking about, the head talk that says, you know, it’s wrong to be depressed, it’s wrong to do – and you know, it’s not wrong, it’s not bad, it’s not right, it just is. And, but every once in a while . . . The best way to equate it is on this side of the – my right shoulder we’ve got my guardian angel. And I use that strictly because I don’t know how else to describe it. And on the other side there’s a vulture. The guardian angel says, “Man, everything is cool.” The vulture jumps on anything.

Jason recalled that in 1991 he received a check from his father in the amount of \$50,000. Rather than be happy, the “vulture” immediately saw the negative side, whereas the “guardian angel” was quite thankful.

This guy over here is, “Shit, we gotta pay taxes on it.” And it wasn’t just, “Oh, we gotta pay taxes on it.” It was, “Yeah, I’m really pissed off!” And that’s, you know, that’s kind of a neuro-war sometimes. And I just try to shut him off.

Similar to Patrick, to cope with the “vulture,” Jason attempted to “shut it off.” Yet at times he was unable to suppress his thoughts, and they consumed him. At those times Jason lived with his negative thoughts, which inevitably worsened his depression.

Connection with health providers: In regards to Jason’s physical health disorder, he connected with medical providers to help him with his prostate cancer. Jason’s sole purpose was to beat his cancer. Thus, he made every effort to see his physician during their scheduled visits.

Ambivalence was the primary coping pattern exhibited by the informants in dealing with their mental illness. They also used isolation to cope with major depressive disorder and anger. These informants employed cautionary measures to protect themselves, either from evoking emotions from past trauma or from the potential for stigmatization. Interestingly, with regard to their physical illnesses, these informants demonstrated greater capacity to engage with their physicians. It appears that it was easier for them to discuss their physical health disorders than it was for them to discuss their physical health disorders than it was for them to talk about their behavioral issues.

Waiting in Defeat

In a third pattern, waiting in defeat, some informants exhibited a pattern of hopelessness and helplessness, a feeling that the world offered them few substantial, positive possibilities. Similar to the previous coping pattern—

ambivalence—this pattern characterized individuals with COD who were unable to cope with their past experiences. However, unlike the coping patterns of interconnectedness and ambivalence—where informants had the capacity to engage with others—here past experiences became a limitation that prevented them from seeking help for either their mental or their physical illnesses.

John

John, a thin African American male, looked 20 years older than his actual age of 54. At age 22 he began to experiment with drugs and eventually became both a dealer and user. In 1986, he was diagnosed with depression and alcohol and cocaine addiction. He identified as an alcoholic and said he would continue to drink because “that is what alcoholics do.” John tried different recovery programs, but the groups he attended merely served as a venue for him to continue using.

I tried to get some help down in Santa Clara County for my drug issues, but the places they referred me to just made it worse. Like I started using more drugs, ‘cause there were people around that I could get loaded with. And we’d go to a meeting or something like that. And then afterwards we’d all go out and get high. It was kinda like a big joke because here we are, supposed to be going to these meetings and trying to recover from drug abuse, and we were all still getting loaded all the time.

He gave up hope that he would conquer his alcoholism. John completely identified with his alcoholism. From his perspective, alcohol was a part of him, and he would continue to live with this friend. Over the years he understood and accepted the impact of alcohol, “black outs,” or memory loss as part of life. If given a choice to see a psychiatrist or go to a bar, John was honest in stating that he would choose the latter. Despite its aftermath, alcohol provided him with momentarily relief and an escape from his depression. Combined with cocaine, alcohol provided him

another reality, where his depressive symptoms were “numbed” and temporarily erased.

At one point John saw a psychiatrist for a short period, but his depression progressively worsened. He attempted suicide multiple times by trying to overdose on medications and street drugs. He recalled 2001 as his worst time; he no longer felt he could tolerate living. He thought of killing himself, yet he could not execute the plan. While aimlessly walking in Oakland, his mind flooded with suicidal thoughts, he fortuitously stumbled upon a mental health clinic. He forced himself to speak with a psychiatrist to prevent himself from committing suicide. Though it was not an easy task, John knew he had to do it. Unfortunately, since that meeting, John had stopped seeing a psychiatrist, feeling that the medications and the therapy sessions were useless and unhelpful. Life as he knew it was not going to change, he thought, whether or not he was on medications. John continued to have suicidal thoughts yet professed two reasons that anchored him to this world. A “small part of [him] wanted to live” for his son, who lived in the East Coast and whom he had not seen or talked with in over six years. He was concerned how his son might react to his death. Despite his struggle with how his actions might impact his son, his shame and embarrassment about his illness paralyzed him from taking action to establish communication with him. John did not know how to explain his illness to his son. Furthermore, if he were able to explain his depression and addiction, he was skeptical about how his son would react. Would it be a positive response, or would his son simply walk away? These

quandaries, in essence, immobilized him from taking any action towards mending his relationship with his son.

You know, I have a son, who just turned 18 years old. And I want to have a relationship with him.

The hope or possibility, though a far-reaching goal, of rekindling a father and son reunion was an incentive for John to continue living. Additionally, John admitted that on an unconscious level he did want to live.

I think what happens is on a deep down inside, part of me wants to, wants to live. It's like an animal. They don't why. All they know is that they've got to drink some water, or that they've got to get some food, or else they're gonna die. Survival. Down to the core.

John's anchors for living were slowly becoming unhooked. Suicidal thoughts continued to invade his mind. But since, he was unable to act on them, he described coping with his illnesses as simply a "waiting game." Life had become meaningless, and he was willing to gamble his life away. Also diagnosed with Hepatitis C, John felt that his death warrant had been signed. Therefore, he thought it was futile to quit the drugs or alcohol usage. He anticipated that "the alcoholism and the Hepatitis [would] kill me." John envisioned himself getting "shot or beaten to death on the street or something like that. I always ha[d] this feeling that I'm gonna die violently." Although John continuously thought about dying or being killed, in actuality he was afraid of death or of being physically beaten.

Victimized self: John's past experiences of repeatedly being beaten were embedded and embodied within himself. These experiences dictated how he lived his life. To protect himself from victimization, he became a recluse. He removed

his means of being connected to society by physically disconnecting his doorbell and living without a telephone.

The fact that I don't go anywhere, I don't do anything, I don't see anybody. I don't make any telephone calls. I don't write any letters. I don't go out and visit people. I don't go – I don't go to movies. I don't go out to restaurants. I don't go to parties. I don't do anything. I just prefer to stay home in my apartment where it's safe or where I know I'm not gonna get beat up. It's just very dangerous out there.

He left his apartment only to purchase food or to go to the soup kitchen. When he did leave, John carefully mapped out in his mind the safest route to his destination. A few days before the interview, while he was on his "safe route," a man in a car waved at him, "yelling at me from across the street, something or other." Afraid that he would be "strong armed" by this man, John rapidly walked to his destination and, because of his overwhelming sense of distress, got lost. Although he eventually made it to his destination, he was distraught. On his walk home, anxious that the man in the car might still be there, John decided that the safe route had been violated and thus decided to walk a different way. His phobias and past experiences triggered his active imagination and created scenarios in his mind that he might be beaten up. It could have been that the man was simply asking for directions. But John interpreted incidents outside his apartment as possibilities for victimization. Every time he left the house, his apprehension about being victimized consumed him.

Whenever I'm out, there's always that fear that I'm going to be strong-armed, because I was strong-armed once. I was jumped once. And I've been beaten up a couple times.

Outside the world: John lived in his mind and his active imagination. He struggled with "being afraid and being obsessed" with suicidal thoughts. Lacking

interconnectedness with others, he did not engage or reach for help. John's thoughts were continuously running in circles. By cutting off the outside world, John was alone in his attempts to cope with his thoughts. Living the life of a hermit, his one link to the outside world was television. A few days before the interview, John heard on the news about a woman who jumped off the 24th floor apartment building in San Francisco. The event prompted him to think about his own mortality and his life. He thought about the many times he tried to kill himself but could not do it. He empathized with the woman and understood the desire not to live. He mirrored his own life with that of the dead woman.

And I just thought, she must have just got to the point where she finally realized in her mind that things couldn't possibly get any worse. They're not gonna get any better. And I don't want to deal with this anymore. And it was like I'm thinking I could really understand, you know, where she was coming from. You know, you get to this point, you get to the point where you think in your mind, when you're thinking in your head, wow, you know, this is just - I've had it. This is enough. You know, the, the fear, the - sense of not having no control over anything in your life, things being totally out of control. There's no end to it. You don't see any end, you don't see any light at the end of the tunnel.

John's powerful sense of empathy for the dead woman evoked his own feelings and thoughts about his lack of control over his own life. In his mind, he had tried over the years to get better—through therapy sessions, groups, and medications—yet he never reached the point of feeling better. His past actions never seemed to move him into the direction of reaching a “healthier self.”

And it's like as hard as you try to get better, you're just not able to achieve that.

John, who in the past attempted suicide multiple times, knew the tremendous sense of hopelessness and helplessness that this woman must have

experienced. In a way, it seemed that John felt sad for this dead woman and relieved for himself. That is, despite the fact that he felt hopeless, he was still able to deter himself from committing suicide.

Past self: John found ways of coping with his mental health through photographs and, in essence, his memories. Photographs of himself at other points in his life triggered emotions of happiness from his past. When he felt severely depressed, he turned to one of his old photographs, where he looked healthy and happy. These pictures elicited within him fond memories and the capacity to continue living. Like the photographs, his memories, the good times, were ways in which he could continue to hold onto his present life. He told himself that perhaps one day he could reach or return to that state of being.

A lot of the things that I rely on is I try to think back to when I wasn't sick. I try to think back, like I keep pictures of myself on the refrigerator, and I got them from different points, different times of my life, and different stages of my life, different ages and stuff, and I try to go back there and say, "Well, what was it like for me back then?" And I look at myself, and I look at myself now, and I try to picture when things were better for me. Like I don't think I look the same. I think I look different. I think I sound different. But if you notice, I have a lot of pictures of myself around here. I try to think back to those times when life was going good for me. And what did I do then?

Other times, he picked up his son's photographs to evoke feelings of love and hope. In a way, he had fatherly concerns for his son albeit he had never practiced being a hands-on father.

Whenever I'm feeling really, really depressed, I just look at a photograph of him, and I tell myself that if I were to kill myself, how would that affect him. You know? Hopefully, he'll be healthy, he won't have any mental health problems like I've had."

John coped with his depressive moods primarily through internal reflection. He constantly thought about “what if’s” and potential possibilities. Thoughts about his past self and the possibility of being with his son served as means of deterring his depression. But he never actualized his relationship in action. It was only a distant possibility, a relationship in the abstract. While Cate and Patrick were able to form relationships, the former more so than the latter, John lacked the capacity to engage with others. His trepidations and past experiences immobilized him. Lacking interconnectedness and consumed by fear, John exhibited a defeated self who foresaw only a bleak future. He lived to merely pass the time and “wait[ed] to die.”

Paul

Waiting in defeat was a coping pattern also demonstrated by another informant. Paul, a 63-year-old African American, was diagnosed with cocaine addiction, alcoholism, major depressive disorder, early onset dementia, hypertension, and coronary artery disease. He had suffered two strokes in the previous five years due to his chronic cocaine use, but it had been over six months since he had seen a medical provider.

Paul’s past experiences with difficulty obtaining care for his physical ailments deterred him from seeking further care. The lack of follow-up by his physician’s office and his difficulty in obtaining refills for prescription drugs were examples of past encounters that prevented his seeking care. Additionally, Paul’s forgetfulness played a role in his ability to follow up with his health issues. As a

result, to help alleviate his physical and mental symptoms, Paul drank alcohol, which momentarily relieved him.

In contrast with John, Paul had two main support people—his sister, who lived in Dallas, and his ex-wife, who helped him by calling and reminding him of his appointments. However, the type of support he obtained from each of these women was quite limited. His wife, who was in her mid 60's, had her own health problems and, therefore, could provide him with only occasional support, and his sister lived in another state.

Paul managed his depression by drinking and isolating himself. When he experienced an overwhelming stress, he:

. . . [stayed] in [his] room. Usually I doze off. I've got pills that I take. And they put me to sleep. You know? But then I'm up at 4:00 o'clock in the morning, and I don't dare take any more, you know.

Both informants lacked the ability to advocate for their own mental and physical health. As a result, they turned to a lifestyle they knew and with which they felt comfortable—to drink and marinate in their depressive state.

Conclusion

Informants in this study foregrounded interpersonal relatedness as a central factor in their turns toward recovery and stability. Observing the coping patterns holistically, interpersonal relatedness and adult attachment were clearly foundational to the patterns of living with COD presented by the informants within this study. Individuals with mental illness and substance abuse often have difficulty forming relationships for a variety of reasons (i.e. insecure attachment, stigma). Studies have documented that mental health problems are strongly

correlated with adult attachment difficulties (Goodwin, 2003), which often leads to problems with forming and establishing supportive and nurturing relationships. The majority of the participants in this study were diagnosed with depression. Numerous studies have documented that depression and insecure attachment are intricately linked (Goodwin, 2003). Additionally, individuals with COD frequently have histories of sexual and past abuse (COCE, 2003), which are significantly associated with insecure attachment in adulthood.

Given that there is a salient relationship between mental health diagnoses, past histories of sexual and physical abuse and attachment, it is interesting that informants in this study demonstrated and sought interpersonal relatedness. It appears that these connections within supportive relationships, whether from family members, friends, and/or healthcare providers, allowed informants to develop the capacity to cope with their overall health.

The first two patterns—interconnectedness and ambivalence—illustrated that the relationships with family members, counselors, and healthcare providers formed the pivot point for significant turns toward health in their lives. Additionally, the presence of these supportive individuals enabled informants to battle addiction, maintain sobriety and cope with mental and physical disorders. The informants highlighted that without these interpersonal relationships, it would have been difficult to manage the numerous and competing demands of illnesses. The first two coping patterns also demonstrate that informants' purposes for changing their lives were either for themselves and/or for their children. To depend on interconnectedness as a coping pattern, persons must have a goal or purpose as

to why they should stop using illicit drugs. Additionally, once that goal or purpose is identified, then they might be able to follow through with sobriety or cleanliness-- but only if they have established salient relationships either family members, friends and/or healthcare providers. The third pattern, Waiting in Defeat, demonstrated that the absence of interpersonal relatedness played a significant role in an inability to cope with illnesses. Additionally, in contrast to the first two patterns, informants who used Waiting in Defeat as a type of coping had neither the drive nor perceived goals to maintain and/or achieve sobriety.

These findings have significant implications for clinical applications and for further research. They suggest that the opportunity to relate in a trusting and continuous manner with someone outside of the self, may be a necessary element in successful living with COD. That within the lives of individuals with COD, some form of interpersonal relatedness is crucial to recovery, and to maintenance of general physical and psychological health. For changes to occur, clinical support is necessary to allow individuals to overcome attachment issues; this appears to be crucial in turning around their lives. Healthcare providers (i.e. social workers, nurses, counselors) have an opportunity to help individuals develop skills and the capacity to be able to form these supportive relationships. Recommendations for clinicians will be discussed in Chapter 6.

CHAPTER 6

IMPLICATIONS & CONCLUSION

Introduction

This interpretive and phenomenological investigation provides the possibility for understanding the rich and complex world of individuals living with and battling COD by taking into account the socio-historical and cultural aspects of their conditions. Additionally, the research findings contribute significant insights into the social and structural barriers this population encounters when managing numerous illnesses and offers various patterns for coping with COD. Thus, this study has practical applications for clinical practice and has the potential to impact mental health social policies. Proposed implications for clinical practice, social policies, and future research are described in this chapter.

Breaking the Barriers

Individuals coping with COD endure significant challenges and difficulties. Managing their illnesses is both complicated and exacerbated by everyday stressors, including but not limited to tenuous habitation, intricacies of their interpersonal relationships with providers, social stigma, low income, and unsupportive physical and policy-governed social environments. Indeed, these factors pose barriers in their attempts to improve their mental and physical conditions.

Open dialogue. The findings of this study emphasize the importance of understanding the complexities of living with COD. Experiences with their

healthcare providers described by these participants suggest providers do not comprehend their vulnerabilities and competing needs. Interviewees underscored the need for empathy and effective communication. Results of the study indicated that reflecting on past clinical encounters further deepened patients' perceptions that they (1) were not heard or listened to, and (2) were not understood. These two perceptions prevented the possibility for communication and trust, and ultimately had a lasting and damaging effect on the health of individuals with COD. Establishing trust was a central concern among participants. Ever-changing assignments of healthcare providers and their inconsistent presence created fragmented relationships, thereby making it more difficult for individuals with COD to trust them.

The study findings corroborated studies with individuals with psychiatric disabilities (Day, Killeen, Sutton & Iezzoni, 2005; Kai & Crosland, 2001) that suggest they experience multiple problems establishing empathic relationships with their health care providers. However, this study articulates the complexities of trying to manage mental health and medical conditions in a population who lacks solid relationships with providers. The need for understanding individuals with COD from a holistic standpoint was starkly highlighted. Participants asked that contextual factors (e.g., socioeconomic status and past experiences) be taken into account when making decisions about treatments for their physical and/or mental disorders, and that they receive individually tailored treatments as opposed to standardized therapies. Moreover, the current study results suggest important areas to be questioned in the lifeworld of patients with co-occurring disorders by

primary health care providers who manage basic healthcare (Frisher, Collins, Millson, Crome, & Croft, 2004). Informants underscored the importance of incorporating: their past histories (i.e. trauma), their financial status, their housing status, and/or their health insurance coverage when providers structure their treatment plans.

Financial strains in healthcare the emphasis on provider productivity and efficiency have led to decreased time spent with patients typically, 15 minutes. Providers are required to treat large number of patients in a given day and, consequently, are able to grasp only a snapshot of each patient's situation during a clinic visit. Additionally, providers often guide their care using evidence-based practice (EBP). Although research studies have demonstrated that EBP guidelines provide the latest evidence regarding diagnoses and treatment for illnesses, controlled research seldom includes contextual factors that impact delivery of care and impede communication between providers and patients (Tracy, Dantas, Moineddinen, & Upshur, 2005). In the following evidence, providers may be subtly influenced to pay less attention to factors that are centrally important to patients.

Effective and open communication between primary care and mental health teams may be a prerequisite for effective care giving to people with COD. Emphatic, hopeful, continuous, and integrated treatment through the course of multiple treatment episodes may lead to greater treatment success (Cline, 2004). A recommendation to enhance listening, empathy, and open communication during clinical encounters would be to elicit narratives about current functioning (Charon, 2005; Kleinman, 1988). It is important to note that an illness disrupts a "lifeworld"

that must be reconstituted through narrative, which gives meaning to experience (Kleinman, Eisenberg & Good, as cited in Aull, 2005). Therefore, narrative conceptual frameworks are useful for examining and understanding medical reasoning, clinical relationships, empathy, and medical ethics (Charon, 2005).

Furthermore, it is also significant to understand and acknowledge the situatedness (socio-historical-cultural experiences) of both patients and providers since these factors may influence the act of "telling and listening" (Aull, 2005, p. 281). Additionally, an individual's interpretation of his or her illnesses and their significance are culturally and socially determined. That is, the body and the self are understood through "socially constructed categories that constrain experience as much as does disordered physiology" (Kleinman, 1988, p.17). Therefore, it is important to acknowledge the patient's socio-historical-cultural underpinnings, which can influence thought processes and decision-making. It may also be helpful for healthcare providers to examine and become attuned to their own biases, which can hinder or impede clinical encounters.

At a larger institutional or social policy level, it would be beneficial for all staff (i.e., case managers, drug counselors, social workers) who work with individuals with COD to be trained to improve communication skills. For example, the University of Pittsburgh established an Institute on Doctor-Patient communication, erected "as [a] part of an ongoing effort to promote the development of effective communication skills between physicians and their patients and to serve as a focal point for education and research on one of the key issues in contemporary medical education"

(<http://www.dgim.pitt.edu/idpc/about.html>, retrieved on October 27, 2007). In addition to establishing research activities within this arena, recent research findings should be disseminated to all staff working with individuals with COD. It might also be useful and beneficial if individuals working with this population are taught the same type of communication skills.

Continuity of care: Inconsistency and lack of continuity with providers is understandable given that providers often have to leave their jobs due to the demands and personal life changes. However, steps might be taken to buffer persons with COD from acute abandonment or rejection. One participant suggested that a simple introduction to the new healthcare provider by his existing doctor made him feel more at ease and comfortable with the changes. Planning services that provide for increased continuity of care is an important health policy agenda for this population. Services that use trainees, whose programs demand frequent provider changes, are not advisable for this extremely sensitive patient group. Although not articulated in this study, emotional burn-out or “compassionate fatigue” have been implicated in high attrition rates among providers working with this population (Hunter et al., 2005; SAMHSA, 2006). It is recommended that clinicians providing COD services work within a team structure rather than in isolation, have opportunities to discuss feelings and issues with other staff members who handle similar cases, be given a manageable caseload, and receive supportive and appropriate supervision (Substance Abuse Treatment for Persons With Co-Occurring Disorders, CSAT, 2005).

Building interpersonal relatedness: Individuals with COD often have difficulty forming interpersonal relationships due to several factors such as cognitive difficulties, lack of social skills, mistrust, and stigma. The participants in this study narrated their successes and failures vis-à-vis their interpersonal relationships to family, informal helpers, formal healthcare providers and the community. Interpersonal relatedness refers to the need to establish close, stable, nurturing, and protective relationships (Shahar, Blatt, Henrich, Ryan, & Little, 2003). Historically and theoretically, interpersonal relatedness and attachment have been significant issues within the COD population. The findings from this study, demonstrated that coping patterns were successful when informants were able to form social connectedness. The presence of positive family support enabled the informants to enter recovery and maintain their sobriety. Additionally, healthcare providers and group sponsors (e.g. AA sponsor) were crucial to their overall health management. The existence of these relationships is integral in helping individuals with COD cope with their multitude of illnesses. As demonstrated by the other informants, lack of supportive relationships played a role in their inability to manage their addiction, mental, and physical health.

Many family members find it difficult to cope with a relative who suffers not only from mental illness but also from substance abuse. As a result, family members tend to abandon loved ones afflicted with co-occurring disorders. Therefore, fostering other types of supportive links are needed so that these individuals can create, build, and sustain supportive social networks.

A recommendation for healthcare providers is to foster supportive relationships within the client-provider relationship. Dolan Arnkoff & Glass (1993) reported that a client's particular attachment style is an important variable in the client-provider relationship, which means that healthcare providers may need to tailor their interpersonal stance according to the person's attachment style. Developing and fostering these types of relationships might lead to a trusting working milieu. For individuals with COD who do not have family members or friends, the healthcare-provider relationship can serve as a surrogate support. Case managers, social workers, substance abuse counselors and public health nurses offer an important platform for beginning such relationships. One participant articulated that the long-term outreach engagement his case manager provided was the most significant relationship he had. He expressed that without his case manager's persistence and "not giving up on [him]" he would not have recovered from methamphetamine addiction.

Basic skill building may be advised for individuals with COD who have lived and struggled within a social environment that lacks examples of interpersonal skills. Therefore, teaching person with COD interpersonal skills as part of their cognitive behavioral therapy and focusing on improving relationships through assertiveness negotiation, asking for help, and active listening should be incorporated within their care (Minkoff, 2000). Social-skill training utilizes behavior therapy principles and techniques for teaching individuals to communicate their emotions and requests so that they are more likely to achieve their goals and meet their needs for affiliative relationships and roles required for independent living

(Kopeliwz, Liberman, Zarate, 2006). Social skills training has been evaluated to be effective. Studies have documented that social skills training are effective for individuals with mental illness, especially those suffering from schizophrenia. Moreover, social skills are crucial to adjustment and normal interpersonal functioning (Matson, Anderson, & Bamburg, 2000). However, efficacy in social skills training requires a person be “capable of assimilating and retaining information and skills” (Kopeliwz, Liberman, Zarate, 2006, S16). Studies have shown that individuals with severe cognitive deficits have poorer response to psychosocial skills training. Additionally, cognitive impairment makes it difficult for individuals to benefit from focused skills interventions that they are offered (Madelia & Lim, 2004). Therefore, individuals with severe cognitive deficits may require different types of intervention to help create and build their interpersonal skills.

Recent advances in social skills training for individuals with severe cognitive deficit, such as those suffering from schizophrenia, might be beneficial for the COD population. Individuals suffering from thought disorder and high levels of distractibility have been viewed as poor candidates for social skills training. Nevertheless, cognitive rehabilitation, specifically neurocognition therapy, proves promising. For instance, recent studies have shown that conversational abilities improved through teaching basic conversation skills using repetition in discrete trials concurrent with behavioral learning techniques (Kopeliwz, Liberman, Zarate, 2006). Another intervention that seemed to improve social skills involved using token and social reinforcement for very brief intervals of paying attention and

constructively participating in the learning of conversational skills. This approach demonstrated even greater success in achieving normal social conversation for individuals with very low functioning social skills. Cognitive enhancement therapy targets directly the deficits in social perception that have been posited to underlie social dysfunction. Here, patients are taught to accurately perceive various parameters associated with selected social cues, such as facial affect, verbal tone and body language. Cognitive enhancement therapy is an integrated approach to the concomitant training of neurocognitive and social cognitive abilities as well as social skills (Kopeliwz, Liberman, Zarate, 2006).

Although these interventions sound very solid and promising, they are still at their nascent stages. Hence, healthcare providers must match the interventions accordingly with the individual's cognitive levels. Since the COD population is quite heterogeneous there might be individuals who might not respond to any types of social skills, behavioral and neurocognitive training. Therefore, for those individuals, it might be more important to help them find their reason to live. Thus, for this group of individuals, fostering their relationships with their healthcare providers is essential.

At a broader social policy level, lack of funding and insurance barriers may impede translating these research studies into clinical practices. Therefore, researchers and policy makers might want to ensure that these tested interventions are disseminated throughout the healthcare industry. Moreover, researchers who conduct these studies might want to present their findings to insurance companies, demonstrating not only the social efficacy of such

interventions, but also how they might eventually be cost-effective.

Weaving a Web of Support: Social network is defined as a map of the relationships between individuals, ranging from casual acquaintance to close familial bonds. Social networks function both as a predictor as well as an outcome of mental illness and substance use (Tracy & Biegel, 2006). This study's findings demonstrate pivotal turns in the lives of individuals with COD and reveal that coping patterns are deeply imbedded in their social networks. Additionally, the results of this study contribute to a small but emerging literature on social networks and co-occurring disorders.

Individuals who demonstrated ineffective and poor coping patterns in addition to hopelessness and helplessness had a greatly reduced, limited, or total lack of opportunity for engaging in individual relationships and/or broader social networks. Studies have shown that establishing positive social support resources and rebuilding non-substance-using social networks during recovery are recognized as important and challenging features of treatment programs with clients who have COD (Carey, 1998; Drake, Bartels, Teague, Noordsy, & Clark, 1998). Hawkins and Abrams' recently (2007) found that social networks critically influence recovery of men and women living with COD. Additionally, previous studies suggest that social support from family and friends can decrease symptomatology (Albert, Becker, McCrone, & Thornicroft, 1998), help individuals reduce substance use (Alverson, Alverson, & Drake, 2000), and keep them active in the rhythms of daily life (Bellack & Muesser, 1986). Social workers, case managers, nurses, and physicians are strongly encouraged to help individuals with

COD build their social networks. Groups and supported living environments are venues for creating and building social networks.

A time for change and restructure. In September 2007, the Senate approved the Mental Health Parity Bill 2007 (S. 558), which would ensure that Americans with employer-sponsored health insurance and their families receive mental health care coverage at the same level as coverage for general health problems. This bill is indicative of a positive step toward the funding of mental health care in the United States. However, this study demonstrates how being uninsured, underinsured, or without adequate coverage for medications impedes care. When unable to obtain medications, participants selected which medications in their regimen were most essential and skipped or delayed taking others. These findings support previous conclusions regarding health insurance restrictions, the uninsured, and the underinsured. For example, Hsu and colleagues (2006), who investigated the impact of insurance capitations on health outcomes on Medicare health plans for individuals 65 and over, found that a cap on drug benefits was associated with lower drug consumption and unfavorable clinical outcomes.

At a clinical level, a temporary solution to medication capitations or lack of insurance coverage might be to utilize patient assistance programs (PAP) available to community health clinics. PAPs, typically sponsored by pharmaceutical companies, provide free or discounted medicines to low-income, uninsured, and underinsured individuals. Nearly all pharmaceutical companies voluntarily offer PAPs. They include some or all of a company's single-source (i.e., brand-name) drugs (Duke, Raube, & Lipton, 2005). Although these services are available,

according to a recent study, PAPs consumed 12 hours of pharmacist time per month and 99 hours of other staff time per month (Duke, Raube, & Lipton, 2005). These results could deter clinics from utilizing such programs, given that most community based clinics are understaffed. However, considering the gravity and severity of problems facing the uninsured and underinsured in this country, PAPs can temporarily fill the void. For such programs to work properly, clinic administrations may want to dedicate a staff member to oversee PAP, as each pharmaceutical company has different requirements. If a clinic is concerned about the cost for additional staff, then a volunteer (commonly found within community clinics), such as an AmeriCorp volunteer or a consumer, could be delegated to provide assistance in filling out PAP forms.

In terms of a broader social policy context, an overhaul of health insurance is needed to provide medical services where they are not currently provided. As one of the wealthiest developed countries in the world, a lack of universal health care deserves serious scrutiny. In the meantime, further evaluation is required on the impact of Medicare Part D on vulnerable populations like the one that is the focus of this study.

Easing the Maze: Accessing and navigating the healthcare system is a challenge for anyone, especially for those afflicted with mental illness and substance abuse. Results of this study demonstrated that individuals with COD experienced difficulties accessing and working with healthcare systems. Participants discussed how rigid structures within health clinics posed barriers when they attempted to visit their health providers. For example, one participant

who suffered from dementia continuously forgot his appointment. When he ran out of medications and attempted to obtain refills, he was told that he would have to wait for another clinic appointment, which meant waiting another thirty days.

Individuals with COD often have cognitive deficits due to their mental illness and/or long-term substance abuse. Hence, many of the informants in this study indicated that the system structure was an impasse in managing their health. Inflexible rules were created to encourage patients to be responsible about keeping appointments; however, their implementation introduced considerable health risks for patients who could not keep them due to personal disorganization and/or life stressors. For individuals who have little or no control over their time organization practices, creating a flexible range of clinic drop-in hours might be useful.

Additionally, it is recommended that clinics, especially mental health clinics, apply for funding via the Mental Health Service Act [MHSA] (2004), which provides increased funding, personnel and other resources to support county mental health programs and monitor progress toward statewide goals for children, transition age youth, adults, older adults and families. The Act addresses a broad continuum of prevention, early intervention and service needs and the necessary infrastructure, technology and training elements that will effectively support this system (http://www.dmh.cahwnet.gov/Prop_63/MHSA/default.asp). Additionally, it mandates programs to include “promotion of the employment of mental health consumer and family members in the mental health system”. According to the act, patients and families, need to be hired not in special, separate consumer-run programs, and not as special consumer or family member staff, but as peers and

teammates to professional providers. In light of this proposition, another resource that might help individuals navigate the system would be to employ consumers, who have succeeded in recovery and have successfully maneuvered the healthcare system. Consumers can act as a "big brother/sister" to other individuals with COD who are experiencing difficulty with their recovery and/or navigating the system.

Health Promotion: Individuals with COD have higher rates of morbidity and mortality when compared to the general population (Chafetz, et al., 2005). Sixty percent of the participants, whose mean age was only 51 years, suffered from more than one medical condition. In light of these results, health promotion and prevention should be incorporated and emphasized within their care. The MHSA has allocated funding for health promotion and prevention. In addition to individual visits, group classes are strongly recommended. Group visits, which are billable visits are feasible and can improve chronic care management (Jaber, Braksmajer, Trilling, 2006). This author has found that incorporating health promotion and prevention during community meetings within the SRO hotels as a great venue for education. For example, when this author worked with this population, she often taught classes, such as "healthy eating and cooking," and "managing diabetes" during community meetings.

A call for cleaner and safer housing environment. Deinstitutionalization has moved psychiatric care from institution into the community. SRO hotels have emerged as a form of housing for individuals with mental illness and with co-occurring disorders. Previous studies have demonstrated that poor housing

ultimately has an impact on health. An association found between increased in physical assaults towards individuals residing in SRO was due to lack of protective shelter, close proximity to high crime areas (Nyamathi, Leake & Gelberg, 2000), mental illness (Desai, 2003), and substance abuse (Wechsberg, 2003). Findings from the present study illustrate that living conditions in the SRO were often unkempt and precarious, ultimately impacting the health of informants. Additionally, results from this and other studies (Smith, 2003) indicate that a lack of security measures, facility monitoring, and exposure to drug related networks place residents of SRO hotels at higher risk of violence. These and previous findings call for changes in these housing environments.

Although SRO buildings provide shelter and are economical, regulations of SRO hotels are strongly recommended. The ubiquitous and uncontrolled use of drugs and/or alcohol on the premises makes sobriety or cleanliness a continuous struggle. Informants discussed how relapses became easier as drugs and/or alcohol were constantly available. It might also be beneficial for staff and patients to investigate and match a given SRO building to the patients need for treatment. Matching an individual's level of recovery to his/her future housing site (wet versus dry versus damp housing) might help him or her progress with the rehabilitation process. Furthermore, lack of hygiene and of monitoring and security measures (Foley, 1998) in the SRO increases the risk of transmitting infectious disease (HIV, HCV, TB) and worsening illnesses. Clearly, more adequate housing options for this community are urgently needed.

Individuals with COD often have difficulty advocating for themselves.

Hence, it might be helpful for healthcare providers (e.g. social workers, public health nurses) who conduct home visits and are witnesses to these hazardous living conditions, to advocate for cleaner and safer living conditions. Another recommendation is for healthcare providers to conduct home visits to enhance their own knowledge about living conditions within these hotels. Provider awareness about these precarious and hazardous living environments may help them tailor their care to this particular population. Furthermore, healthcare providers can teach and inform patients about alternative types of treatment that would be conducive to coping with and/or improving these conditions. For example, if a patient who suffers from diabetes and high blood pressure lives in a place that lacks a cooking facility and/or a refrigerator (as most of the SRO hotels do), then the provider could suggest how the individual might manage his or her diet. To elaborate, the provider could advise patients on the types of food they can eat that do not require cooking (e.g. different types of canned foods or frozen foods). It is critical that physicians, nurses, case managers and/or social workers work closely together to help patients living at these places manage their physical and mental conditions.

Future Studies

This study's findings contribute to the emerging literature in the COD research. However, further studies are needed to enhance and improve delivery of care to this complex and heterogeneous population. First, this study examined the perspective of individuals with COD and their perceived barriers to care. It might be strengthened by also closely examining the providers' perspectives juxtaposed

with patients' perceptions of their illnesses. Second, dyadic interviews might be conducted between patient and provider to determine how to improve communication and trust. Third, with regard to health insurance or lack thereof, it might also be useful to examine the longitudinal impact of Medicare Part D *vis-à-vis* the COD population. Lastly, the dearth of research on social networks and the COD population poses further questions. For example, how do individuals with COD form and maintain their social networks?

Conclusion

Working with individuals with COD is a challenge; however, this study and others provide us with new data and evidence on how to improve our delivery of care. Incorporating and applying these results into our practice might help alleviate some of the difficulties we encounter when engaging this population.

Appendix I

UNIVERSITY OF CALIFORNIA SAN FRANCISCO AND SAN FRANCISCO GENERAL HOSPITAL MEDICAL CENTER CONSENT TO BE A RESEARCH SUBJECT

A. PURPOSE AND BACKGROUND

Anna Villena, RN, MSN, FNP, PhD (c) and Dr. Catherine Chesla, RN, DNSc, from University of California San Francisco, School of Nursing, Family Health Care Nursing Department are conducting a study to understand health beliefs, health practices and health management of individuals with co-occurring disorders of mental illness, substance abuse and chronic diseases. You are being asked to participate in this study because you indicated that you have these disorders.

B. PROCEDURES

If you agree to be in the study, the following will occur:

1. You will meet privately with Ms. Villena to discuss your health, health beliefs and practices.
2. An audiotape will be made of the interview[s].
3. Two interviews, approximately three weeks apart, will be conducted at a time and a place that is convenient for you. Each interview will last no more than 60 minutes

C. RISKS/DISCOMFORTS

1. Some of the interview questions may make you feel worried, uncomfortable or upset. You are free to not answer any question that you don't wish to or stop the interview at any time.
2. If you become tired you may stop the interview and a second interview will be scheduled at a time and place convenient for you.
3. If you become worried, uncomfortable, distressed or upset, you can talk with Ms. Villena, your social worker, or case manager about this. A list of mental health services will be provided should you like additional support.
4. Should you state that you have suicidal thoughts or ideations, it is mandated by law that this be reported. The interviewer must report this to your case manager or social worker.
5. Confidentiality: Participation in this research will involve a loss of privacy. However, your records will be handled as confidentially as possible. Only project staff (Ms. Villena and Dr. Chesla) will have access to the study records and audiotapes. After the study is completed, the tape[s] will be destroyed. The investigator will retain the transcripts. Your name or other information from the study that identifies you will not be used in any reports or publications that may result from this study.

D. BENEFITS

There will be no direct benefit to you from participating in this study. It is possible that the findings from this study will help health care professionals better understand what it is like to have co-occurring disorders.

E. COSTS

There will be no cost to you for participating in this study, except for the loss of your time.

F. PAYMENT

You will be paid ten (\$10) dollars in food vouchers for participating in this study immediately after you have completed the first interview and an additional ten dollars (\$10) in food vouchers paid immediately after completing a second interview if a second interview is necessary.

G. QUESTIONS

This study has been explained to you by Dr. Chesla or Anna Villena, RN, MSN, FNP PhD(c) and any questions answered. If you have further questions you may call Ms. Villena at (510) 367-2239 or Dr. Chesla at (415) 476-4439. If you have any comments or concerns about your participation in this study, you should first talk with Ms. Villena or Dr. Chesla. If for some reason you do not wish to do this, you may contact the Committee on Human Research, which is concerned with the protection of volunteers in research projects. You may contact the office between 8 AM and 5 PM, Monday through Friday by calling (415) 476-1814 or by writing: Committee on Human Research, Box 0692, University of California San Francisco, San Francisco, CA 94143.

H. CONSENT

You will be given a copy of this consent form to keep and the Experimental Subject's Bill of Rights to keep.

PARTICIPATION IN RESEARCH IS VOLUNTARY. You are free to decline or to withdraw from this study at any time. Your decision to participate or not to participate in this study will have no influence on your care at Lifelong Medical Care Supportive Housing Program and Bonita House.

If you agree to participate in this study, you will sign below:

DATE

Signature of Study Participant

DATE

Person Obtaining Consent

Appendix II

Demographic Questionnaire

Today's Date: _____

ID: _____

Location of Interview: _____

Age: _____

Gender : _____

Psychiatric Diagnoses: _____

What illnesses do the participant have now or have been treated for in the past:
(Medical
Diagnoses)

1) _____

2) _____

3) _____

4) _____

5) _____

6) _____

Medications (if known): _____

Primary Phone #: _____

Secondary Phone #: _____

Appendix III Interview Guide

For the purposes of this study, an unstructured interview is planned as means of obtaining subjects' experiences and perceptions about the phenomena being investigated. The questions listed in this appendix are examples of those that the researchers will use to initiate a discourse with the subjects. During the course of the interview other questions and probes may be used to clarify and expand the content being presented by the subjects.

Introduction (Initial interview and subsequent interviews)

Thank you so much for agreeing to talk with me. I want to review with you the purposes of this study. I am interested in exploring the meaning of health beliefs and practices and health management of individuals with co-occurring disorders of mental illness, substance abuse and chronic diseases. I want to remind you that everything you say is important and confidential. Furthermore, if you are feeling tired or uncomfortable you can stop the discussion, decline to answer a question, or take a break anytime during our interview today. I will be tape recording our interview today. Is that okay?

Initial interview questions:

Aim 1: To describe and understand how individuals with COD construct the meanings of health and illnesses.

Research Question 1: How do individuals with co-occurring disorders construct the meanings of their health and illnesses?

1). Please tell me about your health?

Probes:

- A) What does it mean to you when I say the word "healthy?"
- B) How would you describe your health?
- C) What concerns do you have about your health?
- D) Can you tell me a story when you had concerns about your

health?

2). Tell me the story when you first realized you had some health problems?

Probes:

- A) How did you feel?
- B) What was most important to you during all of this?
- C) How did you think about yourself and your health change during this time?

3). Please tell me about your health history?

Probes:

- A) When were you diagnosed with a psychiatric illness?
- B) When did you realize that you had a psychiatric disorder?
- C) How did this affect you?

- D) When did you first realize that your alcohol/drug use was a problem?
- E) When did your healthcare provider first tell you they thought it was a problem or suggest that you needed treatment?
- F) How did this affect you?
- G) When did you realize that you had _____(state current chronic medical condition, such as HIV, hepatitis or HTN)?

Aim 2: To describe and understand how individuals with COD manage their illnesses.

Research Question 2: What actions do individuals with co-occurring disorders undertake to manage their multiple illnesses?

- 1). Can you tell me what happened the last time you were sick?

Probes:

- A) What do you do when you are sick?
- B) How do you cope when you become ill?
- C) When do you decide to ask for help?
- D) Who helps you when you are sick and where do you go?

- 2). How do you take care of yourself?

Probes:

- A) What actions do you take to keep yourself from being ill?
- B) How do you keep yourself healthy?
- C) Can you provide concrete examples or a stories related to this?

- 3) Can you tell me a story or stories that you feel are 'turning points' in how you manage your health today?

Probes:

- A) Can you recall specific experiences or events related to this?
- B) Can you describe that experience?

AIM 3: To describe and understand the perceived impact of multiple illnesses within the lives of individuals with COD.

Research Question 3: What is the perceived impact of the multiple layers of illnesses among individuals with co-occurring disorders?

- 1) Has your life changed since you were diagnosed with your mental disorder, substance disorder and diabetes (or other chronic diseases)?

Probes:

- A) If so, how has it changed? If not, why not?
- B) Can you describe what it was like before and what it is like now?
- C) Can you tell me a specific story?
- C) How has this change affected you?

Aim 4: To describe and understand the support network that individuals with COD utilize.

Research Question 4: What types of support systems do individuals with co-occurring disorders utilize?

1) Who or what has helped you in taking care of your health?

Probes:

A) Can you tell me about a particular person or relationship that has been helpful or unhelpful in regards to your health?

B) Can you provide an example?

Aim 5: To describe and understand social and structural barriers that individuals with COD encounter.

Research Question 5: What are the difficulties that individuals with COD encounter in regards to their healthcare?

1) Can you tell me a story or stories about barriers that you encountered while attempting to take care of your health?

Probes:

A) Do you have a primary care provider? If so, do you often see him or her? If not, why not?

B) What has your experience been when you have sought help for your illnesses?

C) Can you give me a concrete example of the last time you sought care?

2) Is there anything you could think of at the moment that might be helpful in taking care of your health?

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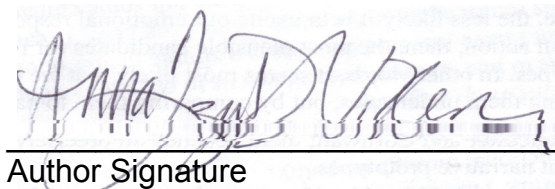
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