ABSTRACT

Title of Document: THE IMPACT OF FORMAL SOCIAL SUPPORT ON OUTPATIENT CARE AMONG A SAMPLE OF ADULTS LIVING WITH HIV/AIDS IN THE UNITED STATES

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Background

The HIV Cost and Services Utilization Study and HIV Research Network (HIVRN) clinical studies showed disparities among HIV-positive men and women in outpatient care use in the U.S. Formal social support provided by case managers may help patients access outpatient care. The primary purpose of this study was to determine if having case managers is associated with levels of outpatient care visits among 797 individuals living with HIV/AIDS, and whether this association varies by patient sex. Other aims were to determine if the number of in-person case management visits and the type of formal social support are associated with these same outcomes. Outpatient visit levels were defined as 2-5 (average) or 6+ (high). Based on Andersen's (1995) Behavioral Model of Health Services Use, a conceptual model was developed as a framework for examining the study's hypothesized relationships.

Methods

The HIVRN is a convenience sample of 17 U.S. clinical sites serving more than 15,000 people living with HIV/AIDS. In 2003, interviews were conducted with a stratified sample of 951 clients at 14 HIVRN sites. The current study sample consisted of 797 adult respondents (543 males and 254 females). Logistic regression was used to identify significant predictors of outpatient care visit levels.

Results

Patients who had one or two case managers versus no case managers were significantly more likely to have 6+ outpatient visits, while patients who were employed and had higher self-reported perceptions of their health were significantly less likely to have 6+

outpatient visits. These relationships did not vary by patient sex. Level of outpatient visits also did not vary by patient sex. No significant associations were found between the number of in-person case management visits or the type of formal social support and level of outpatient visits. In sub-analyses that separated patients with one case manager from those with two case managers, no new predictors emerged.

Conclusion

Case management was associated with higher levels of outpatient visits for both male and female patients in this study. This finding suggests that utilization of HIV-related outpatient care may be increased among both men and women with case management.

THE IMPACT OF FORMAL SOCIAL SUPPORT ON OUTPATIENT CARE AMONG A SAMPLE OF ADULTS LIVING WITH HIV/AIDS IN THE UNITED STATES

By

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Chapter 1: Introduction

Eliminating disparities in health care access and service utilization has become a national priority over the past decade. As documented in Healthy People 2010, the nation's roadmap for health promotion and disease prevention, the elimination of health disparities is a central goal essential to improving health for all Americans (DHHS, 2000; Institute of Medicine, 2001). For persons in the United States (U.S.) living with Human Immunodeficiency Virus/Acquired Immunodeficiency Syndrome (HIV/AIDS), persistent disparities in health care access and service utilization demonstrate that there is a challenge in realizing this goal. The hallmark of HIV is its ability to invade and destroy white blood cells, the cells that make up humans' immune response to disease. As HIV gradually ravages these critical cells, particularly the infection-fighting white blood cells known as CD_4 + T cells, the immune system becomes vulnerable to opportunistic illnesses. The manifestation of these illnesses is one marker of the transition from HIV infection to AIDS. The development of highly active antiretroviral therapies (HAART) in the mid-1990s has altered the natural course of HIV disease by greatly increasing survival times (Cunningham et al., 2000). Still, disparities in access to HAART exist, as can be seen in survival time differentials in various subgroups that are affected by HIV/AIDS.

To be clear, HIV/AIDS is an unprecedented modern-day pandemic. The prevalence of HIV/AIDS worldwide is close to 45 million cases (Centers for Disease Control and Prevention [CDC], 2002). Of these estimated 45 million people living with HIV/AIDS worldwide, 36.3 million are adults. Nearly 50% of this seropositive adult population are women, with the majority of infected women living in sub-Saharan Africa (CDC, 2002). Worldwide, more than three million children under the age of 15 are also living with HIV/AIDS. In the U.S., approximately 40,000 new HIV infections occur annually; 30% of these new infections are among women, particularly African American and Hispanic women (CDC, 2002). HIV/AIDS is now in the top 10 leading causes of death in the U.S for all women aged 25 to 44 and the leading cause of death among African American women aged 25-34. Nearly 468,000 deaths can be attributed to AIDS through 2001 (CDC, 2003).

As the HIV/AIDS epidemic evolved in the early 1980s from an unknown disease affecting relatively few individuals into a pandemic affecting millions around the world (Beaudin & Chambré; Fee & Fox, 1992), researchers have sought to identify individual, social, and organizational factors to better understand health care and service utilization differences, and to reduce treatment costs and human suffering (Kenagy et al., 2003; Shapiro et al., 1999). For example, in a number of studies to date, including the national HIV Cost and Services Utilization Study (HCSUS), researchers have documented reduced access to and use of HIV-related health care services for women as compared to men (Burke et al., 2003; Hellinger, 1993; Palacio, Kahn, Richards, and Morin (1999). HIV- positive men and women who are poor may also postpone seeking care, given other competing day-to-day survival challenges such as food, clothing, or shelter (Cunningham et al., 1999; Ward, 1993). HIV-positive women may be particularly prone to delaying care, given their concerns for children and other family members' well-being above their own health (Raveis, Siegel, & Gorey, 1998).

Reframing HIV/AIDS as a manageable chronic illness similar to many long-term progressive conditions that may be accompanied by periods of disability as well as periods of relative remission from symptoms has significantly changed how care is planned and evaluated in the clinical setting. A continuum of care services that include physical, mental, and social components and that also involve inter-relationships among patients, provider networks, case managers, and community-based organizations has become one best practice model (Conviser & Pounds, 2002). Moreover, the advent of HAART in 1996 as the standard of clinical care has led to significant decreases in the progression of HIV infection to AIDS and death. Approaching HIV/AIDS as a chronic rather than an acute illness, however, raises a number of major challenges and questions, not the least of which is how to effectively manage an illness that continues disproportionately to affect those who are members of disempowered and minority groups, who often have lower social and economic status, and who are likely to lack access to ongoing health care services. Underlying and inter-connected social and economic forces -- namely stigma, discrimination, gender inequality, and poverty -- contribute to increased HIV infection among certain subgroups, as well as the timing of subsequent entry into and maintenance into health care (Devine, Plant, & Harrison, 1999; Farmer, Lindenbaum, & Good, 1993; Goldstein, 1997; Ward, 1993). The lived experience of HIV/AIDS from a chronic illness perspective is not gender-neutral; it is often very different for women than men, as a result of many factors including pre-existing inequality in society, later entry into the health care system, and the expectation that women will continue to fulfill traditional familial caretaking roles, such as mother, daughter, spouse, and partner, when they may be ill themselves (Heath & Rodway, 1999;

Thorne, McCormick, & Carty, 1997). Women living with other chronic illnesses besides HIV/AIDS, such as diabetes and arthritis, have similar challenges as well (Kralik, 2002; O'Neill & Morrow, 2001).

Finally, organizational and health care system barriers, such as provider bias, high health care costs, and lack of insurance coverage can impede access to quality HIV care and treatment. According to Kahn and colleagues (2001), the average cost per patient per year for HIV-related medical care is between $10,000 and $12,000, with higher costs on the order of $25,000 for persons with more advanced HIV-related symptoms. According to Schackman and colleagues (2006), the estimated undiscounted lifetime cost of medical care for HIV-positive adults could be as high as $618,900. This figure does not include costs for mental health and substance abuse treatment or for case management services. Other data suggests that direct medical costs per case vary by race/ethnic background, with the highest costs for Whites ($180,900) and the lowest cost for Blacks ($160,400) (Hutchinson et al., 2006). The cost of HAART is thought to account for one-half to three-fourths of these costs. Although Federal Medicaid and Medicare programs cover a large portion of the uninsured and underinsured, eligibility for and access to HIV/AIDS services vary considerably from state to state, leaving a sizable number of people out of care completely or moving sporadically in and out of care. Often, the lengthy waiting periods and restrictive criteria for program enrollment preclude early treatment that could halt the progression of disease and disability, including an increased number of opportunistic infections and hospitalizations, and poorer quality of life (Bright, Arnett, Blair, & Bayona, 1996; Buchanan & Chakravorty, 1999; McDonnell, Gielen, Wu, O'Campo, & Faden, 2000; Tsasis, 2000). Other safety net programs, including services provided under Title XXVI of the Public Health Service Act (PHS) Act as amended by the Ryan White HIV/AIDS Treatment Modernization Act of 2006 [formerly called the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act], and at public hospitals and community clinics, are also sources of limited care for uninsured or underinsured HIV-positive persons; still, these programs have not been given the financial capacity to provide care to all who are in need.

One of the challenges of retaining individuals in care is the co-occurrence of mental illness and substance abuse with HIV/AIDS. A number of studies have found HIV prevalence rates ranging from 4-18% among the mentally ill population, as compared with 1% in the general population (American Psychiatric Association, 2002). Encandela and colleagues (2003) also note the high prevalence and incidence of HIV among persons with mental illness and substance abuse problems. CDC surveillance figures show injection drug use (IDU) was associated with more than 25% of newly-reported HIV/AIDS cases between 1999 and 2002 among both men and women. Women with mental health and substance abuse issues may be at an even greater risk, with an estimated 5% HIV infection rate as compared to 0.17% in the general population (Carey, Carey, & Kalichman, 1997; Rosenberg et al., 2001). Women who have mental health and substance abuse issues may be less likely to practice condom use and safe sex behaviors, in addition to having poor overall coping skills.

Of particular interest to the present work is how HIV/AIDS-related outpatient care can be better understood when formal social support systems are in place. Such systems and models of care have been successful with a number of other chronic conditions, including heart disease, asthma, depression, and arthritis (Chernesky & Grube, 1999; Lorig, 1996; Rapp & Chamberlain, 1985). A distinguishing feature of chronic illness management is an active patient-provider partnership, which shifts patients' attention away from a reactive position to one of proactive collaboration. A proactive stance features two-way dialogue and shared goal-setting for health maintenance and improvement (Lorig, 1996). One way to operationalize coordination of care is through a case management model, where formal social support is obtained from a health care professional who can connect patients to an array of services in a particular community. Social support researchers have made a strong case for the benefits of social support during times of stress and personal/family illness (Hupcey, 1998; Thoits, 1982). These benefits include improved coping with adverse conditions and less distress with managing a difficult situation. Social support for HIV-positive patients has become increasingly recognized as an important element in maximizing quality of life and better health outcomes; patients accessing regular care can potentially live for many years (Chernesky & Grube, 1999; Indyk, Belville, Lachalle, Gordon, & Dewart, 1993; Kucera, 1998).

The definition of case management varies widely from setting to setting. For illustrative purposes, one definition is proposed below:

> [a] collaborative process that assesses, plans, implements, coordinates, monitors, and evaluates the options and services required to meet an individual's health needs, using communication and available resources to promote quality and cost-effective outcomes (Powell & Ignatavicius, 2001) (p. 3)

Given the myriad of medical and social services needed by HIV-positive persons, case management has become one promising strategy to assist patients in obtaining supportive community services (Chernesky & Grube, 1999; Parish, Burry, & Pabst, 2003; Piette, Fleishman, Mor, & Thompson, 1991; Katz et al., 2001; Katz, et al., 2000; Kucera, 1998). Patients who are connected to clinical and social services are hypothesized to have less unmet need and to have consistent outpatient care visits. They may also be less likely to need costly emergency room (ER) services and inpatient hospitalizations.

HIV/AIDS case managers are often tasked with having knowledge of social service benefits as well as Federal, state and local entitlement programs, and they may serve as one of several groups of formal social support advocates for clients. Sonsel and colleagues (1988) described one of the first concepts of HIV/AIDS case management as a way to increase clients' contact with services. Early work by Piette and colleagues (1991) established one view on case management goals for individuals living with HIV/AIDS. These goals were coordination of services, increased access to care, and decreased costs associated with inpatient care. Work by Chachkes (1993) clarified case management for HIV-positive patients as a combination of in-person contacts to ensure coordinated medical and social services in the best interest of the client. In the early 1990s, case managers were utilized less often for stabilized patients and more often for patients in crisis and those needing palliative care. Also, HIV-positive women were often less likely to have case managers than HIV-positive men, in part because of a failure to recognize women as an at-risk group, as well as longstanding gender-based inequality of care (Fleishman, Mor, & Piette, 1991). As HIV/AIDS was recast as a chronic illness with the advent of HAART in the mid-1990s, the role of case managers also shifted, with a greater emphasis on assisting patients to improve their health rather than preparing for death. Increased numbers of HIV-positive women in the past two decades has also led to the need to address gender-specific case management interventions. Clarifying the specific benefit of case management for HIV-positive men and women in an era in which patients can be expected to *live* is a new direction addressed in this dissertation.

The recent Institute of Medicine (IOM, 2005) report, “The Public Financing and Delivery of HIV Care: Securing the Legacy of Ryan White” addresses the importance of a comprehensive and continuous primary care package of services for uninsured and underinsured persons living with HIV/AIDS. Recommended Federally-funded services include case management and treatment for mental health and substance abuse problems in an effort to stabilize patient care and contribute to overall treatment plans. At the same time, such a standardized benefits package would be aligned with current science-based evidence on HIV/AIDS treatment, theoretically enroll patients earlier after the initial HIV diagnosis, and reduce costly inpatient care and emergency service needs. In the absence of implementation of the IOM recommendations, however, continued attention is needed to address differences in HIV/AIDS health services utilization and to seek innovative ways to provide patients with formal social support systems that may optimize health and well-being.

Purpose of the Study

The primary purpose of this study was to determine if formal social support predicts levels of HIV/AIDS-related outpatient care visits among a subset of 797 individuals living with HIV/AIDS in the U.S., and whether this association varies by patient sex. The study sample is derived from a larger stratified random sample of 951 individuals living with HIV/AIDS. For the purposes of this study, formal social support was defined as having up to two case managers in the last six months. The dependent variable – number of outpatient care visits in the last six months - can vary across a wide continuum. For the purposes of this study, and to narrow the interpretability of outpatient visits in a manageable way, the number of outpatient visits was categorized as follows: 2-5 visits (average use); and 6+ visits (high use). The number of patients with 0-1 visits (n=67, rare use) in this sample was too low to run meaningful bivariate and multivariate analyses; however, this is an important subgroup to address in other research.

The aforementioned categorization should not be interpreted as a standard of care, or a judgment on appropriateness of care, but rather as one schema for examining ranges of outpatient visits that may provide other information about the context of living with HIV/AIDS (personal communication, V. Cargill-Swiren, M.D., M.S.C.E., July 3, 2006). Patients with rare use of outpatient visits may have unaddressed mental health, substance abuse, and other social health issues that interfere with both case management contact and outpatient care appointment keeping. Similarly, patients with high use of outpatient visits may have medication side effects or other illnesses besides HIV/AIDS that may require more clinical oversight. Thus, the important question for this research was whether the number of in-person case management contacts and type of support was sex/gender-specific in predicting levels of outpatient care visits. A better understanding of these relationships may lead to targeted case management and other enabling services for HIV-positive men and women to help them strengthen therapeutic alliances and connect to outpatient care.

For the purposes of this study, the terms “sex” and “gender” were used interchangeably, given that the study data source used the term “gender” to assess an individual’s biological male- or female-ness. However, it is important to recognize that the IOM (2001) has established distinct definitions of the two terms. Specifically, sex refers to being male or female according to reproductive organs and chromosomal make-up, while gender defines one’s sense of self as male or female in society.

Previous research efforts have established that there are significant differences in receipt of HIV-related care and HAART by sex/gender as well as other factors, such as race/ethnicity and injection drug use, with more frequent use of outpatient care among White males and non-injection drug users, and more frequent use of emergency room care for women and substance-abusing persons (Andersen et al., 2000; Cunningham et al., 2000; Fleishman & Hellinger, 2003; Masson, Sorensen, Phibbs, & Okin, 2004; Mauskopf et al. 1994; Menke, Giordano, & Rabeneck, 2003; Mor, Fleishman, Dresser & Piette, 1992; Schoenbaum & Webber, 1993; Sorenson et al., 2003). A recent study by Gebo and colleagues (2005) also found significant differences by race/ethnicity and gender in the receipt of HAART among a sub-sample of 6,192 patients seen at nine HIV

Research Network sites, with significant disparities evident among women, African Americans, and injection drug users (IDUs). Providers may be less likely to prescribe medications to IDUs when they have concerns about adherence to treatment (Escaffre et al., 2000); at the same time, IDUs may be less likely to seek regular care.

The supporting aims of the present research were to determine if the intensity and type of formal social support, respectively, predicted levels of HIV/AIDS-related outpatient care visits, and whether this association varies by patient sex. For the purposes of this study, intensity was defined as the number of in-person contacts across a maximum of two case managers in the last six months; while type of formal social support was defined as either informational or instrumental. In the only nationally representative sample of HIV-positive patients' health services utilization, patients who had at least one case management contact in person or by phone over the six month study period had less unmet need for support services (Katz, 2000). In other studies that were done among patients engaged with HIV/AIDS safety net providers, case management was associated with entry into appropriate medical care (Messeri, Abramson, Aidala, Lee, & Lee, 2002; Sherer et al., 2002). Magnus and colleagues (2001) found that receiving help with transportation –a form of instrumental support – and having more than one contact with a case manager were both significantly related to improved retention in primary care among a sample of 198 HIV-positive women. Data were collected for that study between January 1, 1997 and December 31, 1998, which is after HAART had become the standard of care. Establishing a clearer picture of the role of case managers as one category of formal social support for men and women living with HIV/AIDS in the post-HAART era, and whether the type of support can influence outpatient care utilization were important goals of the present work.

The overall conceptual model behind this study came from research and analysis of health services use first developed by Andersen (1968) and further explored in later years (Andersen, 1995; Phillips, Morrison, Andersen, & Aday, 1998). The core model (see Figure 1) suggests that health services utilization is a function of an individual's predisposition to use services, factors that enable or impede use, and his/her need for care.

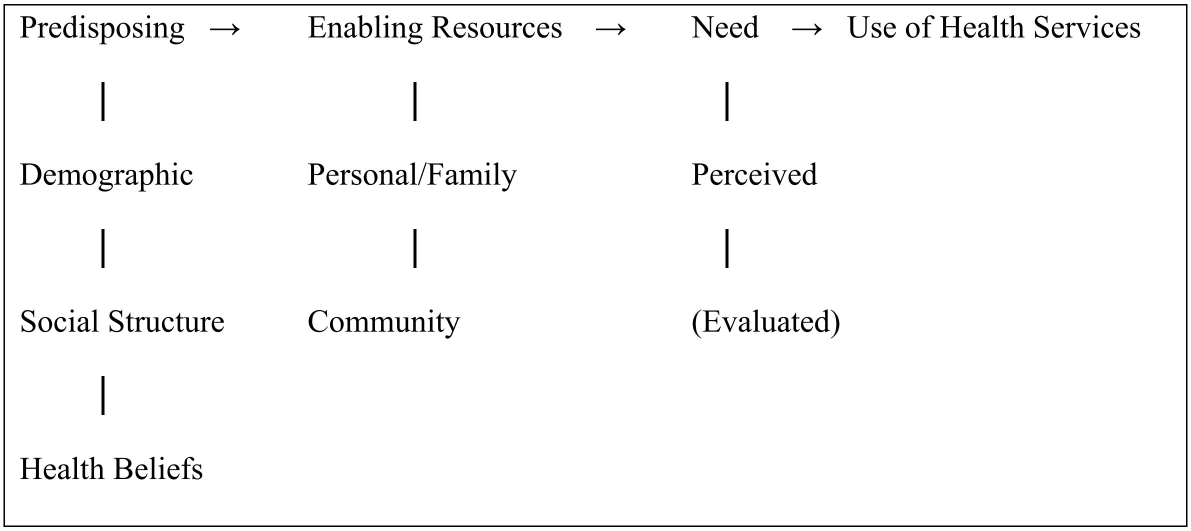

Figure 1. Behavioral Model of Health Services Use, Andersen, R.M. (1968).

These three components – Predisposing Characteristics, Enabling Resources, and Need – include several sub-components. For example, demographics such as age and sex fall under Predisposing Characteristics. Education, employment status and race/ethnicity were originally conceived under the Social Structure sub-component, whereas attitudes, values, and knowledge about health services were subsumed under the Health Beliefs sub-component. Andersen (1995) purported that personal/family and community resources were both important sub-components under the Enabling Resources component. From his point of view, people needed the means and information to access and use health services; at the same time, health care professionals and clinics needed to be located in the same neighborhoods in which people carry on with their daily lives. Proxies for these variables include income, health insurance, and having a regular source of care. Andersen (1995) contended that individual social ties could be put under the Enabling Resources component, as compared to wider social networks –or groups of interactions—that are better accommodated under the Social Structure component.

When explaining the Need component, Andersen (1995) noted that this refers to two parts: first, the perception of health status from the individual's point of view, and second, the health professional's objective evaluation of an individual's health. In some cases, patient perception may be the catalyst for seeking care, whereby a professional's judgment can have a positive or negative impact on what kind of and how much care is provided. The definition of "care" in Andersen's model was not specifically defined; however, Andersen believed that predicting ambulatory health services use was different than predicting inpatient care, and that application to different diseases may change how the model is operationalized. Notwithstanding, the intention of the model is to better understand the components and processes that lead to health services utilization.

The current study took an in-depth look at the Enabling Resources component of Andersen's model, as described above, and its relationship to use of HIV/AIDS-related outpatient care. Thus, it focused in on that part of the model that may predict health services use for a group of people whose health prognosis depends on using the health care system on a regular basis. At the same time, the present study put a greater emphasis on understanding how a demographic factor– patient sex – may interact with a specific enabling resource – formal social support -- which has implications for improving connections to care, establishing stronger therapeutic relationships, targeting case management services, and improving HIV/AIDS patient outcomes. Currently, little is known about the variation of case management services by sex/gender and their possible connection to HIV/AIDS-related outpatient care. As compared to Andersen's original conceptualization, the present study considered education and employment as well as the presence of others in the household as possible Enabling Resources, in that they may contribute to patients' knowledge of and access to outpatient care; in the original model, education and employment were labeled under the Social Structure sub-component, with the idea that they represented a person's position in the community. Adaptations of the Andersen model for different health issues allows for flexibility to better understand health services use.

For the purposes of this study, formal social support provided by one or two case managers served as the primary independent variable; further contextual information came from intensity of formal support and type of support. Given the study's focus on potential sex/gender differences in predicting levels of HIV/AIDS-related outpatient visits as influenced by formal social support, patient sex was the primary Predisposing covariate of interest. Also, as adapted to the HIV/AIDS case, other covariates including race/ethnicity, age, education, employment, perceived health status, change in health status, illicit drug use, availability of informal support, and stage of illness (CD_4 nadir), were measured and adjusted for in multivariate analyses, as appropriate. More details and definitions of the covariates can be found in Chapter 3.

An Analytic Model (See Figure 2, Chapter 3) was developed to inform the study's primary research question and secondary research questions.

Primary Research Question- Does the scope of formal social support predict levels of HIV/AIDS-related outpatient care visits? Does this association vary by patient sex?

Secondary Research Question- Does the intensity of formal social support predict levels of HIV/AIDS-related outpatient care visits? Does this association vary by patient sex?

Secondary Research Question - Does the type of formal social support predict levels of HIV/AIDS-related outpatient care visits? Does this association vary by patient sex?

The dependent outcome examined was level of HIV/AIDS-related outpatient care visits, which was operationalized in this study as 2-5 visits (average use) and 6+ visits (high use). The primary covariate of interest was patient sex. The primary independent variable was formal social support. Other covariates were grouped under three major headings: 1) Other Predisposing Characteristics; 2) Other Enabling Resources; 3) Other Need for Services. Further details on specific variables under each of these groups are given in Chapter 3.

HCSUS studies based on data collected in the mid-1990s suggest that both HIV-positive men and women need case management services; however, Katz and colleagues (2001) did not find a significant relationship between case management receipt and having one outpatient visit during a three month study period. However, newer studies are beginning to revisit the possible relationships among case management receipt, retention in primary care, and outpatient care use, as well as the importance of looking at specific types of social support needed for HIV-positive men and women, given other physical and social demands on their time (Knowlton, Hua, & Latkin, 2005; Magnus et al., 2001).

The following hypotheses were put forth, taking into account what is known to date on the connection of case management to outpatient care for HIV-positive men and women, in addition to the larger literature base on health care utilization. These hypotheses were also informed by studies that illustrate how HIV-positive women may need additional personalized attention in the form of instrumental support to take care of their own needs above those of other family members (Cunningham et al., 1999; Magnus et al., 2001; Raveis, Siegel, & Gorey, 1998; Ward, 1993). Still, because of the lack of previous research on the impact of informational support and the impact of frequency of HIV/AIDS case management contacts, two of the hypotheses were null hypotheses.

Hypothesis 1 - Patients with formal social support will have more HIV/AIDS-related outpatient care visits as compared to patients without formal social support.

Hypothesis 2 - Level of HIV/AIDS-related outpatient care visits will not be associated with levels of intensity of formal social support.

Hypothesis 3a - Increased instrumental formal social support will be associated with increased levels of HIV/AIDS-related outpatient care visits.

Hypothesis 3b - Increased informational formal social support will not be associated with increased levels of HIV/AIDS-related outpatient care visits.

If patient sex was shown to be a significant covariate in tests of any of the above hypotheses, the cross-product of the variables "patient sex" and "social support" would be created and added to the multivariate models to determine if there was an interaction between these variables in predicting levels of HIV-related outpatient visits. An interaction was expected for Hypotheses 1 and 3a. Finally, one additional sub-analysis, which is further explained in Chapter 3, was conducted. This sub-analysis addressed whether any significant relationships found with the entire study sample remained when HIV-positive patients with two case managers were excluded.

Chapter 2: Literature Review

Disparities in health care access and treatment are well documented across a wide number of medical conditions and for a number of different populations, including women and racial/ethnic minorities (AHRQ, 2004; AHRQ, 2002; Alliance for Health Reform, 2003; Pearcy & Keppel, 2002; Satcher, 2001; Wong, Shapiro, Boscardin, & Ettner, 2002), both in the U.S. and around the world (Casas-Zamora & Ibrahim, 2004). In the 2004 National Healthcare Disparities Report (AHRQ, 2004), three key themes emerged:

- Disparities are pervasive.
- Improvement is possible.
- Gaps in information exist, especially for specific conditions and populations. (p. 1)

The American Public Health Association (2004) defines health disparities as "differences that occur by gender, race and ethnicity, education level, income level, disability, geographic location and/or sexual orientation." In the context of health care, the term "differences" suggests inequitable access to, availability of, and distribution of needed services. Across virtually all medical conditions, persons with lower income levels have reduced access to and choice of health care providers and services (Mayberry, Mili, & Ofili, 2000). However, health care disparities are not fully explained by income variation, stage or severity of illness, co-morbidities, or health insurance coverage; other factors, such as historical biases in access to medical care, may be at play (Kaiser Commission on Medicaid and the Uninsured, 2005; Mayberry, Mili, & Ofili, 2000). In addition, patient sex and race/ethnicity can be synergistic disparity factors. In a landmark study controlling for symptom presentation and other factors, Schulman and colleagues

(1999) found that physicians were significantly less likely to refer African American women for cardiac catheterization than White males, Black males, and White female patients.

To put these disparities in context, one model of health services utilization that has been useful to researchers and that is adapted for the current study is Andersen's (1968, 1995) Behavioral Model of Health Services Use. As described in Chapter 1, this model includes a number of factors that are presumed to predict and explain the use of health services. These factors included Predisposing Characteristics, including demographic, social structure, and health beliefs; Enabling Resources, which include personal/family and community variables; and Need, which includes both perceived and evaluated requirements. Over time, the model has been modified and adapted by others to focus more on system or organizational characteristics such as insurance, provider type and training, and geographic location of health facilities (Andersen & Newman, 1973), as well as the mutability of the model components in predicting health service use. Other additions to the model in the 1980s and 1990s have encompassed perceived health status and consumer satisfaction as important components (Andersen, 1995). Access to health insurance has become more important as the model developed over the last three decades.

Lack of health insurance is one of the most significant contributors to health care disparities. Reasons for lack of insurance include but are not limited to the high costs of insurance premiums, lack of appropriate employer-based health plans, geographic location, poverty, and pre-existing health conditions. Women are more likely than men to lack employer-sponsored insurance and to rely on public systems of care (Kaiser Family Foundation, 2004a). Moreover, women living with HIV/AIDS are more likely than men living with HIV/AIDS to be Medicaid beneficiaries, given the potential for pregnancy and responsibility for dependent children (Bozzette et al., 1998). Having a regular source of care significantly increases the chance that men and women receive sufficient preventive care, health education messages, and other important health services. Lack of a regular source of health care is a problem for all, but it is particularly devastating to those living with chronic illnesses, given their elevated need for costly health care services (Kinney & Steinmetz, 1994; Stroupe, Kinney, & Kniesner, 2000).

More than 90 million Americans live with visible and non-visible chronic illnesses (CDC, 2005a). Chronic conditions can be characterized by fluctuating and often unpredictable periods of disability and improvement. Diseases that once were immediately life threatening, such as heart disease, can now be managed over time with appropriate chronic disease management care plans. Many chronic illnesses are a result of advanced age, but an increasing number of these conditions are related to a combination of lifestyle choices; as a result, the diagnosis of a chronic illness must be seen within the context of other life experiences. Some chronic illnesses disproportionately affect women, such as osteoporosis, while men are more likely to be obese. It is not uncommon for people to be living with more than one chronic illness (Lorig, 1996).

For both men and women, living with an ongoing health challenge involves a reorganization of one's life plan. Chronic disease management is a strategy for patients and providers to work together to maintain or improve health and functional status while postponing or preventing functional decline (Bierman & Clancy, 1999; Lorig, 1996). New medications to manage symptoms and support active living can help patients continue with day-to-day activities rather than become housebound. Support groups and other social outlets can help persons living with chronic conditions find others who can provide encouragement during stressful times. As with many aspects of health care delivery in the U.S., however, there are challenges for chronic disease management at personal, social, and economic levels. Some research suggests that women living with chronic illnesses report more symptoms and worse physical health than their male counterparts, as a result of differences in symptom interpretation, health-seeking behavior, and access to resources (O'Neill & Morrow, 2001). Access to chronic care providers may also be different for men and women with the need to afford health care and child care options placing women at a disadvantage. Thorne and colleagues (1997) have also noted that some men and women living with chronic illnesses may focus on different priorities according to socialized roles of paid work for men and family caretaking for women. Additional research is also needed to fully understand how acculturation affects chronic disease management for men and women as well as how individuals learn to live with more than one chronic illness.

Chronically ill persons often lack adequate health insurance coverage and pay more out-of-pocket for care (Hwang, Weller, Ireys, & Anderson, 2001; Stroupe, Kinney, &

Kniesner, 2000). One study by Reed and Tu (2002) found that nearly 63% of the uninsured with chronic health conditions have family incomes below 200 percent of the Federal poverty level; many of these families rely on publicly funded health insurance programs such as Medicaid. However, providers may limit the number of Medicaid-dependent patients in their caseloads or may refuse to see Medicaid-dependent patients altogether.

HIV/AIDS-related services paid by Medicaid cover the care of nearly 50% of all persons in the U.S. with AIDS and 90% of children living with AIDS (Graydon, 2000). In HCSUS, the only nationally representative study of 2,864 persons living with HIV/AIDS in care, 61% of women were covered by Medicaid as compared to 39% of men (Bozette et al., 1998). Indeed, public sector insurance programs, including Medicaid and Medicare, have become two of the largest sources of financing for HIV/AIDS care in the U.S. In fiscal year 2004, the Federal share of Medicaid HIV/AIDS-related spending was $5.4 billion; for Medicare, it was $2.6 billion (Kates & Leggoe, 2005). The President’s fiscal year 2007 budget request for these same programs was $6.8 billion for the Federal share of Medicaid and $3.5 billion for Medicare. Still, it is important to keep in mind that the number of people in need of these benefits is constantly growing, given that there are more than 40,000 new HIV diagnoses each year in the U.S., and fewer than 16,000 HIV-related deaths (CDC, 2005b). The potential per capita increase in public funding is thus relatively small. Private insurance provides coverage for some 30% of all individuals with HIV/AIDS; of those with private insurance, only 26% who are covered have full-blown AIDS. One reason for this latter figure is that many individuals with AIDS no longer work and don't qualify for private employer-based health insurance coverage.

Differences in healthcare-seeking behavior have been shown to vary by health insurance status, patient sex, race/ethnicity, income level, and perception of illness (Adamson, Ben-Shlomo, Chaturvedi, & Donovan, 2003; Park & Buechner, 1997; Puentes-Markides, 1992; Xu & Borders, 2003). For example, a Kaiser Family Foundation Report by Salganicoff, Beckerman, and Wyn (2002) revealed that women often delayed seeking health care as a result of affordability concerns, logistical barriers, including lack of transportation; and competing needs of family members. Several years later, in a separate issue brief, the Kaiser Family Foundation (2004b) noted that health disparities for women exist across several areas, including health status, health insurance, access to culturally competent health professionals, and access to ancillary services such as child care and transportation. Women may have less access to purchasing coverage as a result of their own or their spouse's work situation. As a result of these disparities, some female workers are unable to access primary care services when illness progression is less advanced and treatment may be less costly.

Given the increasingly disquieting statistics about disparate health care access and treatment, in 1999, the Congress charged the National Institute of Medicine (IOM) with addressing this issue through a careful review of the literature. Review parameters included gender, insurance status, and individuals' ability to pay for health care. IOM experts were also requested to ponder explicit or subtle biases by healthcare providers that might affect quality of care. The resulting report, “Unequal Treatment: Confronting Racial and Ethnic Disparities in Healthcare,” uncovered consistent evidence of health care disparities across more than 100 studies in a number of disease areas and across a range of clinical settings, including public and private hospitals (IOM, 2002). Although the present study is not directly addressing system-level disparities nor focusing primarily on race/ethnicity, the reader is reminded of their potential presence in the overall context of unequal care for HIV/AIDS patients.

Historical Context of HIV/AIDS in the United States

The first cases of what would later become known as AIDS were reported in the U.S. in a June 1981 *Morbidity and Mortality Weekly Review* brief (MMWR; CDC, 1981). As with other scourges that had wide impact on social and political discourse, such as leprosy and tuberculosis, CDC scientists were tasked with understanding the epidemiology of the growing number of AIDS cases while trying to limit spread of new infections. In the early 1980s, CDC scientists identified four at-risk groups that came to be known colloquially as the “4-H Club”: homosexuals, heroin users, hemophiliacs, and Haitians (Goldstein, 1997; Rodriguez, 1997). In this classification system, women were not considered at risk. The earliest group of women identified as being at risk was labeled with yet another “H” word - hookers. The first heterosexual woman with AIDS was actually noted in the 1981 *MMWR* brief, while the first descriptions of immunosuppression in heterosexual injection drug users (IDUs) were published later that year. Increasing evidence suggested that an infectious agent carried in the blood might be involved and that certain behaviors, including unprotected sex and injection drug use, placed people at higher risk. The isolation of HIV in a laboratory setting was eventually completed in 1984.

Over the next ten years, HIV/AIDS increasingly spread from gay and more affluent populations into marginalized and impoverished sectors of society that almost always included some groups of women (Tiamson, 2002). Still, for many years, HIV-positive women were typecast as vessels of contagion to innocent babies and male partners (Patton, 1993; Rodriguez, 1997; Smeltzer & Whipple, 1991; Zivi, 1998). Other typecasts divided women based on their work as prostitutes; their lesbian orientation; or their substance-abusing behaviors (Patton, 1993). The social construction of HIV/AIDS as a gendered epidemic has led some researchers to express outrage over the lack of recognition of symptom-specific conditions for women (Zierler & Krieger, 1997). During the first decade of the epidemic, the CDC did not change its AIDS definition to include any female-specific, HIV-related condition, despite growing evidence of increased incidence of vaginal candidiasis and cervical cancer among infected women.

HIV-positive men were also stigmatized based on public fear around homosexual behavior, the practice of anonymous sexual encounters at bathhouses, and simultaneous use of drugs. Misunderstandings about HIV transmission; disbelief about high profile celebrities who became HIV-positive, such as Rock Hudson and Magic Johnson; and mass media stereotyping led to confusion and, in some cases, the emergence of hate crimes. Over time, mass media outlets altered their coverage of HIV/AIDS from a human-interest story among a small stigmatized group to one of hyped alarm among the general population (Cook & Colby, 1992). Political leaders were forced to address the epidemic, but not before social and grassroots advocates demanded answers for the lack of Federal attention and funds for research, education, and treatment. In part, the Federal government's slow response to the epidemic relied on scientists to present evidence-based information that could be translated into programmatic action. Policymakers' unwillingness to change opinions about disease patterns, at-risk populations, and eligibility criteria for publicly financed early treatment also contributed to a delayed response (Rodriguez, 1997).

The historiography of HIV/AIDS - from its early classification in 1981 as a twentieth century plague to its current classification as a manageable, chronic condition comparable to diabetes or heart disease - offers a compelling view of how social, political, and personal agendas influence public policy and public response. The social contexts of HIV/AIDS transmission – sexual behavior and intravenous drug use – have both contributed to the shaping of HIV/AIDS history, as have intersections of gender, race/ethnicity, class, and culture (Goldstein, 1997). Berger (2004) labels this phenomenon "intersectional stigma," arguing that multiple layers of oppression and marginalization, particularly for women, may adversely affect access to care and basic survival. Stigma notwithstanding, it is also possible for new ways of political and collective activism to emerge.

It is clear from historical accounts that the changing conceptualization of HIV/AIDS care from an acute medical paradigm to a chronic illness model was motivated by a number of heated debates around cost containment and HIV/AIDS-specific drug development (Fox, 1992). For example, when a number of NIH-funded drug trials were beginning to show promising results for slowing the progression of HIV infection, policymakers changed their statements about the duration of time from HIV infection to full-blown AIDS. At the same time, HIV/AIDS was moving more quickly into disadvantaged populations, the same groups that had the lowest rates of health insurance coverage to pay for drugs that would slow the rate of disease progression. Thus, the burden on policymakers was not only to support a more positive outlook, given new life-sustaining drugs for HIV-positive persons, but to reconcile this position with existing disparities in health care access and treatment. This task has proved to be difficult and politically charged, with no easy solution. In sum, although the biomedical construction of HIV/AIDS explains how the disease is transmitted from person to person, it is limited in its ability to defend unequal rates of access to early, comprehensive and coordinated treatment. Given the history of longstanding inequalities, Fox (1992) argued that uncertainty in future funding for HIV/AIDS treatment, prevention, and research would continue for the foreseeable future. Since Fox's prediction in the early 1990s, funding for services through the Ryan White CARE Act has increased dramatically; however, access to care is still limited as a result of divergent eligibility policies, non-standard drug formularies across states, and relatively fewer dollars per capita to cover costly HIV-related medications through discretionary Ryan White CARE Act-funded AIDS Drug Assistance Programs ([ADAPs]; Kaiser Family Foundation, 2005).

HIV/AIDS and Disparities

From incidence to prevalence and diagnosis to treatment, disparities are well-documented for persons affected by HIV/AIDS. It is important to remember that sex/gender, race/ethnicity, and social class all intersect to affect HIV risk. Women of color, particularly African American and Hispanic females, have been particularly affected; they comprise the majority of new AIDS cases among women. The rate of reported AIDS cases among African American women is 25 times higher than among White women; for African American men, it is eight times higher than among White men. Among Hispanic women, the reported rate of AIDS cases is six times higher than among White women of non-Hispanic origin; among Hispanic men, it is three times higher than among White men (NIH, 2005).

In 1985, women represented an estimated 8% of AIDS cases; by 2004, women made up 27% of new HIV infections. According to the most recent (2003) reports from CDC on the leading causes of death (National Center for Injury Prevention and Control, 2006), HIV/AIDS was the sixth leading cause of death among all women ages 25 to 34 and the fourth among all women ages 35 to 44. In comparison, HIV/AIDS was the fifth leading cause of death among all men ages 35 to 44. Among men of all races, ages 25 to 34, HIV/AIDS was also the sixth leading cause of death.

Research suggests that there are sex/gender-based differences in HIV/AIDS vulnerability (Cohen, 1997). These differences are both physiologically and socially grounded. For example, experts acknowledge that women are physiologically at greater risk than men for acquiring HIV from heterosexual intercourse (Ickovics & Rodin, 1992; National Institutes of Health, [NIH], 2003; Ward, 1993), while the practice of anal intercourse places men who have sex with men at an increased risk (Gross, 2003). Social and cultural influences also place men and women at risk for HIV infection to different degrees (NIH, 2003; Rao Gupta, 2000; Zierler & Krieger, 1997). Many clinicians and social researchers now understand that women are at increased risk for HIV infection if they lack empowerment to make self-protective health decisions, including those that affect sexual health and HIV risk reduction (Campbell, 1995; Monti-Catania, 1997; North & Rothenberg, 1993; Quina et al., 1997; Stevens, 1995; Stevens & Richards, 1998; Zierler, 1997; Zierler & Krieger, 1997). For example, socio-economic constraints and gender inequality can play a role in women's inability to negotiate safe sexual practices with their male partners (Bunting, 1996; Rao Gupta, 2000; Zierler & Krieger, 1997), as well as increasing the potential for engaging in illicit drug use and sex work, both of which have implications for HIV transmission. Lichenstein, Laska, and Clair (2002), and others (Semple et al., 1993; Wiener, 1991) have observed that the lived experience of HIV/AIDS is different for women than for men, as shaped by social status and sexual norms (Schieman, 1998), and that these contexts affect access to care. In male-dominated hierarchies (often found in Hispanic cultures), women may feel unable to discuss self-protection before sexual encounters (Flaskerud & Calvillo, 1991; Kline, Kline, & Oken, 1992). Ironically, many HIV prevention messages targeted to women assume that there is open and honest communication with sexual partners and that these women have substantial personal power in deciding self-protection and the timing of sexual activity. In reality, these may be remote options.

AIDS Cost and Services Utilization Survey (ACSUS) and HIV Cost and Services Utilization Study (HCSUS)

Much of what is known about HIV/AIDS health services utilization in the contiguous U.S. comes from two forerunner studies – the AIDS Cost and Services Utilization Survey (ACSUS) and the HIV Cost and Services Utilization Study (HCSUS). ACSUS included data collected from 1991-1992 on a wide range of demographic, health, and economic variables for a sample of HIV-infected persons in care. Purposive sampling was carried out in ten cities in the U.S. with high AIDS prevalence; the final number of patients included in ACSUS was 1,949. ACSUS is an important pre-HAART source of information on health services utilization for HIV-positive individuals. For example, using ACSUS data, Pezzin and Fleishman (2003) analyzed the association of inpatient and emergency department care with outpatient care and noted several key findings among a sub-sample of 1,243 ACSUS respondents. First, patients with diagnosed AIDS had higher health services utilization rates than persons who had not developed advanced illness. Also, individuals with drug abuse histories (24% of the sample) were more likely to have inpatient admissions than persons who were not injection drug users. Significant differences by gender were not observed in the results; this may be because women were not oversampled in the study design and comprised less than 20% of the cohort. This limitation is not an issue for the current study, as female adults comprise 30% of the patients in the HIV Research Network interview sample.

In an ACSUS study addressing patterns of contact with health services over a 17- month time period from March 1991 to August 1992, Niemcryk and colleagues (1998) found that utilization of a particular service – emergency room visit, hospital admission, outpatient care, dental care, substance abuse treatment, and counseling - was a strong predictor of subsequent use of that service. Service utilization at time 2 (approximately three months after time 1 baseline) was the best predictor of service over the full study period for all services, except for dental care. Again, women comprised less than 20% of the sample, making it impossible to run meaningful gender analyses. The historically low numbers of women enrolled in general HIV-related studies limit understanding of sex/gender differences in study outcomes. Among another sample of 1,449 ACSUS respondents, Fleishman, Hsia, and Hellinger (1994) also found that the experience of pain or functional limitations associated with HIV/AIDS can motivate patients to seek health services, particularly at emergency rooms.

Since ACSUS, a great deal of knowledge about utilization of HIV/AIDS services has come from HCSUS. Funded by a public-private partnership of Federal agencies and corporations, HCSUS examined a number of variables associated with HIV-related care, including cost, access, quality of care, unmet need, and knowledge of HIV therapies. The core sample of the study consisted of 2,864 HIV-positive adults (age 18+), who came from 28 urban areas and 24 clusters of rural counties in the contiguous U.S, and made at least one visit for regular or ongoing care to a non-military, non-prison clinician other than an emergency room during the first two months of 1996 (note: one site had a study period that began in March 1996). All data were collected using computer-assisted personal interviewing beginning in January 1996 and ending 15 months later, in April 1997. Data were weighted to correct for unequal probabilities of selection into the study across patient and provider respondents, with oversampling for women and minorities. HCSUS was comprised of a core study and seven supplemental studies. The core study addressed the following domains: cost, use, and quality of care; access to care; unmet needs for care; quality of life; social support; knowledge of HIV; clinical outcomes; mental health; and the relationship of these variables to provider type and patient demographics. The supplemental analyses used data from the core study to look at HIV in rural areas; prevalence of mental illness and substance abuse, oral health, and issues related to HIV-positive individuals over age 50. A baseline and two follow-up interviews at 6 months and 12 months after the baseline were completed. Researchers continue to draw upon the HCSUS core study to understand health services use among HIV-positive persons and to use this dataset to answer questions about health services utilization among HIV-positive persons; however, reliability and validity tests of the survey instruments have not been carried out or published on the HCSUS core study (personal communication, J. Fleishman, Ph.D., June 20, 2006).

Given the importance of HCSUS in learning about HIV/AIDS service utilization and trends, researchers developed several policy briefs early on to characterize findings from the data; numerous subsequent studies have been carried out, addressing specific research questions using HCSUS data. Early findings illustrated many significant issues. For example, almost 90 percent of the HCSUS sample was less than 50 years of age; 75% were male; 25% were female; nearly half were non-Hispanic White, and one third were African American. Forty six percent had annual household incomes less than $10,000 (RAND, 1999). A subsequent HCSUS policy brief demonstrated systematic socio-economic differences in access to HIV-related care across the U.S. For example, as early as 1996, 15% of HCSUS respondents had fewer than two outpatient visits during a 6-month period. Persons with private insurance or Medicare fared better than those with Medicaid or no health insurance (RAND, 2000). Follow-up interview data at six and twelve months showed modest progress on some measures; however, the percentage of persons who had fewer than two outpatient visits per 6-month interval remained unchanged.

Numerous articles have been published in peer-reviewed journals based on the HCSUS core study and follow-up datasets. A seminal article by Shapiro and colleagues (1999) provided a comprehensive look at the disparities in care for HIV-positive adults based on HCSUS data. Outcome measures included outpatient visits, emergency room visits, hospitalizations, and medication usage (receipt of antiretroviral therapy and prophylactic drugs for *Pneumocystis carinii* pneumonia [PCP], an opportunistic infection associated with AIDS). Analyses were run with and without adjustment for CD_4 counts. Patients who had fewer than twelve years of education and who were uninsured or on public health insurance had poorer health outcomes at both baseline and follow-up. Even with adjustment for CD_4 counts, female patients, Black patients, and Hispanic patients were more likely than White male patients to have had at least one emergency department visit and less likely to have received antiretroviral therapy or prophylactic medication for PCP. Female HCSUS patients also had less routine patterns of care, though covariate adjustment for age, race/ethnicity, and insurance appeared to explain more of this pattern.

Studies to date suggest that there are significant differences between HIV-positive women and men in care. Shapiro and colleagues (1999) found that in data collected from the HCSUS sample of 2,864 HIV-positive men and women, the women were more likely to have visited the emergency department at least once and to have been hospitalized at least once during the preceding six months. They were also less likely than men to have begun HAART therapy by the end of 1996 or to have taken prophylactic medication for PCP. Another study based on the HCSUS sample found that HIV-positive women were less likely to receive HAART than HIV-positive men, when controlling for other demographics (Cunningham et al., 2000). A third study by Andersen and colleagues (2000) based on HCSUS patients corroborated differences in early access to HAART by gender, race/ethnicity, and education level, with women, African Americans, and persons with less education facing greater challenges in getting early access to HAART. In contrast, Turner and colleagues (2000) found significant differences by race/ethnicity but not by patient sex in delay of medical care following HIV diagnosis among two cohorts of HCSUS participants. For purposes of this study, Turner and her colleagues divided HCSUS participants by time of diagnosis and integration into care: Cohort A (N=1540) was diagnosed by February 1993 and was in care within 3 years; cohort B (N=1960) was diagnosed by February 1995 and was in care within a year of an HIV-positive diagnosis. This latter finding may reflect, in part, an increased understanding among clinicians of the necessity to move newly diagnosed patients into care as soon as possible.

One important limitation of HCSUS is that data was collected between 1996-1998 and are now outdated, given changes in treatment guidelines for HIV/AIDS clinical care. The cost of replicating the design of HCSUS with a new representative sample would be prohibitive. Instead, one alternative has been the creation of the Federally-funded HIV Research Network (HIVRN). The HIVRN was created in 1998; following a pilot phase of development that included 15 sites, the Network now coordinates data from 17 U.S. clinical care sites serving more than 15,000 people living with HIV/AIDS. The goal of the HIVRN is to provide timely information on health services utilization by persons in HIV care. Information learned from studies using the HIVRN data is essential to understanding patient use of services in the post-HAART era. The HIVRN adult patient interview dataset was the source of data for this dissertation. More information about the HIVRN is provided in Chapter 3.

There are mixed findings in the literature concerning disparities in HIV-related inpatient and outpatient utilization in non-HCSUS samples. Mor and colleagues (1992) found that among 939 HIV-positive persons, there was a significant difference between men and women in the rate of outpatient health service use over a three-month period, with men having higher rates of outpatient use than women. In contrast, researchers using now-retired HIVRN data from calendar year 1999 found that women (24% of the sample, N=5,266) had higher rates of both outpatient and inpatient utilization than men at nine primary care sites across the U.S (HIV Research Network, 2002). Finally, in a recent paper analyzing trends in HIV-related inpatient admissions from 1996-2000 across seven states, Fleishman and Hellinger (2003) noted that the proportion of inpatient admissions to total admissions was highest for Black men and lowest for White women, and that admissions for White males and for privately insured patients showed the largest decline over the 4-year study period.

Delays in seeking timely health care can have a negative impact on HIV-related health outcomes, including an increased number of opportunistic infections and hospitalizations and poorer quality of life (Bright, Arnett, Blair, & Bayona, 1996; McDonnell et al., 2000; Tsasis, 2000). Moreover, lack of adherence to prescribed HAART regimens can lead to drug resistance and fewer options for alternative treatment courses (Cunningham et al., 2000; Paterson et al., 2000). Patients who do not adhere to their medication at least 80% of the time may experience less clinical benefit than patients who are adherent (Eldred, Wu, Chaisson, & Moore, 1998; Friedland & Williams, 1999). Some evidence suggests that women seek care at later disease stages than men, yet they may encounter the same general barriers to care, such as lack of transportation and child care, as non-HIV-positive women (Butz et al., 1993; Mocroft, Gill, Davidson, & Phillips, 2000; Palacio, Shiboski, Yelin, Hessol, & Greenblatt, 1999; Raveis, Siegel, & Gorey, 1998; Stein et al., 2000). However, other studies suggest that with equal access to health care services, HIV-positive women do not experience a difference in prognosis relative to men (Brettle & Leen, 1991). Rather, the course of illness and length of survival appear to be significantly influenced by co-morbid illnesses and socio-economic conditions (Cohen, 1997; Eldred & Chaisson, 1996). More research is needed to understand health care accessibility and utilization patterns among HIV-positive men and women so as to minimize barriers that may impede entry into early treatment.

The next section of this literature review addresses important aspects of the evolution of HIV/AIDS standards of care and treatment options, which continue to be unavailable to all patients in need.

HHS Treatment Guidelines for the Use of Antiretroviral Agents in HIV-1 Infected Adults and Adolescents

Early diagnosis of HIV infection is critical for appropriate treatment plans to be developed and implemented. As previously noted, persons living with HIV/AIDS often have numerous medical, psychological, and social needs which can affect early access to and continuity of care. Initial treatment options for persons infected with HIV included single drug regimens, such as the nucleoside reverse transcriptase inhibitor zidovudine (AZT), which quickly proved to be ineffective against the mutating nature of HIV. Drug resistance was also an issue if and when patients failed to follow dosage recommendations consistently. With the introduction of combination therapy (HAART) in 1996, clinicians had improved treatment options in their medical arsenal for HIV-positive patients. Currently, there are several recommended HAART regimens, with combinations drawn from four classes of antiretroviral drugs. From a medical perspective, the Department of Health and Human Services' "Guidelines for the Use of Antiretroviral Agents in HIV-1-Infected Adults and Adolescents" is considered one of the most reputable sources of current clinical knowledge for treating HIV-positive adults and adolescents. The purpose of the Guidelines is to answer several core clinical questions about when to start treatment, what treatment combinations to use, and how to advise clinicians on optimal treatment goals for patients and special subpopulations. Recommendations are based on scientific evidence and experts' opinion; this information is updated often on the HHS AIDSInfo website, http://aidsinfo.nih.gov/.

In gauging when to start treatment, clinicians rely on two surrogate markers of viral activity – *CD_4 + T cells* and *viral load.* CD_4 + T cells (the measure of which is referred to in this document as "CD_4 count") are a type of white blood cell involved with the normally functioning human immune system. A normal adult's CD_4 count is on the order of 1000 cells/mm^3. A CD_4 count below 200 cells/mm^3 is indicative of the substantial degree of immunocompromisation that is called AIDS; however, people with counts higher than 200 cells/mm^3 may also experience AIDS-defining opportunistic infections. Viral load or plasma HIV RNA is an indicator of treatment response and signifies the number of viral copies/mL of blood, with a higher number of copies indicating more advanced illness.

Some data indicate sex-specific differences in viral loads and CD_4 counts. Women may have lower levels of viral load at the time of infection and may progress to full-blown AIDS with lower viral load levels than men. Other sex-specific clinical differences suggest that women are infected by multiple variants of HIV while men are not (NIH, 2005). HIV-positive women also exhibit a high risk for gynecological malignancies, including invasive cervical cancer and human papillomavirus infection (NIH, 2005). These factors notwithstanding, differences in treatment by sex are currently not supported by scientific evidence (nor were they in 2003 when the HIVRN adult patient interview data were collected); however, clinicians are advised to consider potential future pregnancy in women (HHS, 2005). Some antiretroviral drugs can interact with oral contraceptives, increasing the chance of unplanned pregnancy, while other antiretroviral drugs can interfere with fetal development. A primary clinical goal is avoidance of perinatal transmission, which has a greater chance of success with appropriate clinical intervention early in the pregnancy.

Although gender differences in HIV-related morbidity and mortality are well-documented, many if not all of these differences can be attributed to co-occurring social and economic disparities and higher rates of co-morbidities such as hepatitis C (associated with injection drug use) and tuberculosis. In addition, it is important to remember that both client and clinician characteristics can play a role in the initiation of and adherence to HAART regimens (Bird, Bogart, & Delahanty; 2004; Friedland & Williams, 1999; Malcolm, Ng, Rosen, & Stone, 2003; Palacio et al., 2000; Paterson et al., 2000; Power et al., 2003; Roberts, 2002). Clinicians who are more familiar with HAART regimens and potential side effects, and who are seen as trustworthy, can help patients adhere to medications. In the meantime, clinicians and patients can benefit from coordination of care models, including those models built upon case management which have demonstrated promise to improve the quality of HIV/AIDS care. These models are built around social support theory, which is described next.

Social Support Theory

Social support theory suggests that persons with established connections to others in a personal or professional network may be better able to cope with life changes and stressful situations, and they may have improved health outcomes (Thoits, 1982). The conceptualization of social support varies extensively, with numerous multi-dimensional definitions provided in the peer-reviewed literature. Cobb (1976) defines social support as information leading a person to believe that he or she is cared about; loved, esteemed and valued, and part of a network of communication and mutual reciprocation.

Kaplan (1977) defined social support as the degree to which an individual's basic social needs are met through interaction with others. House (1981) suggests social support is an interpersonal transaction encompassing one or more of the following types of assistance: emotional concern, instrumental aid, information, or appraisal relevant to self-evaluation. This latter definition was adapted for the present study.

Work by Vaux (1988) has delved into the theoretical definition of social support by looking at the constructs of networks, supportive behaviors, and subjective appraisal of support. Networks focus on an individual's social integration into a group, the number of people in that group, the frequency of contact among group members, and the kinds of relationships that members have with other members. Social support networks are likely to evolve and go through some change over time (Kimberly & Serovich, 1996). The type of support provided by a network may be emotional, instrumental, informational, financial, or a combination of any of these types. Definitions of support types often vary from one research study to another. In general, emotional support can be thought of as behaviors such as listening, caring, or offering companionship. Instrumental support includes practical help such as assistance with obtaining services or other practical benefits. Informational support is akin to advice or feedback that helps with decision-making and may overlap with emotional support, whereas financial support encompasses the provision of funds (Schwarzer, Dunkel-Schetter, & Kemeny, 1994).

Subjective appraisal connotes how persons perceive social support and their willingness to receive it from a particular source. It is possible that support may be perceived negatively in the context of social network demands and expectations (Coyne & DeLongis, 1986). Some of these demands can be detrimental to health; for example, in active substance use circles, individuals may be “supported” by those who engage in drug use behaviors and encouraged to continue with these behaviors as part of group membership. For some individuals, the cost of asking for and receiving support can be difficult; reaching out to others may be associated with a fear of rejection.

Cohen and Syme (1985) note the importance of matching support to a specific need, the appropriate timing of support, positive and negative support features, and linking recipient and provider characteristics. Social support provided by professional helpers, such as counselors and health care providers, may be characterized as non-reciprocal in nature, as compared to personal contacts in which informal support may follow a give and take pattern. Research has shown that in many cases, the quality of social support is more important than its quantity (Hupcey, 1998). Providers’ understanding of a patient’s health needs, previous experiences, culture, and other factors can influence whether a patient can benefit from a given type of support. Patients who have a trusting ongoing relationship with their health care providers may be more likely to engage in health care decision-making and follow prescribed treatment (Friedland & Williams, 1999; Whetten et al., 2006). For chronic illnesses, such as HIV/AIDS, the presence of formal social support through case managers can be particularly important for maintaining residence in the community and receiving services that meet the myriad of social and medical needs associated with chronic illnesses.

The next section of this literature review provides further background on the importance of social support for HIV-positive men and women. The studies examined have a broad range of sample characteristics and findings.

Social Support and HIV/AIDS

Many researchers have noted that patients at every stage of HIV infection can benefit from social support to help deal with and adjust to the disease (Ciambrone, 2002; Hays, Chauncey, & Tobey, 1990; Kimberly & Serovich, 1996; Knowlton, Hua, & Latkin, 2005; Tsasis, 2000). Social support may help reduce depression and anxiety, improve overall quality of life, and help with HIV-related medication adherence (Cox, 2002; Knowlton, Hua, & Latkin, 2005; Jia et al., 2004). Immediate family and friends may be the first networks of social support that HIV-positive patients turn to; however, for some individuals, these sources are not available. Patients may live far away from their families; moreover, family members and friends may be fearful about the social stigma associated with HIV/AIDS and keep their distance (Hays, Chauncey, & Tobey, 1990; Servovich, Brucker, & Kimberly, 2000; Turner-Cobb et al., 2002). Some research suggests that sex/gender and mode of contracting HIV are predictive of social support networks that are most helpful, with family members being most supportive for women, male IDUs, and heterosexual men, and friends being most supportive for men who have sex with men (Smith & Rapkin, 1996) and lesbians (Kurdek & Schmitt, 1987). HIV-positive men and women who are IDUs have complex social support needs. Family member ties may have been severed, and fellow drug users may comprise the primary support network. Skepticism and mistrust of assistance available through formal sources of support can be formidable hurdles to engaging HIV-positive injection drug users in care (Sorenson et al., 2003).

Other studies have suggested that support systems can vary by age (Scrimshaw & Siegel, 2003); culture (Ciambrone, 2002); and self-acceptance of sexual orientation (Gant & Ostrow, 1995). Timing of different types of support is also important. Tsasis (2000) has noted that informational support is helpful to all patients, particularly in the days following HIV diagnosis. As HIV disease progresses, some evidence suggests that formal social support helpers, including hospice care workers and home health nurses, may be of greater importance to those who are infected (Tsasis, 2000). Emotional support may be particularly needed for AIDS patients near death (Zich & Temoshok, 1987).

Given the focus in the present study on sex/gender differences, the following synopses address research findings from studies that have looked at the role of informal and formal social support in the lives of HIV-positive men and women. Many of these studies draw upon social support provided by family members and friends. More detailed findings from studies that address formal social support provided by professional helpers, including the association of case management with the use of clinical health care services, will be addressed later in this literature review in the Coordination of Care and Case Management Model sections.

Social Support and HIV-Positive Men

A large body of social support research conducted in the early 1990s focused on HIV-positive men who had sex with men. Many researchers utilized qualitative one-on-one interviews to learn about the breadth and depth of social support networks in small samples. For example, among a sample of 25 gay men living with AIDS, Hays and colleagues (1990) found that social support networks were comprised primarily of other gay male friends, including persons who were also living with HIV/AIDS. Friends most often provided emotional support, guidance, and shared experiences with other network members, whereas professional helpers provided limited informational support. Only therapists and physicians were specifically named as sources of formal social support. In a study by White and Cant (2003) looking at social networks among a sample of 30 HIV-positive gay men, results indicated that emotional and instrumental support were most often provided by partners, ex-partners, friends, and family members; in this study, health care providers were not listed. There are few studies that have addressed social support among HIV-positive heterosexual men; one study among a sample of 219 HIV-positive persons stratified by gender and mode of contraction found that heterosexual men perceived family members as more supportive than friends (Smith & Rapkin, 1996).

Other social support research studies have included both male and female persons living with HIV/AIDS. Kimberly and Serovich (1996) explored perceived availability of social support among 77 individuals living with HIV/AIDS in the Southwestern U.S. These researchers hypothesized that friends would be perceived as more supportive than family members. This was not found to be the case: both support systems provided comparable levels of support. The researchers also looked at whether the presence of a significant other would be positively associated with the perception of social support, as compared with HIV-positive persons who did not have an intimate relationship with a spouse or partner. No significant association was found. Of note, the number of women in this study was too low to carry out sex/gender analyses. In contrast, Burgoyne and Saunders (2000) found that having partners and friends was associated with higher ratings of functional support (i.e., material aid), and emotional-informational support (i.e. expressions of understanding and caring) among a sample of 114 newly-registered outpatients at an urban HIV/AIDS clinic. Generalization of study results was also limited by the low number of females who participated in the study.

Social Support and HIV-Positive Women

Several studies have examined the role of social support exclusively among HIV-positive women. Many researchers note that HIV-positive women's needs for social support may be different than those for HIV-positive men, given that women are often fulfilling other gendered roles as mothers and caretakers, and may be putting their own needs last (Andrews, 1995; Ciambrone, 2002; Gurung, Taylor, Kemeny, & Myers, 2004; Heath & Rodway, 1999; Raveis, Siegel, & Gorey, 1998; Solomon & Cohn, 1996). Serovich & colleagues (2001) studied perceptions of perceived and actual social support provided by friends and family members of 24 HIV-positive women. Results showed that perceived social support, as opposed to actual social support, was negatively correlated with mental health indicators such as depression and loneliness. Both family and friends were important sources of social support. Perceived family support explained 56% of the variance for depressive symptoms and 47% of the variance for loneliness in the past year. Although more information is needed on family structure and individual relationships within the family, these results suggest that the perception of family support may be critical to HIV-positive women's mental health and well-being.

In another study, Hudson and colleagues (2001) examined social support and level of distress among a sample of 104 ethnically diverse HIV-positive women in the San Francisco area. Results revealed that race/ethnicity was not a significant predictor of perceived social support, and that friends were significantly more supportive than family members in reducing distress as measured on the Brief Symptom Inventory, a 53-item instrument designed to measure psychological symptoms across nine dimensions. Of relevance to the present study, Hudson and colleagues (2001) note that the extremely high levels of perceived stigma among some HIV-positive women may affect their ability to reach out for the social support they need and cause delayed entry into medical care (Leenerts, 1998). Health care providers, including case managers, may be in a position to fill some of the gaps in a non-judgmental setting to help HIV-positive women obtain services and follow treatment regimens. Andrews (1995), a certified nurse-midwife, also documented the role of formal social support networks during interviews with three of her female HIV-positive clients. Social support sources included doctors and nurses as well as 12-step group facilitators; the type of support provided ranged from emotional to informational. Finally, in an exploratory study examining psychosocial needs of 12 HIV-positive women living in Alberta, Canada, Heath and Rodway (1999) identified several important themes, including the need for informational support at the time of diagnosis;

the need for ongoing emotional support from family, friends, and health care providers, including counseling; and the need for practical (instrumental) support with child care.

In almost all studies that address HIV-positive women's social support needs, instrumental support issues, including child care and transportation, are noted. These social support issues are not as prominently mentioned in studies to date addressing the needs of HIV-positive men. Although study findings cannot be generalized until more research is completed, these early studies suggest that instrumental support may be particularly needed by HIV-positive women. The next section of this literature review focuses on formal social support provided by case managers through the coordination of care model, and its potential link to outpatient care.

Coordination of Care Model

Levi and Kates (2000) state that "…HIV is a lens through which the underlying problems of the United States health care system can be examined." (p. 1033) Lack of coordinated systems, expensive drugs, and long delays in receiving care are some examples of how the current health care system is flawed. For HIV-positive individuals, the need for coordinated systems of medical and ancillary services, also known as integrated HIV care, is especially critical to ensure that patients stay as healthy as possible (Soto, Bell, & Pillen, 2004). Because HIV/AIDS was first characterized as a short-term illness, systems of care were based upon a crisis-oriented medical model with palliative care as the backbone of supportive services. As previously noted, with the availability of HAART since 1996, the management of HIV/AIDS has evolved to follow a chronic illness paradigm, with more outpatient management in the primary care setting. In addition, the prevalence of HIV among women has continued to rise, with close to 30% of new infections now occurring among women. Thus, sex/gender-specific targeted coordinated care models have become increasingly important. These models are designed around services to provide supportive systems for patients and their families and the sharing of data to optimize coordinated services. Health care provider training and support are important components of these models.

In 2002, the Health Resources and Services Administration (HRSA), HIV/AIDS Bureau funded a project that looked at how collaborative systems of care could make a marked difference in care delivery, clinical outcomes, and cost containment (HRSA, 2002). Project findings focused on several models, including one promising framework that came to be known as the “Care Model.” The components of this model included self-management and adherence, decision support, clinical information system, delivery system design, organization of health care, and community. All of these elements are accompanied by several strategies for their integration into the care setting that would support a holistic approach to patient care and support providers in their roles to deliver timely services based on current clinical guidelines. Involving patients in developing their care plans provides an opportunity for empowerment and providing a voice in selecting services that best meet their changing needs. Also of critical importance is the establishment of a clinical information system to keep track of patient characteristics, care planning and delivery, and connections with community resources, including case managers and mental health providers. Leadership commitment to collaborative models of care plays an important role in ensuring that improvements in health care delivery take hold and thrive while linkages with community groups serve to connect patients with a broader array of supportive and ancillary services.

Other coordination of care models funded by the HRSA project included a “Learning Model,” which focused on bringing together hospital teams for 12 to 15 months for rigorous training on HIV/AIDS care within a coordinated system, and an “Improvement Model,” which defines how to test and implement changes in a clinic setting in a rapid and efficient manner. Changes are then studied carefully and refined before they are broadly implemented into patient care delivery. These latter two models focus more on developing innovations in the system of care, while the “Care Model” focuses more on identifying the interactive elements that should become part of a coordinated system.

Coordinated systems of care are important to consider when policy and legislative decisions are being discussed. In its second five-year reauthorization of the Ryan White CARE Act in 2000, Congress directed HRSA to commission a study by the Institute of Medicine (IOM, 2005) addressing current and future challenges of providing care and health-related support services for low income, uninsured, and underinsured persons living with HIV/AIDS. To guide its work, the Committee on Financing and Delivery of HIV Care, which the IOM formed to conduct the study, put forth as its goal “…to improve the quality and duration of life for those with HIV and promote the effective management of the epidemic by providing access to comprehensive care to the greatest number of low-income individuals with HIV infection.” (p. 10)

After reviewing the literature and considering a variety of alternative strategies, the Committee recommended the establishment of a new entitlement program that would be fully funded by the Federal government but administered at the state level. This program would be called the HIV Comprehensive Care Program (HIV-CCP – "the Program") and would be available for persons whose incomes were below 250% of the Federal poverty limit. Persons with higher incomes would be able to qualify through spend-down provisions, allowing them to deduct medical expenses from their incomes, while others would be able to participate by making premium payments. Benefits through the Program would include HAART, obstetric and reproductive health services for women, mental health and substance abuse inpatient and outpatient treatment, case management services, HIV prevention services, and primary care services. The Committee recognized the need to include coverage of ancillary services for co-occurring conditions – substance abuse and mental health – that are frequently associated with HIV/AIDS. As previously noted, these co-morbidities can affect physicians' decisions whether to prescribe HAART and patients' adherence with treatment plans. Interruptions in treatment can lead to the development of strains of HIV that are resistant to drugs. Thus, care for co-morbidities is essential for the successful medical management of HIV/AIDS. Further, case managers are specifically noted in the Committee's report as a component of the move toward a comprehensive standard of care package for HIV/AIDS-affected patients. The comprehensiveness of the Program would support continuity of care, the development of consistent access to treatment across the U.S., and a reduction of the public burden on Medicaid and CARE Act programs.[1]

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[1] These Program recommendations have not been adopted by the current Administration.

Case Management Model

In addition to coordination of care models, many health services researchers and social service advocates believe in the value of a specific type of coordination framework, the case management model. This model, as described earlier in this literature review, employs case management professionals to connect patients to medical and social services in the community. The coordination of care tailored to each patient is believed to reduce costs, help patients receive needed services, and improve health outcomes (Kucera, 1998; Piette et al., 1992). In this way, case managers can be seen as sources of formal social support that help patients remain in the community rather than in hospitals or other acute care facilities (Fleishman, Mor, & Piette, 1991; Piette et al., 1990). To date, a number of research teams have published on the definitions and roles of case management in the HIV/AIDS health arena, while other groups have conducted studies looking at the association of case management with health outcomes. These studies will be discussed below. Some research has been done to examine the impact of case management on reducing unmet needs among HIV-positive persons (Ashman, Conviser & Pounds, 2002; Emlet & Gusz, 1998; Grube & Chernesky, 2001; Katz et al., 2001; Katz et al., 2000; Kucera, 1998; Messeri, Abramson, Lee, & Lee; 2002; Parish, Burry & Pabst, 2003). An assessment of unresolved issues in HIV-related case management is provided to further support the focus of this dissertation.

Case management models for HIV/AIDS have borrowed from similar models developed for other populations needing a continuum of coordinated services, including patients with mental health needs and geriatric populations (Corson, Grannemann & Holden, 1988; Rapp & Chamberlain, 1985). Case management includes planning, arrangement, and delivery of services that are tailored to patient needs in cost-effective ways (Emlet & Gusz, 1998; Fleishman, Mor, & Piette, 1991; Kucera, 1998; Riley, 1992). Often, case managers are part of multi-disciplinary community-based teams that ensure patients receive services such as transportation assistance, child services, home meal delivery, counseling, and preventive services (Fleishman, Mor, & Piette, 1991; Kirton, Ferri, & Eleftherakis, 1999; Piette et al., 1991). Case managers may also encourage patients to adhere to drug regimens (Chernesky & Grube, 2000; Cox, 2002). Case managers may be functioning either exclusively in these roles or in other formal roles in the health care system as nurses, clinical nurse specialists, or social workers.

One set of HIV/AIDS case management clinical practice guidelines was developed by St. Coeur (1996). Case managers can use these guidelines to develop care plans that fit patients' needs over time. These guidelines include the following:

- Promotion of independence
- Empowerment leading to informed decision-making
- Prevention of HIV transmission to others
- Nutritional status maintenance and improvement
- Avoidance of hospitalizations

- Utilization of community resources
- Lessening of stress and feelings of isolation

Chernesky & Grube (1999) have also done considerable work describing thematic statements and strategies behind the work of HIV/AIDS case managers and the types of activities they perform. In their qualitative work describing the HIV/AIDS case management process, these researchers note that many case managers actively see themselves as part of a client's support system. Helpful strategies include assisting clients with managing personal health, obtaining and maintaining entitlements and services, developing skills and support systems, and improving quality of life. Other case management support functions include teaching clients about self-advocacy and behavior change, and empowering clients to find solutions to daily problems.

Early studies addressing the role of case management with HIV/AIDS patients included work done by both Federal and non-Federal researchers. In the late 1980s and early 1990s, CDC and HRSA partnered to address how HIV prevention and early intervention services could be integrated into primary care settings at three community health centers located in cities in which the prevalence of HIV infection was particularly high: Miami, Florida; New York City, New York; and Newark, New Jersey. Results of this small study that used a pre-post study design with 50 persons suggested that ongoing case management could assist clients in maintaining healthier lifestyles (CDC, 1993). Since this early interest in case management in HIV/AIDS care, numerous other studies have been conducted; they will be summarized below.

The proliferation of case management for HIV-positive individuals can be attributed in part to Ryan White CARE Act legislation and funding, which requires each state and Title I-funded (Part A) metropolitan area to design its own service delivery system (Chernesky & Grube, 2000). Early work by Emlet and Gusz (1998) examined service use patterns among a group of HIV-positive patients receiving case management services between 1990-91 and 1994-95 in California. During the study period, HIV care focused primarily upon palliative services since few effective medical options were available. Services provided by case managers included attendant care, mental health counseling, in-home supportive services, and skilled nursing care. For each service type, the mean number of hours of use per year increased across the five-year study period. Results suggest that health and social service needs among HIV-positive patients can be particularly high when there is symptom deterioration and/or new symptom presentation. This study was carried out before the introduction of HAART in 1996.

Fleishman, Mor, and Piette (1991) were pioneers in demonstrating that clients with case managers were more likely to have service needs met than those without case managers. In their study, patients who were unemployed, diagnosed with AIDS, and covered by public insurance were more likely to have case managers than patients who were employed, asymptomatic, and privately insured. In addition, women were less likely than men to have case managers, as were patients with substance abuse problems relative to those without drug problems. Race/ethnicity was not associated with having a case manager. Moreover, the authors noted that more frequent contact with case managers– three or more times per month – resulted in more social service needs being met except for substance abuse treatment referrals and legal/financial assistance. These services may require additional specialized interventions.

Given differences in the services needed for women and men, several research teams have examined how case management can specifically help HIV-positive women and their families. Magnus and colleagues (2001) evaluated the association between receipt of ancillary services, including case management, and clinical and behavioral outcomes among a sample of 198 HIV-positive women in the New Orleans area between January 1, 1997 and December 31, 1998. After adjusting for age, CD_4 count, substance abuse status, and other clinical indicators, researchers found that more than one case management contact per month was significantly related with improved retention in primary care (OR 2.63, 95% CI, 1.60-4.32), defined in the study as at least one clinic visit in the past six months. Study participants who received more than one transportation service – a form of instrumental support – were also significantly more likely to be retained in primary care (OR 2.70; 95% CI 1.56-4.76). Magnus and colleagues (2001) suggest that outpatient care for HIV-positive women must take into account their multiple social roles as well as the greater childcare demands on their time that can interfere with keeping scheduled medical appointments.

In another study, Riley (1992) published a case review about an HIV-positive woman who received case management assistance in transitioning from jail into the community setting. Case managers were instrumental in providing linkages to mental health care and reproductive health services. In another descriptive study, Indyk and co-workers (1993) presented a chronology of a young HIV- positive Hispanic woman from the time of her case management intake to the time of her death. The challenges she faced included communication barriers, child care needs, and confrontations with the health care system. Continuity of care and respect for cultural differences helped case managers make strides in meeting her needs. Finally, Parrish and colleagues (2003) noted the particular challenges faced by a group of 200 HIV-positive African American women in finding job training, housing, and food for themselves and their children. Distrust of the health care system was one of the primary barriers to care.

The role of case management services has also been examined in the HCSUS sample. Using this sample, Katz and colleagues (2000) assessed need and unmet need for supportive services and the impact of case management on unmet need. Supportive services included benefits assistance, housing, home health care, emotional counseling, and substance abuse treatment. With controls for demographics, results showed that clients who had had at least one contact with a case manager in the previous six months had less unmet need for all supportive services. There was a dose-response relationship between the level of contact and unmet need, with more intensive contact being associated with less unmet need for home health care, emotional counseling and all needs taken together. In a later study also using the HCSUS sample, Katz and colleagues (2001) looked at the association of case management with unmet needs and utilization of health services. Women, persons from minority groups, IDUs, those with less education, those on public or with no insurance, and those with lower CD_4 counts were more likely to have contact with a case manager. They found that contact with a case manager was strongly associated with decreased unmet need for supportive services such as home care, emotional counseling, and financial aid. HCSUS respondents who had contact with case managers were also more likely to have taken some specific two- and three-antiretroviral medication combinations between baseline and follow-up interviews; this finding suggests that case managers may play a role in helping patients overcome anxiety about drug treatment. However, similar associations were not found between case management and ambulatory care, hospital, or emergency department visit usage. It is possible that case managers are effective in helping patients connect to short-term needs and to supportive services, but that receipt of certain optimal clinical services within the context of already challenging environments requires different interventions. Also, patient and provider distrust, communication barriers, and limited clinical hours of operation may influence receipt of quality care (IOM, 2003). The number of case managers was not addressed in this latter study. One of the major limitations of the study is that the authors fail to draw attention to the finding that women, among other vulnerable groups, were more likely than men to have had a case management contact in the last six months. That more women than men had contact with a case manager, while controlling for lowest CD_4 count, suggests that case management involvement continues to change over time. Still, the benefit of case management as a predictor of outpatient care for both sexes was not seen, leaving this question open for further study.

One recent study that looked at the association between sources of social support and clinical services use was conducted by Knowlton and colleagues (2005). They found that among a sample of 295 African American HIV-positive persons (34% female) with injection drug use histories, access to the same medical care provider was associated with having greater numbers of females in one's social support network and a larger number of network sources of emotional, financial and instrumental support. Any use of outpatient services was significantly associated with having more female support network members and more sources of instrumental and emotional support. The mean number of female support network members for this sample was 2.58 (SD= 1.61). The researchers controlled for several confounders, including patient sex, AIDS diagnosis, health insurance, and drug use. Future studies should attempt to replicate the finding that there is a connection between outpatient service use and having more female members in one's social support network, which may be indicative of social patterns of female caretaking.

Other research teams have looked at the role that case management can play for individuals living with HIV/AIDS who have mental health and substance abuse issues. The co-occurrence of mental health and substance abuse behaviors with HIV/AIDS is well-documented. Based on the national HCSUS sample of 2,864 adults, Bing and colleagues (2001) discovered that nearly half of the sample screened positive for a psychiatric disorder, 42% reported drug use other than marijuana, and more than 12% screened positive for drug dependence during the previous 12 months. Case management for IDUs with HIV/AIDS may be particularly challenging, given that IDUs may not follow through on medical and social service appointments on a consistent basis. Sorenson and colleagues (2003) found that case management had a minimal effect among a sample of 98 HIV-positive patients with a history of substance abuse relative to a control group (n=92) that received a brief one-time educational and referral contact. Snyder and colleagues (1996) documented a unique approach to the case management of HIV-positive patients with substance abuse and mental health issues, whereby primary care, case management, and local/regional community experts were integrated into teams overseen by a physician. This approach was based on the idea that innovative models are needed to attend to the primary diagnoses of mental health and substance abuse issues that may get overlooked in conventional care plans.

The contribution of case management and other ancillary services, including mental health treatment and substance abuse counseling to improving access to primary care, was the focus of a special 2002 supplement to the journal *AIDS Care*. Articles in this supplemental issue focused on data collected at eight Ryan White CARE Act-funded sites beginning in fiscal year 1998. Investigators were asked to address two primary questions of interest: whether clients' receipt of ancillary services was associated with their entry into primary care in non-emergency room venues, and whether clients' receipt of such services correlated with their retention in primary care. Retention was operationalized as having at least one primary care visit every six months. In addressing the study questions, authors were asked to include controls for client demographics such as race/ethnicity, gender, age, insurance, risk factor, and CD_4 count at entry into care. A summary of findings from several of these articles follows.

Messeri and colleagues (2002) examined longitudinal data from 577 HIV-positive adults in New York City to identify the effect of ancillary services on entry into and retention in medical care. Thirty nine percent of the sample was female; more than fifty percent of all clients were African American. Among the findings were that case management, drug treatment, and mental health services exerted the strongest impact of any services studied on entry into medical care. Medical care was operationalized in several ways – entry into care with any medical provider, entry into appropriate medical care (clinical services reflecting a set of preferred practice guidelines), continuity with any medical provider, and continuity in appropriate medical care. The authors note that the potential to meet one type of need, i.e., housing, can exert further benefit on other needs, such as retention in appropriate medical care. Messeri and colleagues (2002) were able to see effects over time with their study with their longitudinal dataset.

Another study by Sherer and colleagues (2002) in the *AIDS Care* supplement focused on HIV-positive clients receiving services between 1997 and 1998 at a Chicago primary care site. Thirty two percent of clients were female; more than 70% of the total sample was African American. Patients who received case management services (n=2,043) were more likely to be in regular care over a two-year period than patients not receiving case management in both years. Women in this study were significantly more likely than men to need case management, transportation, mental health and substance abuse services. Receiving mental health services was significantly associated with receipt of regular care. However, patients who received substance abuse counseling were *less* likely to receive regular care in this study. This finding raises the issue of matching needs to services, which can change unpredictably for HIV/AIDS patients. It is possible that patients in crisis require more services than are available at any given time. It is also interesting to note that gender and racial/ethnic disparities continued to exist in this study despite the availability of free services.

A third study by Ashman, Conviser, and Pounds (2002) in the *AIDS Care* supplement addressed the association of ancillary services with receipt of primary care at six geographically diverse Ryan White CARE Act-funded sites. Results showed that 73% of clients overall received case management services, while fewer than 20% received substance abuse counseling. Mental health treatment/counseling was received by 28% of clients. Controlling for demographic variables, the receipt of ancillary services was associated with the receipt of any primary medical care from a safety net provider. Among clients with provider-identified mental health needs, those who received case management were 1.8 times more likely to receive mental health services than those not receiving case management. Also, clients with provider-identified substance abuse needs were 2.3 times more likely to receive substance abuse treatment if they had also received case management services. Of note, receipt of mental health and substance abuse counseling and treatment was significantly associated with patients' retention in primary care.

Coordinated HIV/AIDS services continue to evolve and change within and across communities (Conviser & Pounds, 2002). The reduction in fragmented services and retention in primary care through a coordination of care model that includes case management and other ancillary services has shown promise and has been endorsed by the IOM (2005); however, many of these services are vulnerable to funding cuts during periods of budget constraints, leaving behind a rationing of services that limits benefits to persons in need. As a result, researchers continue to be tasked with documenting all findings and explaining in great detail how specific cost-saving coordinated services save lives.

Summary

The aforementioned synopses of HIV-related case management research illustrate several weaknesses in the literature. Of critical importance is the lack of consensus on a standard definition of HIV-related case management that can be used as a basis for practice and reimbursement (Chernesky & Grube, 1999; Snyder, Kaempfer, & Ries, 1996). Additional information is also lacking on those specialized functions and referral systems that may be needed to best assist clients at varying stages of HIV infection (Piette, Fleishman, & Mor, 1992). Patients in later stages of HIV/AIDS may require more emotional and instrumental types of social support than newly diagnosed HIV-positive patients who may need more basic informational types of support (Heath & Rodway, 1999). A definitive recommendation on which types of support are most needed at different stages along the HIV/AIDS trajectory, and whether the recommended services vary by patient sex has yet to be published; at the same time, there are few studies in the literature that address this topic in the post-HAART era. Moreover, the likelihood of having a case manager continues to evolve alongside the changing demographics of the HIV/AIDS epidemic. Early studies suggested that patients who had more advanced illness were more likely to seek out or be referred to case managers (Emlet & Gusz, 1998; Fleishman, Mor, & Piette, 1991). In contrast, some case managers today are more involved with patients at earlier stages of illness to assist with disease self-management, prevention, and other chronic care issues (Chernesky & Grube, 2000; Mitchell & Linsk, 2001). It is not clear whether all asymptomatic HIV-positive patients are more likely to have case managers now, or whether patient sex plays a defined role in this picture (Indyk et al. 1993; Parrish, Burry, & Pabst, 2003). Kenagy and colleagues (2003) found that among a sample of 161 HIV-positive men and women, 81% had someone coordinating their care; of this number, a slightly higher percentage of women (72.7%) than men (69.3%) had a case manager. There may be times when patients are more connected to other individuals in their social support networks and may not need case manager assistance. Among those without a case manager, two possibilities emerge: some clients need a case manager but do not have one, while others do not need a case manager and don't have one. The latter scenario may represent patients who are healthier or have other stable support systems in place to help them navigate medical and social service care. In the present study, several variables that serve as proxies for health status were controlled in an effort to see whether "healthier" patients had more or less access to formal social support through a case manager.

Across numerous studies, cultural sensitivity training provided for case managers and the types of services offered vary significantly. Some assume that case managers are providing administrative, linkage, and referral services, whereas some studies have shown that a greater proportion of time is spent in a formal social support/counseling role (Grube & Chernesky, 2001). Although the administrative side of a case manager's job is important, it is the interpersonal interaction that can help patients feel less alone and isolated, and consequently more likely to follow through with outpatient visit appointments. This formal social support component of a case manager's job was a key focus of this study.

Another important factor to understand regarding case management as a source of formal social support concerns the characterization of HIV/AIDS as a chronic illness requiring an array of medical, psychological, and social interventions. This comprehensive approach to HIV care has not been fully integrated into policy and practice in all parts of the U.S. This may be a result of outdated perceptions of case managers as providing only palliative care for HIV-positive patients, as well as a shortage of funds and expertise to implement coordinated systems of care. Even within clinic settings in which case management exists, the activities of a case manager are determined largely by the structure and mission of the site as well as caseload distribution (Indyk et al., 1993; Piette, Fleishman, & Mor, 1992). Moreover, extended periods of case management inactivity are common in both metropolitan and rural cities. Patients may be entitled to and have the need for services that are beyond the scope and reach of a particular geographic or service site.

The relationship between case management as a source of formal social support and utilization of outpatient care and other clinical care services in general remains undetermined. Some studies have found that case management is associated with use of some clinical care services, while other studies have shown no association. Nationally representative data from HCSUS failed to show a significant association between receipt of case management services and clinical care (Katz et al., 2001), whereas smaller studies with local data have shown some promising associations with retention in primary care (Ashman, Conviser, & Pounds, 2002; Chan, Absher & Sabatier, 2002; Magnus et al., 2001; Messeri et al., 2002). In theory, the supportive and referral services provided by case managers should assist patients with managing their illnesses outside of acute care facilities. Other factors may interfere with this scenario; for example, many HIV-positive female patients often have multiple other responsibilities, such as the unpredictable needs of children and partners that may take priority on any given day (Raveis, Siegel, &

Gorey, 1998). Patients may also encounter system barriers and provider bias, both of which affect access to equal treatment (IOM, 2003). Further studies are needed to learn more about the relationship between case managers as a source of formal social support and the use of outpatient care by HIV-positive men and women. This study contributed to this goal.

Chapter 3: Data and Methods

The purpose of the present study was three-fold: 1) to determine if the receipt of formal social support predicts the level of HIV/AIDS-related outpatient care visits among a subset of 797 individuals living with HIV/AIDS in the U.S.; 2) to determine if the intensity of formal social support (number of in-person contacts) predicts the level of HIV/AIDS-related outpatient care visits; and 3) to determine if the type of formal social support predicts the level of HIV/AIDS-related outpatient care visits. Because of the student researcher's particular interest in sex/gender differences, if patient sex was shown to be a significant covariate when testing any of the above three study goals, the cross-product of the variables "patient sex" and "social support" would be created and added to the multivariate models to determine if there was an interaction between these variables that was associated with levels of HIV/AIDS-related outpatient visits. As previously noted, an Analytic Model (see Figure 2) was developed as a framework for examining the hypothesized relationships between the study's independent variables and the primary outcome variable. The outcome to be examined was HIV/AIDS-related outpatient care visits, which was operationalized in this study as follows: 2-5 visits (average use) and 6+ visits (high use). The primary independent variable (Enabling Resource) examined was formal social support.

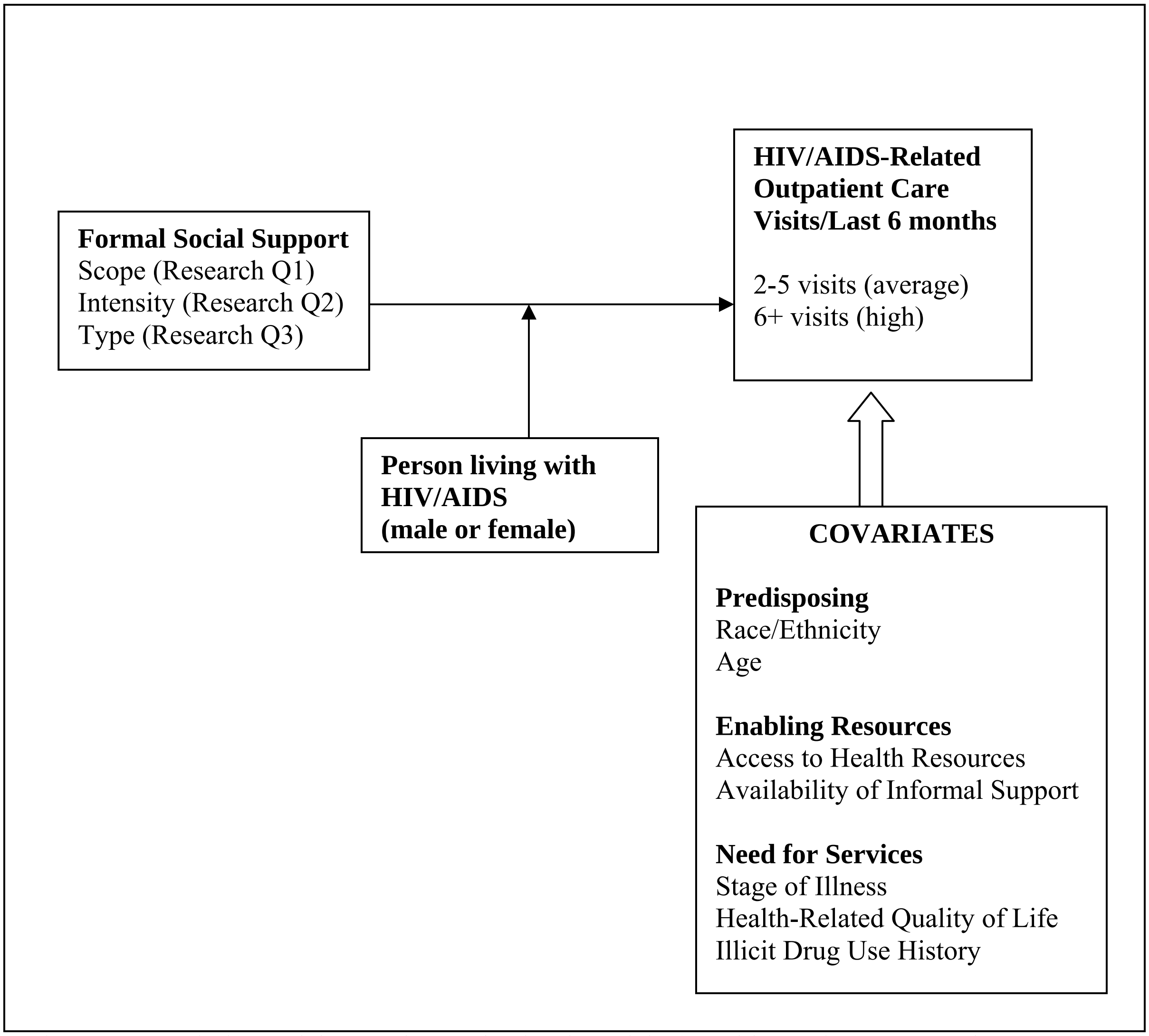

Figure 2. Analytic Model [Based on Behavioral Model of Health Services Use, Andersen, R.M. (1968, 1995)].

For the purposes of this study, and as adapted to the HIVRN sample, other Predisposing covariates included race/ethnicity and age; other Enabling Resources covariates included access to health resources (education, insurance, employment), availability of informal support (living arrangement); and other Need for Services covariates included stage of illness (CD_4 nadir, change in health status); health-related quality of life (perceived health status), and illicit drug use history.

Specifically, it was hypothesized that:

Hypothesis 1- Patients with formal social support will have more HIV/AIDS-related outpatient care visits as compared to patients without formal social support.

Hypothesis 2 - Level of HIV/AIDS-related outpatient care visits will not be associated with levels of intensity of formal social support.

Hypothesis 3a - Increased instrumental formal social support will be associated with increased levels of HIV/AIDS-related outpatient care visits.

Hypothesis 3b - Increased informational formal social support will not be associated with increased levels of HIV/AIDS-related outpatient care visits.

If patient sex was shown to be a significant covariate in tests of any of the above three study goals, the cross-product of the variables "patient sex" and "social support" would be created and added to the multivariate models to determine if there was an interaction between these variables that is associated with levels of HIV-related outpatient visits. An interaction was expected for Hypotheses 1 and 3a.

This chapter describes the sample and the HIVRN adult patient self-report interview instrument. The majority of the items in the HIVRN adult patient interview ask patients to use the immediate past six months as a reference period for providing responses. Data in this study came from interviews conducted in 2003 with a stratified random sample of 951 individuals receiving HIV/AIDS-related care at a convenience sample of fourteen clinics in the U.S. Study protocol and data analysis procedures are described in the next section.

Data Source – The HIV Research Network (HIVRN)

At the time of the interviews, the HIVRN was funded by four entities within the U.S. Department of Health and Human Services: the Agency for Healthcare Research and Quality, the Health Resources and Services Administration, the Substance Abuse and Mental Health Services Administration, and the Office of AIDS Research at the National Institutes of Health. The principal goal of the HIVRN is to offer timely information on utilization of health services by HIV-positive individuals and to study disparities in health care service receipt and trends in usage over time. The HIVRN has some similarities with HCSUS, but unlike HCSUS, its patient sample is not nationally representative of persons living with HIV/AIDS. For the HIVRN, client-level data, including clinical and patient demographics; medications prescribed; and inpatient, outpatient, and emergency room services are abstracted from the records of 17 high volume providers of HIV treatment across the U.S. and submitted to a Data Collection Center at Johns Hopkins University Medical Center (JHU) in Baltimore, Maryland. JHU has been the Data Coordinating Center since the HIVRN was founded in 1998. Data are sent from participating sites to JHU approximately every six months, lagged 9-12 months behind the half-year for which data are being submitted. JHU staff review and enter standardized clinical data from the HIVRN sites into a uniform database. While the complete dataset is not available for public use, some of the data are available on the AHRQ website. Although the HIVRN dataset is not representative of HIV care provided across the U.S., early analyses have shown similarities between its findings and those from HCSUS. Table 1 provides comparisons of HCSUS and HIVRN demographics.

Table 1: Comparison of HCSUS and HIVRN Populations

	Census 2000[2]		HCSUS[3]				HIVRN Adult Patient Interview Data	
	N	%	Unweighted N	Unweighted %	Weighted N	Weighted %	N	%
Age[4]								
18-34	67,035,178	23.8	987	34.0	79,100	34.0	79	8.0
35-49	65,240,931	23.2	1,591	55.0	125,900	54.0	596	63.0
>= 50	76,851,985	27.3	286	10.0	26,400	11.0	269	28.0
Missing							7	
Sex[5]								
Male	100,994,367	35.9	2,017	70.0	179,200	77.0	648	68.0
Female	108,133,727	38.4	847	30.0	52,200	23.0	303	28.0
Race/Ethnicity[1]								
White	211,460,626	75.1	1,399	49.0	114,000	49.0	294	31.0
Black, not Hispanic	3,458,190	1.2	959	33.0	75,800	33.0	491	52.0
Hispanic or Latino	35,305,818	12.5	415	14.0	34,200	15.0	130	14.0
Other			91	3.0	7,400	3.0	36	4.0
Marital Status[4]								
Married	115,796,000	41.1	39	1.0	N/A	N/A	95	10.0
Separated	4,547,000	1.6	106	4.0	N/A	N/A	70	7.0
Divorced	20,895,000	7.4	281	10.0	N/A	N/A	142	15.0
Widowed	14,036,000	5	102	4.0	N/A	N/A	34	4.0
Never Married	51,143,000	18.2	1,135	40.0	N/A	N/A	553	58.0
Missing	N/A		1,201	42.0	N/A	N/A	54	6.0
Education[6]								
Less than HS	28,794,775	10.2	724	25.0	57,700	25.0	244	26.0
HS Diploma or GED	59,906,752	21.3	805	28.0	63,500	27.0	569	60.0
AA Degree, Junior, 2 year college	35,847,343	12.7	809	28.0	65,600	28.0	N/A	N/A
Bachelors or higher	46,577,126	16.6	526	18.0	44,600	19.0	127	13.0
Missing	N/A		1					

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[1] Census 2000 Summary File 1 - Total Pop 281,421,906.

[2] HCSUS Baseline Public Use Dataset does not include age to protect privacy. Numbers have been copied from seminal article by Shapiro et al (1999). Variations in the Care of HIV-Infected Adults in the United States; N for HCSUS Baseline is 2864.

[3] Age categories used in Shapiro et al, 1999.

[4] March 2002 CPS.

[5] Census 2000 Summary File 3.

Table 1: Comparison of HCSUS and HIVRN Populations (cont.)								
	Census 2000[6]		HCSUS[7]				HIVRN Adult Patient Interview Data	
	N	%	Unweighted N	Unweighted %	Weighted N	Weighted %	N	%
Insurance Status[8]								
None	43,574,000	15.5	597	21.0	45,700	20.0	35	4.0
Medicaid	33,246,000	11.8	858	30.0	67,600	29.0	435	46.0
Medicare	38,448,000	13.7	544	19.0	44,300	19.0	319	34.0
Private insurance	198,973,000	70.7	391	14.0	38,200	15.0	162	17.0
Private HMO	N/A		474	17.0	35,500	17.0	N/A	N/A

In the pilot phase of the HIVRN, data on HIV-positive patients' resource use was collected for the first six months of 1998 and for calendar year 1999 among 15 sites. Remuneration to the sites was low ($5,000 to $10,000 per site per year), leading to insufficient resources at some sites to provide complete data. This pilot database has been retired. Site interest, location, management information, and system capacity were key to the selection of additional HIVRN sites in 2001. Under a new contract, payments to sites increased to a minimum of $50,000 per year, and data submission requirements were better defined. Each potential site provided an overview of what data elements could be abstracted; these overviews were ranked as "A," "B," or "C." Most participating sites were ranked "A" or "B" by JHU (the Data Collection Center). No other formal proposal was required, although the sites were and continue to be visited to ensure they remain capable of providing the data agreed to in their contracts with the Data Collection Center. Sites are located across the contiguous U.S. and include urban and rural settings at both academic and community-based centers.

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[6] Census 2000 Summary File 1 - Total Pop 281,421,906.

[7] HCSUS Baseline Public Use Dataset does not include age to protect privacy. Numbers have been copied from seminal article by Shapiro et al (1999). Variations in the Care of HIV-Infected Adults in the United States; N for HCSUS Baseline is 2864.

[8] CPS 2002-2003 Annual Social and Economic Supplements.

An HIVRN patient interview component was explored beginning in 2001. This component was important because if patients had been obtaining any of their care at sites outside the HIVRN, information about that care would not have been in the HIVRN's clinical data set. Also, patient-level interview data provides a more comprehensive picture than is available through clinical data of patients' use of HIV medications and other services. Other important variables in the patient interview (but not in the clinical data set) address satisfaction with care, health-related quality of life, and receipt of home health services.

Sampling Frame

In 2003, JHU subcontracted with Battelle, a survey research company, to conduct patient interviews with a sample of HIVRN adult patients, stratified by provider site, ethnicity, and sex, with intentional oversampling of Hispanics and women. At the outset, random samples from de-identified patient lists at 14 sites were drawn. All provider sites in the HIVRN able to receive local IRB approval contributed proportionally to the interview sample; a minimum of 25 patients was sampled from each patient care site. In the process of patient recruitment, several challenges were encountered including general privacy regulations around collecting sensitive information. After patients were selected from this randomization process, contact information was linked to each patient, and study staff sent out 5,363 invitation letters. Non-response was a significant issue as were incorrect addresses. See Figure 3 for more details about the sampling for the HIVRN adult patient interview. All patients, regardless of whether they were recruited by mail or from waiting rooms, were interviewed face-to-face at the HIVRN site at which they received services.

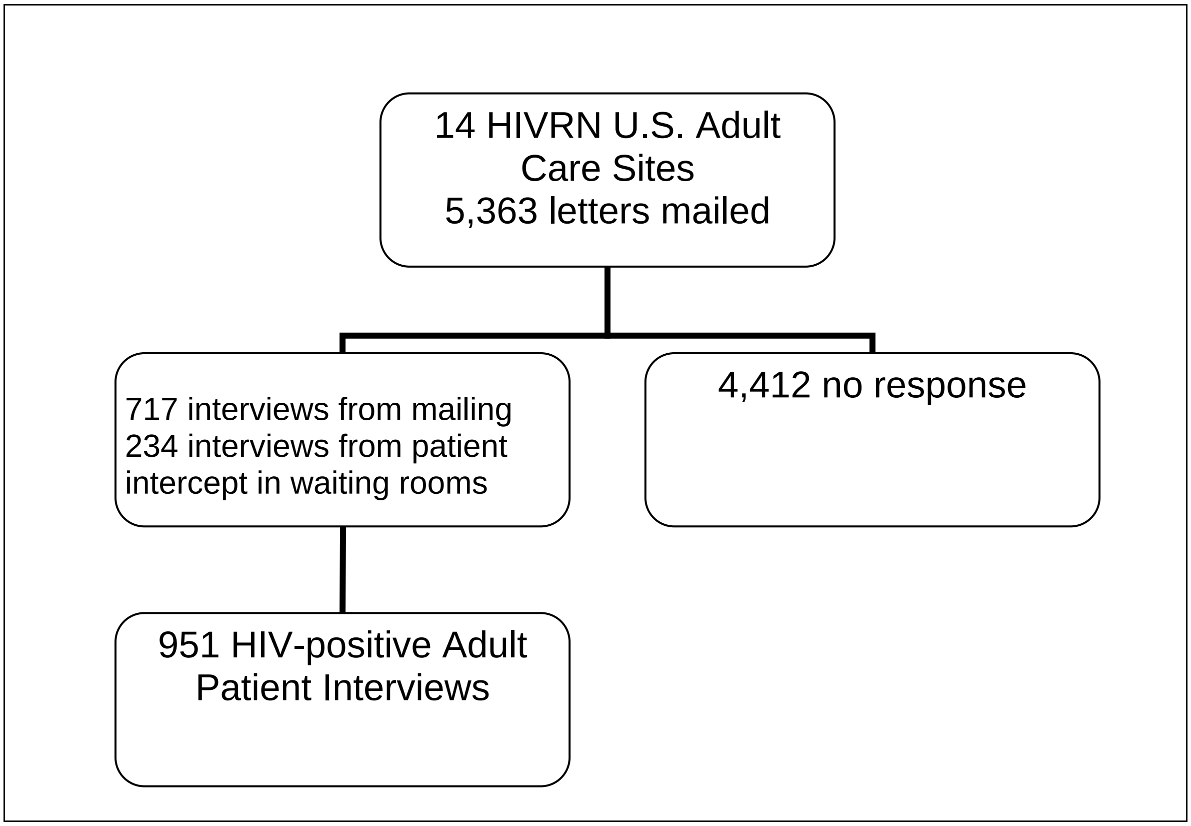


Figure 3. HIVRN Adult Patient Interview Sampling, JHU Original Data Collection.

The patient interview was pilot-tested on a random sample of ten patients at the Johns Hopkins HIV/AIDS Clinic, Baltimore, Maryland. Pilot test questions were created by Federal partners based on HCSUS questions. Patients were recruited from clinic waiting rooms and received $30 each for their participation. Patients under 18 years of age and those who were intoxicated at the time of the interview were ineligible. (A subsequent interview tool was developed for pediatric and adolescent patients, and/or their caregivers; interviews were conducted in 2004 at the four HIVRN sites whose patients were largely or exclusively in younger age cohorts). The HIVRN adult patient interview instrument did not change significantly from the pilot test version. Following the pilot test period, informed consent was given in writing by each patient before interviews took place. Battelle followed an approved protocol for collecting patient-level data. Similar to the pilot test participants, patients had to be at least 18 years of age and sober at the time of the interview to be included. Interviews were conducted one-on-one with patients, and answers were recorded on interview forms. Interviews with each patient were completed in one session. Patients could refuse to answer any question and could stop the interview at any time. Excerpts of the protocol are available upon request from AHRQ. To date, there have been no tests of reliability and validity with the HIVRN adult patient interview questions.

Figure 4 provides a flow chart for the sampling frame for the current study. As noted below, patients with three or more case managers were excluded. Also, due to low frequency, patients who self-reported their race as American Indian/Alaska Native (n=6); other single race (n=20); or Asian/Pacific Islander (n=1) were excluded. Patients who had 0-1 outpatient visits were also excluded because of low frequency (n=67). More information about this subgroup is discussed in Chapter 4.

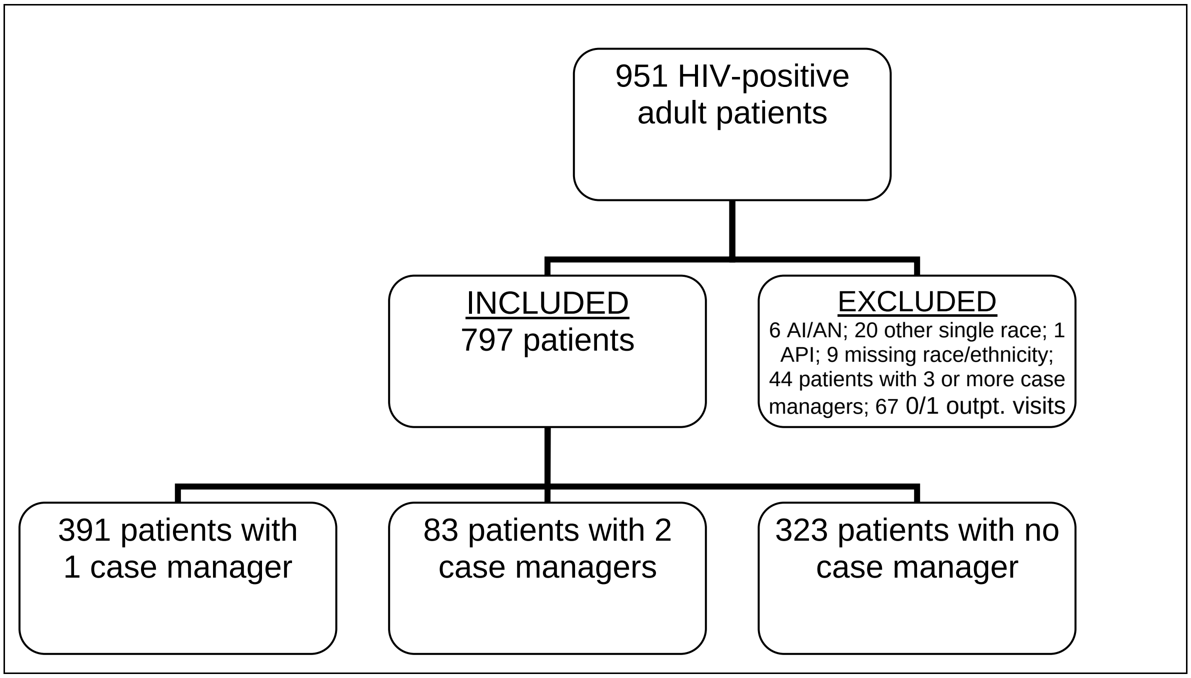


Figure 4. HIVRN Adult Patient Interview Sampling Frame, Current Study.

HIVRN Data Use Permission

The student researcher met in person with clinical managers Drs. Richard Moore and Kelly Gebo of the HIVRN Coordinating Center at JHU, Baltimore, Maryland, on June 16, 2004. Dr. Richard Conviser, a member of the student researcher's dissertation committee and then HRSA project officer for the HIVRN study, was also present. The purpose of the meeting was to obtain permission to use the HIVRN adult patient interview data for dissertation purposes only. Following this meeting, the student researcher signed a confidentiality statement with JHU. A signed confidentiality statement between the student investigator and JHU dated August 2, 2004 is included in Appendix A.

A hard copy of the full set of the patient interview questions was shared with the student researcher as well as a diskette with the requested data in the Statistical Package for the Social Sciences software (SPSS) format. A copy of the HIVRN adult patient interview is included in Appendix B. All patient identifiers, including site ID and names of health care clinics or hospitals, were removed from the dataset provided to the student investigator. Based on the full HIVRN adult patient interview, a codebook with specific information on variables used in the present study was developed; the codebook is included in Appendix C. An IRB package was submitted to the University of Maryland, College Park Human Subject Review Committee in September 2004. A copy of the approved application, dated October 22, 2004, is included in Appendix D. A copy of the approved JHU IRB documents and patient informed consent forms are included in Appendix E.

Variable Construction and Measurement

A. Dependent Variable

HIV/AIDS-related Outpatient Care Visits

The dependent variable in this study was the level of HIV/AIDS outpatient care visits in the last six months. Virtually all HIVRN patients self-report they have a regular source of care, but the number of outpatient care visits may differ. McNeil, Sheffield, and Bartlett (2004) note that seeing patients every three months allows for routine medical evaluation and monitoring of physical health; however, some patients may require more visits if they experience complications with medications, co-occurring health issues, and unpredicted health changes. Provider characteristics may also influence the number of outpatient visits; this information is not available for this study. To assess this dependent variable, the number of outpatient visits reported over the last six months was categorized as follows: 2-5 visits (average use); and 6+ visits (high use). Overall, the number of visits in the sample ranged from 0 through 86, with a mean of 13.24 visits; a median of 5 visits, and a multimodal distribution at both 2 and 6 visits. Outliers were assessed by checking standardized residuals >1.96 at the .05 level. If outliers comprised less than five percent of the data, they were deleted in multivariate analyses so that they did not bias results.

B. Primary Covariate

Patient Sex

Patient sex continues to play an important role in access to appropriate HIV/AIDS-related care. In the original data collection, interviewers recorded patient sex; this was not a self-reported item. The response options for this item were “male” and “female.” For the purposes of this study, the respondent’s sex was coded as “1” for female and “2” for male.

C. Primary Independent Variable: Formal Social Support

Scope

A variety of different measures have been used in research to date to define case managers (i.e., providers of formal social support). HCSUS researchers have defined a case manager as “a social worker, nurse, AIDS service organization staff member, staff in other service organizations, or anyone else who is assigned to help you get and coordinate care." (Katz et al., 2001). Chernesky and Grube (1999), two leaders in the field of HIV/AIDS case management, define case managers as individuals who help HIV-positive persons with the supportive services required to maintain a reasonable quality of life. As operationalized in this study, the definition for a case manager or case worker provided to HIVRN adult patients from the interview instrument is as follows: "…a professional in a medical or social service agency who helps you to arrange for services or programs you need." (p. 56) The similarity of these case manager definitions suggests a reasonable argument for face validity. To the best of the student researcher's knowledge, other types of validity for case management have not been addressed.

HIVRN adult patients were asked if they have a case manager and how many case managers they have had in the last six months. Patients who have one or two case managers were coded "1"; patients who do not have a case manager were coded "0." Patients who have three or more case managers were not asked further questions about number of visits and types of referrals/services provided, and they were excluded from the study.

Intensity

The literature suggests that a connection with a case manager has some benefit on in reducing unmet need (Katz et al., 2001). HCSUS patients who had at least one contact in-person or by telephone with their case manager in the previous six months had less unmet need for several supportive services; however, similar associations were not found for patients who had case manager contact(s) in their use of outpatient care, inpatient hospitalization, or ER usage during the last six months (Katz et al., 2001). Of note, HCSUS data were collected during the period that HAART was becoming the standard of care in 1996. The HIVRN adult patient interview data, which were collected in 2003, may offer new information on this issue. To assess intensity of formal social support for the present study, the number of in-person contacts, a continuous variable, was used. The variable measuring in-person contacts for this study was the sum of the number of visits for patients with one case manager plus the number of visits for those patients with a second case manager.

Type

Formal social support provided by a case manager may be of several types. For the purposes of this study, the two types of social support considered include informational and instrumental. Informational support was operationalized in terms of the number of positive responses to the following two items: personal advice provided by a case manager, yes =1, no=0, and advice about HIV-related medications, yes=1, no =0. Instrumental support was operationalized on the basis of the following three items, summed to form a score: referral to medical services, yes=1, no=0; referral to social services, yes=1, no=0; and/or help with filling out forms to obtain benefits, yes=1, no=0 (overall summative instrumental support score range 0-3). Because this study was interested in addressing the individual type of formal social support provided across up to two case managers, rather than being assigned an overall formal social support score, each patient had a summative score by type of support (0-4 for informational support, and 0-6 for instrumental support).

D. Other Covariates

D.1 Other Predisposing Covariates

Race/Ethnicity

Respondents' race and ethnicity is important to consider in any health study because of well-documented disparities on the basis of this socially constructed demographic. HIVRN adult patient interview respondents self-report their race/ethnicity in eight different categories. For descriptive purposes only, initial recoded categories corresponded to CDC's race/ethnicity reporting system for adults living with HIV/AIDS. These include White, not Hispanic; Black, not Hispanic; Hispanic; Asian/Pacific Islander (AAPI); and American Indian/Alaska Native (AIAN). Because of small frequencies in the latter two categories, these groups were excluded from further bivariate and multivariate analyses. Using White as the reference category, two dummy variables were created. Coding was as follows: Black =1, other=0; Hispanic=1, other=0. This strategy allowed for comparisons among three racial/ethnic groups.

Age

Individuals of all ages are vulnerable to HIV infection; however, the majority of cases in the U.S. are among those aged 25-44 (CDC, 2005b). Respondents' ages were calculated based on the year of the interview minus reported date of birth year. Age was categorized according to HCSUS groups to support comparisons of results. These groups were as follows: 20-34 years, 35-49 years; and 50+. All patients in the HIVRN adult patient interview were at least age 20; the oldest age reported was 85 years. The mean age was 45.34 years, the median was 45 years, and the mode was 44 years. Using the group 35-49 years old as the reference category, two dummy variables were created. Coding was as follows: age 20-34 years =1, other=0; age 50+=1, other=0. This strategy allowed for comparisons among three age groups.

D. 2 Other Enabling Resources

Access to Health Resources - Insurance

Health insurance plays a critical role in patient access to and receipt of timely care. Lack of insurance has been shown to influence health-seeking behaviors among chronically ill patients and to have a negative impact upon early diagnosis and treatment. HIVRN patients are asked to self-report on the type(s), if any, of health insurance they had in the past six months. Patients were asked several series of questions to ascertain if they had any insurance coverage whatsoever during that time. Insurance categories include Medicaid, Medicare, private insurance, other types of public insurance (i.e. WIC, Ryan White, Veterans, Champus/Tricare, other county-level programs), and no health insurance at all. Patients were read a definition for Medicaid and Medicare from the HIVRN patient interview as follows: "Medicaid is a state program for low income persons or for persons on public assistance." (p. 30) "Medicare is a health insurance program for people 65 years old or over and for people who are disabled." (p. 30)

Recoding considered several issues. First, because Medicare is reserved for the very old and the very sick, i.e., patients who have progressed to AIDS or those who are HIV-positive and who also have severe physical or mental disabilities, it was important to consider these patients separately from those receiving other forms of public insurance.

A preliminary review of the HIVRN adult patient interview data indicated that nearly 46% of HIVRN adult patients report Medicaid/Other Public Insurance coverage. There were four proposed insurance categories, as follows:

1. Medicaid/Other Public Insurance (i.e., WIC, Veterans benefits) – this is a combined category of Medicaid plus other forms of public assistance.
2. Medicare
3. Private Insurance
4. No insurance at all

Three dummy variables were created with "Medicaid/Other Public Insurance" as the reference category. This strategy allowed for comparisons by insurance status. These categories included: Medicare=1, other =0; private insurance=1, other =0; and No insurance at all=1, other =0.

Education

Level of education is generally acknowledged as having a relationship with socioeconomic status and access to health care in the United States. Lower levels of education have also been shown to contribute to risky health behaviors that play a role in HIV transmission. Patients who are better educated may also be in a position to better navigate the health care system. To assess education, respondents were asked "What is the highest degree/diploma you have earned?" The full range of responses included "less than high school," "high school/GED," "junior college," "four year college," and "graduate school." For analysis purposes, recoding into three categories included "none/less than high school," "high school/GED," and "college." Using "high school/GED” as the reference category, two dummy variables were created to compare results by educational status: None/less than high school=1, other=0; and college (including junior college, four year college and graduate school) =1, other =0.

Employment

Employed persons may be likely to have health insurance, given their working status; however, this is not true across the board. Health insurance benefits are becoming increasingly limited in many industries and thus, it cannot be assumed that all working individuals have benefits. Persons who are physically able to continue working part-or full-time may also be in better health than their counterparts who are disabled. For analysis purposes, employment was recoded into two categories: working full-time/part-time =1; and not working =0.

Living Arrangement

HIV-positive patients who live in households with other persons may have greater access to informal support through family members, co-habiting partners, and friends. Additional support can help patients with a variety of their day-to-day needs. Respondents were asked if they live alone, if there were others in the household, or if they were homeless. Recoded categories included the following: “living alone,” “others in house,” and “homeless.” Using “living with others in the house” as the reference category, two dummy variables were created: living alone=1, other =0; and homeless=1, other = 0.

D.3. Other Need for Services Covariates

Stage of Illness - CD_4 nadir

CD_4 nadir is an indicator of the greatest extent to which HIV has ravaged the immune system. In addition, specific levels of CD_4 counts are used as guidelines by clinicians for prescribing HAART. CD_4 counts are indicative of a need for HAART (generally when CD_4 <350 cells/mm^3), the transition to AIDS (fewer than 200 cells/mm^3), and a clinical need for other types of services (for advanced illness, generally when CD_4 <50 cells/mm^3). Higher CD_4 counts (above 500 cells/mm^3) generally reflect fewer symptoms and a lower need for crisis-oriented services. Patients whose CD_4 counts are below 200 cells/mm^3 have more advanced disease and are considered to have transitioned from HIV infection to AIDS (HHS Treatment Guidelines, 2003). There are substantive differences in severity of illness and the incidence of opportunistic infections, as reflected by CD_4 count levels. In general, patients whose CD_4 counts are above 500 cells/mm^3 are healthier than those whose CD_4 counts are below 500 cells/mm^3. For the purposes of this study, CD_4 count was recoded into four categories: less than 50 cells/mm^3, 50-200 cells/mm^3, 201-500 cells/mm^3, and over 500 cells/mm^3, respectively. Patients whose CD_4 count was between 201 and 500 cells/mm^3 comprised the reference category. Three dummy variables were created: less than 50 cells/mm^3=1; other =0; 50-200 cells/mm^3 =1; other =0; and over 500 cells/mm^3 =1; other =0. A follow-up yes/no HIVRN question to assess clinical status - has a doctor ever told you that you have AIDS - was also analyzed.

Change in Health Status

A change in HAART regimen is a proxy for a change in health status, specifically (in the short run) a change to poorer health status. HIVRN patients were asked to self-report on the set of individual antiretroviral drugs they were taking at the time of the interview as well as over the previous six months. Subsequently, JHU used this information to create a dichotomous HAART variable, indicating whether the combination of drugs that patients were taking was recommended by medical experts. For the purposes of this study, stable HIV condition was operationalized as no change in health status regimen, i.e., the patient was on HAART six months ago and is still on the same HAART drugs currently; or was not on HAART either six months ago or at the time of the interview. Unstable HIV condition was operationalized as a change in health status; for example, not being on HAART six months ago and being on HAART currently, or having different combinations of HAART drugs at the two times, which is indicative of a failure of the first regimen. Decisions on patient need for HAART and/or a change in regimen were made by HIVRN clinicians who are experienced with HIV/AIDS-related clinical care, not by the student researcher. For analyses, HAART use from the past six months was compared with current HAART use. Patients who have changed regimens were coded "1"; patients who had not changed HAART regimens or have not been prescribed HAART during the interview recall period were coded "0."

Perceived Health Status

Perceived health status provides a measure of self-reported patient health that may affect use of HIV-related health care services. Self-reported health status has been shown to be a strong predictor of health care utilization, with an inverse relationship between ‘good’ or ‘excellent’ health and health services use (e.g., Bierman et al., 1999). For the purposes of this study, perceived health status was assessed on the basis of the HIVRN patient interview item, “Overall, how would you rate your current health?” This item was answered using an 11 point ordinal scale, with “0” assigned to the worst possible health, “5” assigned to half-way between worst and best, and “10” assigned to the “best possible health.” Intermediate numbers, such as “2” and “6,” were subjectively defined by the patient and were not assigned a text value. Perceived health was kept as a continuous variable for analyses, as assigning cut-off levels would be arbitrary.

Illicit Drug Use

HIV-positive patients who have a history of illicit drug use, particularly injection drug behavior, are at higher risk for some co-morbidities, particularly hepatitis C. To assess illicit drug use, patients were asked if they have ever used eight specific drugs, and whether they have used any of these substances by injection. The eight drugs were as follows: sedatives, amphetamines, analgesics, marijuana, cocaine, inhalants, LSD, and heroin. For analysis purposes, three drug use categories were created: no drug use history, drug use history but no injection use, and drug history with injection use. Drug use history but no injection use was the reference category. The recodes for the other categories was as follows: no drug use history =1, other =0; drug use history with injection use =1, other =0.

E. Data Analysis

The Statistical Package for the Social Sciences (SPSS version 12.0 for Microsoft Windows, 2003) was used to analyze the data for the present study. A description of the sample, including numbers and percentages, is provided for all variables in the analytic framework.

Bivariate analyses were conducted to assess the association between the two levels of outpatient visits and each of the independent variables in the analytic framework for each race/ethnic group by sex. Variables besides patient sex that were significantly associated with the outcome variable were retained for inclusion and controlled for in multivariate modeling. If race/ethnicity had been significantly associated with the dependent variable, separate analyses were planned for each racial/ethnic group (White, Black, Hispanic).

In addition, bivariate analyses were conducted to assess associations among formal social support variables, patient sex, and other patient characteristics. Any covariates that appeared to have significant associations with the major independent variable (social support), dependent variable (level of HIV/AIDS-related outpatient visits) and primary covariate (patient sex) were retained in multivariate models and examined for their confounding effects. Multicollinearity was also assessed. High multicollinearity results in a higher probability of non-significant findings, whereas low levels of collinearity usually do not pose a major problem. To identify multicollinearity, various diagnostic tests can be reviewed in SPSS, including the variance inflation factor (VIF) and the tolerance statistic. Experts suggest that a VIF of 10 or higher suggests multicollinearity;

a tolerance figure below 0.1 also indicates reason for concern. Predictors that might have shown high multicollinearity were reviewed for possible deletion from the models. For multivariate analyses, significance level was set at $p < .05$.

The focus of this research was whether formal social support predicts levels of HIV/AIDS-related outpatient care visits. This entailed using a binary logistic regression model that is characterized by a group of predictors and an outcome with two categories. The limitation of this model is that it groups outpatient visits into only two categories and considers them identical; i.e., a group of 2 through 5 visits considers patients with 2 visits the same as patients with 5 visits. This dichotomous outcome may oversimplify and arbitrarily categorize HIV/AIDS health services utilization. Because there were insufficient numbers of patients with 0-1 visits, it was not possible to use a multinomial regression model with more than two outcome categories. Another strategy would have been to keep the dependent variable continuous in multivariate analyses. This strategy was not used because the dependent variable was not normally distributed in this dataset, and it was not clear that an increase in the number of outpatient visits could be interpreted in a meaningful way to represent improvement in care.

Univariate Statistics

To determine the normality of the distribution of the primary independent variable and the covariates, measures of central tendency were assessed. These included frequency distributions that provided information about means, medians, modes, skew and kurtosis, as appropriate for the type of data. Nominal data, such as sex, had a mode; while ordinal data, such as patient perception of current health, had both a median and a mode. The number of case managers before any recoding was an example of a ratio level variable that had a mean, median, and a mode. The shape of the frequency distributions for the key variables patient sex, formal social support, and levels of outpatient visits were also examined for outliers. Numbers and percentages of missing data for each variable were checked as well as whether missing data was random across the sample. Missing data was given a consistent numerical code in SPSS before analyses were run (i.e., a value of 9). Approximately five percent of missing data was accepted before deletion from the analyses (Tabachnick & Fidell, 2001).

Bivariate Statistics

Bivariate statistics are those tests that illustrate a variety of relational associations between two variables and are important to show linear and nonlinear relationships. Bivariate tests were conducted to assess the association between levels of HIV/AIDS-related outpatient visits and each of the independent variables for each racial /ethnic group by patient sex (see Table 2). In addition, bivariate tests for this study helped to identify which covariates were associated with the outcome variable. Significant covariates were included in the multivariate models. Table 2 shows each of the independent variables, the type of variable (after recoding takes place), and the bivariate test performed across levels of the dependent variable.

Table 2
Level of HIV/AIDS-related Outpatient Visits by Formal Social Support,
Patient Sex, Race/Ethnic Group and Other Covariates

Independent Variable	**Type of Variable after Recode**	**Bivariate Test**
Case Manager		
Scope	Categorical	Chi-square
Intensity (in person)	Interval	Spearman Rho
Type (instrumental)	Interval	Spearman Rho
Type (informational)	Interval	Spearman Rho
Sex	Nominal	Chi-square
Race/Ethnicity	Nominal	Chi-square
Age	Ordinal	Chi-square
Change in Health Status	Nominal	Chi-square
CD_4 Nadir	Ordinal	Chi-square
Illicit Drug Use	Nominal	Chi-square
Perceived Health	Ordinal	Spearman Rho
Health Insurance	Nominal	Chi-square
Education	Ordinal	Chi-square
Employment	Nominal	Chi-square
Living Arrangement	Nominal	Chi-square

Bivariate relationships between social support and the covariates were examined to determine whether significant interactions with formal social support should be tested in the multivariate analyses to clarify the relationship between social support and the dependent variable. As noted above, multicollinearity was also examined to determine whether any covariates should be dropped from the analysis because of redundancy.

In Table 3 below, each of the independent variables, the type of variable (after recoding takes place), and the bivariate test with formal social support is shown.

Table 3
Formal Social Support-Scope (1 or 2 Case Managers vs. No Case Manager) by Select HIVRN Patient Covariates

Independent Variable	**Type of Variable after Recode**	**Bivariate Test**
Sex	Nominal	Chi-square
Race/Ethnicity	Nominal	Chi-square
Age	Ordinal	Chi-square
Change in Health Status	Nominal	Chi-square
CD_4 Nadir	Ordinal	Chi-square
Illicit Drug Use	Nominal	Chi-square
Perceived Health	Ordinal	Spearman Rho
Health Insurance	Nominal	Chi-square
Education	Ordinal	Chi-square
Employment	Nominal	Chi-square
Living Arrangement	Nominal	Chi-square

In Table 4 below, each of the independent variables, the type of variable (after recoding takes place), and the bivariate test with patient sex is shown.

Table 4
Patient Sex by Other Select HIVRN Patient Covariates

Independent Variable	**Type of Variable after Recode**	**Bivariate Test**
Race/Ethnicity	Nominal	Chi-square
Age	Ordinal	Chi-square
Change in Health Status	Nominal	Chi-square
CD_4 Nadir	Ordinal	Chi-square
Illicit Drug Use	Nominal	Chi-square
Perceived Health	Ordinal	Spearman Rho
Health Insurance	Nominal	Chi-square
Education	Ordinal	Chi-square
Employment	Nominal	Chi-square
Living Arrangement	Nominal	Chi-square

F. Data Analysis Approach

In general, logistic regression models are used to predict a binary dependent variable and to determine the percentage of variance – or R^2 in this variable explained by a group of independent variables. Additionally, the logistic regression family of models can be useful in looking at interaction effects, and to learn about the influence of covariates serving as controls (Garson, 2006).

The main statistical analysis for this study was binary logistic regression, which is called for when the dependent variable is a dichotomy. This type of regression uses the principles of maximum likelihood estimation, also referred to as the natural log of the odds of the dependent variable occurring or not. Logistic regression estimates the probability of an event taking place (Garson, 2006).

Assumptions for binary logistic regression include no outliers, low error in explanatory variables, low multicollinearity, and a large enough sample to reduce the possibility of high standard errors. A normal distribution is not required for this type of regression model; thus, skewed distributions can be used without transformation. In SPSS, binary logistic regression is found under the Analyze-Regression-Binary Logistic drop down option. If the chi-square test of goodness of fit is not significant, the model has adequate fit. In SPSS output, this information is shown in the "Goodness of Fit" table. The log-likelihood ratio and overall classification percentages were used to interpret significance and classification for all predictors in the model. Exponential beta coefficients were used to interpret the extent of classification for individual predictors.

G. Research Questions

Primary Research Question - Does the scope of formal social support predict the levels of HIV/AIDS-related outpatient care visits? Does this association vary by patient sex?

Data Analysis Approach

To answer this question, a binary logistic regression was conducted with patient sex, Predisposing covariates, Enabling Resources covariates and Need for Services covariates entered in Block 1 of the model, and Formal Social Support-Scope (one or two case managers) entered in Block 2. This sequence addressed the specific classification of Formal Social Support-Scope after controlling for the variables in Block 1. The categorical outcome variable was the levels of HIV/AIDS-related outpatient care visits, as previously described. If patient sex was shown to be a significant covariate in the testing of this model, the cross-product of the variables "patient sex" and "Social Support-Scope" would be created and added to the multivariate model to determine if there was an interaction when predicting levels of HIV-related outpatient visits.

Secondary Research Question - Does the intensity of formal social support received predict the levels of HIV/AIDS-related outpatient care visits? Does this association vary by patient sex?

Data Analysis Approach

To answer this question, a binary logistic regression was conducted, respectively, with patient sex, Predisposing covariates, Enabling Resources covariates and Need for Services covariates entered in Block 1 of the model, and Formal Social Support-Intensity entered in Block 2. This sequence addressed the specific classification of Formal Social Support-Intensity after controlling for the variables in Block 1. The regression analysis included the in-person contact summative score for the first case manager plus the continuous score for those patients with a second case manager. The categorical outcome variable was the levels of HIV/AIDS-related outpatient care visits, as previously described. If patient sex was shown to be a significant covariate in the testing of this model, the cross-product of the variables "patient sex" and "Social Support-Intensity" would be created and added to the multivariate model to determine if there was an interaction when predicting levels of HIV-related outpatient visits.

Secondary Research Question – Does the type of formal social support received predict the levels of HIV/AIDS-related outpatient care visits? Does this association vary by patient sex?

Data Analysis Approach

To answer this question, a binary logistic regression was conducted, respectively, with patient sex, Predisposing covariates, Enabling Resources covariates, and Need for Services covariates entered in Block 1 of the model, and Formal Social Support-Type entered in Block 2. This sequence addressed the specific classification of Formal Social Support-Type after controlling for the variables in Block 1. As previously described, this latter covariate is of two types: instrumental or informational support, with several items comprising each of the types. Because this study was interested in addressing the individual type of formal social support by up to two case managers, rather than an overall formal social support score, each patient had a summative score by type of support (0-4 for informational support and 0-6 for instrumental support). Each of these scores was entered in Block 2, respectively. The categorical outcome variable was levels of HIV/AIDS-related outpatient care visits, as previously described. If patient sex was shown to be a significant covariate in the testing of these models, the cross-product of the variables "patient sex" and "Social Support-Type" would be created and added to the multivariate models to determine if there was an interaction when predicting levels of HIV-related outpatient visits.

One additional sub-analysis was undertaken in this study to further explore possible relationships. This sub-analysis addressed whether any significant relationships found in the entire study sample remained when HIV-positive patients with two case managers were excluded. The number of patients who self-reported having two case managers was 83. The analyses under the secondary research questions were repeated, selecting out those patients with two case managers. Given the lack of a strong connection in the literature between having more than one case manager and outpatient care visits, no differences were expected between HIV-positive patients with one case manager and those with two case managers.

Quality of HIVRN Data

The HIVRN adult patient interview includes self-reported data from 951 HIV-positive patients who receive primary care at 17 U.S. clinical care sites serving more than 15,000 people living with HIV/AIDS. Quality control and coordination of data collection is carried out by Johns Hopkins University Medical Center, under contract with the Federal Department of Health and Human Services. Survey questions on sensitive topics, such as drug use, and the potential for recall bias, can affect the number of missing data as well as over- and under-reporting. To limit these occurrences, an approved protocol was followed for data collection, using one-on-one patient interviews. Patients could refuse to answer any question or could stop the interview at any time. To date, there have been no other tests of reliability and validity with the HIVRN patient interview questions.

These analyses may give further support to the view that acute care-based systems need to be changed to alternative systems that focus on chronic illness models (as the IOM's 2003 report proposes). Alternatively, the findings may suggest that an even deeper transformation of healthcare delivery may be required.

Chapter 4: Results

The 2003 HIVRN Adult Patient Interview sampling frame included 951 participants from 14 HIVRN sites across the country. The sample was stratified by provider site, ethnicity, and patient sex, with intentional oversampling of Hispanics and women. Of the total, 648 (68%) of participants were male and 303 (32%) were female. For purposes of the current study, the sampling frame consisted of 797 adult respondents. Of this total, 543 participants were male and 254 were female. Respondents who self-reported three or more case managers (n=44); were American Indian/Alaska Native (n=6); or single race other than White, Black or Hispanic (n=21) were excluded due to low frequencies. Nine participants (<1%) of the overall HIVRN adult patient interview sample recorded their race/ethnicity as "don't know," "refused," or left the race/ethnicity question blank. These respondents were also excluded from analyses.

Univariate Statistics

The mean age for the study sample (N=797) was 45.51 (SD=8.31); the median was 45; and the mode was 44. A majority of the study sample was African American (53%), followed by White (33%), and Hispanic (14%). A total of 41% (n=324) of the respondents had ever been given an AIDS diagnosis by a doctor. Also, a majority of the participants in the study sample reported having one or two case managers (59%) as compared to no case manager (41%); and more than three-quarters of patients (77%) were not working. About 5% of participants in the larger HIVRN adult patient interview sample (N=951) self-reported having three or more case managers over the past six months. Other demographic characteristics of the study sample can be found in Table 5.

Table 5
Demographic and Background Characteristics of the Study Sample

Variable	**Study Sample n (%)**	**Males n(%)**	**Females n(%)**
Respondents	797(100)	543 (68)	254 (32)
Age			
20-34 years	63(8)	36(7)	27(11)
35-49 years	500(63)	333 (61)	167 (68)
50+ years	229 (29)	169 (31)	60 (24)
Don't Know	5 (<1)	5 (<1)	0 (0)
Race/Ethnicity			
White	264 (33)	219 (40)	45 (18)
Black	422 (53)	255(47)	167 (66)
Hispanic	111 (14)	69 (13)	42 (17)
CD_4 count			
<50 cells/mm^3	285 (36)	205 (38)	80 (32)
50-200 cells/mm^3	218 (27)	158 (29)	60 (24)
201-500 cells/mm^3	178 (22)	108 (20)	70 (28)
>500 cells/mm^3	44 (6)	29 (5)	15 (6)
Don't Know	72 (9)	43 (8)	29 (11)
Ever been told have AIDS (yes)	324 (41)	244 (45)	80 (32)
Illicit Drug Use History			
No Drug Use	233 (29)	144 (27)	89 (35)
Drug Use/No Injection	391 (49)	280 (52)	111(44)
Drug Use/Injection	171 (22)	118 (22)	53 (21)
Missing	2 (<1)	1 (<1)	1 (<1)
Insurance			
Medicaid/Other Public[a]	564 (71)	361(67)	203 (80)
Medicare	95(12)	75(14)	20 (8)
Private[b]	124 (16)	96(18)	28 (11)
No Insurance	14 (2)	11 (2)	3 (1)
Education			
None/Less than High School	212 (27)	108(20)	104 (41)
High School/GED	374 (47)	269 (50)	105 (41)
College	207 (26)	162 (30)	45 (18)
Refused/Don't Know	4 (<1)	4 (<1)	0 (0)
Employment			
Full/part time	183 (23)	135 (25)	48 (19)
Not working	614 (77)	408 (75)	206 (81)

Table 5 (continued)
Demographic and Background Characteristics of the Study Sample

Variable	**Study Sample n(%)**	**Males n(%)**	**Females n(%)**
Living Arrangement			
Living Alone	318 (40)	242 (45)	76 (30)
Others in house	414 (52)	268 (49)	146 (58)
No usual place to live	64 (8)	32 (6)	32 (13)
Missing	1 (<1)	1 (<1)	0 (0)
Change in Health Status			
Change in HAART Regimen	61 (8)	45 (8)	16 (6)
No Change in HAART Regimen	736 (92)	498 (92)	238 (94)
Perceived Health Status (11 point scale, 0= worse, 10= best)			
Mean	7.19	7.16	7.25
Median	7.00	7.00	7.00
Mode	8.00	7.00	8.00

Note.
[a] includes WIC, VA, Ryan White, Champus/Tricare, other county-level programs.
[b] includes current private insurance and private insurance six months ago.

Table 6 illustrates respondents' responses to questions about ever using illicit drugs broken down by eight individual drugs. Marijuana was the drug most frequently used by the study sample (n=444, 56%), while inhalants were the drug least frequently self-reported (n=113, 14%). A total of 22% of patients in the study sample reported ever having injected one or more of these eight substances.

Table 6
Frequencies and Percents for Ever Used Select Illicit Drugs

Illicit Drug	**Yes n(%)**	**No n(%)**	**DK/Ref/Missing n(%)**
Sedatives	151 (19)	643 (81)	3 (<1)
Amphetamines	149 (19)	646 (81)	2 (<1)
Marijuana	444 (56)	350 (44)	3 (<1)
Analgesics	135 (17)	660 (83)	2 (<1)
Cocaine	339 (43)	450 (57)	8 (1)
Inhalants	113 (14)	682 (87)	2 (<1)
LSD	141 (18)	653 (82)	3 (<1)
Heroin	163 (21)	632 (79)	2 (<1)

Note. N=797.

Table 7 illustrates univariate level statistics for the primary independent variable – formal social support. As previously noted, for the purposes of this study, formal social support was defined as having one or two case managers. A majority of patients reported having one or two case managers in the last six months. Of those patients who reported having one or two case managers (n=474), 82% had 1 case manager.

Table 7
Formal Social Support – Scope (Number of Case Managers
in the Last 6 months)

Scope (# of Case Managers)	**n(%)**
0 Case Managers	323 (41)
1 Case Manager	391 (49)
2 Case Managers	83 (10)
1 or 2 Case Managers	474 (59)
More than 3/Don’t Know	45 (5)

Note. N=842.

For patients with one case manager, the number of in-person visits ranged from 0 to 180, with a mean of 5.89, a median of 2, and a mode of 1. For patients with a second case manager, the number of visits for the second case manager ranged from 0 to 32, with a mean of 3.25, a median of 2, and a mode of 2. The number of in-person contacts was kept as a continuous variable in this study. A summative score of the continuous score for patients with one case manager plus the continuous score for patients with a second case manager was created.

Tables 8 and 9 show information about the type of formal social support provided. Two types of social support – informational and instrumental –made up of a total of five individual survey items were used as proxies for these support types. The three items that comprised instrumental support included referral to medical services, referral to social services, and help with filling out forms to obtain benefits. The two items that comprised informational support included personal advice provided by a case manager and advice about HIV-related medications. Patients reported what types of services they received across up to two case managers. For the first case manager, the most frequent response across both types of formal social support – informational and instrumental - was personal advice (n=177; 45%). For the second case manager, the most frequent response across both types of formal social support –information and instrumental - was help with social services (n=36; 43%).

Table 8
Frequencies and Percents for Items Comprising Type of Formal Social Support (Instrumental and Informational) in the last 6 months, First Case Manager

Type of Support	Yes n (%)	No n (%)
Instrumental		
Medical Services	167 (43)	221 (57)
Social Services	164 (42)	223 (57)
Benefit Forms	146 (37)	241 (62)
Informational		
Advice about HIV meds	138 (35)	250 (64)
Personal advice	177 (45)	211 (54)

Note. n=388.

Table 9
Frequencies and Percents for Items Comprising Type of Formal Social Support (Instrumental and Informational) in the last 6 months, Second Case Manager

Type of Support	Yes n (%)	No n (%)
Instrumental		
Medical Services	30 (36)	52 (63)
Social Services	36 (43)	46 (55)
Benefit Forms	27 (33)	54 (65)
Informational		
Advice about HIV meds	24 (29)	58 (70)
Personal advice	34 (41)	47 (57)

Note. n=81.

Each patient in the study sample who reported having one or two case managers was given an informational support score and an instrumental support score, respectively. Among the patients with one case manager, for instrumental support, 85 patients (n=388; 22%) self-reported receiving help with all three types of support - help with medical services, help with social services, and help with filling out forms for benefits; for informational support, 116 patients (n=388, 30%) self-reported receiving both personal advice and HIV-related medication advice. Among patients with a second case manager, for instrumental support, 17 patients (n=81, 21%) self-reported receiving all three services; for informational support, 19 patients (n=81, 23%) received both services. See Tables 10 through 13 for more information about the type of formal social support provided to patients in the study sample. For each patient, a summative score by type of support (0-4 for informational support and 0-6 for instrumental support) was created and was used in the bivariate analyses, described below.

Table 10
Instrumental Support Score, First Case Manager

Number of Services[a]	**n (%)**
None	152 (39)
1 Service	76 (19)
2 Services	73 (19)
3 Services	85 (22)

Note. n=386.
[a] Maximum of 3 services: help with medical services, help with social services, help with forms for benefits.

Table 11
Instrumental Support Score, Second Case Manager

Number of Services[a]	**n (%)**
None	34 (42)
1 Service	18 (22)
2 Services	12 (15)
3 Services	17 (21)

Note. n=81.
[a] Maximum of 3 services: help with medical services, help with social services, help with forms for benefits.

Table 12
Informational Support Score, First Case Manager

Number of Services[a]	**n (%)**
None	189 (48)
1 Service	83 (21)
2 Services	116 (30)

Note. n=388.
[a] Maximum of 2 services: HIV-related medication advice; personal advice.

Table 13
Informational Support Score, Second Case Manager

Number of Services[a]	**n (%)**
None	42 (51)
1 Service	20 (24)
2 Services	19 (23)

Note. n=81.
[a] Maximum of 2 services: HIV-related medication advice; personal advice.

Bivariate Analyses

Before bivariate tests were carried out, recoding of variables was completed, as described in Chapter 3. As depicted in Table 14, the main outcome variable – level of outpatient visits – was recoded into two levels: average (2-5 visits) and high (6+ visits). Of note, a small minority of patients (n=67) had 0-1 visits in the larger study sample. This comprised less than 10% of the study sample.

Table 14
Frequencies and Percents for Level of HIV-related Outpatient Visits, Last Six Months

Level of Outpatient Visits	**Study Sample n(%)**
Average (2-5 visits)	397 (50)
High (6+ visits)	400 (50)

Note. N=797.

Of the group of 67 patients with 0-1 visits, 18 were female and 49 were male. Twenty-one of these patients were White; 41 were Black; and five were Hispanic. Given the statistical limitations of using these numbers in bivariate and multivariate analyses, this group of patients was not included in further analyses. Notwithstanding, this group is an important cohort to explore in future research to better understand their particular needs that lead to inconsistent contact with their outpatient clinical care site. For continuity of care, clinical HIV experts recommend that patients see their providers at least once per quarter.

Bivariate tests - primarily Pearson chi-squares - were carried out to illustrate a variety of relational associations between the variables in the analytic framework. The first series of these tests was conducted to determine if there were any significant associations between the two levels of outpatient visits – average (2-5 visits) or high (6+ visits) and each of the independent variables in the analytic framework by patient sex (see Figure 2, Chapter 3). Variables besides patient sex that may be significantly associated with the dependent variable were retained and controlled for in multivariate modeling. This group of tests also was informative to see how all study variables related to each other, and which confounding variable relationships needed to be addressed in the final multivariate models.

Given the importance of determining if a significant association existed between race/ethnicity and the dependent variable, given the possibility of a three-way interaction with patient sex, this bivariate test was run first. There was no significant association found between race/ethnicity and level of outpatient visits for this study- χ^2 (2, *N*=797) = 4.49, *p*=.106 (not shown). This bivariate test was repeated with patient sex – the primary covariate – as a stratifying variable. As seen in Tables 15 and 16, no significant associations were found - *p*=.348; Males -χ^2 (2, *N*=543) = 2.11; *p*=.256; Females- χ^2 (2, *N*=254) = 2.50.

Subsequently, a series of chi-square tests with the dependent variable was carried out, with patient sex as a stratifying variable (see Tables 15 and 16). Results showed that having one or two case managers, perceived health status, and employment were all significantly associated with level of outpatient visits for both males and females. Age was also significant for females - χ^2 (2, *N*=254) = .040, *p*=.045, but not for males.

Table 15
Bivariate Test, Level of HIV/AIDS-related Outpatient Visits by
Study Covariates, Male Patients

Variable	**Chi-Square**	**df**	**P-value**
Case Manager Scope	27.13	1	.000*
Race/ethnicity	2.11	2	.348
Age	.042	2	.979
Change in Health Status	3.53	1	.060
CD$_4$ Nadir	4.38	3	.224
Illicit Drug Use	3.77	2	.152
Health Insurance	6.79	3	.079
Education	.505	2	.777
Employment	15.60	1	.000*
Living Arrangement	1.55	2	.461
		Spearman Rho	**Significance**
Case Manager Intensity (in person visits)		.204	.075
Instrumental Support		.024	.679
Informational Support		-.003	.959
Perceived Health Status		-.200	.000*

Note. n=543.
**p*<.01.

Table 16
Bivariate Test, Level of HIV/AIDS-related Outpatient Visits by
Study Covariates, Female Patients

Variable	Chi-Square	df	P-value
Case Manager Scope	10.55	1	.001*
Race/ethnicity	2.50	2	.286
Age	.04	2	.045*
Change in Health Status	.600	1	.439
CD_4 Nadir	1.59	3	.662
Illicit Drug Use	.954	2	.621
Health Insurance	6.03	3	.110[a]
Education	.589	2	.745
Employment	9.33	1	.002*
Living Arrangement	3.66	2	.160
		Spearman Rho	**Significance**
Case Manager Intensity (in-person visits)		.011	.892
Instrumental Support		-.017	.826
Informational Support		-.001	.992
Perceived Health Status		-.151	.016*

Note. n=254.
[a] 2 cells had an expected count less than 5.
*p<.05.

There was no significant relationship between level of outpatient visits and informational support scores for male and female patients in the study sample. Likewise, there was no significant relationship between level of outpatient visits and instrumental support scores for male and female patients (see Tables 15 and 16). A point biserial Spearman correlation was conducted to examine if a relationship existed between perceived health status (an ordinal variable) and level of outpatient visits. Results showed that a significant negative relationship existed for both males and females and level of outpatient visits, suggesting that as perceived health status increases, outpatient visits decrease. Of note, for patients with 0, one or two case managers, patient sex was not significantly associated with level of outpatient visits - χ^2 (1, N=797) = 1.30, p=.253.

Because patient sex was the primary covariate of interest, it was retained in the multivariate analyses.

As discussed in Chapter 3, bivariate tests were carried out with formal social support (one or two case managers vs. no case manager) by select HIVRN patient covariates under the Predisposing, Enabling Resources, and Need for Services headings from the study's analytic model. Table 17 shows the results from these analyses. Significant associations were found between formal social support (one or two case managers vs. no case manager) and patient sex- χ^2 (1, *N*=797) =9.53, *p*=.002; health insurance- χ^2 (3, *N*=797) =56.22, *p*=.000; education - χ^2 (1, *N*=797) =29.82, *p*=.000; and employment – χ^2 (1, *N*=797) =29.83, *p*=.000. There were no significant associations found between formal social support (one or two case managers vs. no case manager) and race/ethnicity, age, perceived health, CD_4 nadir, illicit drug use, change in health status, or living arrangement.

Table 17
Formal Social Support – Scope (1 or 2 Case Managers vs. no Case Manager) by Select HIVRN Patient Covariates

Variable	**Chi-Square**	**df**	**P-value**
Patient Sex	9.53	1	.002*
Race/ethnicity	4.05	2	.132
Age	3.78	2	.151
Change in Health Status	.006	1	.940
CD_4 Nadir	.224	3	.974
Illicit Drug Use	1.28	2	.527
Health Insurance	56.22	3	.000*
Education	18.87	2	.000*
Employment	29.83	1	.000*
Living Arrangement	3.91	2	.141
		Spearman Rho	**Significance**
Perceived Health Status		-.055	.12

Note. N=797.
**p*<.01.

Additionally, bivariate tests were carried out with patient sex (male/female) by select HIVRN patient covariates under the Predisposing, Enabling Resources, and Need for Services headings from the study's analytic model. Table 18 shows the results from these analyses. Significant associations were found between patient sex (male/female) and race/ethnicity, age, CD_4 nadir, illicit drug use, health insurance, education, and living arrangement. Female patients in the study sample were more likely to be Black, between the ages of 20-49; have less than a high school education; have higher CD_4 counts; be unemployed; and have Medicaid as their form of insurance than male patients in the study sample. Variables that were not significant were change in health status, employment, and perceived health status.

Table 18
Patient Sex by Select HIVRN Patient Covariates

Variable	**Chi-Square**	**df**	**P-value**
Race/ethnicity	40.08	2	.000*
Age	7.39	2	.025*
Change in Health Status	.968	1	.325
CD_4 Nadir	8.34	3	.040*
Illicit Drug Use	6.54	2	.038*
Health Insurance	15.17	3	.002*[a]
Education	40.99	2	.000*
Employment	6.54	1	.062
Living Arrangement	21.18	2	.000*
		Spearman Rho	**Significance**
Perceived Health Status		-.022	.526

Note. N=797.
[a] 1 cell had an expected count less than 5.
*p<.05.

In determining which variables to retain for multivariate analyses, and to limit confounding, multicollinearity was assessed using the variance inflation factor option in SPSS. High multicollinearity can result in a higher probability of non-significant findings. As discussed below, none of the covariates entered into the logistic regression models had high multicollinearity.

In the following section on multivariate analyses, the goal was to identify significant associations between formal social support and level of HIV/AIDS outpatient visits. Significant covariates from the first series of bivariates were included to control for their effect in the analysis. These included formal social support-scope (one or two case managers vs. no case manager), employment status, age, and perceived health status.

Because patient sex was the primary covariate of interest, it was retained in the multivariate analyses.

Multivariate Analyses

The frequency distributions for formal social support-scope (one or two case managers vs. no case manager), and level of outpatient visits – 2-5 visits (average) and 6+ visits (high)- were examined for outliers before recoding took place. Because the current study sample excluded individuals who had more than three case managers, outliers were not a concern for this variable. The number of outpatient visits in the full HIVRN adult patient sample (N=951) ranged from 0 through 86, with a mean of 13.24; a median of 5, and a multimodal distribution at 2 and 6 visits. The number of outpatient visits in the study sample (N=797) ranged from 2 through 81 with a mean of 7.17; a median of 6, and a mode of 6. The frequency distribution for this outcome variable was extremely right-skewed (skewness =4.395); however, the multivariate test for this study – a logistic regression - allows for a non-normal distribution. Because the dependent variable did not remain as a continuous variable for bivariate and multivariate analyses, there was no outlier issue.

Hypothesis Testing

The following section of Chapter 4 addresses the three research questions and hypotheses that were introduced in Chapter 1. Results are presented for each question, followed by the results for the sub-analysis. The sub-analysis addresses the secondary research questions, excluding patients with two case managers.

Primary Research Question - Does the scope of formal social support predict levels of HIV/AIDS-related outpatient care visits? Does this association vary by patient sex?

It was hypothesized that patients with formal social support (one or two case managers) would be more likely to have HIV/AIDS-related outpatient care visits as compared to patients without formal social support (without a case manager). This hypothesis was supported for both males and females.

To answer this question, a binomial logistic regression was conducted with perceived health, employment, and age entered in Block 1 of the model, and formal social support – scope (one or two case managers vs. no case manager) entered in Block 2. The dichotomous outcome variable was level of HIV/AIDS-related outpatient care visits (2-5 visits vs. 6+ visits). Mulicollinearity diagnostics were conducted to determine if two or more variables were sharing too much of the same variance. Variance inflation factors were under 2.0 for all variables in the model, suggesting the absence of multicollinearity.

Results from the first block of the equation (not shown) were significant, χ^2 (5) =50.14, p<.000. The predictors in the equation – perceived health status, employment, age, and patient sex – correctly classified 53.4% of patients who had 2-5 outpatient visits, and 65.7% of the patients who had 6+ visits. The overall correct classification occurred 59.6% of the time. In Block 2 of the model, formal social support - scope was entered. The model remained significant, χ^2 (6) =79.94, p<.000. With all five predictors in the model, 60.8% of the patients who had 2-5 outpatient visits were correctly classified as were 66.5% of patients with 6+ visits. The overall correct classification rose to 63.6%.

Beta coefficients are presented in Table 19. For patients who were employed, the odds of having 6+ outpatient visits decreased by 1.81 times (1.0 ÷ value of Exp(B). For every unit increase in perceived health status, the odds of having 6+ outpatient visits decreased by 1.21 times. In comparison, for patients who have one or two case managers, the odds of having 6+ outpatient visits increased by 2.33 times. Patient sex and age were not significant predictors of outpatient utilization.

Table 19
Logistic Regression on Employment, Perceived Health Status, and Formal Social Support-Scope Predicting Levels of HIV/AIDS-related Outpatient Care Visits

	B	S.E.	Wald	Sig.	Exp(B)	95.0% C.I. for Exp(B)	
						Lower	Upper
Block 1							
Patient sex	-.147	.158	.859	.354	.863	.633	1.18
Age 20-34	.379	.279	1.85	.174	1.46	.845	2.53
Age 50+	.078	.165	.223	.637	1.08	.782	1.49
Employment	-.751	.180	17.47	.000	.472	.332	.671
Perceived Health Status	-.192	.041	21.53	.000	.825	.761	.895
Block 2							
Patient sex	-.060	.162	.136	.712	.942	.685	1.29
Age 20-34	.501	.283	3.135	.077	1.65	.948	2.87
Age 50+	.128	.169	.577	.448	1.137	.817	1.58
Employment	-.594	.185	10.324	.001*	.552	.384	.793
Perceived Health Status	-.193	.042	21.163	.000*	.825	.759	.895
FSS-Scope[a]	.844	.156	29.196	.000*	2.33	1.71	3.16

Note. N=797. Age 35-49 was the reference category.
[a] FSS = Formal Social Support - Scope.
**p*<.01.

Secondary Research Question - Does the intensity of formal social support predict levels of HIV/AIDS-related outpatient care visits? Does this association vary by patient sex?

It was hypothesized that level of HIV/AIDS-related outpatient care visits would not be associated with levels of intensity of formal social support. As previously noted, intensity refers to in-person contact with one or two case managers. This hypothesis was supported; there was no difference for patients in their levels of outpatient visits on the basis of the number of in-person contacts with one or two case managers. Only employment and perceived health status remained significant predictors in the final multivariate model.

To answer this research question, a binomial logistic regression was conducted with patient sex, age, perceived health, and work status (not employed vs. employed full- or part-time) entered in Block 1 of the model, and formal social support – intensity (number of in-person case manager visits across up to two case managers) entered in Block 2. The dichotomous outcome variable was level of HIV/AIDS-related outpatient care visits (2-5 "average" vs. 6+ "high" visits). Mulicollinearity diagnostics were conducted. Variance inflation factors were under 2.0 for all variables in the model, suggesting the absence of multicollinearity.

Results from the first block of the equation (not shown) were significant, χ^2 (5) =18.36, *p*<.003. The predictors in the equation – perceived health and work status – correctly classified 23.0% of patients who had 2-5 outpatient visits, and 90.6% of the patients who had 6+ visits. The overall correct classification was 63.1%. In Block 2 of the model, formal social support - intensity was entered. The model remained significant, χ^2 (6) =18.62, p<.005. With all five predictors in the model, 23.0% of the patients who had 2-5 outpatient visits were correctly classified, as were 90.6% of patients with 6+ visits. The overall correct classification did not change.

Beta coefficients are presented in Table 20. For patients who were employed, the odds of having 6+ outpatient visits decreased by 2.12 times. For every unit increase in perceived health status, the odds of having 6+ outpatient visits decreased by 1.15 times. Formal social support - intensity (number of in-person case manager visits across up to two case managers), patient sex, and age were not significant in further classifying the level of HIV/AIDS-related outpatient visits.

Table 20
Logistic Regression on Employment, Perceived Health Status, and Formal Social Support-Intensity Predicting Levels of HIV/AIDS-related Outpatient Care Visits

	B	S.E.	Wald	Sig.	Exp(B)	95.0% C.I. for Exp(B)	
						Lower	Upper
Block 1							
Patient sex	-.054	.532	8.38	.791	.947	.634	1.42
Age 20-34	.347	.409	.720	.396	1.42	.635	3.15
Age 50+	.103	.224	.212	.645	1.11	.715	1.72
Employment	-.762	.264	8.36	.004	,467	.279	.782
Perceived Health Status	-.139	.055	6.42	.011	.871	.782	.969
Block 2							
Patient sex	-.059	.205	.082	.775	.943	.631	1.41
Age 20-34	.348	.408	.726	.394	1.42	.636	3.15
Age 50+	.106	.224	.225	.635	1.11	.717	1.73
Employment	-.751	.264	8.07	.004*	.472	.281	.792
Perceived Health Status	-.140	.055	6.51	.011*	.870	.781	.968
FSS-Intensity[a]	.003	.007	.249	.618	1.00	.990	1.02

Note. n=452. Age 35-49 was the reference category.
[a] FSS - Intensity: number of in-person case management visits over the past six months.
**p* <.05.

Secondary Research Question – Does the type of formal social support predict levels of HIV/AIDS-related outpatient care visits? Does this association vary by patient sex?

It was hypothesized that increased instrumental formal social support would be associated with increased levels of HIV/AIDS-related outpatient care visits. It was also hypothesized that increased informational formal social support would not be associated with increased levels of HIV/AIDS-related outpatient care visits.

The first part of this hypothesis was not supported. Patients who received instrumental support from case managers were not significantly more likely to have HIV/AIDS-related outpatient care visits than patients without this type of support. The second part of the hypothesis was supported: there was no significant difference for patients receiving informational support from case managers in their levels of HIV/AIDS-related outpatient visits.

To answer this research question, a binomial logistic regression was conducted with patient sex, age, perceived health and work status (not employed vs. employed full-or part-time) entered in Block 1 of the model, and formal social support – (summed instrumental and informational scores, respectively, for up to two case managers) entered in Block 2. The dichotomous outcome variable was level of HIV/AIDS-related outpatient care visits (2-5 “average” vs. 6+ visits “high” visits). Mulicollinearity diagnostics were conducted. Variance inflation factors were under 2.0 for all variables in the model. These results suggest the absence of multicollinearity.

Results from the first block of the equation (not shown) were significant, χ^2 (5) =22.56 *p*<.000. The predictors in the equation – patient sex, age, perceived health, and employment status – correctly classified 26.3% of patients who had 2-5 outpatient visits, and 87.3% of the patients who had 6+ visits. The overall correct classification was 62.4%. In Block 2 of the model, both instrumental and informational type summary scores were entered. The model remained significant, χ^2 (7) =24.42, *p*<.001. With all six predictors in the model, 27.4% of the patients who had 2-5 outpatient visits were correctly classified, as were 87.0% of patients with 6+ visits. The overall correct classification remained nearly the same at 62.7%.

Beta coefficients are presented in Table 21. For patients who were employed, the odds of having 6+ outpatient visits decreased by 2.30 times. For every unit increase in perceived health status, the odds of having 6+ outpatient visits decreased by 1.18 times. Patient sex and age were not significant predictors. Neither instrumental nor informational type of formal social support was significant in further predicting the level of HIV/AIDS-related outpatient visits.

Table 21
Logistic Regression on Employment, Perceived Health Status, and Formal Social Support-Type (Instrumental and Informational) Predicting Levels of HIV/AIDS-related Outpatient Care Visits

	B	S.E.	Wald	Sig.	Exp(B)	95.0% C.I. for Exp(B)	
						Lower	Upper
Block 1							
Patient sex	-.045	.203	.048	.826	.956	.642	1.42
Age 20-34	.210	.391	.288	.591	1.23	.573	2.66
Age 50+	.179	.222	.648	.421	1.19	.77	1.85
Employment	-.796	.261	9.32	.002	.451	.271	.752
Perceived Health	-.161	.054	8.77	.003	.851	.765	.947
Block 2							
Patient sex	-.043	.204	.044	.833	.958	.642	1.43
Age 20-34	.202	.392	.265	.607	1.22	.567	2.64
Age 50+	.175	.222	.621	.431	1.19	.771	1.84
Employment	-.832	.264	9.93	.002*	.435	.259	.730
Perceived Health Status	-.168	.055	9.35	.002*	.846	.760	.942
FSS[a]-Instrumental	-.106	.078	1.83	.177	.900	.772	1.05
FSS[a]-Informational	.064	.110	.336	.562	1.06	.859	1.32

Note. n = 466. Age 35-49 was the reference category.
[a]FSS- Formal social support.
**p* <.01.

Sub-Analysis- Formal Social Support Intensity and Type

A sub-analysis was conducted to address whether any significant relationship found in the study sample remained when patients with two case managers (n=83) were excluded. The main analyses under the secondary research questions were repeated, selecting out those patients with two case managers. No significant differences were expected when patients with two case managers were selected out. As hypothesized, and explained below, no significant differences were found on levels of HIV/AIDS-related outpatient visits.

Intensity

Patient sex, age, perceived health, and work status (not employed vs. employed full-or part-time) were entered in Block 1 of the model, and formal social support - intensity (number of in-person case manager visits) was entered in Block 2. The dichotomous outcome variable was the level of HIV/AIDS-related outpatient care visits (2-5 “average” vs. 6+ “high” visits). Mulicollinearity diagnostics were conducted. Variance inflation factors were under 2.0 for all variables in the model, suggesting the absence of multicollinearity. Results of the first block of the equation were significant, $\chi^2(5) = 20.54$, $p < .001$. Patient sex, age, perceived health and work status correctly classified 27.0% of patients with 2-5 outpatient visits and 86.9% of patients with 6+ outpatient visits with an overall correct classification of 63.5%. Formal social support - intensity was entered into the second block of the equation, $\chi^2(6) = 20.94$, $p < .002$. The correct classification decreased to 63.2%.

Beta coefficients are presented in Table 22. For patients who were employed, the odds of having 6+ outpatient visits decreased by 2.18 times. For every unit increase in perceived health, the odds of having 6+ outpatient visits decreased by 1.19 times. Formal social support - intensity did not individually predict the level of outpatient visits for participants with only one case manager.

Table 22
Logistic Regression on Employment, Perceived Health Status, and Formal Social Support-Intensity Predicting Levels of HIV/AIDS-related Outpatient Care Visits

	B	S.E.	Wald	Sig.	Exp(B)	95.0% C.I. for Exp(B)	
						Lower	Upper
Block 1							
Patient sex	-.221	.224	.968	.324	.802	.516	1.24
Age 20-34	.419	.448	.874	.350	1.52	.632	3.65
Age 50+	.116	.242	.231	.631	1.12	.699	1.81
Employment	-.776	.285	7.40	.007	.460	.263	.805
Perceived Health Status	-.173	.060	8.35	.004	.842	.749	.946
Block 2							
Patient sex	-.216	.225	.920	.338	.806	.519	1.25
Age 20-34	.432	.449	.025	.336	1.54	.369	3.72
Age 50+	.117	.242	.235	.628	1.12	.700	1.81
Employment	-.780	.285	7.46	.006*	.459	.262	.802
Perceived Health Status	-.174	.060	8.43	.004*	.841	.748	.945
FSS[a]-Intensity	.000	.000	.041	.525	1.00	.999	1.00

Note. n=389. Participants with 2 case managers were excluded from the analysis. Age 35-49 was the reference category.
[a] FSS- Formal Social Support - Intensity: the number of in-person case management visits over the past six months.
**p*< .01.

Type

To answer this sub-question, a binomial logistic regression was conducted that excluded participants with two case managers. Patient sex, age, perceived health and work status (not employed vs. employed full- or part-time) were entered in Block 1 of the model, and formal social support - type (instrumental and informational scores) was entered in Block 2. The dichotomous outcome variable was the levels of HIV/AIDS-related outpatient care visits (2-5 "average" vs. 6+ "high" visits). Mulicollinearity diagnostics were conducted. Variance inflation factors were under 2.0 for all variables in the model, suggesting the absence of multicollinearity.

Results of the first block of the equation were significant, $\chi^2 (5) = 22.31$, $p < .000$. Patient sex, age, perceived health and work status correctly classified 27.3% of patients with 2-5 outpatient visits and 87.2% of patients with 6+ visits, with an overall correct classification of 63.8%. Formal social support - type (instrumental and informational) were entered into the second block of the equation, $\chi^2 (7) = 22.33$, $p < .002$. The overall correct classification rose slightly to 64.1%.

Beta coefficients are presented in Table 23. For patients who were employed, the odds of having 6+ outpatient visits decreased by 2.28 times. For every unit increase in perceived health, the odds of having 6+ outpatient visits decreased by 1.20 times. Patient sex, age, informational support and instrumental support were not significant predictors in the final model.

Table 23
Logistic Regression on Employment, Perceived Health Status, and Formal Social Support-Type (Instrumental and Informational) Predicting Levels of HIV/AIDS-related Outpatient Care Visits

	B	S.E.	Wald	Sig.	Exp(B)	95.0% C.I. for Exp(B)	
						Lower	Upper
Block 1							
Patient sex	-.231	.228	1.02	.312	.794	.508	1.24
Age 20-34	.437	.450	.945	.331	1.55	.641	3.74
Age 50+	.154	.244	.396	.529	1.17	.723	1.88
Employment	-.817	.288	8.02	.005	.442	.251	.778
Perceived Health Status	-.182	.061	8.97	.003	.834	.740	.939
Block 2							
Patient sex	-.234	.230	1.04	.308	.791	.504	1.24
Age 20-34	.433	.451	.923	.337	1.54	.637	3.73
Age 50+	.152	.245	.384	.536	1.16	.720	1.88
Employment	-.823	.294	7.82	.005*	.439	.247	.782
Perceived Health Status	-.182	.061	8.95	.003*	.834	.740	.939
FSS[a]- Instrumental	-.003	.103	.000	.976	.997	.814	1.22
FSS[a]- Informational	-.013	.142	.009	.925	.987	.747	1.30

Note. n=384. Patients with 2 case managers were excluded. Age 35-49 was the reference category.

[a]FSS- Formal Social Support.

**p*<.01.

Chapter 5: Discussion, Recommendations, and Conclusions

There are few other studies that address the impact of case management on the level of HIV/AIDS outpatient visits in the post-HAART era from a sex/gender perspective. The evolution of HIV/AIDS from an acute condition into a chronic illness, and the increasing incidence of cases among women both call for greater attention to targeted supportive interventions. This chapter highlights and discusses significant results, provides recommendations for future study within a changing health and socio-political context, and draws out implications for public health research and policy.

Summary of Results

The study sample was derived from the 2003 HIVRN adult patient interview, which included 951 participants from 14 HIVRN sites across the country. Of this total, 648 (68%) of participants were male and 303 (32%) were female. For the purposes of the current study, the sampling frame consisted of 797 adult respondents (543 males and 254 females) who self-reported their race/ethnicity as Black, White or Hispanic; had 0, one or two case managers; and had at least two outpatient visits during the six month study period. The outcome variable for the current study was operationalized as an “average” (2-5) or a “high” (6+) number of outpatient visits based on input from three HIV/AIDS experts. Patients with two outpatient care visits meet the minimum recommended number of visits per six month period put forth by the International AIDS Society. Patients with fewer than two outpatient visits per six month period were not included in the study sample because of their low frequency in the dataset. Given provider expertise and other structural supports at HIVRN sites, these patients may be more likely to maintain continuity of care than those at other clinical sites.

Formal social support was operationalized as having one or two case managers. In bivariate analyses, age was a significant predictor of the level of outpatient visits for female patients but not for males. Significant results in multivariate analyses were as follows: both male and female patients who were employed either part- or full-time, or had higher self-reported perceptions of their health were significantly less likely to have 6+ outpatient visits, while patients with one or two case managers were significantly more likely to have 6+ outpatient visits. No significant associations were found among the study participants between the number of in-person case management visits and the level of outpatient visits, nor was there a significant difference in the level of outpatient visits corresponding to the type of support – instrumental or informational - provided by one or two case managers. Patient sex was not a significant predictor of the level of outpatient visits in the multivariate analyses. In sub-analyses that separated out patients with one case manager from those with two case managers, no new predictors emerged.

Discussion- Primary Research Question

The primary research question for this study focused on whether formal social support was associated with the level of HIV/AIDS-related outpatient care visits. For both adult males and females in the study sample, having one or two case managers versus not having a case manager more than doubled the odds of having a high level of outpatient visits (6+ visits). There are at least two possible explanations for this finding. The first explanation is that both case management and outpatient visits are patient-driven, and formal social support is not associated with level of outpatient visits. Patients with one or two case managers versus those with no case manager may be particularly well-invested in slowing disease progression, managing symptoms, and maintaining and improving their quality of life in the community setting. This group of patients may also have a history of active healthcare seeking behavior before their HIV/AIDS diagnosis from other chronic illness experiences. Therefore, engaging with their health care providers more frequently is part of their commitment to chronic illness self-management and their sense of personal self-efficacy. This explanation supports a view of case management as a patient-driven service as opposed to an integrated system component. Patient satisfaction with characteristics of their health care setting, such as limited waiting time, clear information, and provider availability during an urgent crisis may also contribute to this perspective.

The second explanation views the process as case-manager driven, suggesting that formal social support is indeed associated with the level of outpatient visits. Case managers may be playing a supportive role in helping patients make and keep their outpatient appointments. Also, the integration of primary care and ancillary services may reduce fragmentation of services (Conviser & Pounds, 2002). In the current study, information on where patients went for case management visits and whether these locations were part of HIVRN clinical sites was not available, but this is an area for future exploration.

Current study findings also support work published in the 2002 *AIDS Care* journal supplement that focused on the role of case managers to facilitate entry into and retention in primary care; that is, patients with case managers were more likely to have continuity of care than patients without them. Having a case manager provides HIV-positive individuals with a person who can listen to their health status concerns as well as help plan and arrange services tailored to patient needs in cost-effective ways. These conversations between patients and their case managers may lead to the identification of a clinical need for outpatient care and coverage for other needed services.

Using the HCSUS sample, Katz and colleagues (2001) did not find a significant association between case management and receipt of appropriate levels of outpatient care (the latter being defined as one visit per three month period between January 1996 and April 1997). Nonetheless, in that study, persons who were more likely to have case managers were women, non-Whites, injection drug users, persons with other risk factors (defined as heterosexual transmission, persons who had received infected blood, and persons with other known or unknown exposures), and those with lower education levels, lower incomes, public or no insurance, or lower CD_4 counts. Katz and colleagues (2001) found that HCSUS patients who needed income assistance and were categorized as unemployed were more likely to have contact with case managers; however, this contact was not associated with any difference in the level of outpatient care. In the current study, those more likely to have one or two case managers were women, Hispanics, those with less than a high school education, those on Medicaid or Medicare, and those who were not employed – all consistent with the HCSUS findings. Thus, both studies suggest that socially disadvantaged groups of patients may need the assistance of case managers to navigate the health care system.

Two groups of patients who may have challenging health care issues are patients with lower CD_4 counts and those with a history of illicit drug use. Interestingly, there was no significant association in the current study between CD_4 count and the likelihood of having one or two case managers. Furthermore, there was no significant association between CD_4 count with the level of outpatient visits, although a majority of the study sample at the time of the interview (n=486, 61%) would be classified as having had AIDS based on a self-reported CD_4 count of less than 200 cells/mm^3. Fewer patients (n=324, 41%) recalled that they had ever been told by a doctor that they had AIDS. This discrepancy suggests that providers may not be communicating clearly with their patients about their compromised immune systems, or that patients may not understand the connection between a low CD_4 count and an AIDS diagnosis. Patients may also have forgotten they had been told by a doctor some time ago that they had AIDS. For those patients who are aware of their AIDS diagnosis, inpatient care may be needed. Inpatient and ER care use has been looked at elsewhere in both HCSUS and non-HCSUS studies in relation to ancillary service use (Betz et al., 2005; Katz et al., 2001, Markson et al., 1998).

In relation to illicit drug users, previous research has suggested that HIV-positive patients who are also substance users have more difficulty than non-drug users with keeping in contact with outpatient care providers (Bing et al., 2001; Masson, Sorenson, Phibbs, & Okin, 2004; Sorenson et al., 2003). In the current study, there were no significant differences between patients with and without histories of illicit drug use in having one or two case managers; neither did having one or two case managers versus not having a case manager predict the level of outpatient visits. HIVRN adult patients with a history of substance use may have received or may currently be receiving substance abuse treatment through other connections at HIVRN sites, which could be confounding any case manager impact on the level of outpatient service use.

Other Significant Findings

Other significant covariates in the final multivariate models besides having one or two case managers were part- or full-time employment and self-perception of health status. In the analytic model for the current study (see Chapter 2), employment was considered an Enabling Resource, while self-perception of health was regarded as a Need for Service. Patients in the study sample who were employed part- or full-time (n=183, 23%) were significantly less likely to have 6+ outpatient visits. Practically speaking, those who are able to work part- or full-time are likely to be in better health; they may also be less likely to take the time to visit a health care provider, or alternatively, to be able to take time off during the work day to take advantage of clinic hours of operation. Working patients were also less likely than those who were unemployed to have one or two case managers. These patients may have social support systems in the workplace instead. Working patients may also be going for fewer outpatient visits to preserve limited health insurance benefits, or to avoid drawing attention to their health because of absences during the work day. Workplace policies that allow HIV-positive workers to take time off for health care appointments during the day may help them follow through with outpatient visits.

Interestingly, although more than 75% of patients in the study sample were not working, their self-perception of health was relatively high, as discussed below. They may be engaged in activities other than a paid job that provide a sense of well-being, such as volunteering or mentoring others in the community. Feeling well may also be a result of participation in mental health or faith-based services. Patients who feel well could be expected to postpone or delay outpatient care. These ideas speak to the larger subject of quality of life for patients living with a chronic illness and how addressing this complex issue can help to understand other facets of their health service utilization.

For both males and females, the mean self-reported health status score on the scale used in the study was 7.19, with a score of 10 representing “best health.” Interestingly, female patients’ mean score was slightly higher – 7.25 – than male patients’ mean score at 7.16; this was not a statistically significant difference (the study measure of perceived health status was based on a 0-11 point ordinal scale, with “0” assigned worst possible health and “10” assigned “best possible health”). There was a negative correlation between self-reported health scores and level of outpatient visits: patients with higher self-reported health status scores were significantly less likely to have 6+ outpatient visits (r= -.183, *p*=<.01).

As theorized by Andersen’s (1968) conceptual model of health services utilization described in Chapter 1, patient perception of health status is an important consideration that drives need. From a policy standpoint, Meyerson and colleagues (2007) noted that a standard number of HIV primary care visits may not align with patients’ perception of their own well-being and other day-to-day priorities, and that being “in care” or “out of care” is more complex when viewed through the patient lens. Further research is needed to examine the relationship between self-reported health status and the level of outpatient visits for patients living with HIV/AIDS.

Discussion- Secondary Research Questions

Two secondary research questions in the present study addressed whether the intensity and types of formal social support were associated with levels of HIV-related outpatient care visits. Intensity of formal social support was defined as the number of in-person visits with a case manager. A summative score was created, consisting of the number of visits for patients with one case manager plus the number of visits for patients with a second case manager. The total number of in-person visits with these case managers did not predict the level of HIV-related outpatient visits. However, the quantity of case management visits may not be as important as the quality of visits, or the tailoring of the frequency of visits to patient social service needs. If this is true, patients with fewer visits may benefit as much as those with more visits. Patients’ perceived health status may also have a stronger influence on outpatient health care utilization than case management contact, as discussed above.

HCSUS patients who saw or spoke to their case manager at least once in the six months before the baseline data collection period (January 1996 and April 1997) and still had a case manager at follow-up (data collection between December 1996 and July 1997) did not differ in their utilization of primary care from patients without a case manager at baseline or at follow-up. In contrast, Magnus and colleagues (2001) found that more than one contact per month with a case manager among a cohort of 198 HIV-positive women was associated with improved retention in primary care. Although the research literature affirms the role of case managers in helping HIV-positive patients manage their illness (Chernsesky & Grube, 1999; Katz et al. 2000; Kucera, 1998; Piette, Fleishman, & Mor, 1992), it is likely that each patient has different needs and challenges in connecting to a case manager, who may serve as a link to outpatient clinical care. A pre-determined number of case management contacts for all HIV-positive patients may help contain costs but may not be in the best interest of patients across all situations.

Besides the impact of intensity of case management contact on levels of HIV-related outpatient visits, this study also addressed the type of formal social support in an effort to further understand the impact of case management for HIV-positive patients. Although a few published studies have categorized case management services, the present study is believed to be one of the first to investigate whether certain types of formal social support are sex/gender-specific and the extent of the role they play in connecting HIV-positive men and women to outpatient care. Two types of formal social support – informational and instrumental – made up of two and three individual HIVRN interview items, respectively, were used as proxies for these support types. Patients reported what types of services they received across up to two case managers. In multivariate analyses, neither type of formal social support was significant in predicting levels of HIV-related outpatient visits. It is possible that the instrumental and informational support items, which were taken from the larger HIVRN adult patient interview, did not reflect these particular constructs. Other possible individual services provided by case managers, including linkages to transportation, housing, legal help, childcare, complementary and alternative therapies, and final will preparation, were not included in the development of the study proxies; it is possible some of these services may have been sex/gender-specific, e.g., childcare. Formal reliability and validity tests on the informational and instrumental support constructs were outside the scope of this dissertation; however, these constructs were perceived to have acceptable face validity.

In the early 1990s, Fleishman, Mor, and Piette (1991) noted that patients with a greater need for social services had more frequent contact with case managers, suggesting that a positive relationship exists between need and contact. The HIVRN items used in the current analyses dealt with patient self-reported receipt of a particular service, which is different from patient self-reported need; an item example of the former was “did you receive help with medical services?” There exists a set of HIVRN items that ask patients about whether they <u>needed</u> a particular service. An item example was “did you <u>need</u> home care or personal assistance in the last six months?” These items should be used in a future study to examine the potential relationship between patient identified need, receipt of a service to meet that need from a case manager, and other clinical care services.

Other Findings

Among patients who had one case manager, the most frequent response across both types of formal social support – informational and instrumental - was personal advice (n=177; 45%). Among patients with two case managers, the most frequent response across both types of formal social support – informational and instrumental - was help with social services (n=36; 43%). Another interesting observation in the study sample was that although a majority of patients reported having one or two case managers, this did not necessarily mean they saw the case manager during the study period and received study-defined services. For example, among patients who self-reported having one case manager (n=391, 49%), 152 (39%) said they did not receive one of three possible services falling under instrumental support, including help with medical services, help with social services, or help with filling out forms for benefits. Similarly, among patients who self-reported having two case managers, (n=83, 10%), 34 (42%) said they did not receive any of these services. One hundred eighty nine (48%) patients with one case manager did not receive one of two possible services under the informational support type, including help with HIV-related medications and personal advice. On the other hand, a small minority of patients with one or two case managers did receive all three services under instrumental support as well as both services under informational support. These results suggest that there are multiple factors that influence patient receipt of formal social support provided by case managers. Patient self-perceived and actual need, enabling resources, case manager access and availability, and other features and dimensional qualities of the patient-provider relationship, not all of which were addressed in the current study, may all contribute to receipt of services and subsequent connections to outpatient care.

Limitations

Several limitations of the present study must be noted. Although the HIVRN patient interview questions evolved from the HCSUS research, and preliminary results using the

HIVRN clinical dataset show a resemblance to HCSUS findings, the HIVRN is not a nationally representative sample of patients living with HIV/AIDS or of institutions providing their care. The HIVRN patient interview data provides a cross-sectional view of health services use in 2003 and thus, cannot be used to examine trends over time in health services. The Data Coordinating Center at Johns Hopkins University Medical Center has combined data across sites to achieve a uniformly constructed multi-site database. To protect patient confidentiality, no researcher outside of JHU has been given access to site-specific information.

A potential bias may exist as a result of patient interview data coming from intact clinical sites where clients are well-situated in regular care, and are virtually all covered by some form of public/private health insurance. This bias may lead to an overestimate of the number of outpatient and case manager visits among HIVRN adult patients relative to a cross-section of people in care for HIV/AIDS. If this were so, patients may have more outpatient visits because they have more complex needs, because HIVRN providers have greater than average expertise, because more enabling services are available to them, or for a variety of other possible reasons. It is reasonable to believe that formal social support can facilitate entry into and retention in HIV care and enhance other outpatient care services. Overcoming barriers to meeting social and personal needs may allow patients to focus on maintaining HIV-related outpatient clinical care (Conviser & Pounds, 2002).

Patients with 6+ outpatient visits may have had all their visits in one month, or these visits may have been spread out over the study period. Each of these scenarios presents a different picture of patient health: clustered visits may be more likely to occur during health crises, while evenly distributed visits might represent adherence to a standard of outpatient care. It is possible that several follow-up visits were linked to a single visit or that some outpatient visits were follow-up visits related to medication side effects, lab results, or other co-morbid conditions; it is also possible that case managers and outpatient clinic care providers were located near one another or even in the same building, allowing easier and more frequent access to care. Dates for outpatient visits, available in the HIVRN clinical dataset, may be useful to better understand these possible situations.

For the purposes of the current study, the number of outpatient visits was operationalized as “average” (2-5 visits) and “high” (6+ visits), based on input from three HIV/AIDS experts. Other HIV/AIDS-related studies have used an even more basic framework than the current study for recording medical services use; in a recent article by Knowlton and colleagues (2005), the operationalization of outpatient medical service use was recorded as “none” versus “any” during the previous six months. The categories for outpatient visits used in this study assume that patients with dissimilar numbers of visits, e.g., two and five visits, are similar. Developing strategies to model the number of outpatient visits as a continuous variable is a goal for further research. A broader range of outpatient visit categories may provide a closer approximation to the continuum of care provided to HIV-positive patients.

Diversity of patient racial/ethnic backgrounds was limited, as patients who participated in the HIVRN adult patient interview were predominantly White (31%) and Black (51%). Furthermore, patients were asked to self-identify with only one racial/ethnic group. This limits understanding regarding multi-racial patients. Also, patients who were transgendered were not identified. Data on patient household income, as well as self-reported HIV risk factors such as transmission route, were not available in the HIVRN adult patient interview database. Viral load, an additional important indicator of illness progression and treatment response, was not collected during the HIVRN adult patient interview but was captured in the HIVRN clinical dataset. Cross-referencing the HIVRN clinical and patient interview datasets is an ongoing effort by the JHU Data Coordinating Center.

It is possible that patients with mental health and substance abuse problems were underrepresented in the HIVRN sample since such patients may be less likely than others to have sought clinical care in the settings in which the interviews were conducted or to have made themselves available for interviews. All of the HIVRN items related to mental health employed the same six-month reference period (or a shorter period, i.e., four weeks) as the clinical service use outcomes. Thus, it was not possible to establish a history or lifetime experience of mental health issues that may have been associated with level of HIV-related outpatient visits in this study sample. In contrast, interview items about patients' <u>ever</u> having used illicit drugs allowed for consideration of this variable as a covariate. Illicit drug use was not found to be a significant predictor of the level of HIV-related outpatient visits in this study. This may speak to the level of experience or skill of providers in the HIVRN in dealing with patients with histories of substance abuse.

For the purposes of this study, case managers were conceptualized as one kind of formal social support system to help connect patients to outpatient care. Still, the natural progression of HIV/AIDS may include some inpatient hospitalizations, despite providers' best attempts to maintain connections to community-based resources, including outpatient care (Katz et al., 2001). Patient follow-through with referrals for services by case managers was not verified in the HIVRN adult patient interview. Also, only those patients who self-reported having a case manager were asked follow-up questions about supportive/referral services. It is possible that some patients were referred to social services by individuals, such as friends and colleagues, who fill informal social support roles and are part of a larger social support network. Also, patients who live with others may have access to informal social support in their living environments as compared to those who live alone or are homeless; however, patients' other family members may also include elderly parents or dependent children whose needs may take precedence over their own. Information about the positive or negative aspects of informal social support was not available from the HIVRN adult interview dataset. In the present study, a significant association was found between patient sex and living arrangement (defined as living alone, living with others, or homeless). HIV-positive men were more likely to be living alone than HIV-positive women in the current study. There was no difference between male and female study patients in the proportions who were homeless. There was no significant association between having a case manager or not having a case manager and living arrangement, nor did living arrangement significantly predict the level of outpatient visits. Given that more than 50% of the total study sample lived with others, more research is needed to understand how shared living space influences patient participation in outpatient disease management.

Because information about the HIVRN case management support service/referral items was limited, the validity and reliability of these patient interview sections must be interpreted with caution. Informational and instrumental support, as well as other types of support such as financial and emotional, are multi-dimensional constructs with transactional qualities between helpers, clients, and networks that are not fully captured in the HIVRN adult patient interview. Other research has shows that ongoing emotional support is particularly important to patients living with HIV/AIDS (Heath & Rodway, 1999; Zich & Temoshok, 1987). Emotional support may also play a role in helping some patients access outpatient services (Knowlton, Hua & Latkin, 2005).

As previously noted, the interview sections have not undergone reliability and validity tests. Lack of reliability testing raises the question whether different items within the same construct will yield similar results under similar conditions; lack of validity testing for types of formal social support raises the question whether what was measured in the present study may actually be instrumental or informational support. Notwithstanding, the literature on case managers as one form of social support for HIV-positive patients suggests there is a reasonable degree of face validity. Other HIVRN researchers may shed additional light on these issues. The findings from the present exploratory study can be used as a starting point for further examining and evaluating the relationship between types of formal social support and levels of outpatient care in samples of HIV-positive men and women, thus contributing to the understanding of HIV/AIDS comprehensive care.

As previously noted, the student researcher was not able to assess findings by HIVRN site. The data comes from 14 different sites; although a standard protocol was used for the interviews, it is possible that some variation in the interview process took place by site. Along these lines, given the sensitive nature of HIV-related care, fear of stigma and discrimination, and other challenges associated with living with HIV/AIDS, it is possible that patients' self-reported answers may reflect some measure of social desirability bias. The overall number of items to respond to during the interview may have been physically tiring for some patients, thus affecting the accuracy of their responses. Finally, not all variables in the HIVRN adult patient interview were analyzed for this study; it is possible that additional variables may contribute to a better understanding of HIV/AIDS-related health services utilization.

Conclusions and Recommendations for Future Study

In this study, HIV-positive men and women who had one or two case managers were significantly more likely to have a high level of outpatient visits (6+) than their counterparts who did not have a case manager. While these results could suggest the importance of case managers for helping patients living with HIV/AIDS connect to outpatient care, this study did not find that informational or informational support provided by case managers led to this outcome. An alternative patient-driven explanation for the relationship between case management and more outpatient visits is that some patients who seek case managers also seek more outpatient care. The number of in-person case management contacts over the six month study period and the type of support – informational or instrumental - provided by the case manager(s) were not significant predictors of the level of outpatient care. There is an ongoing need to understand the transactional nature of case manager-provided support and those tangible services that may help connect patients to outpatient care. Patients who were employed part- or full-time and had higher self-perceptions of their health were also significantly less likely to have high levels of outpatient visits. No sex/gender-specific differences were found in the current study. Recommendations for future areas of research are outlined below.

Recommendations for HIV/AIDS Case Management Research

This study was unique in its focus on the impact of case management from a sex/gender perspective on levels of HIV/AIDS outpatient visits in the post-HAART era, and in its question concerning whether a "one size fits all" approach to case management is the best strategy. Research to date has shown that having HIV/AIDS is not a "one size fits all" experience; that men and women affected by HIV/AIDS have different physical, social, cultural, and mental health issues (Heath & Rodway, 1999; Lichenstein, Laska, & Clair, 2002; Thorne, McCormick, & Carty, 1997; Rao Gupta, 2000; Zierler & Krieger, 1997) as well as different priorities in managing their own health and caring for those around them. Thus, it remains possible, although it was not observed in this study, that certain HIV/AIDS case management services may be more helpful for women than for men, just as some services may be more helpful for men than for women. Focus groups and other qualitative research strategies could be useful to gather more information about these similarities and differences. Addressing case management from a sex/gender perspective supports other similar HHS research and policy efforts that are addressing the importance of effective models and systems of care from this angle (HHS, 2007).

Other studies may also address the creation of different formal social support service scales organized by type as well as a composite scale of services that could be adapted and tested for use among different groups of HIV-positive persons. When developing descriptions of case management services and frequency of use, researchers should pay attention to making response options as measurable as possible. Studies that address networks of formal social support provided by case managers, in addition to informal social support provided by family members, friends, and colleagues, may be helpful in further understanding the personal and functional aspects of social support in HIV/AIDS patients' lives. Because the course of HIV illness changes over time, it is also essential to learn more about which case management services may be best introduced into patient care at different times in the illness trajectory; for example, at the time of initial diagnosis or when a patient has developed full-blown AIDS.

Recommendations for Patient-Level Research

As previously noted, patients in the study sample who had one or two case managers were significantly more likely to have 6+ outpatient visits than those without a case manager. There were no sex/gender-specific differences in the association of the level of outpatient visits. As to other sex/gender-specific differences, female patients in the study sample were more likely to be Black, between the ages of 20-49; have less than a high school education; have higher CD_4 counts; be unemployed; and have Medicaid as their form of insurance.

There was a small group of patients in the study sample (n=43, 5%) who had three or more case managers. This group of patients was not asked follow-up questions about the types of services they received from case managers and thus, they were not included in the bivariate or multivariate analyses. It is possible that patients were assigned different case managers at different sites where they obtained care. More information is needed about the characteristics of this cohort in larger samples and whether having multiple case managers improves health outcomes. HIV-positive patients with three or more case managers may be at a disadvantage if their care coordination is not well-managed and communicated with all members of their medical and social service team.

There were 323 patients (41%) in the study sample who reported they did not have a case manager during the study period. It is possible a case manager was not available to these patients or that they did not want a case manager at the time. These patients may also have had other persons helping them coordinate their care, obviating the need for a case manager. Previous HIV/AIDS case management research has suggested that persons with greater needs were more likely to have a case manager (Emlet & Gusz, 1998; Fleishman, Mor, & Piette, 1991), while more recent literature has suggested that case managers can intercede early and help patients meet their social service needs while maintaining a high quality of life (Chernesky & Grube, 2000; Mitchell & Linsk, 2001).

How case managers fit into the existing social support structure of HIV-positive patients' lives, as well as over time, is an important area for further research.

Additional patient-level research is needed to learn more about how perceptions of health and need play into receipt of outpatient care. As noted earlier, Meyerson and colleagues (2007) posited that HIV-positive patients' relationship with the outpatient care system is complicated by their own sense of well-being or illness and does not always follow policymakers' recommendations. Other researchers have also noted that self-perceptions play a large role in patient receptivity to social support (Burgoyne & Saunders, 2000; Gant & Ostrow, 1995; Hudson, Lee, Miramontes, & Portillo, 2001; Serovich, Brucker, & Kimberly, 2000). At the same time, if CD_4 count alone were used as a measure of health, a significant number of male and female patients in this study could be expected to self-report a low perception of health status, given that their self-reported counts were at or below 200 cells/mm^3 (the cut-off point for AIDS); however, this was not found to be the case. Patients who have low CD_4 counts and have high perceptions of their health status may have found worthwhile connections to support systems that were not addressed in the current study, such as mental health, faith-based, and workplace support groups, all of which can help with feeling well. Further research is needed to determine whether these types of supportive activities are sex/gender-specific and whether or how they influence levels of HIV/AIDS-related outpatient care. Quality of life studies are particularly important in HIV/AIDS research.

Recommendations for Health Care Policy

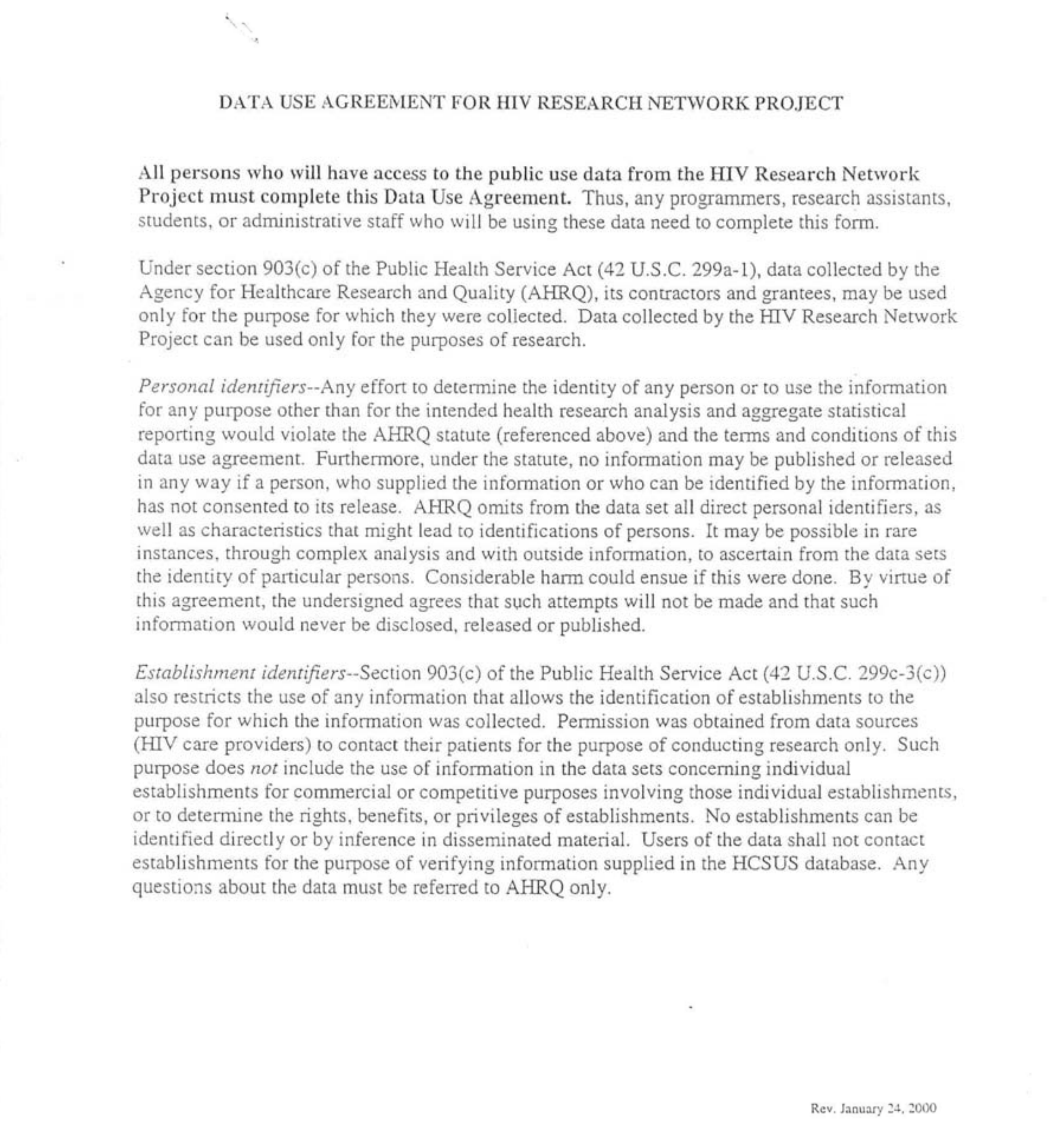
As researchers continue to develop new HIV treatments that can help patients live with and manage their illness for years to come, the U.S. health care system will face critical challenges. As health insurance plans increasingly impose restrictions and limitations on paying for care, long-term HIV/AIDS treatment costs continue to grow. According to Schackman and colleagues (2006), the estimated undiscounted lifetime cost of medical care for HIV-positive adults could be as high as $618,900. This figure does not include costs for mental health and substance abuse treatment or for case management services. Payers of last resort continue to be stretched to meet more patient needs.

Federal funding for HIV/AIDS has undergone major changes in the past few years. The Ryan White CARE Act, which was reauthorized for three years in December 2006 and is now referred to as Title XXVI of the PHS Act as amended by the Ryan White HIV/AIDS Treatment Modernization Act of 2006, has redefined criteria and formulas for funding eligibility to states, territories, public and private providers, and organizations to cover costs for more than half a million people a year (Kaiser Family Foundation, 2007). For the first time in the history of CARE Act legislation, at least 75% of funds must be spent on a group of "core medical services" for Parts A-C (formerly known as Titles I-III). These core medical services include, among other services, outpatient care, mental health and substance abuse services, and medical case management. Although there has been some concerted effort to shift funding toward evidence-based HIV prevention, public funding through Medicaid, Medicare, and Ryan White programs is focused largely on treatment (Kaiser Family Foundation, 2007). Analyzing the impact of the reauthorized

Ryan White Program over the next three years will be critical to future health policy and research decisions. Health care policymakers should also address the gender-based inequities in HIV risk within the larger context of diverse social, economic, and political systems.

In the current study, nearly all patients had some form of health insurance, which may explain why the levels of outpatient visits were so positively skewed, and why health insurance was not found to be a significant predictor of outpatient service utilization. Of the 797 patients in the study sample, 71% had Medicaid or a combination of Medicaid with WIC, Veterans, Ryan White CARE Act, Champus/Tricare, or other county level program benefits, while 12% of the sample was covered under Medicare and 16% had private insurance. Among HCSUS patients in the mid-1990s, researchers estimated that nearly 20% of individuals living with HIV/AIDS were uninsured, one-third had private insurance, and the remainder were covered by Medicaid and Medicare (Kaiser Family Foundation, 2004). Currently in various parts of the U.S., the number of HIV-positive patients with health insurance coverage is highly variable, as are the experience levels of HIV/AIDS clinicians. Patients who are not well-connected to providers, who do not have the means to pay for their care, and whose other social service needs are not met are likely to be in and out of the health care system. In contrast, HIV-positive and other chronic care patients who have support to navigate the health care system and maintain continuity of care may be able to extend the length and quality of their lives.

Appendix A – Confidentiality Statement



DATA USE AGREEMENT FOR HIV RESEARCH NETWORK PROJECT

All persons who will have access to the public use data from the HIV Research Network Project must complete this Data Use Agreement. Thus, any programmers, research assistants, students, or administrative staff who will be using these data need to complete this form.

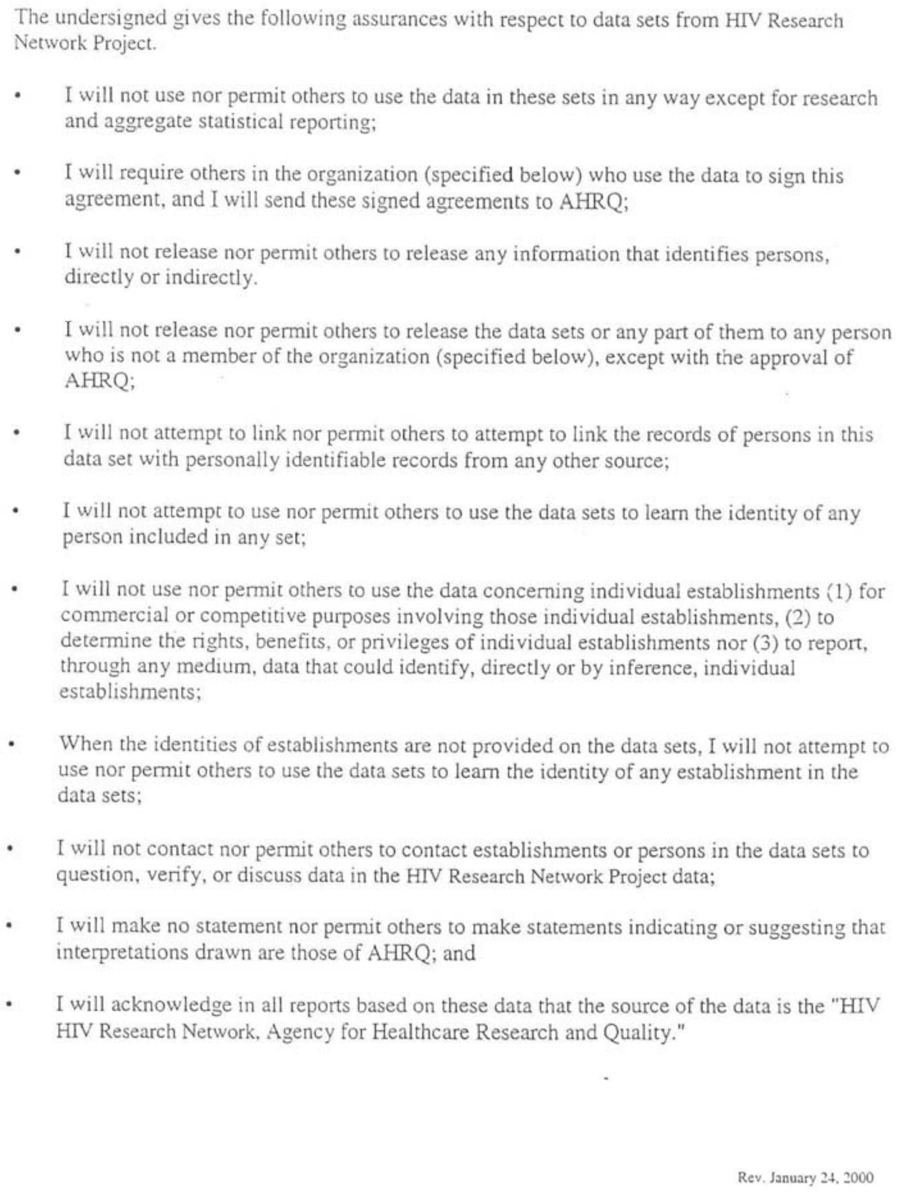
Under section 903(c) of the Public Health Service Act (42 U.S.C. 299a-1), data collected by the Agency for Healthcare Research and Quality (AHRQ), its contractors and grantees, may be used only for the purpose for which they were collected. Data collected by the HIV Research Network Project can be used only for the purposes of research.

Personal identifiers--Any effort to determine the identity of any person or to use the information for any purpose other than for the intended health research analysis and aggregate statistical reporting would violate the AHRQ statute (referenced above) and the terms and conditions of this data use agreement. Furthermore, under the statute, no information may be published or released in any way if a person, who supplied the information or who can be identified by the information, has not consented to its release. AHRQ omits from the data set all direct personal identifiers, as well as characteristics that might lead to identifications of persons. It may be possible in rare instances, through complex analysis and with outside information, to ascertain from the data sets the identity of particular persons. Considerable harm could ensue if this were done. By virtue of this agreement, the undersigned agrees that such attempts will not be made and that such information would never be disclosed, released or published.

Establishment identifiers--Section 903(c) of the Public Health Service Act (42 U.S.C. 299c-3(c)) also restricts the use of any information that allows the identification of establishments to the purpose for which the information was collected. Permission was obtained from data sources (HIV care providers) to contact their patients for the purpose of conducting research only. Such purpose does *not* include the use of information in the data sets concerning individual establishments for commercial or competitive purposes involving those individual establishments, or to determine the rights, benefits, or privileges of establishments. No establishments can be identified directly or by inference in disseminated material. Users of the data shall not contact establishments for the purpose of verifying information supplied in the HCSUS database. Any questions about the data must be referred to AHRQ only.

Rev. January 24, 2000

Appendix A – Confidentiality Statement

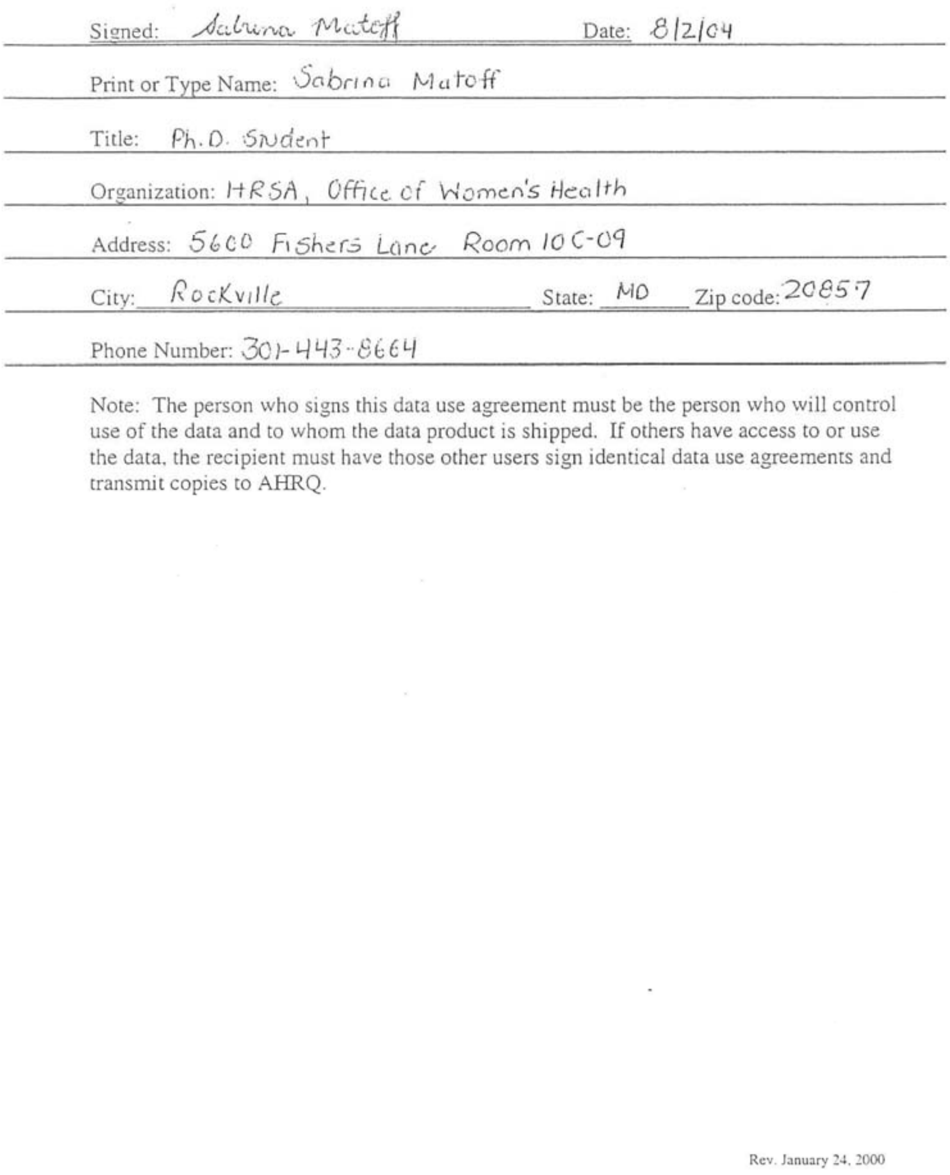


The undersigned gives the following assurances with respect to data sets from HIV Research Network Project.

- I will not use nor permit others to use the data in these sets in any way except for research and aggregate statistical reporting;
- I will require others in the organization (specified below) who use the data to sign this agreement, and I will send these signed agreements to AHRQ;
- I will not release nor permit others to release any information that identifies persons, directly or indirectly.
- I will not release nor permit others to release the data sets or any part of them to any person who is not a member of the organization (specified below), except with the approval of AHRQ;
- I will not attempt to link nor permit others to attempt to link the records of persons in this data set with personally identifiable records from any other source;
- I will not attempt to use nor permit others to use the data sets to learn the identity of any person included in any set;
- I will not use nor permit others to use the data concerning individual establishments (1) for commercial or competitive purposes involving those individual establishments, (2) to determine the rights, benefits, or privileges of individual establishments nor (3) to report, through any medium, data that could identify, directly or by inference, individual establishments;
- When the identities of establishments are not provided on the data sets, I will not attempt to use nor permit others to use the data sets to learn the identity of any establishment in the data sets;
- I will not contact nor permit others to contact establishments or persons in the data sets to question, verify, or discuss data in the HIV Research Network Project data;
- I will make no statement nor permit others to make statements indicating or suggesting that interpretations drawn are those of AHRQ; and
- I will acknowledge in all reports based on these data that the source of the data is the "HIV HIV Research Network, Agency for Healthcare Research and Quality."

Rev. January 24, 2000

Appendix A – Confidentiality Statement



Signed: Sabrina Matoff Date: 8/2/04

Print or Type Name: Sabrina Matoff

Title: Ph.D. Student

Organization: HRSA, Office of Women's Health

Address: 5600 Fishers Lane Room 10C-09

City: Rockville State: MD Zip code: 20857

Phone Number: 301-443-8664

Note: The person who signs this data use agreement must be the person who will control use of the data and to whom the data product is shipped. If others have access to or use the data, the recipient must have those other users sign identical data use agreements and transmit copies to AHRQ.

Rev. January 24, 2000

Appendix B – HIVRN Adult Patient Interview

HIV Research Network -- Patient Interview DRAFT 7

1.8 INTERVIEWER: CODE ONE

PERSONAL INTERVIEW 1

TELEPHONE INTERVIEW 2

1.9 INTERVIEWER: CODE ONE

INTERVIEW WITH RESPONDENT 1

INTERVIEW WITH PROXY 2

1.10 INTERVIEWER: CODE ONE

ENGLISH INTERVIEW 1

SPANISH INTERVIEW 2

0. INTRODUCTION AND INFORMED CONSENT

Introduction

Unless otherwise indicated, every item has these "hidden" values refused = -1
don't know = -2

This interview is about your health care and related issues. It will take about 2 hours. We can take a break any time you feel you need one; just let me know. You will be paid $30 in cash for completing the interview.

1. Before we begin, I need to give you an informed consent document to read and sign, along with a brochure that explains more about the study.

(Circle One)

FULL INFORMED CONSENT ALREADY SIGNED .... 1 □□SKIP TO NEXT SECTION

FULL INFORMED CONSENT NOT SIGNED 2

HAVE RESPONDENT READ AND SIGN INFORMED CONSENT FORM.
RETAIN TOP COPY OF INFORMED CONSENT FORM.
LEAVE BOTTOM COPY AND BROCHURE WITH RESPONDENT.

POINT OUT 1-800 NUMBER IN BROCHURE IN CASE RESPONDENT
HAS ANY QUESTIONS OR PROBLEMS (1-800-700-2464).

2. HAS R SIGNED INFORMED CONSENT?

(Circle One)

YES 1

NO .... 2 □□DO NOT PROCEED UNTIL R SIGNS FORM

Section A: Usual Source of Medical Care

RECORD TIME THIS SECTION BEGINS:________________

A0. CODE RESPONDENT’S GENDER.

(Circle One)

MALE	1	
FEMALE	2	

I’d like to start by asking <u>where</u> you get medical care for HIV.

A1. Is there one place in particular, like a doctor's office or clinic, where you usually go <u>for most of your HIV treatment</u>, like examinations, CD4 tests or prescriptions for HIV-related medicines?

(Circle One)

YES	1	
NO	2	□□□SKIP TO A7
DON'T KNOW	-2	□□□SKIP TO A7

A2. What is the name of this place?

____

PROVIDER NAME

A3. Let's call this your usual source of care. How long have you had this usual source of care for treatment of HIV?

ENTER HOW LONG: __	CIRCLE UNIT:	DAYS	1
(VARIABLE COMBINES 2 RESPONSES — UNITS-DAYS)		WEEKS	2
		MONTHS	3
		YEARS	4

A4. In the past 12 months, have you had an **urgent** problem due to your HIV infection? This would be a problem that you thought needed care **right away** from a doctor, nurse or other health care provider.

(Circle One)

YES	1	
NO	2	□□□SKIP TO A5
DON'T KNOW	-2	□□□SKIP TO A5

A4a When you had an urgent problem due to HIV, how would you rate the length of time you had to wait before you could see your usual source of HIV care (when you did not already have an appointment scheduled)?

(Circle One Number)

|_____|_____|_____|_____|_____|_____|_____|_____|_____|_____|

0	1	2	3	4	5	6	7	8	9	10
Worst possible					Half-way					Best possible

DID NOT SEE -- JUST SPOKE OVER THE PHONE …………………-3

A4b. When you had an urgent problem due to HIV, how would you rate the length of time it took for you to get advice over the telephone from your usual source of HIV care?

(Circle One Number)

|_____|_____|_____|_____|_____|_____|_____|_____|_____|_____|

0	1	2	3	4	5	6	7	8	9	10
Worst possible					half-way					best possible

DID NOT SPEAK ON PHONE -- SAW PROVIDER ………………….-3

A5. About how much time does it usually take you to get to your usual source of HIV care from where you live?

a. ENTER HOW LONG: ______b. CIRCLE UNIT: MINUTES 1
HOURS 2

A6. When you go to your usual source of HIV care for a scheduled appointment, about how long do you usually have to wait from the time you arrive to the time you actually see a doctor, nurse, or other care provider?

a. ENTER HOW LONG: ______b. CIRCLE UNIT: MINUTES 1
HOURS …….2

Now I have some questions about the medical people who treat your HIV infection. These are doctors, nurses, or physician's assistants who you see for HIV treatment. I'll call them "HIV care providers."

A7. In the last 12 months, how often did your HIV care providers listen carefully to you?

(Circle One)

Never 1
Sometimes ……………………..…….2
Usually …………………………..3
Always………………………………….....4
DON'T KNOW….……………………….-2

A8. In the last 12 months, how often did your HIV care providers explain things in a way you could understand?

(Circle One)

Never 1
Sometimes ……………………..…….2
Usually……………………………………3
Always…………………………………….4
DON'T KNOW…..……………………….-2

A9. In the last 12 months, how often did your HIV care providers show respect for what you had to say?

(Circle One)

Never 1
Sometimes…………………………..…….2
Usually……………………………………3
Always…………………………………… 4
DON'T KNOW…………………………..-2

A10. In the last 12 months, how often did your HIV care providers spend enough time with you?

(Circle One)

Never 1
Sometimes………………………………. 2
Usually……………………………………3
Always……………………………………4
DON'T KNOW…………………………-2

A10a. In the last 12 months, how often did your HIV care providers talk to you about possible problems you had with taking your HIV medicines?

(Circle One)

Never 1
Sometimes……………………………….2
Usually… ..……………………………3
Always…………………………………...4
NOT TAKING MEDS………………… -3
DON'T KNOW…………………………-2

A10b. How would you rate how well your HIV care providers informed you about the possible side effects of your medications?

(Circle One Number)

|______|______|______|______|______|______|______|______|______|______|
0 1 2 3 4 5 6 7 8 9 10
Worst possible half-way best possible

NEVER DISCUSSED SIDE EFFECTS -5

A11. We want to know your rating of your HIV-related health care in the last 12 months. Use any number from 0 to 10, where 0 is the worst health care possible and 10 is the best health care possible. How would you rate your health care?

(Circle One Number)

|______|______|______|______|______|______|______|______|______|______|
0 1 2 3 4 5 6 7 8 9 10
Worst possible health Care Half-way Best possible care

B. Symptoms

B1. I am now going to ask you several questions about your health during the past three months. In the past three months have you had any of the following problems . . .

	A	B	C	D	E
	1= No **2= Yes** **-2= Refuse/ DK** ***If no, GO TO NEXT SYMPTOM***	**Do you think that this is related to HIV medicines** 1= No 2= Yes -2= DK -3 = Don't take HIV medicines	**Have you discussed this problem with your HIV doctor?** **1= No** **2= Yes** ***If no, GO TO NEXT SYMPTOM***	**Did your HIV doctor do anything in response?** **1= No** **2= Yes** **-2 = DK** ***If no, GO TO NEXT SYMPTOM***	**What did he/she do? (Circle all that apply)** **1= Started treatment with another medication** **2=Stopped a medication** **3= changed dose of med** **4=other** **-2 = DK** ***GO TO NEXT SYMPTOM***
1 Problems with sleep					
2 Changes in mood					
3 Dizziness or problems with balance					
4 Frequent or severe headaches					
5 Fatigue or loss of energy					
6 Aches, weakness, or inflammation in muscles or joints					
7 Nausea or stomach difficulties (swelling, pain, bloating)					
8 Bowel problems (diarrhea, loose stool)					
9 Problems with sexual function					
10 Skin rash, itching, sores or discoloration					
11. Problems with your liver, like hepatitis, liver abnormalities, or abnormal liver function tests					

12. Changes in your body shape due to fat deposits					
13. Loss of appetite or change in the taste of food					
14. Vivid dreams					
15. Trouble with your eyes, such as seeing spots or blind areas in your vision					
16. Fevers, sweats, or chills					
17. Pain, numbness, or tingling in your hands or feet					
18. Persistent coughing, difficulty breathing, or difficulty catching your breath that lasted for more than 1 week					

B2. Of all the CD4 tests you have ever had, what was your lowest count?

ENTER COUNT 1 COUNT: ☐☐☐☐
NEVER HAD A CD4 TEST .... -5
DON'T KNOW…………………………..-2

IF B2 = DK, REF GO TO B3, ELSE GO TO B6

B3. Was your lowest CD4 count less than 500?

YES 1
NO...2

IF B3 = 2, REF, GO TO B6

B4. Was it less than 200?

YES 1
NO...2

IF B4 = 2, REF, GO TO B6

B5. Was it less than 50?

YES 1
NO..2

B6. Has a doctor ever told you that you had AIDS?

YES 1
NO..2

C. UTILIZATION OF CARE

Section CA. Nursing Home / Residential Care Stays

CA1. During the last 6 months, were you a patient in a residential care facility, a nursing home or hospice overnight or longer?

(Circle One)

YES 1
NO .... 2 SKIP TO CB1

CA2. How many different times were you admitted to such a facility during the last 6 months?

TIMES: ___________ IF ‘0’, SKIP TO NEXT SECTION

CA3. In total, how many nights did you spend in residential facilities in the last 6 months?

NIGHTS: _________

CA4. CHECK: ANSWER TO CA3 MUST BE LESS THAN 180 NIGHTS.

Section CB. Inpatient Hospital Stays

CB1. During the last 6 months, were you a patient in a hospital overnight or longer? CODE YES IF CURRENTLY INPATIENT.

(Circle One)

YES	1	
NO	2	□□□□□SKIP TO CB34

CB2. How many times were you admitted to the hospital overnight or longer during the last 6 months?

TIMES: ___________ IF ‘0’, SKIP TO NEXT SECTION

CB3. Let’s start with the most recent stay. What is the name of the hospital?

____
HOSPITAL NAME

CB4. How many nights were you in the hospital for this stay?

NIGHTS: __________

CB4a. Were you in an intensive care unit during this hospital stay?

(Circle One)

YES	1	
NO	2	□□ SKIP TO CB5
REFUSED	-1	
DON'T KNOW	-2	

CB4b. How many nights (were you in intensive care)?

NIGHTS: __________

CB5. While you were in the hospital for this stay, did you have any kind of surgery or procedure performed in the operating room?

(Circle One)

YES	1
NO	2
REFUSED	-1
DON'T KNOW	-2

CB6. INTERVIEWER: CHECK QUESTION CB2

CB2 = 1 TIME	1□□□	SKIP TO CB32
CB2 = 2 OR MORE TIMES	2	

HOSPITAL STAY 2

CB7. Did you have any other hospital stays during the last 6 months?

(Circle One)

YES	1	
NO	2□□	SKIP TO CB32
REFUSED	-1□□	SKIP TO CB32
DON'T KNOW	-2□□	SKIP TO CB32

CB8. Now let's talk about the stay <u>before</u> your most recent stay. What is the name of the hospital?

(Circle One)

SAME HOSPITAL AS FIRST STAY .. 2

____

HOSPITAL NAME

CB9. How many nights were you in the hospital for this stay?

NIGHTS: ____

CB10. Were you in an intensive care unit during this hospital stay?

(Circle One)

YES 1
NO .... 2□□ SKIP TO CB11
REFUSED .... -1
DON'T KNOW .... -2

CB10a. How many nights (were you in intensive care)?

NIGHTS: __________

CB11. While you were in the hospital for this stay, did you have any kind of surgery or procedure performed in the operating room?

(Circle One)

YES 1
NO 2
REFUSED .... -1
DON'T KNOW .... -2

CB12. INTERVIEWER: CHECK QUESTION CB2

CB2 = 2 TIMES .... 1□□□SKIP TO CB32
B2 = 3 OR MORE TIMES 2

HOSPITAL STAY 3

CB13. Did you have any other hospital stays during the last 6 months?

(Circle One)

YES 1
NO .... 2□□ SKIP TO CB32
REFUSED .... -1□□ SKIP TO CB32
DON'T KNOW .... -2□□ SKIP TO CB32

CB14. Now for the stay <u>before</u> the one you just told me about. What is the name of the hospital?

(Circle One)

SAME HOSPITAL AS STAY #1 1
SAME HOSPITAL AS STAY #2 2

____
HOSPITAL NAME

CB14a. How many nights were you in the hospital for this stay?

NIGHTS: __________

CB15. Were you in an intensive care unit during this hospital stay?

(Circle One)

YES 1
NO .... 2□□ SKIP TO CB16
REFUSED .... -1
DON'T KNOW .... -2

CB15a. How many nights (were you in intensive care)?

NIGHTS: __________

CB16. While you were in the hospital for this stay, did you have any kind of surgery or procedure performed in the operating room?

(Circle One)

YES 1
NO 2

CB20. INTERVIEWER: CHECK QUESTION CB2

CB2 = 3 TIMES .... 1□□□SKIP TO CB32
CB2 = 4 OR MORE TIMES 2

HOSPITAL STAY 4

CB21. Did you have any other hospital stays during the last 6 months?

(Circle One)

YES	1	
NO	2□□	SKIP TO CB32
REFUSED	-1□□	SKIP TO CB32
DON'T KNOW	-2□□	SKIP TO CB32

CB22. Now for the stay before the one you just told me about. What is the name of the hospital?

(Circle One)

SAME HOSPITAL AS STAY #1	1
SAME HOSPITAL AS STAY #2	2
SAME HOSPITAL AS STAY #3	3

____

HOSPITAL NAME

CB23. How many nights were you in the hospital for this stay?

NIGHTS: __________

CB24. Were you in an intensive care unit during this hospital stay?

(Circle One)

YES	1	
NO	2□□	SKIP TO CB25
REFUSED	-1	
DON'T KNOW	-2	

CB24a. How many nights (were you in intensive care)?

NIGHTS: __________

CB25. While you were in the hospital for this stay, did you have any kind of surgery or procedure performed in the operating room?

(Circle One)

YES	1
NO	2

CB26. INTERVIEWER: CHECK QUESTION CB2

CB2 = 4 TIMES	1	□□□SKIP TO CB32
CB2 = 5 OR MORE TIMES	2	

HOSPITAL STAY 5

CB27. Did you have any other hospital stays during the last 6 months?

(Circle One)

YES	1	
NO	2	□□ SKIP TO CB32
REFUSED	-1	□□ SKIP TO CB32
DON'T KNOW	-2	□□ SKIP TO CB32

CB28. Now for the stay <u>before</u> the one you just told me about. What is the name of the hospital?

(Circle One)

SAME HOSPITAL AS STAY #1..........	1
SAME HOSPITAL AS STAY #2..........	2
SAME HOSPITAL AS STAY #3..........	3
SAME HOSPITAL AS STAY #4..........	4

____

HOSPITAL NAME

CB29. How many nights were you in the hospital for this stay?

NIGHTS: __________

CB30. Were you in an intensive care unit during this hospital stay?

(Circle One)

YES 1
NO .... 2□□ SKIP TO CB31
REFUSED .... -1
DON'T KNOW .... -2

CB30a. How many nights (were you in intensive care)?

NIGHTS: ___________

CB31. While you were in the hospital for this stay, did you have any kind of surgery
or procedure performed in the operating room?

(Circle One)

YES 1
NO 2

CB32. Were any hospitalizations in the past six months due to side effects of HIV medications you were taking?

(Circle One)

YES 1
NO 2
REFUSED…………………… -1
DON'T KNOW……………… -2

CB33. Were any hospitalizations in the past six months due to complications of AIDS, like PCP, MAC, "toxo," "crypto", or some other opportunistic infection?

(Circle One)

YES 1
NO .... 2 (go to CB34)
REFUSED…………………. -1 (go to CB34)
DON'T KNOW…………….. -2 (go to CB34)

CB33a. How many different times were you admitted to the hospital to treat an opportunistic infection in the last six months?

____________ times
DON'T KNOW -2

CB34. We've been talking about inpatient hospitalizations in the past six months. Now think about the six months before that. In this earlier six-month period, were you a patient in a hospital overnight or longer?

(Circle One)

YES………… 1
NO . 2 □□□SKIP TO NEXT SECTION

CB35. How many times were you admitted to the hospital overnight or longer during the earlier 6 month period?

TIMES:_________
DON'T KNOW -2

Section CC. Visits to Emergency Rooms and Urgent Care Centers

CC1. During the last 6 months, did you ever go to an emergency room, or urgent care center for medical care?

(Circle One)

YES 1
NO .... 2 □□ SKIP TO D1

CC2. How many <u>different</u> ER's or urgent care centers did you visit during the last 6 months?

ER's: _____________ IF '0', SKIP TO NEXT SECTION

CC3. What was the name of the emergency room that you went to (IF > 1 ADD: most often)?

NAME:____

CC4. Thinking about <u>all the visits</u> you made to the (NUMBER IN CC2) different emergency rooms, how many total visits did you make in the past 6 months?

PROBE IF ZERO: You told me earlier that you went to an emergency room in the last 6 months. Please include that visit in your answer

VISITS: __________

CC5. How many of the (NUMBER IN CC4) visits led directly to a hospital stay?

VISITS: __________

CC6. Think about the last time you went to an emergency room. What did you go there for?

(Circle One)

1. An illness that you thought was related to HIV infection……………..1
2. An accident or an injury……………………………………………….2
3. Pregnancy-related care…………………………………………..….3
4. Alcohol or drug-related condition……………………………………..4
5. An illness that wasn't related to HIV infection ………………………. 5
6. Another person was sick or injured……………………………………6
7. Don't remember………………………………………………………..7

CC7. When you went to the emergency room last time, did you decide to go on your own, or did a health care provider tell you to go there?

ON MY OWN………………………..1

TOLD TO GO THERE………………2

CC8. Were any emergency room visits in the past six months due to side effects of HIV medications you were taking?

(Circle One)

YES 1
NO 2
REFUSED ……………………-1
DON'T KNOW………………..-2

Section CD. Medical Visits

People with HIV infection often make visits for medical care. Many also get treated for mental or emotional problems, and some get treated for problems with drugs or alcohol. I'd like to ask you about all these services. Let's start with medical care, for HIV and for other medical problems that you may have had. For these questions, please don't include visits that were **only** to treat mental or emotional problems, or for drug or alcohol problems.

CD1. In the past 6 months, how many times did you go to a clinic, private doctor's office, or HMO for medical care? Don't count visits to an emergency room.

Visits______________________

PROBE IF NONE: Please think about visits to your usual sources of medical care and any other kinds of doctors or clinics you might have gone to in the last 6 months.

CD2. Think about the care center you visited the greatest number of times. What was the name of this place?

NAME____________________________________

CD3 Did you go to any other office or clinic for medical care in the past 6 months?

(Circle One)

YES	1	
NO	2	□□ SKIP TO CD4
REFUSED	- 1	□□ SKIP TO CD4
DON'T KNOW	-2	□□ SKIP TO CD4

CD3a. Besides (NAME from CD2), how many different places did you go for medical care in the past 6 months?

NUMBER__________________

CD4. Think about (NAME from CD2). What kind of care center is this?

(Circle One)

A private doctor's office	1
An STD or public health clinic	2
A hospital clinic or outpatient department	3
Another kind of medical clinic or health center	4
REFUSED	-1
DON'T KNOW	-2

CD5. How many visits did you make to (NAME from CD2) in the last 6 months?

VISITS: ___________________

REFUSED	-1
DON'T KNOW	-2

CHECK CD3a. IF NUMBER OF PROVIDERS > 1, CONTINUE WITH CD6. IF ONLY ONE PROVIDER, GO TO CD10.

CD6. Think about the clinic, doctor's office, or HMO that you visited the second most number of times. What kind of care center was this?

(Circle One)

A private doctor's office	1
An STD or public health clinic	2
A hospital clinic or outpatient department	3
Another kind of medical clinic or health center	4

CD7. How many visits did you make to this care center in the last 6 months?

VISITS: _____

REFUSED	-1
DON'T KNOW	-2

CHECK CD3a. IF NUMBER OF PROVIDERS > 2, CONTINUE WITH CD8. IF ONLY TWO PROVIDERS, GO TO CD10.

CD8. Think about the clinic, doctor's office, or HMO that you visited the third most number of times. What kind of care center was this?
((**Circle One)**

A private doctor's office	1
An STD or public health clinic	2
A hospital clinic or outpatient department	3
Another kind of medical clinic or health center	4

CD9. How many visits did you make to this care center in the last 6 months?

VISITS: _____
REFUSED -1
DON'T KNOW -2

CD10. Have you had a doctor visit in the last six months mainly because you had a medication side effect?

(Circle One)

YES 1
NO 2
REFUSED……………………………………………………….-1
DON'T KNOW……………………………………………..-2

Section CE. Mental Health Providers

CE1. Now let's talk about treatment for mental or emotional problems, or for problems with stress or nerves. Did you visit a mental health provider on an <u>individual</u> or family basis for emotional or personal problems during the last 6 months? Include any visits to a psychiatrist, psychologist, psychiatric social worker, psychiatric nurse, or marriage or family counselor. Don't include any visits that were **only** for drug or alcohol problems.

(Circle One)

YES	1	
NO	2	□□ SKIP TO CE3
REFUSED	-1	□□ SKIP TO CE3
DON'T KNOW	-2	□□ SKIP TO CE3

CE2. In total, how many visits to mental health providers did you make during the last 6 months?

VISITS: _____

CE3. Did you attend support or psychotherapy groups in the last 6 months? (Do not include 12-step groups or groups primarily for substance abuse.)

(Circle One)

YES	1	
NO	2	□□ SKIP TO CE5
REFUSED	-1	□□ SKIP TO CE5
DON'T KNOW	-2	□□ SKIP TO CE5

CE4. In total, how many visits to support or psychotherapy groups did you make during the last 6 months?

VISITS: ___________

CE5. Did you ever visit with any other provider, such as a minister, priest, or rabbi about emotional or personal problems in the last 6 months?

(Circle One)

YES	1
NO	2

Section CF: Substance Abuse Treatment Services

CF1. During the last 6 months, did you receive any treatment or counseling for drug or alcohol use? This would include going to any groups such as NA or AA.

(Circle One)

YES	1
NO	2 □□

SKIP TO CG1

CF1a. In the last 6 months, did you attend any NA or CA meetings?

(Circle One)

YES	1
NO	2

CF1b. In the last 6 months, did you attend any meetings of Alcoholics Anonymous?

(Circle One)

YES	1
NO	2

CF1c. In the last 6 months, how many times did you attend a 12-step or self-help group (such as AA, NA, or CA) or support group primarily for drug or alcohol related problems?

TIMES: ___________

CF2. Let's talk about outpatient visits for drug or alcohol problems, other than the ones we just mentioned. How many **different** outpatient treatment programs or providers did you use in the past six months?

_______________ (NUMBER)

Only NA or AA	-3

CF2a. Think about the outpatient drug or alcohol treatment program or provider you went to most often. How many days did you receive treatment in this outpatient program, or visit this professional in an outpatient setting for drug or alcohol related problems? Don't include any medical visits you've already told me about.

DAYS: ______

CHECK CF2. IF NUMBER OF PROVIDERS > 1, CONTINUE WITH CF2b. IF ONLY ONE PROVIDER, GO TO CF3.

CF2b. Think about the drug or alcohol treatment provider you went to the next most number of times. How many days did you receive treatment from this provider?

DAYS: ______

CHECK CF2. IF NUMBER OF PROVIDERS > 2, CONTINUE WITH CF2c. IF ONLY ONE OR TWO PROVIDERS, GO TO CF3.

CF2c. Think about the drug or alcohol treatment provider you went to the next most number of times. How many days did you receive treatment from this provider?

DAYS: ______

CF2d. Of all the visits you just told me about, how many were for **detox only**?

DAYS: ______

CF3. In the last six months, were you enrolled in a residential treatment program, a halfway house, or a therapeutic community for drug or alcohol problems?

(Circle One)

YES	1	
NO	2	□□ SKIP TO CF4
REFUSED	-1	□□ SKIP TO CF4
DON'T KNOW	-2	□□ SKIP TO CF4

CF3a. How long were you enrolled in this program?

______________DAYS
______________WEEKS
______________ MONTHS

CF3b. Were any of these times for **detox only**?

(Circle One)

YES	1	
NO	2	☐☐ SKIP TO CF4
REFUSED	-1	☐☐ SKIP TO CF4
DON'T KNOW	-2	☐☐ SKIP TO CF4

CF3c. How long were you in inpatient or residential detox?

_______________DAYS
_______________WEEKS
_______________ MONTHS

CF4. In the last six months, were you enrolled in a methadone maintenance program?

(Circle One)

YES	1	
NO	2	☐☐ SKIP TO CF5
REFUSED	-1	☐☐ SKIP TO CF5
DON'T KNOW	-2	☐☐ SKIP TO CF5

CF4a. How long were you enrolled in this program?

_______________DAYS
_______________WEEKS
_______________ MONTHS

Section CG. Home Health Services

CG1. During the last 6 months, did you receive help at home with medical problems, personal care, housekeeping, or other services?

	(Circle One)	
YES	1	
NO	2	□□ SKIP TO CH1

CG2. (HAND R CARD #31) Please look at this card and tell me which specific types of help you received at home during the last 6 months. PROBE: Any other type of help? CODE EACH TYPE OF HELP RECEIVED BELOW. INCLUDE PAID AS WELL AS UNPAID HELP.

	(Circle All That Apply)
a. TPN OR PARENTERAL NUTRITION (FEEDING BY VEIN)	1
b. INFUSION THERAPY	2
c. INJECTIONS OR SHOTS	3
d. OTHER MEDICAL TREATMENT OR EXAMINATION (SUCH AS ADMINISTERING MEDICATION BY MOUTH OR INHALATION OR CHANGING BANDAGES)	4
e. PHYSICAL, OCCUPATIONAL OR SPEECH THERAPY	5
f. PERSONAL CARE SUCH AS ASSISTANCE GETTING DRESSED AND UNDRESSED, BATHING, OR GETTING INTO OR OUT OF BED	6
g. HOUSEKEEPING OR FOOD PREPARATION	7
h. MEAL DELIVERY	8
i. OTHER	9

CG3. (HAND R CARD 32) Who helped you during the last 6 months?
PROBE: Anyone else?

(Circle All That Apply)

PAID HELPER	1
UNPAID VOLUNTEER	2
FRIEND OR RELATIVE WHO LIVES WITH YOU	3
FRIEND OR RELATIVE WHO DOES NOT LIVE WITH YOU	4
OTHER HELPER	5

CG4. INTERVIEWER CHECK CG3.

(Circle One)

CODE 1 IS CIRCLED	1	
CODE 1 IS <u>NOT</u> CIRCLED	2	□ SKIP TO CG6

CG5. On average, how many hours per week of paid home help did you have in the last 6 months? Please include <u>all</u> types of paid home help in your answer—not just help related to health care.

HOURS: _____________

CG5a. How many weeks did you have paid home help in the last 6 months?

WEEKS: ____________

CG6. INTERVIEWER CHECK CG3.

(Circle One)

CODE 2 OR 3 OR 4 OR 5 IS CIRCLED	1	
CODE 2 OR 3 OR 4 OR 5 IS <u>NOT</u> CIRCLED	2	□ SKIP TO CH1

CG7. Think about the unpaid helper who helped you most often during the last 6 months.
Is that person:

	(Circle One)	
A volunteer,	1	□□SKIP TO CG9
A friend,	2	
Your partner or spouse,	3	□□SKIP TO CG9
Another family member,	4	
Some other helper	5	

CG8. Does he or she live with you?

	(Circle One)
YES	1
NO	2

CG9. On average, how many hours per week of help did you get from all unpaid helpers in the last 6 months?

HOURS: ____________

CG9a. How many weeks did you have unpaid helpers in the last 6 months?

WEEKS: ____________

Section CH. Dental Services

CH1. During the last 6 months, did you see a dentist, oral surgeon, or other professional dental care provider?

(Circle One)

YES 1

NO............................. 2

CH2. During the last 6 months, how many times did you see the dentist, dental surgeon, oral surgeon, orthodontist, periodontist, endodontist, dental hygienist, dental technician, denturist, or any other person for dental care for a dental check-up?

VISITS: _____

Section CI. Other Services

CI1. Did you receive care from any medical practitioners such as optometrists, foot doctors, nutritionists or chiropractors in the past six months?

(Circle One)

YES 1

NO 2

CI2. Did you receive treatment from any alternative therapist, for example, a massage therapist, acupuncturist, herbalist, or any other alternative practitioner?

(Circle One)

YES 1

NO 2

CI3. During the last 6 months, did you buy or replace any special medical equipment like eyeglasses, a cane, a hospital bed, a wheelchair, or a nebulizer?

(Circle One)

YES 1

NO 2

D. INSURANCE COVERAGE

RECORD TIME THIS SECTION BEGINS:________________

Now I’d like to talk with you about health insurance.

D1. Have you been covered by Medicaid or (STATE NAME FOR MEDICAID) in the last 6 months? (Medicaid is a state program for low income persons or for persons on public assistance.)

(Circle One)

YES	1	
NO	2	□□ SKIP TO D5
REFUSED	-1	□□ SKIP TO D5
DON'T KNOW	-2	□□ SKIP TO D5

D2. Are you presently covered by Medicaid?

(Circle One)

YES	1
NO	2
REFUSED	-1
DON'T KNOW	-2

D3. In what month and year were you <u>first</u> covered by (Medicaid/STATE PROGRAM NAME)?

MONTH: ____YEAR: ____________

D4. During the last 6 months, for approximately how many months were you covered by (Medicaid/STATE PROGRAM NAME)?

____________ MONTHS

D5. Are you presently covered by Medicare? (Medicare is a health insurance program for people 65 years old or over and for people who are disabled.)

(Circle One)

YES 1
NO .... 2 □□ SKIP TO D6a
REFUSED .... -1□□ SKIP TO D6a
DON'T KNOW .... -2□□ SKIP TO D6a

D6. In what month and year were you <u>first</u> covered by Medicare?

MONTH: __________ YEAR: ___________________

D6a. Do you get help paying for drugs through the ADAP program, also known as the AIDS Drug Assistance program?

(Circle One)

YES 1
NO 2

D7. Have you received coverage from any <u>other</u> public insurance program during the last 6 months? This includes any public programs such as VA benefits, TRICARE, or a county program.

(Circle One)

YES 1
NO .... 2 □□ SKIP TO D10
REFUSED .... -1□□ SKIP TO D10
DON'T KNOW .... -2□□ SKIP TO D10

D8. (HAND R CARD #25) What are the names of these programs?

(Circle All That Apply)

a. WIC (WOMEN, INFANTS AND CHILDREN) 1
c. VETERANS ADMINISTRATION (VA) 2
d. CHAMPUS/TRICARE 3
e. COUNTY PROGRAM 4
f. OTHER 5

D9. Are you presently covered by any of these programs?

(Circle One)

YES	1	
NO	2	

D10. Are you now covered by any <u>private</u> health insurance that pays any part of hospital or doctor bills?

(Circle One)

YES	1	
NO	2	□□ SKIP TO D12
REFUSED	-1	□□ SKIP TO D12
DON'T KNOW	-2	□□ SKIP TO D12

D10a. Are you covered by more than one private insurance plan that pays for any part of your hospital or doctor bills?

(Circle One)

YES	1	
NO	2	□□ SKIP TO D11
REFUSED	-1	□□ SKIP TO D11
DON'T KNOW	-2	□□ SKIP TO D11

D10b. How many private insurance plans do you have (that cover any part of your hospital or doctor bills)?

#: ___________

D11. (<u>READ IF D10a CODED 1 [YES]:</u> I want to ask you about your **primary private** insurance plan, that is, the plan that pays most of the cost of your hospital or doctor bills.)

It is important that we have the complete and accurate name of your (primary) private insurance plan. Do you have something like an ID card or bill with the name of your (primary) private insurance plan on it?

(Circle One)

YES	1
NO	2

D11a. RECORD NAME FROM CARD OR ASK:
What is the complete name of this plan?

____

D11b. Is this plan a health maintenance organization or HMO?

(Circle One)

YES	1
NO	2
REFUSED	-1
DON'T KNOW	-2

D11c. Does (this plan/PLAN NAME FROM D11a) allow you to go to any doctor you want or does it require you to choose from a group or list of doctors?

(Circle One)

ANY DOCTOR	1
SELECT FROM GROUP/LIST	2
REFUSED	-1
DON'T KNOW	-2

D11d. Does your insurance require you to obtain approval from them before seeing a specialist
for medical care?

(Circle One)

YES	1
NO	2

D11e. In what month and year were you <u>first</u> covered by this plan?

MONTH: __________ YEAR: ____________

D11f. Does your private insurance pay for treatment of mental or emotional problems?

	(Circle One)
YES	1
NO	2
DON'T KNOW	-2

D11g. Does your private insurance pay for treatment of drug or alcohol abuse problems?

	(Circle One)
YES	1
NO	2
DON'T KNOW	-2

D11h. Do you have insurance that covers dental services?

	(Circle One)
YES	1
NO	2
REFUSED	-1
DON'T KNOW	-2

D11i. Do you have <u>private</u> insurance that covers prescription medication?

	(Circle One)
YES	1
NO	2
REFUSED	-1
DON'T KNOW	-2

CHECK D10.

	(Circle One)	
D10 IS CODED 1	1	→ SKIP TO D13
ALL OTHERS	2	

D12. Did you ever have private health insurance?

(Circle One)

YES 1
NO 2 □□ SKIP TO D13
DK……………………………………….-2

D12a. When was the last time you had <u>private insurance</u> coverage?

□□/ □□
MO/YR

D13. INTERVIEWER: CHECK D1, D5, D9, D10. IS ANY OF THESE CODED 1?

(Circle One)

YES .... 1 □□ SKIP TO D15
NO 2

D14. I have recorded that you have not been covered by any private <u>or</u> public health insurance in the last 6 months. Is that correct?

(Circle One)

YES .... 1 □□ SKIP TO D17
NO 2
REFUSED .... -1□□ SKIP TO D17
DON'T KNOW .... -2□□ SKIP TO D17

D14a. Were you covered by private or public insurance in the last 6 months?

(Circle One)

PRIVATE ……………………….. 1□□ RETURN TO D10
PUBLIC .... 2 □□ RETURN TO D1
BOTH .... 3 □□ RETURN TO D1

D15. Have you been without public or private insurance at any time during the last 6 months?

(Circle One)

YES	1	
NO	2	□□ SKIP TO D18
REFUSED	-1	
DON'T KNOW	-2	

D16. During the last 6 months, for how many months were you without insurance — either public or private?

MONTHS: ________

OR

REFUSED	-1
DON’T KNOW	-2

CHECK D10. IF D10 CODED 2 (NO), ASK D17. ALL OTHERS SKIP TO D18.

D17. (HAND R CARD #27) Why don’t you have private health insurance?

(Circle All That Apply)

a. TOO EXPENSIVE	1
b. LOST JOB WITH INSURANCE COVERAGE	2
c. DENIED COVERAGE BECAUSE OF HIV STATUS	3
d. DENIED COVERAGE FOR OTHER MEDICAL CONDITION	4
e. FEAR OF JEOPARDIZING PRIVACY	5
f. OTHER	6

D18. At the time you first tested positive for HIV, did you have any public or private health insurance?

(Circle One)

YES	1	
NO	2	□□ SKIP TO D19
REFUSED	-1	□□ SKIP TO D19
DON'T KNOW	-2	□□ SKIP TO D19

D18a. What kind of health insurance did you have at that time?

(Circle All That Apply)

Private insurance,	1
Medicaid,	2
Medicare, or	3
Other public insurance?	4

D19. Are you currently participating in any clinical trials or clinical research studies?

(Circle One)

YES	1	
NO	2	□□ SKIP TO D21
REFUSED	-1	□□ SKIP TO D21
DON'T KNOW	-2	□□ SKIP TO D21

D20. (HAND R CARD #28) What services are being provided in the trial(s)?

(Circle One)

CHECK-UPS ONLY	1
MEDICATIONS ONLY	2
MEDICAL CARE (NO MEDICATIONS) ONLY	3
MEDICATIONS AND MEDICAL CARE	4
NO MEDICAL CARE OR MEDICATION	5

D21. CHECK D10. IF D10 CODED 1 (YES), ASK D22. ALL OTHERS SKIP TO NEXT SECTION.

D22. During the <u>last 6 months</u>, did you ever make a decision not to use private insurance to pay for medical care or prescription medications related to HIV infection?

(Circle One)

YES	1
NO	2

D23. During the <u>last 6 months</u>, did you ever make a decision not to use private insurance to pay for treatment for drug or alcohol problems?

(Circle One)

YES …………………………...1
NO …………………………… 2

E. HEALTH-RELATED QUALITY OF LIFE

RECORD TIME THIS SECTION BEGINS:________________

These next questions are about your overall health and quality of life.

E1. (HAND R CARD 33). Overall, how would you rate your <u>current health</u> ? Use any number from 0 to 10

(Circle One Number)

|______|______|______|______|______|______|______|______|______|______|
0 1 2 3 4 5 6 7 8 9 10

Worst possible health (as bad as or worse than being dead)	Half-way between worst and best	Best possible health

E2. I'm going to read you a list of activities. Please tell me if your health limited you <u>a lot</u>, <u>a little</u> or <u>not at all</u> in doing each of these activities in the <u>past four weeks</u>. IF R SAYS HE/SHE DOES NOT DO ACTIVITY FOR REASON OTHER THAN HEALTH, CODE 3 - NOT LIMITED AT ALL.

(Circle One Number on Each Line)

	Yes, Limited a Lot	Yes, Limited a Little	No, Not Limited at All
a. Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports?	1	2	3
b. Climbing one flight of stairs?	1	2	3
c. Walking more than a mile?	1	2	3

d. Walking one block?	1	2	3
e. Bathing or dressing yourself?	1	2	3
f. Preparing meals or doing laundry?	1	2	3
g. Shopping?	1	2	3
h. Getting around inside your home?	1	2	3
i. Feeding yourself?	1	2	3
j. The kinds or amounts of moderate activities you can do, like moving a table, carrying groceries, or bowling?	1	2	3

E3. During the <u>past four weeks</u>, has your health prevented you from (READ ACTIVITY) <u>all of the time</u>, <u>some of the time</u>, or <u>none of the time</u>?

(Circle One Number on Each Line)

	Yes, For All of the time	Yes, For Some of the Time	None of the Time
a. Working at a job, doing work around the house, or going to school?	1	2	3
b. Doing certain kinds or amounts of work, housework, or schoolwork?	1	2	3
c. Taking care of paperwork for health insurance or medical bills?	1	2	3

E4. During the <u>past four weeks</u>, how many days did your health cause you to stay in bed for 1/2 a day or more?

DAYS: ___________

NOTE: RESPONSE CAN'T BE >28.

E5. During the past four weeks, how much did pain interfere with your normal work (including work outside the house and housework)? Would you say:

	(Circle One)
Not at all,	1
A little bit,	2
Moderately,	3
Quite a bit, or	4
Extremely?	5

E6. During the past four weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups? Would you say:

	(Circle One)
Not at all,	1
A little bit,	2
Moderately,	3
Quite a bit, or	4
Extremely?	5

E7. In general, would you say your health in the past four weeks was:

	(Circle One)
Excellent,	1
Very Good,	2
Good,	3
Fair, or	4
Poor?	5

E8. (HAND R CARD #35) Please indicate the extent to which the following statements are true or false for you during the past four weeks:

(Circle One Number on Each Line)

	Definitely True	Mostly True	Don't Know	Mostly False	Definitely False
a. I seem to get sick a little easier than other people	1	2	3	4	5
b. I have been feeling bad lately	1	2	3	4	5
c. I am somewhat ill	1	2	3	4	5

E9. (HAND CARD #36) How much of the time during the past four weeks (READ ITEM). Would you say all of the time, most of the time, a good bit of the time, some of the time, a little of the time, or none of the time?

(Circle One Number on Each Line)

	All of the time	Most of the Time	A Good Bit of the Time	Some of the Time	A Little of the Time	None of the Time
a. Have you felt calm and peaceful?	1	2	3	4	5	6
b. Have you felt downhearted and depressed?	1	2	3	4	5	6
c. Did you feel tired?	1	2	3	4	5	6
d. Have you been a happy person?	1	2	3	4	5	6
e. Have you been a very nervous person?	1	2	3	4	5	6
f. Did you have enough energy to do the things you wanted to do?	1	2	3	4	5	6
g. Have you felt so down in the dumps that nothing could cheer you up?	1	2	3	4	5	6
h. Have you been anxious or worried?	1	2	3	4	5	6
i. Have you felt depressed?	1	2	3	4	5	6
j. Did you have a lot of energy?	1	2	3	4	5	6

E10. During the past four weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)? These answer choices are a little different. Would you say:

	(Circle One)
All of the time,	1
Most of the time,	2
Some of the time,	3
A little of the time, or	4
None of the time?	5

E11.How much bodily pain have you had during the past four weeks? Would you say:

	(Circle One)
None,	1
Very mild,	2
Mild,	3
Moderate,	4
Severe, or	5
Very severe?	6

Section F: Medications and Adherence

RECORD TIME THIS SECTION BEGINS:________________

F1. Drugs for HIV infection are sometimes called antiretroviral drugs. I'm going to show you a list of antiretroviral drugs. Over the last 6 months, which of the following drugs have you taken?

CODE ALL THAT APPLY

Antiretroviral drugs

AZT (Retrovir, Zidovudine, ZDV)	Y	N
ddI (Videx, Didanosine)	Y	N
ddC (Hivid, Zalcitabine)	Y	N
D4T (Zerit, Stavudine)	Y	N
3TC (Lamivudine, Epivir)	Y	N
Ritonavir (Norvir)	Y	N
Indinavir (Crixivan)	Y	N
Saquinavir (Invirase, Fortovase)	Y	N
Nevirapine (Viramune)	Y	N
Delavirdine (Rescriptor)	Y	N
Nelfinavir (Viracept)	Y	N
Abacavir (Ziagen)	Y	N
Efavirenz (Sustiva)	Y	N
Amprenavir (Agenerase)	Y	N
Trizivir	Y	N
Lopinavir (Kaletra)	Y	N
Combivir	Y	N
Tenofovir	Y	N

DID NOT TAKE ANY IN LAST 6 MONTHS .... 1 □ SKIP TO F17
DON'T KNOW……………………………….-2 □ SKIP TO F17

IF MORE THAN ONE DRUG CIRCLED, ASK F2, OTHERWISE SKIP TO F5

F2. Over the last 6 months, on about how many days did your doctor tell you to take more than one anti-HIV drug?

PROMPT: 6 MONTHS = 180 DAYS

ENTER NUMBER OF DAYS: ____________________

F3. F3 DROPPED
F4. F4 DROPPED

F5. Which of the following drugs are you supposed to be taking **<u>today</u>**? (DO NOT ASK ABOUT DRUGS THAT THE PERSON HAS NOT TAKEN IN THE PAST 6 MONTHS.)

CODE ALL THAT APPLY

<u>Antiretroviral drugs</u>

AZT (Retrovir, Zidovudine, ZDV)	Y	N
ddI (Videx, Didanosine)	Y	N
ddC (Hivid, Zalcitabine)	Y	N
D4T (Zerit, Stavudine)	Y	N
3TC (Lamivudine, Epivir)	Y	N
Ritonavir (Norvir)	Y	N
Indinavir (Crixivan)	Y	N
Saquinavir (Invirase, Fortovase)	Y	N
Nevirapine (Viramune)	Y	N
Delavirdine (Rescriptor)	Y	N
Nelfinavir (Viracept)	Y	N
Abacavir (Ziagen)	Y	N
Efavirenz (Sustiva)	Y	N
Amprenavir (Agenerase)	Y	N
Trizivir	Y	N
Lopinavir (Kaletra)	Y	N
Combivir	Y	N
Tenofovir	Y	N

NOT TAKING ANY .... 1 □ SKIP TO F17
DON'T KNOW………………………………………………... -2 □ SKIP TO F17

F6. Most people with HIV have many pills to take at different times during the day. Many people find it hard to always remember their pills. We need to understand how people with HIV are really doing with their pills. We want to ask you about does you may have missed. Don’t worry about telling me that you don't take all your pills. We want to know what is really happening. (ASK THE FOLLOWING FOR EACH PILL PERSON IS CURRENTLY TAKING.)

F6a1. Let's start with _____ (FIRST DRUG). How many doses did you miss taking yesterday?

______________doses

F6a2. How many doses did you miss taking the day before yesterday (that is, two days ago)?

______________doses

F6a3. How many doses did you miss three days ago?

______________doses

F6a4. How many doses did you miss altogether in the past two weeks?

______________doses

(ASK IF PERSON TAKING 2 OR MORE DRUGS) F6b1. Now let's talk about_____ (SECOND DRUG). How many doses did you miss taking yesterday?

______________doses

F6b2. How many doses did you miss taking the day before yesterday (that is, two days ago)?

______________doses

F6b3. How many doses did you miss three days ago?

______________doses

F6b4. How many doses did you miss altogether in the past two weeks?

______________doses

(ASK IF PERSON TAKING 3 OR MORE DRUGS) F6c1. Now let's talk about_____ (THIRD DRUG). How many doses did you miss taking yesterday?

______________doses

F6c2. How many doses did you miss taking the day before yesterday (that is, two days ago)?

______________doses

F6c3. How many doses did you miss three days ago?

______________doses

F6c4. How many doses did you miss altogether in the past two weeks?

______________doses

(ASK IF PERSON TAKING 4 OR MORE DRUGS) F6d1. Now let's talk about_____ (FOURTH DRUG). How many doses did you miss taking yesterday?

______________doses

F6d2. How many doses did you miss taking the day before yesterday (that is, two days ago)?

______________doses

F6d3. How many doses did you miss three days ago?

______________doses

F6d4. How many doses did you miss altogether in the past two weeks?

______________doses

F7. During the past three days, on how many days have you missed taking **all your pills**?

None	1
One day	2
Two days	3
Three days	4
DON'T KNOW	-2

F8. Most anti-HIV medications need to be taken on a schedule, such as "two times a day" or "three times a day" or "every eight hours." How closely did you follow your specific schedule over the last three days?

Never	1
Some of the time	2
About half the time	3
Most of the time	4
All of the time	5

[Next 2 questions are part of Chesney scale but not part of Chris Mathews' shortened instrument.]

F9. Do any of your HIV medications have special instructions, such as "take with food," or "on an empty stomach," or "with plenty of fluids"?

YES…………………..	1	
NO……………………	2	SKIP TO F10
DON'T KNOW	-2	SKIP TO F10

F9A. How often did you follow those special instructions over the last three days?

Never	1
Some of the time	2
About half the time	3
Most of the time	4
All of the time	5

F10. Some people find that they forget to take their pills on the weekend days. Did you miss any of your anti-HIV medications last weekend -- last Saturday or Sunday?

YES…………………..	1
NO……………………	2
DON'T KNOW	-2

F11. When was the last time you missed any of your medications?

Within past week	1
1-2 weeks ago	2
2-4 weeks ago	3
1-3 months ago	4
More then 3 months ago	5
Never skip medications	6
DON'T KNOW	-2

F12. How well does taking HIV medications fit into your daily routine?

Not at all well	1
A little bit	2
Somewhat	3
Very well	4
Extremely well	5
DON'T KNOW	-2

F13. In the past six months, have you had any symptoms that made you stop taking any of your HIV medications?

No	1
Yes	2
Never stopped a med	3
DON'T KNOW	-2

F14 DROPPED

F15. How much difficulty do you have taking your HIV medications because of side effects?

No difficulty	1
Some difficulty	2
A lot of difficulty	3
DON'T KNOW	-2

F16. How would you rate your HIV doctor in terms of his or her concerns for your safety from bad side effects of HIV medications?

Excellent	1
Very good	2
Good	3
Fair	4
Poor	5
DON'T KNOW	-2

F17. Please tell me if your doctor, nurse or another health care provider did any of the following things the last time he or she gave you your antiretroviral medication.

Your doctor, nurse, or other health care provider explained why it was important that you take every dose of your antiretroviral medication.

YES 1
NO..2

F17A. (Your doctor, nurse or other health care provider) Gave you special ways to remember to take your antiretroviral medication.

YES 1
NO..2

F17B. (Your doctor, nurse or other health care provider) Clearly explained how and when to take your antiretroviral medication.

YES 1
NO..2

F18. In the past 6 months, have you taken any drugs to prevent an episode of PCP (Pneumocystis or AIDS pneumonia) ?

READ LIST IF NEEDED:

Septra or Bactrim (TMP/SMX, Trimethoprim/Sulfamethoxazole) by mouth

Inhaled or aerosolized Pentamidine (AeroPent, NebuPent, PneumoPent)

Dapson, Trimethoprim, Atovaquone (Mepron)

YES..1
NO..2
DON'T KNOW…………………………………………….-2

F19. In the past six months, have you taken any drugs to prevent an episode of MAC (Mycobacterium avium complex) infection?

READ IF NECESSARY:

Clarithromycin (Biaxin, Klacid)
Azithromycin (Zithromax)
Rifabutin (Mycobutin)
Rifampin

YES..1
NO..2
DON'T KNOW……………………………… -2

F20. In the past six months, have you taken any drugs to prevent other opportunistic infections besides PCP and MAC?

YES..1
NO 2 (go to next question)
DON'T KNOW……………………………………-2 (go to next question)

F20a. What are the names of the medicines that you took to prevent opportunistic infections in the past six months?

RECORD
NAMES____

F21. In the past six months, have you taken any drugs to treat hepatitis or other problems with your liver?

YES..1
NO 2 (go to next question)
DON'T KNOW……………………………………-2 (go to next question)

F21a. What are the names of the medicines that you took to treat hepatitis or liver problems in the past six months?

RECORD
NAMES____

F22. In the past six months, have you taken any drugs to treat high blood pressure or hypertension?

YES 1
NO 2 (go to next question)
DON'T KNOW……………………………-2 (go to next question)

F22a. What are the names of the medicines that you took to treat high blood pressure in the past six months?

RECORD
NAMES____

F23. In the past six months, have you taken any drugs to treat diabetes or problems with high blood sugar?

YES 1
NO 2 (go to next question)
DON'T KNOW…………………………….-2 (go to next question)

F23a. What are the names of the medicines that you took to treat diabetes or high blood sugar in the past six months?

RECORD
NAMES____

F24. In the past six months, have you taken any drugs to treat high cholesterol?

YES 1
NO 2 (go to next question)
DON'T KNOW……………………………-2 (go to next question)

F24a. What are the names of the medicines that you took to treat high cholesterol in the past six months?

RECORD
NAMES____

F25. In the past six months, have you taken any drugs to treat arthritis?

YES 1
NO 2 (go to next question)
DON'T KNOW…………………………….-2 (go to next question)

F25a. What are the names of the medicines that you took to treat arthritis in the past six months?

RECORD
NAMES____

F26. In the past six months, have you taken any drugs to treat chronic pain?

YES 1
NO 2 (go to next question)
DON'T KNOW……………………………….-2 (go to next question)

F26a. What are the names of the medicines that you took to treat chronic pain in the past six months?

RECORD
NAMES____

F27. In the past six months, have you taken any drugs to treat asthma?

YES 1
NO 2 (go to next question)
DON'T KNOW……………………………….-2 (go to next question)

F27a. What are the names of the medicines that you took to treat asthma in the past six months?

RECORD
NAMES____

F28. In the past six months, have you taken any drugs to treat stomach ulcers or reflux (gastroesophageal reflux)?

YES 1
NO 2 (go to next question)
DON'T KNOW……………………………… -2 (go to next question)

F28a. What are the names of the medicines that you took to treat reflux or ulcers in the past six months?

RECORD
NAMES____

F29. In the past six months, have you taken any drugs to treat cancer?

YES 1
NO 2 (go to next question)
DON'T KNOW……………………………….-2 (go to next question)

F29a. What are the names of the medicines that you took to treat cancer in the past six months?

RECORD
NAMES____

F30. In the past six months, have you taken any drugs to treat skin problems?

YES 1
NO 2 (go to next question)
DON'T KNOW……………………………….-2 (go to next question)

F30a. What are the names of the medicines that you took to treat skin problems in the past six months?

RECORD
NAMES____

F31. <u>Over the last 6 months</u>, have you regularly taken any drugs for depression, anxiety, or emotional problems?

(Circle One)

YES 1
NO .... 2 □□□SKIP TO NEXT
SECTION

F32. Is it one of the drugs on this card? (SHOW CARD #24)

<u>Drugs to treat depression, anxiety, or emotional problems</u>

Fluoxetine (Prozac)
Paroxetine (Paxil)
Sertraline (Zoloft)
Fluvoxamine (Luvox)
Venlafaxine (Effexor)
Nefazodone (Serzone)
Clomipramine (Anafranil)

Buspirone (Buspar)
Prazepam (Centrax)
Paxipam (Halazepam)
Clozapine (Clozaril)
Risperidone (Risperdal)
Naltrexone (Revia)

(Circle One)

YES	1	
NO	2	□□□SKIP TO NEXT SECTION

F32a. <u>Over the last 6 months</u>, on about how many days did you take <u>any</u> of these drugs?

PROMPT: 6 MONTHS = 180 DAYS

ENTER NUMBER OF DAYS: ....

F33. Other than the medicines that you've already mentioned, what other drugs have you taken in the past six months? (RECORD VERBATIM)

____

____

G: Drug Use- Dependence

RECORD TIME THIS SECTION BEGINS:________________

G1. The next questions are about your use of drugs on your own. By "on your own" we mean either without a doctor's prescription, in larger amounts than prescribed, or for a longer period than prescribed. (HAND R CARD #40) With this definition in mind, did you ever use any of the following drugs on your own?

(INTERVIEWER: If necessary, clarify: "By 'on your own' we mean either without a doctor's prescription, in larger amounts than prescribed, or for a longer period than prescribed.")

(Have you ever used...)	NO (5)	YES (1)	NO (5)	YES (1)
G1a. ...sedatives, sleeping pills, or tranquilizers on your own? (e.g. Librium, Valium, Ativan, Meprobamate, Xanax, Seconal, Halcion, Methaqualone)	GO TO G1b	Did you use in the past 6 months? ☐		
G1b. ...amphetamines (am-FET-ah-means) or other stimulants on your own? (e.g. Methamphetamine, Crystal Methamphetamine, Preludin, Dexedrine, Ritalin, "Speed," Ketamine [Special K], Cat, Ecstasy)	GO TO G1c	Did you use in the past 6 months? ☐		
G1c. ...analgesics (an-uhl-JEEZ-icks) or other prescription painkillers on your own? (NOTE: this does not include normal use of aspirin, Tylenol without Codeine, etc., but does include use of Tylenol with Codeine and other Rx painkillers like Demerol, Darvon, Darvocet, Percodan, Percoset, Codeine, Morphine, Methadone, and Fentanyl)	GO TO G1d	Did you use in the past 6 months? ☐		
G1d. ...marijuana (mare-ih-WAH-nah) or hashish (HASH-eesh)?	GO TO G1e	Did you use in the past 6 months? ☐		

L1e. ...cocaine (snort) or crack (rock, gravel) or free base?	GO TO G1f	Did you use in the past 6 months? □		
(Have you ever used...)	NO (5)	YES (1)	NO (5)	YES (1)
G1f. ...inhalants (other than cocaine) that you sniff or breathe to get high or to feel good? (e.g. Amyl nitrate [Poppers, Ammo], Freon, Nitrous Oxide ["Whippets"], Gasoline, Spray Paint)	GO TO G1g	Did you use in the past 6 months? □		
G1g. ...LSD or other hallucinogens (ha-LOOSE-en-oh-jens)? (e.g. PCP, angel dust, peyote, ecstasy [MDMA], mescaline)	GO TO G1h	Did you use in the past 6 months? □		
G1h. ...heroin (horse, smack, tar)?	GO TO G2	Did you use in the past 12 months? □		

G2. INTERVIEWER CHECKPOINT

☐ 1. AT LEAST ONE "YES" RESPONSE IN G1a - G1h □□ ASK G3

☐ 2. ZERO "YES" RESPONSES IN G1a - G1h □□ GO TO NEXT SECTION

(INTERVIEWER: THE NEXT QUESTIONS ARE AWKWARDLY WORDED. READ SLOWLY.)

G3. In your lifetime, did you ever find that you had to use much larger amounts of (NAME OF DRUG/any of these substances) than usual to get the same effect or that the same amount had less effect on you than before?

1. YES	5. NO
☐	☐ GO TO G4

G3a. Have you had to use more to get the same effect in the past 6 months?

1. YES	5. NO

G4. In your lifetime, did you ever have any emotional or psychological problems from using -- such as feeling uninterested in things, feeling depressed, suspicious of people, paranoid,
or having strange ideas?

1. YES	5. NO
☐	☐ GO TO NEXT SECTION

G4a. Have you had any emotional or psychological problems from using drugs in the past 6 months?

1. YES	5. NO

G5. Have you ever used any of these substances by injection?

(Circle One)

YES 1

NO............................. 2 SKIP TO G6

G5a. In the past 6 months, have you injected any of these substances?

(Circle One)

YES 1

NO............................. 2

G6 In the past six months, did you talk about your drug use with the doctor who's treating your HIV infection?

(Circle One)

YES 1

NO............................. 2

H. Alcohol Use

RECORD TIME THIS SECTION BEGINS:________________

These next questions ask about the past 4 weeks, rather than the past 6months.

H1. During the past 4 weeks, on how many days did you have a drink containing alcohol?
IF NONE, ENTER 0 AND GO TO NEXT SECTION.

DAYS: _______________

H2. During the past 4 weeks, how many drinks did you have on a typical day when you were drinking? By a drink we mean a can of beer, a glass of wine, or a shot of hard liquor.

DRINKS: _____________

H3. On how many days in the past 4 weeks did you have 5 or more drinks? By a drink we mean a can of beer, a glass of wine, or a shot of hard liquor.

DAYS: ________________

H4. In the past six months, did you talk about your alcohol use with the doctor who's treating your HIV infection?

(Circle One)

YES	1
NO............................	2

I. Social Services

RECORD TIME THIS SECTION BEGINS:________________

I1. Do you now have a case manager or case worker? This is a professional in a medical or social service agency who helps you to arrange for services or programs you need.

(Circle One)

YES	1
NO	2 (SKIP TO I9)

I2. In the last six months, how many different people have been your case manager or case worker?

NUMBER________________

I3. (IF MORE THAN 1 IN I2: Think of the case manager that you have the most contact with.) Over the last six months, how many times did you see this case manager in person?

NUMBER ______________

I4. How many times did you talk to this case manager on the phone in the last six months?

MORE THAN ONCE A WEEK……………………	1
ABOUT ONCE A WEEK	2
EVERY OTHER WEEK	3
ABOUT ONCE A MONTH	4
LESS THAN ONCE A MONTH	5
NO PHONE CONTACT AT ALL	6

I5. How did this case manager help you in the past six months? **(Code all that apply)**

a. Helped you get or referred you to medical services	Y	N
b. Helped you get or referred you to social services	Y	N
c. Helped you fill out forms for benefits or entitlements (like SSI)	Y	N
d. Gave you advice about taking your HIV medications	Y	N
e. Gave you advice about your personal life or your problems	Y	N

CHECK: IF NUMBER OF CASE MANAGERS EQUALS ONE IN I2, SKIP TO I9.

I6. Think of the case manager that you have the next most contact with. Over the last six months, how many times did you see this case manager in person?

NUMBER ______________

I7. How many times did you talk to this case manager on the phone in the last six months?

MORE THAN ONCE A WEEK……………………	1
ABOUT ONCE A WEEK	2
EVERY OTHER WEEK	3
ABOUT ONCE A MONTH	4
LESS THAN ONCE A MONTH	5
NO PHONE CONTACT AT ALL	6

I8. How did this case manager help you in the past six months? **(Code all that apply)**

a. Helped you get or referred you to medical services	Y	N
b. Helped you get or referred you to social services	Y	N
c. Helped you fill out forms for benefits or entitlements (like SSI)	Y	N

d. Gave you advice about taking your HIV medications	Y	N
e. Gave you advice about your personal life or your problems	Y	N

I9. I'm going to read a list of problems that people with HIV often have. For each one, please tell me if you had a problem or needed assistance with it in the last six months.

A. Did you receive any housing assistance in the last six months? **(Circle One)**

YES	1
NO	2
REFUSED	-1
DON'T KNOW	-2

1. Did you have a problem with housing or need help in finding a place to live in this time period?

(Circle One)

YES	1	
NO	2	□□ SKIP TO I9B
REFUSED	-1	□□ SKIP TO I9B
DON'T KNOW	-2	□□ SKIP TO I9B

2. Did any professional (like a case manager, nurse, doctor) try to help you deal with your housing problem?

(Circle One)

YES	1
NO	2
REFUSED	-1
DON'T KNOW	-2

B. Did you receive any financial assistance (like SSI) in the last six months? **(Circle One)**

YES	1
NO	2
REFUSED	-1
DON'T KNOW	-2

1 Did you have a problem with your finances or need help in getting income assistance in this time period?

(Circle One)

YES	1	
NO	2	□□ SKIP TO I9C
REFUSED	-1	□□ SKIP TO I9C
DON'T KNOW	-2	□□ SKIP TO I9C

2. Did any professional try to help you deal with your financial problem?

(Circle One)

YES	1
NO	2
REFUSED	-1
DON'T KNOW	-2

C. Did you receive any transportation assistance in the last six months?

(Circle One)

YES	1
NO	2
REFUSED	-1
DON'T KNOW	-2

1. Did you have a problem with or need help with transportation in this time period?

(Circle One)

YES	1	
NO	2	□□ SKIP TO I9D
REFUSED	-1	□□ SKIP TO I9D
DON'T KNOW	-2	□□ SKIP TO I9D

2. Did any professional try to help you deal with your transportation problem?

(Circle One)

YES	1
NO	2
REFUSED	-1
DON'T KNOW	-2

D. Did you receive any assistance in trying to get a job in the last six months?

(Circle One)

YES	1
NO	2
REFUSED	-1
DON'T KNOW	-2

1. Did you have a problem with employment or need to find a job in this time period?

(Circle One)

YES	1	
NO	2	□□ SKIP TO I9E
REFUSED	-1	□□ SKIP TO I9E
DON'T KNOW	-2	□□ SKIP TO I9E

2. Did any professional try to help you deal with your employment problem?

(Circle One)

YES	1
NO	2
REFUSED	-1
DON'T KNOW	-2

E. Did you receive any legal assistance in the last six months?

(Circle One)

YES	1
NO	2
REFUSED	-1
DON'T KNOW	-2

1. Did you have a legal problem or need help getting legal advice in this time period?

(Circle One)

YES	1	
NO	2	□□ SKIP TO I9F
REFUSED	-1	□□ SKIP TO I9F
DON'T KNOW	-2	□□ SKIP TO I9F

2. Did any professional try to help you find someone to help you with your legal problem?

(Circle One)

YES	1
NO	2
REFUSED	-1
DON'T KNOW	-2

F. Did you need treatment for drug or alcohol problems in the last six months?

(Circle One)

YES	1	
NO	2	□□ SKIP TO I9G
REFUSED	-1	□□ SKIP TO I9G
DON'T KNOW	-2	□□ SKIP TO I9G

1. Did any professional try to help you get treatment for drug or alcohol problems?

(Circle One)

YES	1
NO	2
REFUSED	-1
DON'T KNOW	-2

G. Did you need treatment for emotional or psychological problems in the last six months?

(Circle One)

YES	1	
NO	2	□□ SKIP TO I9H
REFUSED	-1	□□ SKIP TO I9H
DON'T KNOW	-2	□□ SKIP TO I9H

2. Did any professional try to help you get treatment for emotional or psychological problems?

(Circle One)

YES	1
NO	2
REFUSED	-1
DON'T KNOW	-2

H. Did you need home care or personal assistance in the last six months?

(Circle One)

YES 1
NO .... 2 □□ SKIP TO NEXT
SECTION
REFUSED -1 □□ SKIP TO NEXT
SECTION DON'T KNOW 2
□□ SKIP TO NEXT SECTION

3. Did any professional try to help you get home care or personal assistance?

(Circle One)

YES 1
NO 2
REFUSED -1
DON'T KNOW -2

J. PATIENT DESCRIPTION

RECORD TIME THIS SECTION BEGINS:________________

J1. What is your date of birth?

________ /__________ /__________
MO DAY YR

J2a. Which of these would you say is your main racial or ethnic group?
READ GROUPS AND CODE ONE.

(Circle One)

White or Caucasian, but not Hispanic or Latino 1 → SKIP TO J3

Black or African-American, but not Hispanic or Latino 2 → SKIP TO J3

Hispanic or Latino 3 → SKIP TO J3

American Indian or Alaskan Native 4 → SKIP TO J3

Asian or Pacific Islander 5 → SKIP TO J3

MIXED RACE 6

OTHER SINGLE RACE 7 → SKIP TO J3
WHAT? ____

J2b. What groups are your main racial or ethnic groups?

(Circle All That Apply)

WHITE OR CAUCASIAN	1
BLACK OR AFRICAN-AMERICAN	2
HISPANIC OR LATINO	3
AMERICAN INDIAN OR ALASKAN NATIVE	4
ASIAN OR PACIFIC ISLANDER	5
SOMETHING ELSE	6

WHAT? ____

J3. How many years of regular school or college did you ever complete and get credit for? DO NOT COUNT VOCATIONAL EDUCATION AFTER HIGH SCHOOL.

YEARS OF SCHOOL _______

J4. What is the <u>highest</u> degree or diploma you have?

(Circle One)

NONE/LESS THAN HIGH SCHOOL 1
HIGH SCHOOL DIPLOMA OR G.E.D. 2
A.A. OR ASSOCIATE DEGREE, JUNIOR OR 2-YEAR COLLEGE 3
B.A., B.S., BACHELOR’S, 4-YEAR COLLEGE DEGREE 4
GRADUATE OR PROFESSIONAL DEGREE 5

J5. At this time, are you:
CODE HIGHEST CATEGORY THAT APPLIES.

(Circle One)

Working full time or part time, ... 1 ☐ SKIP TO J6
With a job and on sick leave, ... 2 ☐ SKIP TO J6
With a job and not working for other reasons................. 3 ☐ SKIP TO J6
Laid off,... 4 ☐ SKIP TO J6
Unemployed and looking for work, ... 5 ☐ SKIP TO J9
Not working or not looking for work............................. 9 ☐ SKIP TO J9
Disabled and not working .... 6 ☐ SKIP TO J9
Or retired and not working?... 7 ☐ SKIP TOJ11
NONE OF THE ABOVE 8☐ SKIP TO J9

J6. During the last month, how many hours did you usually work for pay per week?

ENTER NUMBER OF HOURS __

OR

REFUSED .... -1 ☐ SKIP TO J6b

DON'T KNOW .... -2 ☐ SKIP TO J6b

J6a. CHECK:

(Circle One)

Q6 = 34 HOURS OR LESS .... 1 ☐ SKIP TO J7
Q6= 35 HOURS OR MORE .... 2 ☐ SKIP TO J8

J6b. Was it:

(Circle One)

35 HOURS OR MORE	1	SKIP TO J8
20-34 HOURS	2	
OR LESS THAN 20 HOURS PER WEEK?	3	

J7. Have health problems related to HIV kept you from working full time in the last 6 months?

(Circle One)

YES	1
NO	2

J8. How many hours or days of work did you miss because of HIV-related illness or treatment in the last month?

(Circle One)

a. ENTER NUMBER: ________

b.CODE UNIT:		
	HOURS	1
	DAYS	2

J9. Have you ever been employed?

(Circle One)

YES	1	
NO	2	SKIP TO J11
REFUSED	-1	SKIP TO J11
DON'T KNOW	-2	SKIP TO J11

J10. On your last job were you working:

(Circle One)

Full-time, or	1
Part-time?	2

J11. At this time, are you living alone or are there others in your household?

(Circle One)

LIVING ALONE	1
OTHER(S) IN HOUSEHOLD	2
NO USUAL PLACE TO LIVE, HOMELESS, MOVING AROUND	3

J12. (SKIP IF 20A = 1) What is your current legal marital status? Are you now:
IF SINGLE, PROBE: Is that divorced, widowed, or never married?

(Circle One)

Married,	1
Separated,	2
Divorced,	3
Widowed, or	4
Never Married?	5

J13. We need to ask about program participation. Are you currently receiving Social Security Disability payments?

(Circle One)

YES	1
NO	2

J14. Do you currently receive assistance through the Aid to Families with Dependent Children program, sometimes called AFDC or ADC?

(Circle One)

YES	1
NO	2

J15. Are you currently receiving Supplemental Security Income or SSI?

(Circle One)

YES	1
NO	2

RECORD TIME THIS SECTION ENDS:________________

Appendix C – Study Codebook

Construct: Health Status/Need for Services	
Stage of Illness	
Operational Definition	**Lowest CD_4**
Note	CD_4 count is a measure of a patient's immune system strength, how far advanced HIV has progressed, and one predictor of risk for complications and debilitating infections. A CD_4 below 200 cells/mm^3 is indicative of AIDS. Lowest CD_4 count is an indicator of the greatest extent to which HIV has ravaged the immune system.
HIVRN Item Number	B2-B5
HIVRN Question(s)	B2) Of all the CD4 tests you have had, what was your lowest count? (if DK, 3 probes). B3) Was your lowest CD4 count less than 500? B4) Was it less than 200? B5) Was it less than 50?
Categories	Yes/No
Created Variable/Recode	B2) Less than 50 cells/mm^3, 50-200 cells/mm^3, 201-500 cells/mm^3, over 500 cells/mm^3, missing data Recode with B3, B4, B5 to eliminate as many missing as possible
Note to Committee	None
Operational Definition	**Change in Health Status**
Note	JHU has used F1 items to come up with appropriate combinations of drug categories that represent highly active antiretroviral therapy (HAART). HAART is a Yes/No variable. HAART should be prescribed for patients whose CD_4 count is below 200 cells/mm^3, but may be initiated at higher CD_4 counts for some patients who have other co-morbidities.
HIVRN Item Number	F1, F5
HIVRN Question(s)	F1) Over the last 6 months, which of the following drugs have you taken? F5) Which of the following drugs are you supposed to be taking today?
Categories	Multiple drugs
Created Variable/Recode	Stable HIV Condition (No Change in HAART regimen or not on HAART regimen for both times because not clinically indicated), Unstable HIV Condition (Change in HAART regimen), missing data

Note to Committee	JHU created new HAART variable that uses F5 items (current antiretroviral medications). HAART use from past 6 months (F1 items in specific combinations) compared with current HAART use. A HAART change is a proxy for less stable health status. The onus of "clinically indicated" is assigned to HIVRN clinicians who have the experience to make educated HAART decisions for their patients.
Health-Related Quality of Life	
Operational Definition	**Patient perception of current health**
Note	May contribute to health care seeking behavior. HIVRN patients self-report high level of good health.
HIVRN Item Number	E1
HIVRN Question(s)	Overall, how would you rate your current health?
Categories	1=worst health to 10=best health
Created Variable/Recode	None
Note to Committee	Creating cutoffs for better/worse health i.e. recoding above/below the mean may help with recode but would be arbitrary. Variable will be kept continuous.
Illicit Drug Use	
Operational Definition	**Ever Inject**
Note	Injection-related co-morbidities may be higher for IDUS.
HIVRN Item Number	G5
HIVRN Question(s)	Have you ever used any of these substances by injection
Categories	Sedatives, amphetamines analgesics, marijuana, cocaine, inhalants, LSD, heroin
Created Variable/Recode	Created the following 3 drug use categories: no drug use history; drug history but not by injection; and drug history with injection use.
Note to Committee	None
Primary Covariate	
Operational Definition	**Patient Sex**
Note	No transgender category. Demographic factors can play a role in disease progression and in how others, including providers and others respond. For example, women respond differently to HAART than men, and historically have not been perceived to be at risk for HIV/AIDS.
HIVRN Item Number	AO

HIVRN Question(s)	Interviewer notes patient sex. This is not a self-reported variable.
Categories	Male, Female
Created Variable/Recode	None
Note to Committee	None
Other Demographics	
Operational Definition	**Race/Ethnicity**
Note	Providers may respond differently to people from different racial/ethnic groups; Other category will be deleted from bivariate and multivariate analyses given small number.
HIVRN Item Number	J2a
HIVRN Question(s)	J2a) Which of these would you say is your main racial or ethnic group?
Categories	White, Black, Hispanic, AI/AA, Asian Pacific Islander, Mixed Race, Other Single Race
Created Variable/Recode	White, Black, Hispanic, missing data
Note to Committee	Not sufficient numbers to analyze AI/AN, API, Mixed Race/Other Single Race
Operational Definition	**Age**
Note	Providers may respond differently to people from different racial/ethnic groups; Other category will be deleted from bivariate and multivariate analyses given small number.
HIVRN Item Number	J1
HIVRN Question	What is your date of birth?
Categories	Mo/Day/Year
Created Variable/Recode	Interview year date minus reported date of birth year
Note to Committee	None
Enabling Resources: Access to Health Resources	
Operational Definition	**Health Insurance**
Note	Disabled persons may be more likely to be on Medicaid.
HIVRN Item Number	D2, D5, D9, D10, D14

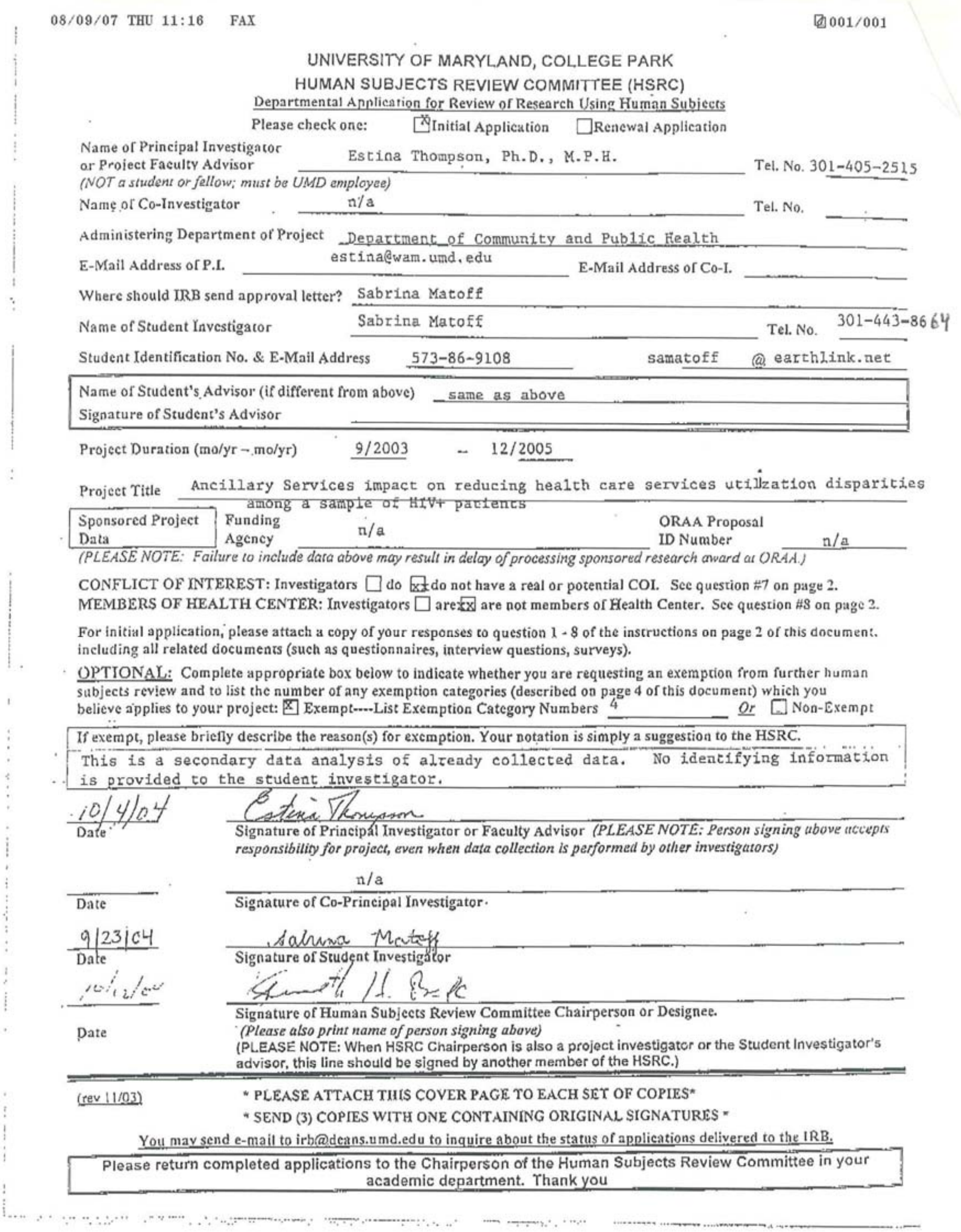
HIVRN Question(s)	D2) Are you presently covered by Medicaid? D5) Are you presently covered by Medicare? D9) Are you presently covered by any of these other public health programs (WIC, VA, Champus, county, other)? D10) Are you now covered by any private health insurance? D14) Have you not been covered by any private or public health insurance in the last 6 months?
Categories	Yes/No
Created Variable/Recode	Patients with one or more of these types of public insurance were combined with patients who had Medicaid.
Note to Committee	None
Operational Definition	**Education**
Note	More educated patients may be better able to navigate health care system.
HIVRN Item Number	J4
HIVRN Question(s)	What is the highest degree or diploma you have?
Categories	None/Less than HS, HS/GED, 2 year college, 4 year college, Grad
Created Variable/Recode	None/less than HS, HS/GED, College, missing
Note to Committee	None
Operational Definition	**Employment**
Note	Employed persons may be more likely to have health insurance, but this is not true for all persons. They may also be in better health. Not all employed persons have health insurance, particularly those working part time and those in service industry jobs.
HIVRN Item Number	J5
HIVRN Question(s)	J5) At this time are you: working full time or part time, with a job and on sick leave, with a job and not working for other reasons, laid off, unemployed and looking for work, not working or not looking for work, disabled and not working, or retired and not working
Categories	Working full time or part time, with a job and on sick leave, with a job and not working for other reasons, laid off, unemployed and looking for work, not working or not looking for work, disabled and not working, or retired and not working
Created Variable/Recode	Full-time or part-time, not working, missing
Note to Cte.	None

Informal Social Support	
Operational Definition	**Living Arrangement**
Note	Persons in household may provide some support, but whether this is positive or negative social support is unknown.
HIVRN Item Number	J11
HIVRN Question(s)	At this time, are you living alone or are there others in your household?
Categories	Living alone, others in household, no usual place to live/homeless/moving around
Created Variable/Recode	Alone, Others in House, Homeless, missing
Note to Committee	None
Formal Social Support: Scope	
Operational Definition	**Case Manager**
Note	45% of patients had 1 case manager in the last 6 months, 9.5% had 2 case managers. Patients with more than 3 case managers will be excluded.
HIVRN Item Number	I2
HIVRN Question(s)	In the last 6 months, how many case managers did you have? This is a professional in a medical or social service agency who helps you to arrange for services or programs you need.
Categories	Number of case managers
Created Variable/Recode	0, 1 (1 = 1 or 2 case managers)
Note to Committee	None
Formal Social Support: Intensity	
Operational Definition	**Frequency of In-Person Visits across 2 case managers**
Note	In HCSUS studies, patients who had at least 1 case management contact by phone or in person in the last 6 months had less unmet need for support services.
HIVRN Item Number	I3
HIVRN Question(s)	How many times did you see this case manager in person in the last 6 months?
Categories	Number of times
Note to Committee	None

Formal Social Support: Type of Support	
Operational Definition	**Informational**
Note	Two items: Advice about HIV meds, Personal advice
HIVRN Item Number	I5d, I5e
HIVRN Question(s)	I5d) How did 1st case manager help in the past 6 months? I5e) Advice about HIV meds, personal advice
Categories	Yes/No
Created Variable/Recode	None
Note to Committee	None
Operational Definition	**Instrumental**
Note	Three items: Referral to Medical Services, Referral to Social Services, Help with Forms/Benefits Look at individual types of support
HIVRN Item Number	I5a, I5b, I5c
HIVRN Question(s)	How did first case manager help in the past 6 months? Composite score of each type of formal social support
Categories	Yes/No 0-2 Informational, 0-3 Instrumental
Created Variable/Recode	None
Note to Committee	None
Operational Definition	**Informational**
Note	Two items: Advice about HIV meds, Personal advice
HIVRN Item Number	I8d, I8e
HIVRN Question(s)	18d) How did 2nd case manager help in the past 6 months? 18e) Advice about HIV meds. Personal advice
Categories	Yes/No
Created Variable/Recode	None
Note to Cte	None
Operational Definition	**Instrumental**

Note	Three items: Referral to Medical Services, Referral to Social Services, Help with Forms/Benefits Look at individual types of support Look at individual types of support across up to 2 case managers
HIVRN Item Number	I8a, I8b, I8c
HIVRN Question(s)	18a, I8b, I8c) How did second case manager help in the past 6 months? Composite score each type of formal social support
Categories	Yes/No 0-2 Informational, 0-3 Instrumental 0-4 Informational, 0-6 Instrumental
Created Variable/Recode	None
Note to Committee	None
HIV/AIDS-related Outpatient Care: Clinical Care	
Operational Definition	**Number of outpatient Visits**
Note	Outpatient care is categorized into rare, average and high use for purposes of this study. These categories have been informed by 3 HIV/AIDS experts.
HIVRN Item Number	CD1
HIVRN Question(s)	In the past 6 months, how many times did you go to a clinic, private Dr's office, or HMO for medical care?
Categories	0-1 visits (rare), 2-5 visits (average), 6+ visits (high)
Created Variable/Recode	0-1 visits (rare), 2-5 visits (average), 6+ visits (high)
Note to Committee	2 visits per 6 month period is standard of routine care. Due to low frequency of patients with 0-1 visits, this group was deleted in multivariate analyses

Appendix D – University of Maryland, College Park Human Subject Review IRB Approval



08/09/07 THU 11:16 FAX ☑001/001

UNIVERSITY OF MARYLAND, COLLEGE PARK
HUMAN SUBJECTS REVIEW COMMITTEE (HSRC)
Departmental Application for Review of Research Using Human Subjects

Please check one: ☒ Initial Application ☐ Renewal Application

Name of Principal Investigator or Project Faculty Advisor (*NOT a student or fellow; must be UMD employee*) Estina Thompson, Ph.D., M.P.H. Tel. No. 301-405-2515

Name of Co-Investigator n/a Tel. No.

Administering Department of Project Department of Community and Public Health

E-Mail Address of P.I. estina@wam.umd.edu E-Mail Address of Co-I.

Where should IRB send approval letter? Sabrina Matoff

Name of Student Investigator Sabrina Matoff Tel. No. 301-443-8664

Student Identification No. & E-Mail Address 573-86-9108 samatoff @ earthlink.net

Name of Student's Advisor (if different from above) same as above
Signature of Student's Advisor

Project Duration (mo/yr – mo/yr) 9/2003 – 12/2005

Project Title Ancillary Services impact on reducing health care services utilization disparities among a sample of HIV+ patients

Sponsored Project Data Funding Agency n/a ORAA Proposal ID Number n/a

(PLEASE NOTE: Failure to include data above may result in delay of processing sponsored research award at ORAA.)

CONFLICT OF INTEREST: Investigators ☐ do ☒ do not have a real or potential COI. See question #7 on page 2.
MEMBERS OF HEALTH CENTER: Investigators ☐ are ☒ are not members of Health Center. See question #8 on page 2.

For initial application, please attach a copy of your responses to question 1 - 8 of the instructions on page 2 of this document, including all related documents (such as questionnaires, interview questions, surveys).

OPTIONAL: Complete appropriate box below to indicate whether you are requesting an exemption from further human subjects review and to list the number of any exemption categories (described on page 4 of this document) which you believe applies to your project: ☒ Exempt----List Exemption Category Numbers 4 *Or* ☐ Non-Exempt

If exempt, please briefly describe the reason(s) for exemption. Your notation is simply a suggestion to the HSRC.
This is a secondary data analysis of already collected data. No identifying information is provided to the student investigator.

10/4/04 Estina Thompson
Date Signature of Principal Investigator or Faculty Advisor *(PLEASE NOTE: Person signing above accepts responsibility for project, even when data collection is performed by other investigators)*

n/a
Date Signature of Co-Principal Investigator

9/23/04 Sabrina Matoff
Date Signature of Student Investigator

10/12/04
Signature of Human Subjects Review Committee Chairperson or Designee.
Date *(Please also print name of person signing above)*
(PLEASE NOTE: When HSRC Chairperson is also a project investigator or the Student Investigator's advisor, this line should be signed by another member of the HSRC.)

(rev 11/03)

* PLEASE ATTACH THIS COVER PAGE TO EACH SET OF COPIES*
* SEND (3) COPIES WITH ONE CONTAINING ORIGINAL SIGNATURES *

You may send e-mail to irb@deans.umd.edu to inquire about the status of applications delivered to the IRB.

Please return completed applications to the Chairperson of the Human Subjects Review Committee in your academic department. Thank you

Sabrina Matoff
September 2004

HUMAN SUBJECT REVIEW COMMITTEE (IRB APPLICATION) for University of Maryland, College Park

Abstract

Highly active anti-retroviral therapy (HAART) revolutionized HIV care in 1996, transforming HIV from a terminal illness into a chronic disease best managed by coordinated care, including medication management, substance abuse and mental health treatment, and other ancillary services. Patients with case managers may have less unmet needs, and less frequent use of costly emergency room and inpatient hospitalization. The relationships among HIV/AIDS case management, ancillary services, and health care utilization, and previously documented sex and race/ethnic disparities impacting HIV-related care, need further scrutiny.

Data for this work will come from the HIV Research Network (HIVRN), patient interview survey. The Federally-funded HIVRN is a convenience sample of 19 U.S. clinical care sites serving about 14,500 people living with HIV/AIDS. The goal of the HIVRN is to provide timely information on health services utilization by persons in HIV care. In 2003, interviews were conducted with a stratified sample of approximately 950 clients at 14 HIVRN sites to ascertain patient level information about HIV care received at all provider sites. Interviews were conducted in both English and Spanish by trained interviewers, with prior informed consent from each patient. All sites had IRB approval. Data are not available for public use.

Subject Selection

In 1998, Johns Hopkins University (JHU), Baltimore, Maryland, was selected as the data coordinating center (DCC) for the HIVRN. The first phase of the HIVRN focused on health care utilization collecting clinical, demographic, and utilization data from 18 high-volume providers of HIV treatment. Standardized clinical data elements are abstracted from medical charts and sent to JHU to be cleaned and put into a uniform database.

In 2003, JHU subcontracted with Battelle, a survey research company to conduct patient interviews with a stratified sample of HIVRN patients. All patients in the larger HIVRN clinical dataset were eligible to participate. Each site, including JHU, received local IRB approval (see Appendix A). The patient interview survey was pilot tested on a sample of ten patients at the Johns Hopkins HIV/AIDS Clinic, Baltimore, Maryland. Patients were recruited from the clinic waiting room and received $30 for their participation.

Patients who were under 18 years of age, and those who were drunk or intoxicated at the time of interview were ineligible. Oversampling for women and Hispanics was done to ensure representation of these underserved groups. The student investigator will be using a sub-sample of the HIVRN patient-level data.

Procedures

This dissertation will be an analysis of data previously collected by JHU and its subcontractor, Battelle. The data were collected following IRB approval at each HIVRN site and informed consent was given in writing by each patient before interviews took place. JHU followed an approved protocol for collecting patient level data. Interviews were conducted one-on-one with patients and answers were recorded on interview forms. Patients could refuse to answer any question or stop the interview at any time. Excerpts of the protocol are available upon request.

The present study will use a subsample of the HIVRN patient-level data to analyze disparities in the receipt of HIV-related health care services. A signed confidentiality statement between the student investigator and JHU is on file and a copy is attached to this IRB application package under Appendix B.

A copy of the HIVRN patient interview survey is attached to this IRB application in Appendix C. Not all items will be included in this secondary data analysis. All patient identifiers, including site ID, and names of health care clinics or hospitals have been removed from the dataset provided to the student investigator.

Risks and Benefits

Patient risks are minimized by the strict study protocol followed by JHU. In the original data collection effort, patients were assigned unique numeric identifiers; patient names are not recorded anywhere on interview forms. The student investigator is not provided with patient identifier or site identifier information to further protect patient confidentiality.

There is no direct benefit to patients who participated in the HIVRN patient interviews. Information obtained from the HIVRN patient interviews will help investigators better understand why and how HIV patients seek their care at multiple provider sites. At any one site, medical records may be incomplete. More complete data regarding patients' use of pharmaceuticals and ancillary services such as case management, substance abuse, and mental health treatment can help program planners justify the need for a comprehensive set of primary care services for HIV positive individuals. The Health Resources and Services Administration's (HRSA), HIV/AIDS Bureau and its partners also plan to use the information to optimize service delivery patterns for persons living with HIV/AIDS.

Confidentiality

The student investigator is not provided with patient identifier or site identifier information to further protect patient confidentiality. If potentially identifying information is discovered, the student will notify the original investigators immediately, remove those data, and not disclose the information learned.

As previously noted, the student investigator has signed a written statement of confidentiality for using the HIVRN patient interview dataset. A copy of this signed statement is attached to this package and is on file with JHU. The statement clearly establishes guidelines for protecting the data. Patient interview data will be kept on the student's home computer during the dissertation process, which is expected to conclude in late 2005 or early 2006. The student's home computer is password protected. As noted in the confidentiality statement, the data will not be shared with others not involved with the HIVRN study. Persons with access to the data include Dr. Richard Conviser (HRSA), Dr. Kelly Gebo, (JHU co-principal investigator); Dr. Richard Moore (JHU principal investigator), other Federal partners at the Agency for Healthcare Research and Quality (John Fleishman, Ph.D.), and other HIVRN coordinating center staff at JHU. Upon completion of this dissertation, all HIVRN data will be removed from the student's computer and destroyed, and any hard copies of analyses will be shredded.

Information and Consent Forms

As noted above, all HIVRN patients or any proxies who participated in an interview were required to sign an informed consent form. An example of a patient consent form is attached under Appendix D. Original copies of the signed consent forms are kept on file at JHU. Copies of signed consent forms from each HIVRN site are kept at the respective sites.

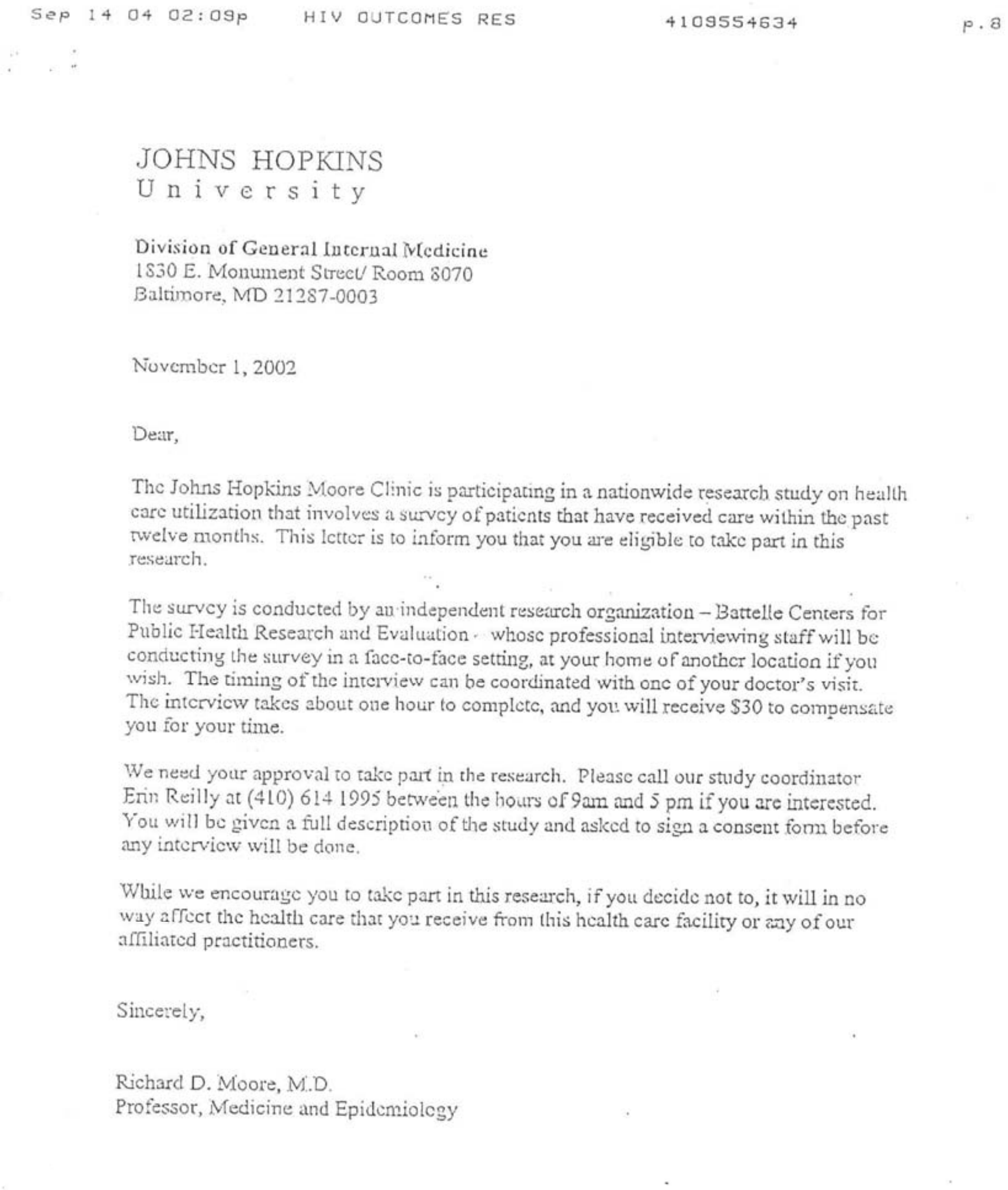
Conflict of Interest

There is no conflict of interest associated with this study.

HIPAA Compliance

This research will use de-identified protected health information that does not identify an individual by name, geographic site, clinical care site or other identifying information. For further protection, a data use agreement/statement of confidentiality has been signed by the student investigator and is on file at JHU, Baltimore, Maryland.

Appendix E
Johns Hopkins University IRB Document and Patient Informed Consent Forms



Sep 14 04 02:09p HIV OUTCOMES RES 4109554634 p.8

JOHNS HOPKINS
University

Division of General Internal Medicine
1830 E. Monument Street/ Room 8070
Baltimore, MD 21287-0003

November 1, 2002

Dear,

The Johns Hopkins Moore Clinic is participating in a nationwide research study on health care utilization that involves a survey of patients that have received care within the past twelve months. This letter is to inform you that you are eligible to take part in this research.

The survey is conducted by an independent research organization – Battelle Centers for Public Health Research and Evaluation - whose professional interviewing staff will be conducting the survey in a face-to-face setting, at your home of another location if you wish. The timing of the interview can be coordinated with one of your doctor's visit. The interview takes about one hour to complete, and you will receive $30 to compensate you for your time.

We need your approval to take part in the research. Please call our study coordinator Erin Reilly at (410) 614 1995 between the hours of 9am and 5 pm if you are interested. You will be given a full description of the study and asked to sign a consent form before any interview will be done.

While we encourage you to take part in this research, if you decide not to, it will in no way affect the health care that you receive from this health care facility or any of our affiliated practitioners.

Sincerely,

Richard D. Moore, M.D.
Professor, Medicine and Epidemiology

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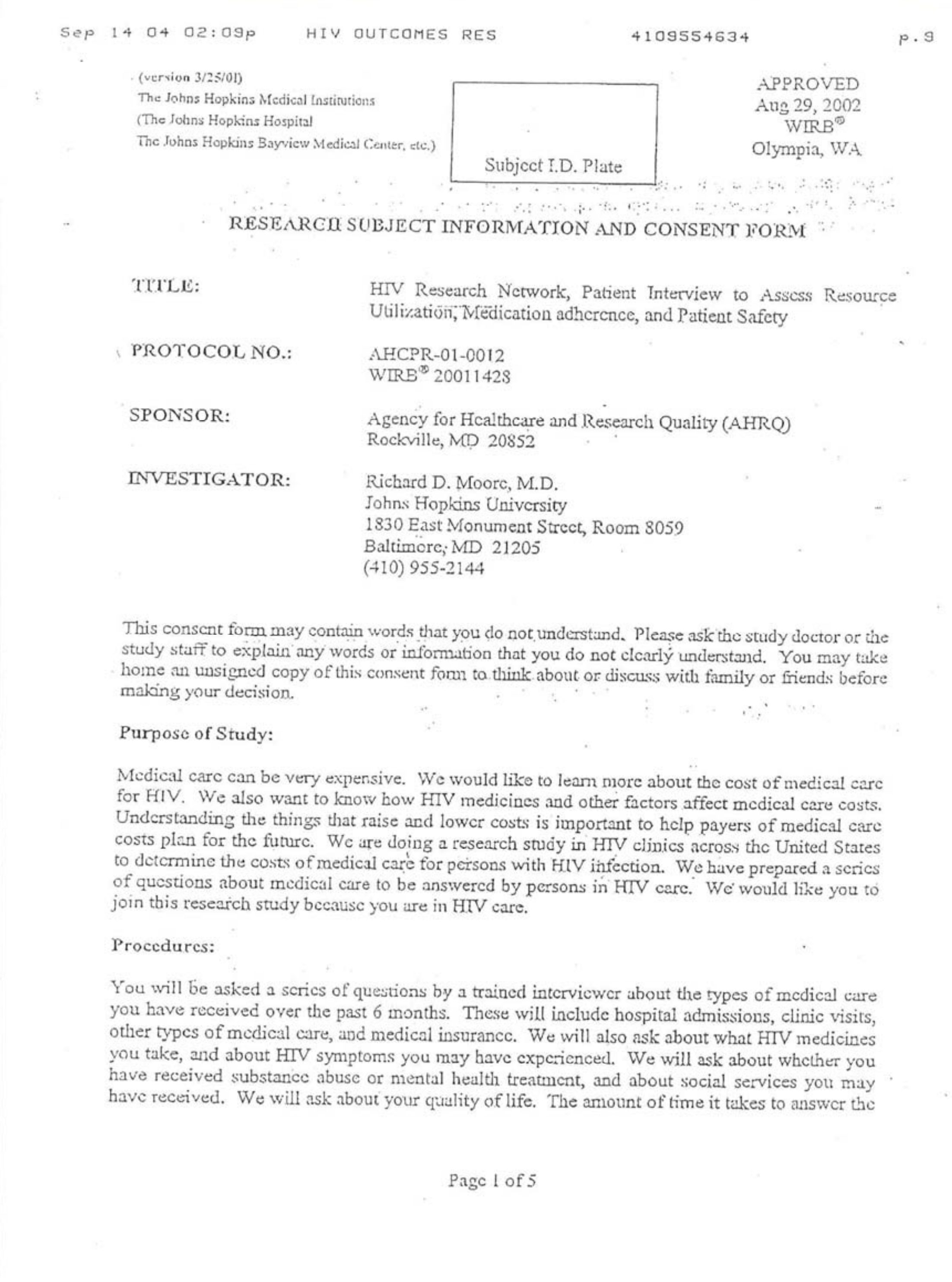

(version 3/25/01)
The Johns Hopkins Medical Institutions
(The Johns Hopkins Hospital
The Johns Hopkins Bayview Medical Center, etc.)

Subject I.D. Plate

APPROVED
Aug 29, 2002
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Olympia, WA

RESEARCH SUBJECT INFORMATION AND CONSENT FORM

TITLE:	HIV Research Network, Patient Interview to Assess Resource Utilization, Medication adherence, and Patient Safety
PROTOCOL NO.:	AHCPR-01-0012 WIRB® 20011428
SPONSOR:	Agency for Healthcare and Research Quality (AHRQ) Rockville, MD 20852
INVESTIGATOR:	Richard D. Moore, M.D. Johns Hopkins University 1830 East Monument Street, Room 8059 Baltimore, MD 21205 (410) 955-2144

This consent form may contain words that you do not understand. Please ask the study doctor or the study staff to explain any words or information that you do not clearly understand. You may take home an unsigned copy of this consent form to think about or discuss with family or friends before making your decision.

Purpose of Study:

Medical care can be very expensive. We would like to learn more about the cost of medical care for HIV. We also want to know how HIV medicines and other factors affect medical care costs. Understanding the things that raise and lower costs is important to help payers of medical care costs plan for the future. We are doing a research study in HIV clinics across the United States to determine the costs of medical care for persons with HIV infection. We have prepared a series of questions about medical care to be answered by persons in HIV care. We would like you to join this research study because you are in HIV care.

Procedures:

You will be asked a series of questions by a trained interviewer about the types of medical care you have received over the past 6 months. These will include hospital admissions, clinic visits, other types of medical care, and medical insurance. We will also ask about what HIV medicines you take, and about HIV symptoms you may have experienced. We will ask about whether you have received substance abuse or mental health treatment, and about social services you may have received. We will ask about your quality of life. The amount of time it takes to answer the

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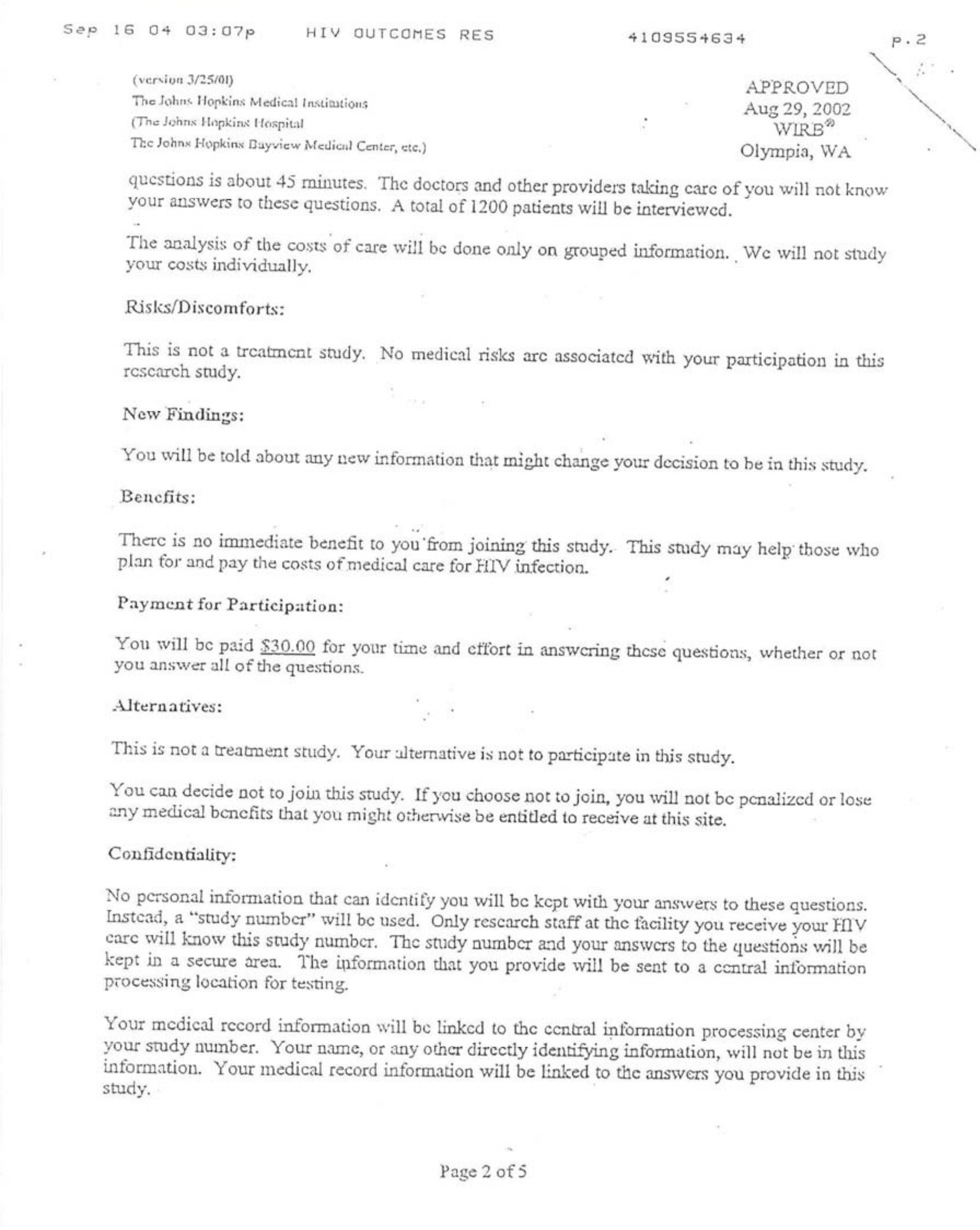

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questions is about 45 minutes. The doctors and other providers taking care of you will not know your answers to these questions. A total of 1200 patients will be interviewed.

The analysis of the costs of care will be done only on grouped information. We will not study your costs individually.

Risks/Discomforts:

This is not a treatment study. No medical risks are associated with your participation in this research study.

New Findings:

You will be told about any new information that might change your decision to be in this study.

Benefits:

There is no immediate benefit to you from joining this study. This study may help those who plan for and pay the costs of medical care for HIV infection.

Payment for Participation:

You will be paid $30.00 for your time and effort in answering these questions, whether or not you answer all of the questions.

Alternatives:

This is not a treatment study. Your alternative is not to participate in this study.

You can decide not to join this study. If you choose not to join, you will not be penalized or lose any medical benefits that you might otherwise be entitled to receive at this site.

Confidentiality:

No personal information that can identify you will be kept with your answers to these questions. Instead, a "study number" will be used. Only research staff at the facility you receive your HIV care will know this study number. The study number and your answers to the questions will be kept in a secure area. The information that you provide will be sent to a central information processing location for testing.

Your medical record information will be linked to the central information processing center by your study number. Your name, or any other directly identifying information, will not be in this information. Your medical record information will be linked to the answers you provide in this study.

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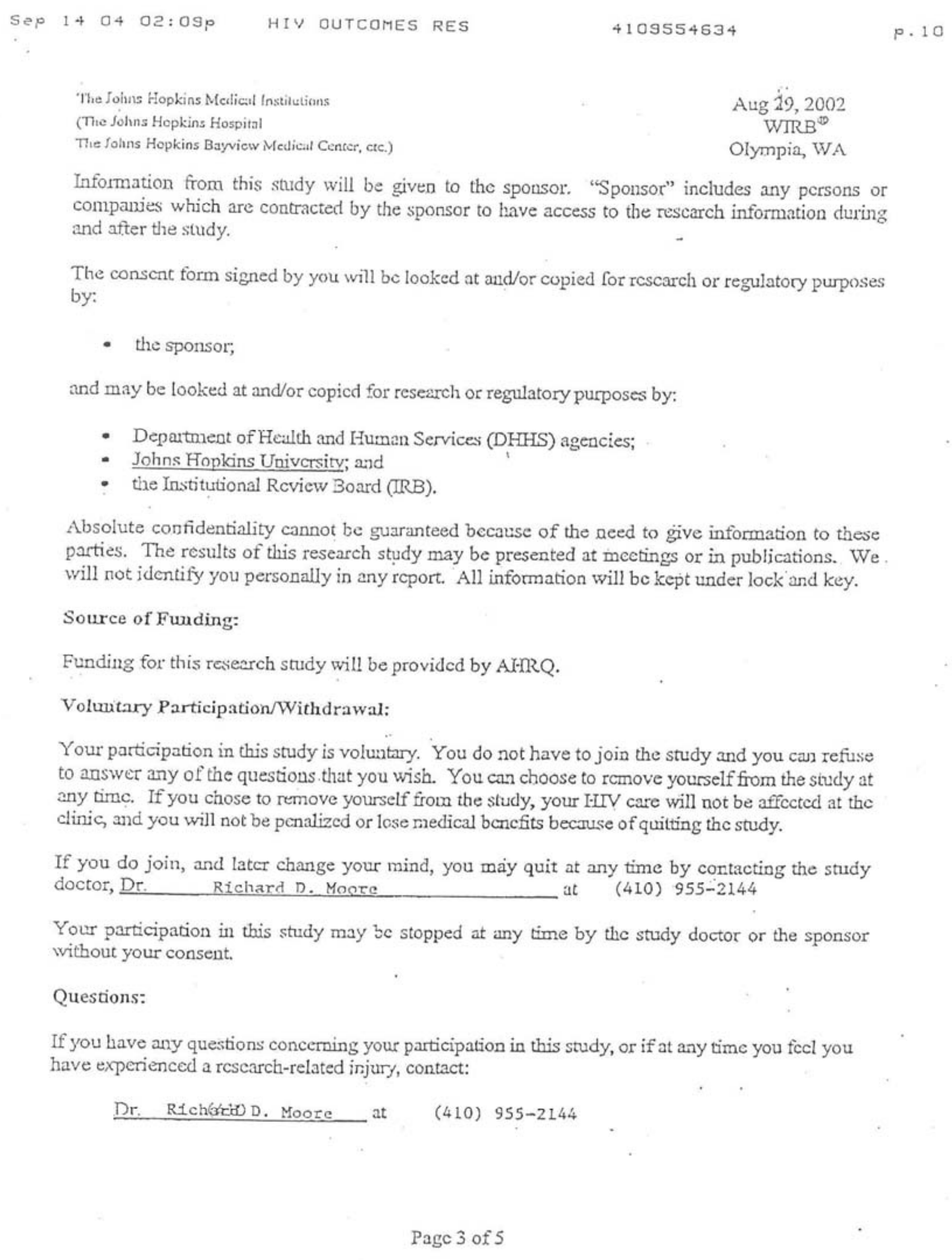

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Information from this study will be given to the sponsor. "Sponsor" includes any persons or companies which are contracted by the sponsor to have access to the research information during and after the study.

The consent form signed by you will be looked at and/or copied for research or regulatory purposes by:

- the sponsor;

and may be looked at and/or copied for research or regulatory purposes by:

- Department of Health and Human Services (DHHS) agencies;
- Johns Hopkins University; and
- the Institutional Review Board (IRB).

Absolute confidentiality cannot be guaranteed because of the need to give information to these parties. The results of this research study may be presented at meetings or in publications. We will not identify you personally in any report. All information will be kept under lock and key.

Source of Funding:

Funding for this research study will be provided by AHRQ.

Voluntary Participation/Withdrawal:

Your participation in this study is voluntary. You do not have to join the study and you can refuse to answer any of the questions that you wish. You can choose to remove yourself from the study at any time. If you chose to remove yourself from the study, your HIV care will not be affected at the clinic, and you will not be penalized or lose medical benefits because of quitting the study.

If you do join, and later change your mind, you may quit at any time by contacting the study doctor, Dr. Richard D. Moore at (410) 955-2144

Your participation in this study may be stopped at any time by the study doctor or the sponsor without your consent.

Questions:

If you have any questions concerning your participation in this study, or if at any time you feel you have experienced a research-related injury, contact:

Dr. Richard D. Moore at (410) 955-2144

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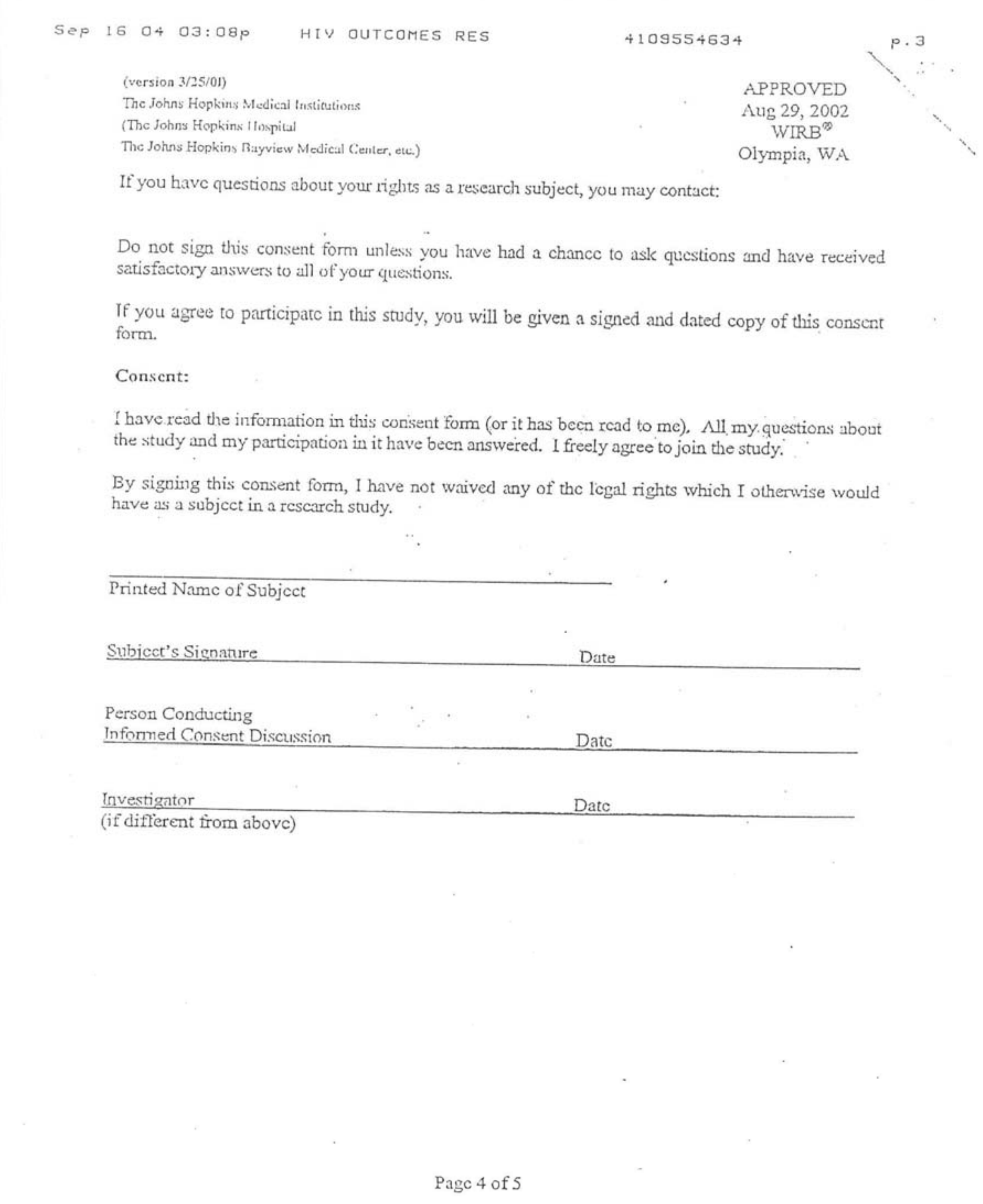

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If you have questions about your rights as a research subject, you may contact:

Do not sign this consent form unless you have had a chance to ask questions and have received satisfactory answers to all of your questions.

If you agree to participate in this study, you will be given a signed and dated copy of this consent form.

Consent:

I have read the information in this consent form (or it has been read to me). All my questions about the study and my participation in it have been answered. I freely agree to join the study.

By signing this consent form, I have not waived any of the legal rights which I otherwise would have as a subject in a research study.

Printed Name of Subject

Subject's Signature Date

Person Conducting
Informed Consent Discussion Date

Investigator Date
(if different from above)

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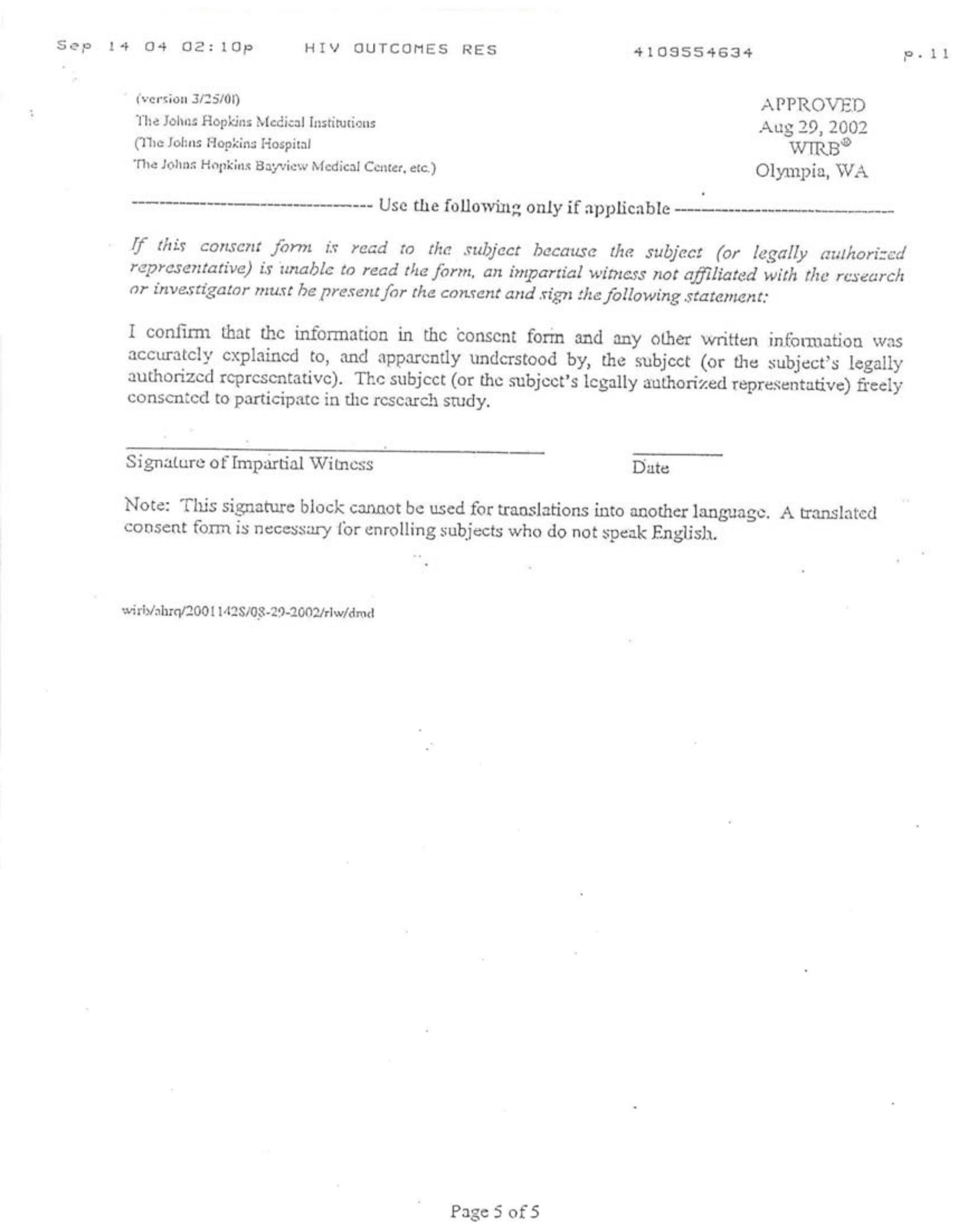

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------------------------------------ Use the following only if applicable ------------------------------------

If this consent form is read to the subject because the subject (or legally authorized representative) is unable to read the form, an impartial witness not affiliated with the research or investigator must be present for the consent and sign the following statement:

I confirm that the information in the consent form and any other written information was accurately explained to, and apparently understood by, the subject (or the subject's legally authorized representative). The subject (or the subject's legally authorized representative) freely consented to participate in the research study.

Signature of Impartial Witness ____________________ Date ____________

Note: This signature block cannot be used for translations into another language. A translated consent form is necessary for enrolling subjects who do not speak English.

wirb/ahrq/20011428/08-29-2002/rlw/dmd

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