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An Examination of HIV Case Management Using a Behavioral Model for Vulnerable Populations

by

Melanie Anne Egorin DISSERTATION

Submitted in partial satisfaction of the requirements for the degree of

DOCTOR OF PHILOSOPHY

in

Sociology

in the

GRADUATE DIVISION

of the

UNIVERSITY OF CALIFORNIA, SAN FRANCISCO

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Melanie Anne Egorin, Ph.D.

DEDICATION

I dedicate this dissertation to Mildred Kantor and Toba Egorin, my grandmothers and two of the strongest women I knew. May this work be up to your standards and may I always strive to make you proud.

And to Robert Lee Johnson who called Dr. Mel from the beginning and really believing I could be this mythic figure. I wish you were here to share this with me.

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AN EXAMINATION OF HIV CASE MANAGEMENT USING A BEHAVIORAL MODEL FOR VULNERABLE POPULATIONS Melanie Anne Egorin, Ph.D. University of California, San Francisco

Case management became a standard part of HIV and AIDS care in many American cities during the first decade of the epidemic. Based on these early successes and the precedent of using case management for people with long-term illnesses, the practice of providing HIV case management services to coordinate care and reduce costs became a recommended standard of care nationally. This dissertation focuses on the experiences of 150 English-speaking clients receiving HIV case management in Alameda County. California. Using a variation of the behavioral model for vulnerable populations developed by Gelberg, Andersen, and Leake (2000), regression models show specific predisposing, enabling, need, and health behavior variables affect how clients perceive their needs, evaluate their satisfaction with case management, appraise their health status, and utilize medical service.

Case management clients in Alameda County have high utilization of routine health care services and low emergency room use. While case management services may not be predictive of current level of health care utilization, it does appear that the services are addressing medical needs and assisting clients in entering into and sustaining medical care. The inclusion of vulnerable characteristics increased the predictive ability of the regression models. Drug comorbidity and mental health comorbidity predicted many outcomes and often these results were divergent. A history of homelessness was predictive of several outcomes. Early in the study, this variable was not expected to have the impact that it did. The long-term implications of experiencing homelessness and other vulnerable characteristics such as drug use, competing needs, and use of public benefits should be investigated further. Income in relation to the poverty line and having a caregiving role were not as relevant to the model as other vulnerable characteristics. Having a care-giving role was predictive of only general health perception.

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CHAPTER I

INTRODUCTION TO THE STUDY

HIV case management covers a wide range of services with the common goal of providing "a range of client-centered services that link individuals with health care, psychosocial and other services and ensure timely coordinated access to services (Alameda County HIV Health Services Planning Council, 1998)." While HIV case management was first embraced for the cost savings it offered, goals of case management have evolved along side the HIV epidemic. The role and perceived importance of case management for individuals with HIV has become entrenched in the funding structures and the political discussion of appropriate HIV care delivery. Contemporary goals of case management include improved utilization of available health care and social programs and increased coordination of the multiple programs needed to manage HIV. This objective operates on the assumption that HIV case management is an integrated and valued part of a system of health care delivery. This dissertation study aims to examine the relationship of such HIV case management to health care utilization, health status, and satisfaction with services, traditional markers of health care access.

This dissertation employs data from the Alameda County (California) HIV Case Management Evaluation and Redesign Project (Rani Eversley, PI). The Ryan White CARE Act Title I and II Planning Council (the Planning Council) contracted the study to examine the efficacy of HIV case management in Alameda County and to recommend procedural changes for the county and individual agencies. The two-year study collected

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data from HIV case management agencies, case managers, and clients. The project examined the structure of the case management agencies, the perceptions of effectiveness by case managers, the procedural issues within the county that helped or hindered service provision, and the satisfaction of clients with HIV case management services.

This dissertation focuses on the experiences of 150 English-speaking clients receiving HIV case management in Alameda County. Using a conceptual framework designed to examine access to care for vulnerable populations, adapted from Andersen's widely used, and well recognized, conceptual model of health care access and utilization (Andersen, 1995; Gelberg, Andersen, & Leake, 2000), this study focuses on understanding the role of case management in the lives of low-income individuals living with HIV. Specifically, this dissertation study examines the relationship between the amounts and types of HIV case management and four outcomes: client-perceived HIV case management need, selfreported health status, health care utilization, and client satisfaction with case management, taking into account the predisposing, enabling and need factors for individuals with HIV. Findings indicate that specific predisposing, enabling, need, and health behavior variables affect how clients perceive their needs, evaluate their satisfaction with case management, appraise their health status, and utilize medical service. Findings indicate that utilization of case management services has limited impact on access to care and health status.

Alameda County as a Case Study of HIV Case Management Previous studies of case management primarily examined large national data sets (Bozzette et al., 1998; Bozzette et al., 2001; Cunningham et al., 1999), demonstration projects (Fleishman, 1998; Fleishman, Mor, & Piette, 1991; Piette, Fleishman, Mor, & Dill, 1990; Piette, Fleishman, Mor, & Thompson, 1992), or agency specific findings (Cunningham, Hays et al., 1995; Kuehnert, Matthes, & White, 1998; Mercier & Racine, 1995; Sonsel, 1998; Taylor-Brown, Teeter, Blackburn, Oinen, & Wedderburn, 1998; Weissman et al., 1995). While nationally representative sampling allows for an understanding of case management throughout the United States, the true effectiveness of local case management practices are hidden in such analyses. Because case management systems, including federally funded programs such as the Ryan White CARE Act Title IIfunded case management, are structured differently in each local context it is important to focus research attention on local systems to better understand if case management services continue to reap the benefits touted in research from the beginning of the HIV epidemic (Arno, 1986; Arno & Hughes, 1987; Benjamin, Lee, & Solkowitz, 1988; Jellinek, 1988).

The examination of Alameda County HIV case management demonstrates that a fully integrated system is more of an ideal than a reality of local health care. Much of the delivery of services to clients in the HIV case management system occurs through a series of fluid networks connecting case management agencies. Problems getting referral resources and coordination between agencies existed in Alameda County just as they has existed in many other systems (Maslanka, Lee, & Freudenberg, 1995; Piette et al., 1990; Roberts, Severinsen, Kuehn, Straker, & Fritz, 1992; Sonsel, 1998; Wright, Henry, Holzemer, & Falknor, 1993). In Alameda County, HIV case management agencies relied on informal staff interactions rather than formal procedures for information exchange and links between different programs. This pattern was also found in a study of New York community-based case management organizations (Maslanka et al., 1995). Relying on these personal, and informal, networks created problems for linking HIV service organization clients.

As formal case management is introduced into the health care system, the political nature of the development of a case management system often works against the development of a fully integrated system (Jellinek, 1988). Providers are either introduced to the collaborative effort or denied entry. Some providers and agencies choose not to affiliate or hesitate to do so because such affiliations often cost them a degree of autonomy and power. Additionally, the competition for funding plays in to the manner in which allegiances are formed. In an earlier study of nurse case managers in California, problems in coordination and collaboration were credited to the animosity between community organizations related to competition for funding (Wright et al., 1993).

In Alameda County, the funding process is very political process and this both drives, and destroys, the work done by the Planning Council. The Alameda County Planning Council has a long history of conflict and adverse outcomes (Marconi et al., 1994; Scannell, 1999). For example, in 1994, due to confusion of roles between the Planning Council

members and the county health department as well as hostility among community-based organizations, the planning council was only able to secure 65% of its Title I funding grant (Kieler, Rundall, & Saporta, 1996; Kieler, Rundall, Saporta et al., 1996). The controversy and resistance that occupied the federally mandated annual needs assessment and funding allocation process as observed by Kieler (1996) continued through the twoyear study period of the project. Since many members on the planning council work for the organizations about which funding decisions are made, political will is often expressed through the distribution of Ryan White CARE Act resources. Struggles concerning funding often lead to significant financial investment in consultants to perform evaluations of the system with hopes of noting the need for change. Case-inpoint, the project on which this dissertation is based came about because of such a political battle between agencies and after the project report had been delivered, another study was commissioned to examine a very similar set of questions.

Significance

There are three principal reasons why this study will add to the existing knowledge based about health care access by HIV-positive individuals: it offers support for modification to the widely accepted behavioral model of health services utilization ; it argues for the inclusion of case management utilization patterns in the study of health services utilization; and it clarifies the focus on local level implementation of case management.

Gi ven the widespread acceptance of the behavioral model of health services utilization (Andersen, 1968, 1995; Andersen & Aday, 1978; Andersen, McCutcheon, Aday, Chiu, &

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Bell, 1983; Andersen & Newman, 1973), often referred to as the "Andersen model", an examination of populations with special health care needs within the general framework of the model continues to be important. Gelberg, Andersen and Leake (2000) adapted the model for vulnerable populations and the unique issues of access experienced by these groups. This most recent adaptation served to further the utility of the Andersen model for "vulnerable populations." This study tests the vulernable populations model with a focus on HIV-positive individuals and the myriad of other vulnerable characteristics often associated with these individuals. While this dissertation study was unable to examine all factors that influence health services utilization, it does provide support for the incorporation and recognition of vulnerable characteristics for future studies of health services utilization.

Incorporation of case management into the model of health utilization allows one to examine social services as a health behavior and its effect on the measures of health outcomes. The behavioral or "Andersen" model and its various theoretical derivations are useful in examining case management services among an HIV-positive population because of their focus on access to care as a function of personal, environmental, and structural influences (Katz et al., 2001). However, previous studies focused only on the presence or absence of services. The sample used in this dissertation was those enrolled in case management and , thereby, allows for the examination of intensity and duration of case management services in relation health utilization and outcomes.

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Case management is supported by federal, state and local governments, as well as by private philanthropies, because it is believed that such social support services assist patients in accessing social support and health services. Examination of local level implementation of case management moves the discussion of case management service delivery beyond studies of individual agencies (e.g., Sonsel's study of AIDS Project LA) or nationwide samples (e.g., the HIV Cost and Service Utilization Study). While case management has been utilized nationwide, the services are typically implemented at the local level and therefore should be studied as such. By examining Ryan White CARE Act-funded case management services in a decentralized system, such as Alameda County, CA, one can get a better understanding of how small social service agencies, health care agencies, hospitals, and local constituencies work to meet HIV-positive individual and community needs.

Structure of the Dissertation

The specific aims of this dissertation are:

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- To describe and examine the relationship among predisposing characteristics, enabling characteristics and the self-perceived case management needs of HIVpositive individuals.
- To describe and examine the relationship among predisposing, enabling and need factors, utilization of HIV case management services, and consumer satisfaction with case management.

- 3) To describe and examine the relationship among predisposing, enabling and need factors, utilization of HIV case management services and perceived health status.
- To describe and examine the relationship among predisposing, enabling and need factors, utilization of HIV case management services and utilization of health care services.

HIV case management needs among the sample were hypothesized to be predicted by vulnerable characteristics, especially HIV level and care-giving role. Based on an examination of past literature related to access to care and HIV case management, it was hypothesized that vulnerable characteristics will predict poorer satisfaction, utilization, and health status outcomes

This dissertation is organized in six chapters. Following this brief overview of the dissertation study, the second chapter provides review of HIV case management including a review of the acceptance of HIV case management and the literature on efficacy of HIV case management. The second chapter also presents the national, state and local HIV case management guidelines used by Alameda County during the study period. The third chapter reviews the Behavioral Model of Health Utilization, more commonly referred to as the Andersen Model. This chapter specifically explores the development of a model variation that examines the access issues of vulnerable population. In the third chapter, a literature review of variables of interest is presented.

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The fourth chapter discusses the methodology of the dissertation study and the analyses conducted in accordance with the four specific aims. Challenges and problems with the data are discussed in the methodology chapter. Results of the analyses are discussed in chapter five. The chapter begins with a presentation of the descriptive data per the conceptual model categories and then a discussion of the seven regression models concludes the chapter. The final chapter begins with a discussion of the dissertation results in light of the previous literature and then discusses future research and sociological and policy implications of the dissertation study.

CHAPTER II

REVIEW OF HIV CASE MANAGEMENT

Case management became a standard part of HIV and AIDS care in many American cities during the first decade of the epidemic. Early studies of HIV case management and other social support services found this type of combination approach successful in reducing the financial burden of inpatient care by reducing the number of inpatient days as well as the need for multiple hospitalizations (Arno, 1986; Arno & Hughes, 1987; Benjamin et al., 1988). A national demonstration project of case management further illustrated the benefits of case management for HIV-positive people (Fleishman et al., 1991; Piette et al., 1992). Based on these early successes and the precedent of using case management for people with long-term illnesses, the practice of providing HIV case management services to coordinate care and reduce costs became a recommended standard of care nationally (US Department of Health and Human Services, 1994).

HIV case management, however, has neither a standard definition nor a universally accepted checklist of practices. Rather, covers a wide range of services. While HIV case management often involves the coordination of health care and social services for an HIV-positive individual, it often also involves the delivery of specific care services as well. The federal government asserts that HIV case management is designed to be a patient-centered process to which people with HIV and AIDS can turn for emotional, medical, and financial support (US Department of Health and Human Services, 1994). The elements of HIV case management, funded by the federal government through the Health Resources and Services Administration, AIDS Division, include the coordination of medical care services, addressing access to services, and planning for the future needs of HIV-positive individuals and their families.

The Alameda County Health Department in California defines case management as "a range of client-centered services that link individuals with health care, psychosocial and other services and ensure timely coordinated access to services (Alameda County HIV Health Services Planning Council, 1998)." For purposes of this dissertation, the Alameda County definition of HIV case management will be employed to understand the services provided to clients within a specific framework of regulations, administration, and funding structures.

Regardless of whether the term 'case management' is discussed theoretically, structurally, or politically, HIV case managers must attempt to balance the needs of clients, the system, and themselves as a case manager. Case managers engage in a wide range of ongoing care coordination and management activities (e.g., finding housing for clients and following treatment adherence) designed to assist patients in effectively navigating the health care system, as well as other social support structures, while controlling health care and other costs associated with the care of HIV-positive individuals. Case management activities vary in scope and frequency according to the structure of the particular care management system (e.g., nursing case management as opposed to psychosocial case management) (Emlet & Gusz, 1998; Katz et al., 2000), as well as the case manager's training (Piette et al., 1990; Piette et al., 1992). Additionally, limitations on financial and other resources (e.g., people, space, and time) determine both the case management activities that are offered and the services that clients receive.

The following chapter begins with a brief history of HIV case management. It then discusses the structure, funding, benefits and problems of HIV case management. When appropriate, references to the Alameda County case management system are made to provide a context for how the individuals studied in this dissertation interact with a specific system. A brief overview of the structure of HIV care and case management in Alameda County is provided in the Methods Chapter of the dissertation. The chapter concludes with the presentation of the significance and specific aims of this dissertation study.

A Brief History of Case Management, HIV, and National Acceptance The current widespread national and local support for HIV case management is based on early studies showing that San Francisco, in comparison with New York, was able to control medical costs of people living with AIDS (Benjamin, 1989; Benjamin et al., 1988). The use of a loose system of community and social service programs by people with HIV was shown to reduce the cost of health care through the reduction of days of inpatient hospital care and the cost per day of such care. (Arno, 1986; Arno & Hughes, 1987). The San Francisco model of service coordination was effective but "the local responses to the epidemic did not occur in a vacuum (p267)(Arno & Hughes, 1987)." The San Francisco case management system during the 1980s was an evolving system that adapted to meet the changing knowledge about, and outcomes of, AIDS as well as to ^OPerate within a specific medical and political geography (Arno & Hughes, 1987; Benjamin et al., 1988). Because of the dramatic growth in AIDS- affected individuals, medical and social services, including case management, developed hastily and in a rather informal manner. The case management provided to HIV-positive individuals in San Francisco was rather informal and was not delivered through a centralized means. The only formal planning that existed in the earliest stages of the epidemic was hospital discharge planning (Jellinek, 1988).

In a study published in 1987, Arno and Hughes examined how New York City and San Francisco responded to HIV health care delivery in the early years of the epidemic with differing levels of economic support and different funding priorities. New York was spending more money overall, as well as more money per capita than San Francisco. New York spent over \$111 million in AIDS-related funds. By comparison, San Francisco spent only \$37 million. New York spent approximately \$36,000 per person with AIDS, while San Francisco spent only approximately \$22,000. In both cities the majority of spending was for inpatient care. The researchers found the main difference in cost of inpatient care was not the actual cost of inpatient care per day, but rather the duration and frequency of a patient's stay in a hospital. Patients in San Francisco on average remained in the hospital less than half the number of days of patients in New York (12 vs. 25 respectively). This difference was consistent with complementary spending on social services costs.

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While the majority of funds in each city paid for inpatient care, San Francisco spent approximately 7 out of every 10 AIDS-related dollars on inpatient services while New York spent 9 out of every 10. San Francisco spent about 11% of its AIDS related funds on social services where as New York spent under 2% of its AIDS-related funds on social services. With the difference, San Francisco developed a set of social, financial and medical services. The Arno and Hughes study became one of the seminal pieces of research used by HIV advocates and policy makers to argue that HIV service coordination produced both better service utilization and lower medical costs (Benjamin, 1988; Benjamin et al., 1988).

Jellinek (1988) suggested that the development of the case management system in San Francisco in the early 1980s was in response to the potential economic and social implications of a large number of people receiving AIDS services at a single site: San Francisco General Hospital. Jellinek (1988) further found that it was economic factors, specifically a county-funded health care system in conjunction with the recession of the time that not only spurred the development of but also generated support for the case management model used in San Francisco. However, without such specific economic conditions creating necessity, the financing of a case management system and the implementation of case management services is often problematic. Many payers of health services would rather pay for hospitalization than for community services. In response, the Medicaid Waiver program and the Ryan White CARE Act are both attempts by the Federal Government to support community services. However, such efforts are often inserted into an existing environment that neither values the role of community services nor has the structural capacity to support them. The over-commitment of economic and human resources are also problems faced in the further development and maintenance of case management systems.

In the late 1980s and early 1990s, the Robert Wood Johnson Foundation, along with the Federal Government, invested heavily in initiatives to develop case management systems nationally. The Robert Wood Johnson Foundation AIDS Health Services Program (RWJF AHSP) was initiated to help communities develop case management programs with the goal of increasing coordination of care for people with HIV. Investment in such a program reflects the belief that case management and the coordination it provides have health and social benefits for people living with HIV. Case management was accepted as a tool despite the fact that the factors that influenced AIDS care delivery in early 1980s' San Francisco (Benjamin et al., 1988) were notreplicated in other US cities. Moreover, case management for other populations with long-term illnesses had not been found to be effective in reducing hospitalizations or the costs of medical care (Benjamin, 1988).

Nine communities were selected to participate in a nationwide demonstration project funded by the Robert Wood Johnson Foundation. Within these communities 20 organizations, housed in both hospitals and community-based settings, were given funds to provide case management. It was hoped that the San Francisco model, which had developed swiftly and organically (Jellinek, 1988), would transfer well to RWJF AHSP communities. However, these communities often did not have the same conditions that made case management successful in San Francisco. These communities often had smaller populations of HIV-positive individuals, which were less politically and civically active, and medical providers who were unwilling to become public advocates for the treatment of HIV (Piette et al., 1990; Piette et al., 1992). Regardless of the differences in the communities, the early acceptance of case management drove the manner in which HIV policy was developed nationwide and continues to permeate how policies develop and are financed.

In Alameda County the case management system is decentralized, varied and driven by the interests of community-based organizations as well as the most active HIV constituencies. Like San Francisco and New York, Alameda County has provided medical and social care to HIV-positive individuals through public, county hospitals and community-based organizations since the earliest days of the epidemic. As with most urban areas in the early 1980s, the earliest cases of AIDS strained the economic and medical resources of the county (Honey, 1988; Scannell, 1999). More like New York than geographically proximate San Francisco, Alameda County has since the earliest days of the epidemic, faced the problem of providing services to an economically, racially, and socially diverse group of patients (Scannell, 1999). In Alameda County, community-specific support services and organizations developed and grew to meet the needs of these distinct, diverse populations. From this diversity, developed a system with conflicting goals and systemic strain (Robertson, Zlotnick, & Westerfelt, 1997).

It has been suggested that although the San Francisco model was a good beginning a more comprehensive and centralized model would be best to meet the future needs of people with HIV (Jellinek, 1988). A successful system should have a firm commitment from civic and political community leaders, secure, but flexible financing, and support for both case management and community-based organizations. However, such an ideal system rarely exists, especially in communities where HIV-infection is widespread.

Questions about the use and viability of case management need to be asked because of the changing demographics of the HIV population, the rapid changes in treating HIV, and the inflation in health care spending. Since inpatient care is no longer the primary medical treatment for people with HIV and AIDS, policy makers and researchers should ask what the intended benefits of case management are? Does case management provide the economic benefits seen in San Francisco or does it increase health care and social service utilization without regard to cost effectiveness? And even if yes, is this a bad outcome of case management? With a shift to pharmaceutical management of disease and symptoms, does care coordination still benefit the local community in the same ways?

Governmental Funding of Case Management

With the success of early case management programs and the national demonstration projects, HIV case management as a means of coordinating health, psychosocial and economic services, has become the standard of care. HIV case management retains strong levels of financial and rhetorical support because of the perception by many policy makers, health care providers, and clients that such services help clients to meet a wide range of needs. Medicaid (Title 19 of the Social Security Act) and the Ryan White CARE Act programs pay for the majority of HIV care management provided in California and across the United States. The increase in the number of HIV-positive individuals and the growing cost of case management programs makes funding policy and funding distribution areas frequently revisited during federal and local budgetary and planning discussions.

In 1998, 0.5% of the federal budget (\$8.7 billion) was targeted for HIV and AIDS (Foster, Gregory, Niederhausen, Rapallo, & Westmoreland, 1998). Of the monies allocated to HIV and AIDS in 1998, 71% was used for patient care and assistance, 19.5% was devoted to research, 8.1% was for prevention and 1.4% was used for international HIV issues (Foster et al., 1998). Domestically, Medicaid accounted for 21.8% of the total budget, the NIH for 18.5%, Medicare for 16.1% and Ryan White CARE Act funding for 13% (Foster et al., 1998). It is important to note that the overall figure of \$8.7 billion figure includes dollars targeted to HIV and AIDS as well as to more general activities that impact HIV and AIDS such as tuberculosis research. Using such a liberal definition for AIDS and HIV funding allows for the inflation of the amount spent on direct HIV and AIDS care. The federal figures on AIDS spending on direct care have been problematic since the early days of the epidemic (Shilts, 1988). Federal officials in budget preparations often linked direct service funding with prevention programs as well as with services for other diseases such as tuberculosis.

At the federal level, HIV care and assistance programs include such programs as Medicaid, Medicare, the Ryan White CARE Act, and Housing Opportunities from People with AIDS (HOPWA). HIV care and assistance funding also comes from Social Security Disability Insurance (SSDI) for people with an AIDS diagnosis, Supplemental Security Income (SSI), and Substance Abuse and Mental Health Services Administration (SAMHSA). In 1998, of the \$6.2 billion dollars allocated from patient care and assistance, 30.7% is used to support Medicaid, 22.7% is used for Medicare and 18.6% is used to support the Ryan White CARE Act programs (Foster et al., 1998). The direct benefit programs, SSDI and SSI, utilized only 16.1% of the total spent on care and assistance (Foster et al., 1998). Within care and assistance spending, 60.5% of programs funded were not means tested for patient support. This reflects the focus on client disease status rather than federal income guidelines in determining support for HIV infected and AIDS diagnosed patients.

Ryan White Care Act

The Ryan White CARE Act, one of the largest disease specific health initiatives at the federal level, funds state and non-profit organizations allowing them to meet the needs of underserved populations with HIV. The large governmental investment in both medical and social services makes the program unique among other federal health services programs. Ryan White CARE Act funding is divided into 7 groups: Title I, Title II, Title III, Title IV, Special Projects of National Significance, AIDS Education Training Centers and Dental Reimbursments. It should be noted that in the United States, these same care organzations already provide 60% of medical care to the AIDS population through Medicaid programs. This dissertation project focuses on programs funded by Title I to provide HIV case management services.

Title I grants support community-based services provided by public and non-profit entities through the funding of eligible metropolitan areas (EMAs) (Health Resources and Services Administration, 1999; US Department of Health and Human Services, 2002). Services supported through Title I funds include outpatient health care, rehabiliative services, case management, home health care, hospice care, and inpatient case management (Health Resources and Services Administration, 1999). While Title I services provide medical and psychosocial care for people with HIV and AIDS, it does not extend to family members and caregivers who may be in need of services.

The allocation of funds to specific programs and agencies is conducted by the local EMA HIV Health Services Planning Council (Planning Councils). Membership in these Planning Councils, as required by federal legislation, must include representatives from health care organizations, community based organizations and people living with HIV (US Department of Health and Human Services, 2002). As Kieler and colleagues (1996) note, planning councils were popular with both local and federal organizations. Planning councils offer more local control to meet specific population needs. Furthermore, planning councils forced AIDS constituencies to work with existing local organizations to create change rather than appealing on a federal level to impact local change. This allowed the federal government to shift accountability for adequate funding to the local level. An Examination of HIV Case Management 21

While Title I does not provide for family-based care, Title IV of the Ryan White CARE Act provides funding for community based care that focuses on women, minors, and families living with HIV-positive individuals. Services provided include medical care and psychosocial support to people with HIV as well as outreach and prevention efforts aimed at vulnerable populations (Health Resources and Services Administration, 1999; McKinney et al., 2002). Title IV funding differs from the other Ryan White CARE Act programs in that it allows case managers to receive funding for services provided to HIVnegative family members. By focusing on the family as an entity needing care, the federal legislation and guidelines attempt to address the needs of families in psychosocial and behavioral realms. However, funding for these family programs occurs beyond the control of the local planning council and is often not aligned with the goal and programs of the Title I funded programs.

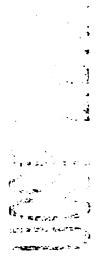
In the fiscal year 1999, HRSA estimated that 103,870 people with HIV or those affected by HIV received care through Ryan White CARE Act funded programs (US Department of Health and Human Services, 2000). California received over \$221 million through the Ryan White CARE Act during the 1999 fiscal year, with over \$101 million dollars allocated for Title I and \$3.8 million allocated for Title IV programs. California had 9 eligible metropolitan areas that received Title I funding (Health Resources and Services Administration, 1999). California represents the largest number of EMAs of any state.



Medicaid and Other Governmental Sources of Case Management Funding

The Center for Medicare and Medicaid Services (CMS), formerly Health Care Financing Administration (HCFA), allows states to apply for waivers to the Medicaid program to provide a fuller complement of services to people enrolled in the state Medicaid programs if such services can be justified as reducing the overall cost of care. Many states have applied for these programs to cover home care, case management, transportation and home medical services. The justification for these services is reducing overall cost of treating people in public insurance programs. However, these programs often result in higher costs due to increased utilization of as well as increase access to health care services (Mor, 1993).

In California, Medicaid waiver programs are used to pay for HIV and other case management services. In 1989 the Federal government granted California a Medicaid Waiver to provided community and home based care for people living with HIV. It should be noted that in California an earlier project was developed to provide case management services clients. In 1986, the state implemented Pilot Care Projects statewide to better provide home and community services to people living with AIDS. When the Pilot Care projects were implemented they targeted people at later stages of and HIV-related illnesses. Projects were initially funded by the state. The majority of the Pilot Care Projects received funding though the Medicaid Waiver program. To improve access to services, local project sites were given funds to purchase needed services where these services were not previously available. In California, these included



skilled nursing care, attendant care, counseling about psychosocial, financial and benefits issues, medical equipment, and subsidies for housing, food and transportation.

Current Case Management Guidelines

Guidelines for HIV case management are set at several levels including federal, state, county, and agency. The Department of Health and Human Services (DHHS) established federal recommendations for HIV case management in 1994. Developed by the Early **HIV** Infection Guideline Panel, the guidelines recommended that the primary care **provider** do the majority of care coordination for patients in early stages of HIV. The **guidelines** did not recommend moving care coordination to a case management system **unt** il a patient's disease status progressed to a greater level of need than could be **provided** by a primary health care provider. The DHHS recommended that this transition **occ** ur at the request of the primary care provider. These primary care provider were to **have** learned about HIV case management through "continuing education and training, **contracting with local and regional case management system, or [by] employing a case manager** to assist in the primary care setting (p.97)"

The federal government recommended that case management occur through a process of intake, assessment, and development. A patient would enter into the case management ^{system}, be assessed, and have a case management plan developed with an eye towards ^{continual} re-evaluation. Based on the work of Piette, Fleishman, and Mor (1992), the ^{fed}eral guidelines describe each of the steps. Intake involves identifying who is eligible for and/or seeking services. During assessment, the patient and case manager in tandem



i dentify the patient's needs, strengths, and weaknesses. The information gathered during the intake and assessment should be used to develop a care plan to include setting goals and objectives based on health, psychosocial, and community needs. Ideally, the care plan would implemented through a series of referrals, therapy, client and case manager advocacy as well as the coordination of related services. Patients and care providers together would monitor progress towards the goals, and reassess the situation as

California guidelines for case management follow the steps laid out by the federal government (California Department of Health Services Office of AIDS, 1997; Health Resources and Services Administration, 1998). The California regulations recommend using the Karnofsky Performance Status Scale for evaluating persons with HIV and AIDS. This standard measure, used to evaluate activities of daily living for patients with chronic disease, has been adapted for people living with HIV and AIDS. The evaluation examines functional status in terms of dependence on others for carrying out activities of daily living. Using the state guidelines, criteria utilized to evaluate disease progression include tasks and social condition and do not rely on purely medical indicators.

At the county level, the guidelines define who is eligible for services and what agencies are given funding. This is because federal funds are administered through local, eligible metropolitan areas (EMA) as designated by the Ryan White CARE Act. In California, the nine designated EMAs employ different case management standards thereby complicating statewide coordination and evaluation.



Individual agency guidelines for case management have the greatest variability because they are tailored to clients and also have differences in funding. This variability creates discordant and divergent care for clients accessing different services in different locales. Changes in services that were essential for clients (e.g. child care or transportation) and were once provided, may no longer be available to them. Differences between local case management standards may create situations where clients "shop" for services by enrolling in multiple case management agencies. This duplication of services is expensive and wasteful (Fleishman et al., 1991; Layzell & McCarthy, 1992). These local agencies are also responsible for utilizing the guidelines that come from funding and oversight organizations (ie States Department of Health, HRSA). Competing models and repeat measures make continuity difficult to measure.

This dissertation examines the case management experiences of clients in Alameda County who receive services in agencies funded by Ryan White CARE Act Title I funds. These agencies balance the recommendations of the federal and state government, local control, and the Ryan White CARE Act Planning Council for Alameda County. Additionally, most case management agencies support HIV case management services through several funding mechanisms including the Medicaid Waiver Program and California state funds. Relying on multiple sources of funding, as well as balancing competing recommendations, often makes coordination and long term planning of services difficult for individual agencies. Additionally, the service needs identified by the

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Planning Council might be better addressed by another funding source but that may not be possible due to the fragmented structure.

Efficacy of Case Management

As discussed previously in this chapter, HIV case management was initially embraced due to the efficacy and cost savings it offered early in the HIV epidemic. However, in the past 20 years, the results of other research on case management has found case management not to be as cost effective as initially believed (Bozzette et al., 2001). Still more contemporary research has shown that case management does serve those individuals with high levels of social and medical need and does increase utilization of medical services (Cunningham et al., 1999; Cunningham, Hays et al., 1995; Johnson et al., 2003; Katz et al., 2001; Katz et al., 2000; London, LeBlanc, & Aneshensel, 1998; McKinney & Marconi, 2002; Shapiro et al., 1999). Studies have also pointed to many of the barriers to efficacy, most of which come from sources external to case management agencies themselves.

Use of case management has correlated to increased use of community services and fewer unmet client needs (Johnson et al., 2003; Katz et al., 2001; Katz et al., 2000; London et al., 1998; Scott, Hu, Hanson, Fleming, & Northup, 1995). In a longitudinal study of case management and informal care giving, people who were enrolled in case management at the beginning of a seven month study reported an increase in community services (London et al., 1998). Katz and colleagues (2000; 2001), using data from the HIV Cost and Services Utilization Study (HCSUS) found that case management was associated with fewer unmet needs. They also found that more contact with a case manager led to fewer unmet needs. Case management appeared to be effective in the areas of home health care and emotional support (London et al., 1998). However, structural barriers of the support services system often limit case manager effectiveness. For example the availability of housing services limits a case manager's ability to help clients find and remain in stable housing situations.

Case management appears to be most effective in providing services during the initial periods of care (Coffey, 2003; McKinney et al., 2002; Sorensen et al., 2003). A random trial of case management type found that duration of case management only affected outcomes in the first six-month period but that continuing care correlated with continuation of other medical care. In a study of case manager connection, frequency of contact in the initial months of case management was linked to the use of services further along in HIV treatment but not with an improvement in outcomes after the initial period (Coffey, 2003).

Data from HCSUS, also, demonstrates that case management has mixed effectiveness for improving access to and use of HIV medications (Katz et al., 2001). Respondents with case managers were significantly more likely to take at least 2 antiretrovirals and a PI or NNRTI. However, case management did not seem to lower costs or affect the use of less "risky" therapies such as PCP or toxoplasmosis prophylaxis, or taking only one antiretroviral medication. This finding was also found in a pediatric population, where children enrolled in the case management program were twice as likely to receive



antiretroviral therapy (standard of care at the time of the study) and/or PCP prophylaxis (Scott et al., 1995).

Level of Need

HIV-positive individuals experiencing multiple risks for limited access to health care and poor health outcomes utilize case management at high levels (S Abramowitz, N Obten, & H Cohen, 1998; Johnson et al., 2003; Katz et al., 2001; Katz et al., 2000; London et al., 1998; Thompson et al., 1998). Having an increased level of social service needs have been **s** hown to increase utilization of case management services for the general population as well for women (Katz et al., 2001; Katz et al., 2000; Thompson et al., 1998). When looking at activities of daily living, people with more limitations on their independence and those who rely on outside care giving services to meet these needs are likely to enroll in case management (London et al., 1998).

It appears that HIV-positive clients receiving family case management have increased levels of medical and social support needs. People receiving family HIV case management present more complex case management cases with multiple case management needs (Susan Abramowitz, Nessa Obten, & Henry Cohen, 1998). For ex ample, clients receiving family case management were twice as likely to have a history of physic al abuse and domestic violent and a third more likely to be living in a unstable housing situation (Susan Abramowitz et al., 1998). History of substance abuse was reported by the majority of HIV-postive individuals receiving family case management (Susan Abramowitz et al., 1998). As expected from a population with an increased

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number of vulnerable characteristics, the case management needs of such individuals are more complex and require multiple type of medical and social services (other cites) (Susan Abramowitz et al., 1998; Thompson et al., 1998).

Gender

Data from the HIV Cost and Services Utilization Study, a nationally representative sample of HIV-positive individuals, show that women are more likely to identify themselves as having multiple social and medical needs (Katz et al., 2001; Katz et al., 2000). Women were also more likely to report contact with a case manager in the past six months, and as a result reported fewer unmet needs than men in the sample (Katz et al., 2000).

In a chart review study of HIV-positive women in New York state, researchers found that once service needs were identified, proper referrals were made to other agencies that helped clients meet their needs (Maslanka et al., 1995). However, when female-specific services were examined trends appeared to indicate poor or no service utilization. The researchers found that no clients were referred to family planning services. Women were not referred frequently to clinical trials, an area with known access problems for women. Perhaps the most apparent lack of service need identification and service provision was drug treatment. The researchers estimate that almost 2/3 of HIV positive women in New York were infected via drug use, but in this study less than 10% of clients were identified as needing drug treatment services. Such poor service delivery in relation to gender-^sPecific needs and drug treatment reflect the lack of interaction on a structural level between HIV community based organizations and other organizations which provide these services.

Setting

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The bulk of HIV case management in the United States is delivered through hospital and community based organizations (Piette et al., 1990). The setting of case management affects its nature and how services are delivered (Susan Abramowitz et al., 1998; S Abramowitz et al., 1998; Mercier & Racine, 1995; Piette et al., 1990). One explanation for the differences caused by setting is the training and education of those providing HIV case management. Case managers in hospital settings have have more formal education and ex perience than their counterparts (Piette et al., 1990), including more specialized advanced training such as completing an MSW or nursing degree (S Abramowitz et al., 1998; Piette et al., 1990).

In a study of the Robert Wood Johnson AIDS Health Services demonstration project, Piette and colleagues (1990) found hospital case managers attained a higher level of education with 96% having at least a bachelor's degree. Less than 80% of communitybased case managers had a bachelors degree. Hospital based case managers were more likely to have either a social work degree (64%) or a nursing degree (15%) than case managers in community based organizations where less than 35% had either a nursing or social work degree. Additionally, hospital case managers had on average 2 years more experience than community based case managers (5.9 vs 3.6 years of experience). Additionally, Piette et al (1990) found that the philosophy and nature of the work performed by the case managers was different in each setting. Case managers working in community based organizations focused more on "activities that foster client independence (p 750)" and hospital based case managers more often assumed the role of agent or advocate for clients in need of services.

The se differences were clear when the researchers examined the needs of clients based on the setting where they received care. Not surprisingly hospital based clients needed more assistance with residential placement, long term care, transportation and psychological counseling. Community based organization clients were more likely to need assistance with legal issues and support services such as a emotional support volunteer ("buddy program) (Piette et al., 1990). This reflects the variety of services offered by community based organizations as opposed to the hospital along with the differences in patient needs.

Community based case workers visit clients away from the agency and work with clients when they need services delivered as opposed to initiating contact with their clients (Piette et al., 1990; Roberts et al., 1992). Hospital based case managers contacted clients on a regular basis and were less likely to report waiting for clients to contact them rather than initiating contact (Piette et al., 1990). These differences reflect the fact that case management appointments in the hospital are often coordinated with medical appointments.

Both groups reported difficulty obtaining a wide variety of services for HIV-positive clients. Though drug treatment services were difficult for both groups to obtain,

community based case managers reported more difficulty obtaining such services for their clients. Community based case managers reported more difficulty obtaining social welfare services (SSI, Medicaid etc) for clients. Hospital-based case managers reported more difficulty obtaining volunteer services.

The client settings also affected the amount of time a case manager spent with client addressing HIV needs. In a study of case management for homeless women, case management visits that occurred outside of the agency required more time with the most time intensive visits being those where the client was visited in jail (Mercier & Racine, 1995).

Barriers to Efficacious Service

Barriers to efficacious service delivery are most often linked to the scarcity of resources available to agencies, HIV case manager working conditions, and client involvement in the case management process. Specifically, funding, coordination with multiple organizations, case manager training and turnover, and consistency of client participation are identified as causing problems with the current structure of case management delivery.

As with any social service, the lack of economic and human resources provides the largest barrier for agencies being able to provide a full complement of needed services for HIV-PO sitive clients. Studies have found that AIDS service organization have honorable intentions but lack the resources to meet ever growing client demands (Roberts et al., 1992; Sonsel, Paradise, & Stroup, 1988). Additionally, because of the limitation of economic resources and the burgeoning work of case managers with large case loads, the needs of clients often are not met in a timely fashion.

Lirzking to outside services

The availability of services outside of the purview of the case management agency and working with them creates obstacles that often cannot be overcome by case management workers or even the system (Piette et al., 1990; Wright et al., 1993). Additionally, if an agency and its workers are not experienced handling the bureaucratic organizations as well as community organizations, the quality of services is often compromised (Indyk, Belville, Lachapelle, Gordon, & Dewart, 1993; Roberts, 1999; Sonsel, 1998; Wright et al., 1993). The difficulty obtaining services undermines the ability of HIV case managers to do their jobs leaving client needs unmet. Regardless of whether a case manager sees himself or herself as an advocate for the clients or an assistant in helping the client become independent, the structural problems locating and obtaining housing, substance use treatment and other outsider services does not help the case manager fulfill the role.

HIV case mangers have identified problems with referral resources and coordination of Outside services as causes of problems delivering care (Maslanka et al., 1995; Piette et al., 1990; Roberts et al., 1992; Sonsel, 1998; Wright et al., 1993). These barriers arise in both the avail ability of services as well as the ability of organizations to work with each other. In a study of the Robert Wood Johnson Demonstration Project, housing services, substance use treatment, home health care, and homemaker services were identified as being services that were the most difficult for case managers to obtain for clients (Piette et al., 1990). In a study of nurse case managers in California, respondents noted encountering community and medical services that were unavailable or inadequate, specifically rations the lack of residential and long term care facilities (Wright et al., 1993). Nurse case managers also noted problems with the relationships between organizations including poor coordination of services, lack of organization, or animosity between correst runnity organizations including competition for funding (Wright et al., 1993).

Even in a study of integrated service delivery where case management was delivered across setting and client need, Indyk (1993) found that bureaucracy in negotiating for outside services often created insurmountable obstacles for service delivery. This study found that the case managers required aggressive intervention with social services to ensure benefits were secured and that city provided services were consistent requiring time and energy is often in short supply in agencies with heavy case loads.

In an evaluation of community based services funded by the New York State Department of Health's AIDS Institute, agencies were found most often to rely on staff interactions between agencies as the main source of information exchange and links between different programs (Maslanka et al., 1995). Relying on these personal and informal networks created problems for linking HIV service organization clients to drug treatment services and maternal-child health services. To paraphrase a famous axiom, a system of health care delivery is only as good as its weakest part. Most often this weakness lies in the lack of coordination between the different elements of service delivery: physicians, nurses, social worker, treatment advocates, drug treatment professionals, mental health providers and case managers.

High Rates of Turnover

HIV case managers have high rates of turnover in their jobs. In one study of case managers over 70% of them had been in the field for over 4 years but over half had been in their current job for less than one year (S Abramowitz et al., 1998). It is interesting that the turnover rates are specific to the agencies and not to the case management profession or for HIV related work. This points to a commitment to case management work and to HIV work but also points to problems in the HIV case management system.

Within the focus groups for the Alameda County HIV Case Management Evaluation and Redesign **Project**, the high turnover rate and the disruption of the relationship between case manager and client was a reason case managers often cited for leaving case management, delaying use of services and/or dissatisfaction. Clients perceive a case manager's leaving as abandonment as well as a failing of the system. Clients also noted that such shifts in service provider meant starting over the process of having their needs met.

Large Case Loads

Case load exceeding the recommend size of 50 for individuals with HIV have been directly associated with ineffective delivery of services where activities such as monitoring of clients slips by the wayside and in turn clients have needs unmet (Jellinek, 1988; Piette et al., 1990; Piette et al., 1992). Large case loads decrease the efficacy of case manage r s ability to deal with complex cases that require a large amount of care coordination or to handle referrals to outside organizations (Sonsel et al., 1988).

The use of volunteers alleviates the problems associated with large HIV case loads (Sonsel et al., 1988). In a study of the effectiveness of AIDS Project Los Angeles, the organization relied on a large number of volunteers to help meet the service needs of clients where professional case managers maintained case loads exceeding 125 clients(Sonsel et al., 1988). These findings support the assertion that a large volunteer community and a strong public commitment to such services are essential to the development of a successful case management system (Benjamin, 1988; Benjamin et al., 1988; Jellinek, 1988). However, the use of volunteers creates another set of barriers and challenges to providing effective case management.

While volunteers reduce the impact of large HIV case loads, their lack of professional training creates other dilemmas for case management delivery. Training is also an issue for the whole profession. Professional case managers also identify training as an issue reducing the efficacy of service delivery (S Abramowitz et al., 1998; Wright et al., 1993).

In Alameda County, case managers repeatedly expressed this lack of HIV training during planning council meetings, informal discussions, and in the case manager survey administered as part of the larger project from which this dissertation data draws. Case managers expressed frustration not just at the lack of available training but also at the lack of time **i n** their schedules for in-service training. The sentiment was that large case loads and age ncy responsibilities were priorities which superceded the ability to gain additional training on a regular basis.

Consistency of Enrollment

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Case manage rnent utilization is a dynamic process with clients rotating through services and agencies In a study of case management services in California researchers found that 52% of the **care** recipients had a case manager at the initial interview and at the sevenmonth follow-up interview, 32% of those who initially had no case manager had enrolled in services **a** the seven-month follow-up, while 24% of those with case managers discontinued services (London et al., 1998). As a client moves between of services, the coordination of care and the ability to follow client needs becomes more difficult. Case managers who actively seek out their clients beyond the clinic or community-based organization reported less time for care coordination (S Abramowitz et al., 1998; Mercier & Racine, 1995; Thompson et al., 1998).

Conclusions

Beginning in the late 1980s and continuing today, case management in now entrenched in the structure of health care delivery for people living with HIV. The wide-scale

acceptance of HIV case management is further reified through governmental funding and local adoption of such programs. Because of the economic investment, HIV case management is an important area of investigation. But economics are not the only reason a social servi ce system is worth examining. Case management is worth discussing because of the larger role it plays in HIV care as well as the role of social support that cannot be me asured purely on economic levels. Case management is an integral part of the system the at delivers health care and social services to HIV-positive individuals.

People living with HIV who utilize case management are most often those with the greatest number of social and medical support needs (S Abramowitz et al., 1998; Katz et al., 2001; Katz et al., 2000; London et al., 1998; Thompson et al., 1998). Case management services, unfortunately, serve as a proxy for dealing with larger structural issues such as poverty, education and housing. Case managers are asked to help people address issues of inequality and injustice that are not specific to HIV. Because case management is asked to help meet the needs of clients and to help overcome structural barriers to care and inequality of services, case management is a system destined to fail on pure pragmatic cost outcomes.

Case management needs to be part of a system of health care delivery. It can be argued that the goal of case management is not cost savings as was first embraced as the reason for HIV case management implementation nationwide. Rather the goal of case management is increased utilization of health care and social programs and increased coordination of the multiple programs needed to manage HIV. As a result, case

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CHAPTER III

CONCEPTUAL MODEL

Although many studies have looked at the structures of case management systems and others have looked at the impact of case management on medical service use, few studies have examined the role case management plays in access to care for individuals with specific attention to vulnerable characteristics, including people in care roles. This dissertation study examined the relationships among the amount and type of HIV case management, client-perceived HIV case management need, self-reported health outcomes and client satisfaction of HIV-positive individuals, taking into account the predisposing, enabling and need factors for individuals with HIV. Using a conceptual framework designed to examine access to care for vulnerable populations that was adapted from Andersen's widely used and well recognized conceptual model of health care access and utilization (Andersen, 1995; Gelberg et al., 2000), this study focuses on understanding of the role of case management in the lives of individuals living with HIV.

Theoretical Model

The behavioral model of health services utilization is one of the most widely used models in the study of health care access. This model, developed by Ronald Andersen (1968), examines a series of personal and structural components as predictors of health care use. The model was created by Andersen to predict and explain health care use (Andersen, 1995). The original model has been adapted several time (Aday & Andersen, 1974, 1978; An dersen, 1995; Andersen & Aday, 1978; Andersen & Newman, 1973) to provide different ways of examining health care. While the earlier versions of the model were designed for a "general population," Gelberg, Andersen and Leake (2000) adapted the model for vulnerable populations and the unique issues of access experienced by these groups. The behavioral or "Andersen" model and the various theoretical derivations have proven useful in examining case management services among an HIV-positive population because of its focus on access to care as functions of personal, environmental, and structural influences (Katz et al., 2001). In the section below, the evolution of the Andersen model is discussed from its use in examining issues of access to care for general populations to its use in examining access to care for specific vulnerable populations.

In the first published versions of the behavioral model, Andersen (1968) and Andersen and Newman (1973) presented a theoretical framework that would be adapted, and later revised, to meet the changing needs of health policy research as the nature and structure of American health care changed. The model described a way of understanding the utilization of health care on both a societal level and individual level (Andersen, 1968; Andersen & Newman, 1973). The authors modeled health care utilization with an understanding that "societal determinants of utilization are shown to affect the individual determinants both directly and through the health services system (Andersen & Newman, 1973)." Societal determinants (technology, norms) and health services systems (resources and organization) interact as well as independently impact individual *de*terminants of health (predisposing, enabling and illness level) which in turn impacts *he*- alth services utilization (type, purpose and unit of analysis).



The 1974 model of access to medical care developed by Aday and Andersen built on Andersen's earlier published model (Aday & Andersen, 1974). The 1974 revision introduced notions of health policy and consumer satisfaction while expanding the understanding of utilization to include the notion of access. By including health policy, the authors recognized the political and economic nature of the American health care system and considered the role of financing, education and manpower in health care. Unlike the earlier model of health utilization, this model recognized that federal, state and large organizational (i.e., AMA and insurance agencies) policies affect how health delivery systems operate on a local level. Also, national policies impact how individual characteristics, especially enabling and need characteristics, are experienced. Aday and Andersen recognized that many policies are "intended to directly affect characteristics of the delivery system (p215) (Aday & Andersen, 1974)."

In their 1978 article, Andersen and Aday established two categories of access: potential and realized. Although the two were presented as distinct and mutually exclusive, the authors noted that interrelationships between the categories existed and were potentially more important than the individual aspects. Potential access is defined as the variables that reflect the probable access to medical care. Under potential access the authors examined structural indicators and process indicators, which are constructed of three individual level variables: predisposing characteristics, enabling characteristics, and need *ch*aracteristics. Realized access, in contrast, was measured by factors that assessed how, *w* hen and what health services were used and consumer satisfaction with services. The

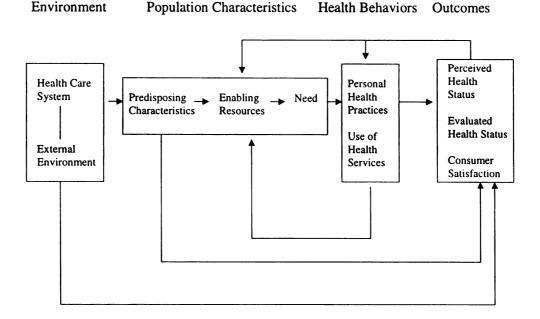


concepts of potential and realized access are not included in the 1995 revision of the Andersen model nor in the 2000 revision for vulnerable populations and hence won't be explored in this dissertation.

In 1995, Andersen provided a retrospective evaluation and proposed a further revision of the model he had developed a quarter century earlier. This revised model offered a more robust understanding of how environmental characteristics, population characteristics, health behavior, and outcomes are related. Specifically, Andersen proposed that outcomes cycle back to impact population characteristics. He further noted that social relationships, something not fully considered in previous versions of his model, are worth examining because they can "facilitate or impede health services' use (p2) (Andersen, 1995)." The 1995 revision brought together the work of Andersen and other theorists to provide a model that met the contemporary needs of health services research by looking at specific populations with more focus on measures of access as well as factors impacting it.

Figure 1

The Behavioral Model of Service Utilization from Andersen (1995)

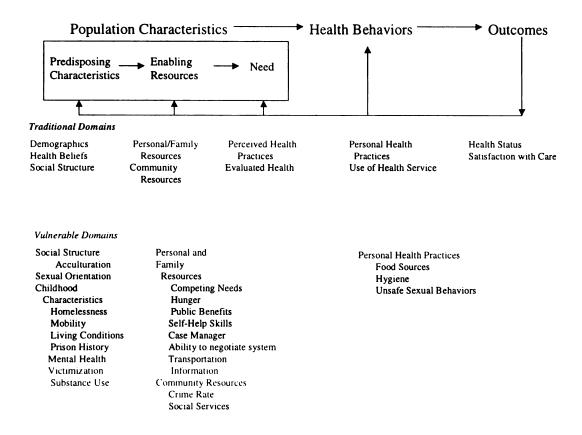


Focusing on vulnerable populations, specifically homeless individuals, Gelberg, Andersen and Leake (2002) presented another revision of Andersen's model that expanded the scope of factors affecting access to care. One change in this revision was that personal health practices were seen as outcomes of health care utilization rather than as health behavior practices that influenced other health outcomes such as satisfaction or utilization. The authors also added a list of domains specific to vulnerable populations. This list included social structures and childhood characteristics, personal resources and personal health practices such as food sources and hygiene that were viewed as being specific to vulnerable populations.

Figure 2

The Behavioral Model for Vulnerable Populations

from Gelberg Andersen and Leake (2000)



The theoretical concepts of the "Andersen" models continue to be organized in a series of broad areas. Environment variables relate to the health care system and external environmental conditions, such as federal policies. Population characteristics are measured in terms of categories of predisposing characteristics, enabling resources, and health care needs of individuals. Health behavior variables relate to personal health practices and use of health services. Access or health outcomes are measured in relation to health care utilization, health status, and consumer satisfaction.

Environment Variables

Societal determinants reflect the culture and context in which health care is practiced as well as utilized (Andersen & Newman, 1973). Health care policies on a national, state, and local level are driven by how society views health care. "Societal norms [that have] the greatest effect on health services utilization have to do with how medical care is financed (p104) (Andersen & Newman, 1973)." In 1973, Andersen and Newman pointed to the growth of the population covered under voluntary health insurance and governmental insurance programs as a reflection of the societal concern about the hardship of out-of-pocket expenses relating to health care. In contemporary terms, the debates about the viability of Medicaid and Medicare reflect the same social processes.

The study of the environmental or structural component of health care presupposes that the method by which labor and capital resources are allocated throughout the system affect health care delivery and use. Furthermore, there is an assumption that the availability of more and better-organized resources should improve the utilization by individuals. Andersen and Newman (1973) note that these societal level measures are the most difficult components of the model to define and to measure. Many of the elements used in the model, and in measurement, are interrelated and seldom create a parsimonious and elegant model to test (Phillips, Morrison, Andersen, & Aday, 1998).



The difficulty of measuring environmental characteristics limits their utility in research on health care access. Twenty-five years after the publication of the Andersen model, a structured literature review examined how environmental and provider-related variables had been used by researchers employing the Andersen model of health care utilization (Phillips et al., 1998). The researchers found environmental and provider characteristics are more often excluded from analysis than characteristics about the population seeking care and the utilization of services. Less than 15% of the papers reviewed included environmental measures and provider-related characteristics. Specifically relating to environmental characteristics, problems arise from a lack of data. Most often environmental characteristics are collected about an aggregate, and connecting this information to information generated about individuals is both complicated and often methodologically unsound. Though these measures are often hard to conceptualize and operationalize in a research design, the authors cite such exclusion as explaining "the low amount of variance explained by studies using the behavioral model (Phillips et al., 1998: p.586)."

Population Characteristics

The individual characteristics and the three categories (predisposing, enabling and need) of population characteristics which comprise one component of the model have remained unchanged throughout the revisions of the health care service utilization model (Aday & Andersen, 1974, 1981; Andersen, 1995; Andersen & Aday, 1978; Andersen et al., 1983; Andersen & Newman, 1973). The category of predisposing variables in the original model included the sub-categories demographics, social structures, and beliefs (Andersen



& Newman, 1973). Demographics were defined as individual characteristics that affect the equitable distribution of health services. These characteristics include age, gender, illness level and health. Social structure variables included education, race, occupation, family size, ethnicity and residential mobility. Beliefs incorporated how a person, or family, understands health and health care, including knowledge about disease and attitudes towards health services. Enabling sub-categories included family and community. In the 1973 model, access to regular sources of care, income, health insurance and type of regular care were all subsumed under the rubric of family. Community elements include access to health personnel and facilities, cost of services, and region.

Illness level includes subcategories of perceived illness and evaluated illness. Perceived illness is how the patient or his family defined the disease experience, including disability, symptoms and general health state. Evaluated illness level is the assessment by a health care provider of acuity and includes symptoms and diagnosis. Andersen and Newman (1973) ranked illness level as having the highest relative importance to utilization of hospital, physician and dental services. They found beliefs and community resources, in the predisposing and enabling categories respectively, to have low relative importances in the utilization of these three health services. All other subcategories were found to be of medium impact, except social structure, which was found to have low impact on hospital utilization and high impact on dental utilization, and family resources, which had a relatively high impact on dental services. The differences in dental services



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probably reflected the lower number of individuals with third-party coverage of dental services.

Health Behavior and Outcomes

The Andersen model evolved over time to include an understanding of the appropriate outcomes to examine while looking at environmental and population characteristics. Initial models looked at health behaviors as a measure of utilization as an outcome of the model. Later revisions of the model broadened the understanding of health outcomes to include both objective and subjective measures, while considering individual health behaviors as predictors. However, many studies continue to look at health behaviors as outcomes of access to care. In the review below, the evolution of these concepts is discussed.

In terms of health services utilization, Andersen and Newman (1973) were concerned not only with the number of contacts a patient had but also with the type of care they utilized (e.g. hospitals, dental care, nursing homes), the reason for seeking care (e.g. primary care, custodial care) and the volume of services. By using a dynamic and multidimensional measure of health services utilization, the model reflected the varied nature of health care as well as the patterns of use in America.

Aday and Andersen in the 1974 adaptation of the model addressed how access (as a marker for, or a synonym of, utilization) can be conceptualized, operationalized and measured. Access can be measured in many ways, including coverage of the population

by insurance, number of doctor visits or hospital days, and the ability to use services when they are needed, either because of number of doctors or ability to pay. The authors argued that accessibility moves beyond "the mere existence or availability of resources at any given time (Aday & Andersen, 1974)," and suggested measuring health care access from two diverse perspectives, process and outcomes. Process indicators examine how patients, as well as resources, move through the health care system. This is done by evaluating delivery system characteristics such as volume of services and distribution of resources, especially in relation to the population of interest. Outcome indicators reflect the end results of the health delivery system, in terms of health policy impacting the whole model as well as individual aspects. Measures of utilization are suggested as the best measure of access from an outcomes perspective.

Using a modified version of Andersen's health model to understand issues of access, the Institute of Medicine undertook a review of access to health services in the United States (Institute of Medicine, 1993). This report clearly explained the leap the Andersen model made when access to care was split to include both objective measures (i.e. utilization) as well as subjective outcomes including " the timely use of personal health services to achieve the best possible health outcomes (p4)." The expanded view of access allowed the Institute of Medicine committee to look beyond service utilization to other health and service outcomes.

Aday and Andersen (1981) note that both measures of what is appropriate access as well as what are specific levels of need are often subjective. They argue that consumer satisfaction levels are just as reliable a measure of access and perhaps more socially important when looking at medical success. Consumer satisfaction, as defined by Aday and Andersen (1974), refers to the subjective components of the health care utilization experience. These components include how patients evaluate their satisfaction with care, how they evaluate the quality of the care they receive, and what they believe about the medical system in general. In terms of measurement of consumer satisfaction, Aday and Andersen note, "consumer satisfaction, however, is probably best evaluated in context of specific, recent and identifiable episode of medical care seeking (p215)."

Modifications of the Behavioral Model for Vulnerable Populations

This dissertation employed the 2000 adaptation to the Andersen model developed to study vulnerable populations (Gelberg et al., 2000). Vulnerable populations in relation to health care are defined as populations "at risk of poor physical, psychological, or social health (Aday, 2001)." Populations identified as vulnerable tend to have serious and often debilitating needs that require concentrated medical and social services. However, the current level of services is often not adequate to meet the needs of these populations (Aday, 2001). From a policy perspective, vulnerable populations create a challenge for policy makers in that they place a greater proportion of demands on existing services (Aday, 2001). The model employed in this dissertation was developed to study a population of homeless individuals to better explain the nature of health access for individuals with structural disadvantages to the health care system (Gelberg et al., 2000). Because of health care complexities associated with HIV, as well as the disproportionate number of ethnic minority individuals, substance users, and gay men living with HIV,

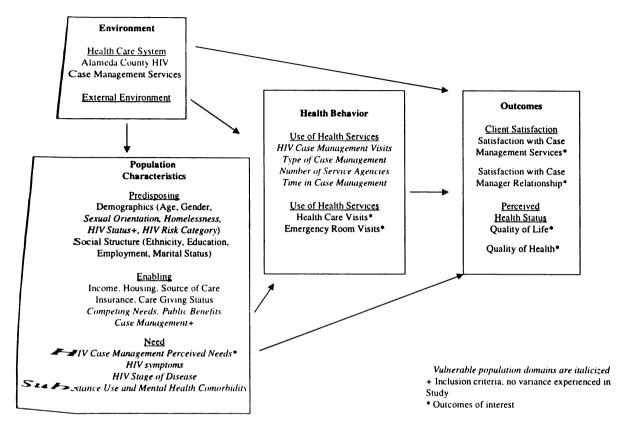


Aday (2001) identifies individuals who are HIV-positive as a vulnerable population. Hence, the vulnerable population model proposed by Gelberg (2000) should better be able to examine the access to health care than would the more general models developed by Andersen and colleagues.

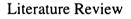
One further adaptation of the health behavior utilization model is the inclusion of, and focus on, case management as a component of health care access. Though the Andersen model was developed to examine health care access more generally, Katz and colleagues (2000) used the model to examine access to case management. This dissertation moves beyond Katz and colleagues by including use of case management services as a health behavior impacting client quality of life, quality of health and clients satisfaction with care. Furthermore, this dissertation builds on previous case management work by including the types of case management and the number of case managers seen in the model.







Adaptation of the Behavioral Model for Vulnerable Populations



Environment

As d iscussed earlier, very few studies incorporate environmental characteristics in their
 analysis of HIV services (Health Resources and Services Administration, 2000; Phillips
 et al., 1998). However, of the few HIV studies that do consider environmental
 characteristics, community settings are the most often explored. Those studies that did
 amine the community in which a person who had HIV lived show that combination of
 factors play a role in accessing medical care. Individuals living in communities with low

HIT prevalence report having a greater number of unmet social and medical needs than in \mathbf{d} ividuals living in areas with high HIV prevalence (Bonuck et al., 1996). This reflects the absence of a formal infrastructure to care for individuals living with HIV that is present in areas with high prevalence of HIV. Looking at urban centers, mixed results were found in relation to accessing pharmaceutical therapies.

A study of Medicaid patients in New Jersey found that individuals living in urban areas were more likely to receive a prescription for new drug therapies compared to those living in suburban and rural communities (Sambamoorthi, Moynihan, McSpiritt, & Crystal, 2001). However, a study in Baltimore found that individuals living in an urban sett ing were less likely than those living in suburban settings to receive complicated and advanced pharmaceutical treatments such as HAART (Keruly, Conviser, & Moore, 2002). These conflicting findings might reflect the benefits of being in a high prevalence area or near an academic medical center but also reflect problems of access commonly found in urban centers in the United States such as insurance, income and education.

Population Characteristics: Predisposing

For i ndividuals with HIV, age has been found to have mixed influence on access to HIV
services. A national study of AIDS patients found that being younger was associated with
delaying care (Turner et al., 2000). Being older was associated with increased
bospitalization, increased mental health needs and increased use of psychotherapeutic
medications (Hellinger & Fleishman, 2001; Schuman et al., 2001). Individuals over 50
were found to have lower PCP prophylaxis use (Shapiro et al., 1999). However, studies



individuals living with HIV in Northern California, Houston and New Orleans found
 age-related differences in access to medical care (Magnus et al., 2001; Montoya,
 i chard, Bell, & Atkinson, 1997; Shiboski, Palacio, Newhaus, & Greenblatt, 1999).

With regard to access to case management, younger individuals who are HIV-positive were more likely to need social support services (Katz et al., 2000) and were more likely to initiate use of services (London et al., 1998). While older individuals were found to use fewer community services (London et al., 1998), they were likely to have fewer unmet cours seling needs (Montoya et al., 1997).

The majority of studies examining gender and HIV found that women had less access to medical care than men (Bozzette et al., 2001; Hellinger, 1993; Hellinger & Fleishman, 2001; Mor, 1993; Rogers, Futterman, Levin, & D'Angelo, 1996; Stein & Mor, 1993; Stone, Weissman, & Cleary, 1995; Weissman et al., 1995). This reflects the fact that women were more likely than men to be experience barriers to care due to other social conditions such as housing and care giving roles (Arno et al., 1996; Stein et al., 2000). Weissman (1995) found that men, after testing HIV-positive, were more likely to be told to Seek medical treatment and were more likely to receive more assistance in doing so. Women with HIV were less likely than men to see the same health care provider at each health care visit and were more likely to be seen at a clinic as opposed to a private Physician's office (Stein & Mor, 1993). With respect to pharmaceutical treatments, women waited longer to be prescribed HIV-related medication and were less likely to receive PCP prophylaxis, AZT and PI therapies than men (Bozzette et al., 2001; Keruly et al., 2002; Mor, 1993; Shapiro et al., 1999). Overall, women with HIV tended to be more dissatisfied with the quality of the medical care they received than men (Stone et al., 1995).

On other hand, several studies found no association between gender and access to medical care or unmet needs for individuals with HIV (Bonuck et al., 1996; Cunningham, Mosen, Hays, Andersen, & Shapiro, 1996; Heslin et al., 2001; Montoya et al., 1997). Perhaps earlier in the HIV epidemic, women did not face barriers to medical care but this may have been an artifact of small sample sizes as well as the sampling strategies of selecting individuals already using medical services (Bonuck et al., 1996). Two of the studies that did not find gender differences in access were based on samples of patients from specific urban centers where other factors such as income and insurance may have mitigated gender differences (Cunningham et al., 1996; Montoya et al., 1997).

The relationship between gender and access to social services is not as clear. A national study of case management showed that HIV-positive men were more likely than women to receive case management (Fleishman et al., 1991). In a study of HIV-positive *inc*lividuals living in Denver, women were found to contact social workers and support *serv*ices less often than men (Davidson et al., 1998). However, a study in California as **well** as a national study of individuals with HIV found that being female was associated **with** increased use of case management (Katz et al., 2001; London et al., 1998). Another **at** ional study found that though women had more service needs, they had fewer unmet **soc**ial needs (Katz et al., 2000). This mixed result in terms of social services, as opposed

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to medical services, reflects local differences in social service delivery which is not as pronounced in the delivery of medical services.

Education was consistently associated with access to care. HIV-positive individuals with higher levels of education experience greater access to medical and social services (Bozzette et al., 2001; Cunningham et al., 1999; Cunningham et al., 1996; Gifford et al., 2002; Heslin et al., 2001; Katz et al., 2001; Katz et al., 2000; Kilbourne et al., 2002; Marcus et al., 2000; Mor, 1993; Schuman et al., 2001; Shapiro et al., 1999; Stein & Mor, 1993). Only two studies found education was not associated with access to care for HIV-positive individuals and the measures of access in both studies were very specific types of access, such as Pap smears and dental care (Shiboski et al., 1999; Stein et al., 2001). With regard to the use of case management, individuals with higher education levels to used fewer case management services (Heslin et al., 2001; Katz et al., 2000).

Employment was consistently associated with access to medical care and social services for HIV-positive individuals (Cunningham et al., 1999; Fleishman et al., 1991; Heslin et al., 2001; London et al., 1998; Marcus et al., 2000; Shiboski et al., 1999). It is worth noting that Cunningham (1999) found that individuals who were employed were more likely to delay care due to conflicts with employment. HIV-positive individuals who were employed had decreased utilization of case management and social services but also reported fewer unmet needs (Fleishman et al., 1991; Heslin et al., 2001; London et al., 1998; Marcus et al., 2000). Even with a relationship between employment and access to

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care, improved access also reflect the presence of health insurance as well as better general health status of employed individuals (Stein, Fleishman, Mor, & Dresser, 1993).

The vast majority of studies examined found differences in access for HIV-positive individuals based on race and ethnicity. Decreased levels of access to medical care across all measures of access were consistently identified for African American and Latino individuals with HIV (Bozzette et al., 2001; Curtis & Patrick, 1993; Fleishman et al., 1991; Gifford et al., 2002; Hellinger & Fleishman, 2001; Heslin et al., 2001; Keruly et al., 2002; Kilbourne et al., 2002; Marcus et al., 2000; Mor, 1993; Sambamoorthi et al., 2001; Schuman et al., 2001; Shapiro et al., 1999; Stein & Mor, 1993; Turner et al., 2000). African Americans with HIV had more adverse medical experiences related to their HIV as well as greater unmet needs than Caucasians living with HIV (Burnam et al., 2001; Cunningham et al., 1999; Curtis & Patrick, 1993; Hellinger & Fleishman, 2001; Kilbourne et al., 2002; Marcus et al., 2000; Shapiro et al., 1999; Turner et al., 2000). Less use of pharmaceutical treatments for HIV was found in the African American and Latino communities (Bozzette et al., 2001; Gifford et al., 2002; Keruly et al., 2002; Mor, 1993; Sambamoorthi et al., 2001; Shapiro et al., 1999). The differences in utilization were mirrored in client satisfaction with health care, with African Americans and Latinos being more dissatisfied with their health care than were Caucasians (Siegel & Raveis, 1997; Stone et al., 1995).

Several studies, however, did not find that race was associated with access to medical care (Bonuck et al., 1996; Cunningham et al., 1996; Magnus et al., 2001; Montoya et al.,

1997; Shiboski et al., 1999; Stein et al., 2001). Studies of women with HIV tended to show that race was not associated with access (Magnus et al., 2001; Shiboski et al., 1999; Stein et al., 2001). This finding suggest that in populations already disadvantaged in terms of access to care race becomes a less significant factor in relation to access.

Racial and ethnic minority populations had an increased need for social services, including case management (Katz et al., 2000; Schuman et al., 2001; Smith & Rapkin, 1995). Non-white individuals experienced increased utilization of case management services (Fleishman et al., 1991; Katz et al., 2001; Katz et al., 2000). These populations also had greater levels of unmet and competing needs in areas of social services such as housing, counseling, benefits advocacy and transportation (Arno et al., 1996; Cunningham et al., 1996; Heslin et al., 2001; Katz et al., 2001; Katz et al., 2000; Smith & Rapkin, 1995). It is important to note that the significance of race disappeared in studies of race-specific case management programs (Montoya et al., 1997; Shiboski et al., 1999). These smaller studies indicate that local communities did an effective job at reducing barriers to care based on race.

Population Characteristics: Enabling

Personal and household income for HIV-positive individuals was associated with access to medical care. HIV-positive individuals who had higher income levels experienced better access to medical services, regardless of the measure of utilization (Cunningham et al., 1996; Diaz et al., 1994; Heslin et al., 2001; Kilbourne et al., 2002; Marcus et al., 2000; Montoya et al., 1997; Preston-Martin et al., 2002; Shapiro et al., 1999; Shiboski et al., 1999). However, income was negatively associated with social support service utilization and unmet needs. Individuals with lower incomes were more likely to use case management services (Katz et al., 2001; London et al., 1998). Individuals with higher incomes reported more problems accessing to social services (Montoya et al., 1997). The only area where individuals of lower socioeconomic status consistently had greater unmet social service need was housing (Katz et al., 2000).

The type of health insurance a person with HIV was associated with access to medical care care. Individuals with private insurance consistently found better access to medical care than individuals with any other type of medical coverage or with no health insurance (Bozzette et al., 2001; Cunningham, Hays et al., 1995; Cunningham et al., 1996; Fleishman & Mor, 1993; Hellinger & Fleishman, 2001; Heslin et al., 2001; Keruly et al., 2002; Kilbourne et al., 2002; Knowlton et al., 2001; Marcus et al., 2000; Mor, 1993; Schuman et al., 2001; Shapiro et al., 1999; Shiboski et al., 1999; Stein & Mor, 1993; Turner et al., 2000). When gender was considered, having private insurance had a greater impact on unmet health care needs for women than for men (Bonuck et al., 1996).

Studies examining access to care for HIV-positive individuals with public insurance offer mixed results, especially when Medicare and Medicaid patients were compared. HIVpositive Medicare patients, while having shorter hospital stays than individuals with private insurance, had significantly longer stays than individuals with Medicaid (Hellinger & Fleishman, 2001; Kim, Stoskopf, & Glover, 2001). Medicare patients were more likely to be prescribed complicated and costly HIV medical regimens (e.g. PI and NNRTI combinations and HAART) than individuals with Medicaid, (Keruly et al., 2002; Sambamoorthi et al., 2001). Findings related to pharmaceutical treatments are particularly interesting since federal and state drug assistance programs often offset the costs associated with such treatments. Individuals with Medicaid coverage were less likely to voluntarily delay care when compared to Medicare patients and patients with no insurance (Turner et al., 2000). HIV-positive individuals with Medicaid, however, were least satisfied with their medical care and were most likely to have perceived barriers to accessing medical care (Cunningham, Hays et al., 1995; Seals et al., 1995; Stein et al., 1993).

HIV-positive individuals with no health insurance had the lowest medical utilization compared to individuals with public and private insurance (Bonuck et al., 1996; Cunningham, Hays et al., 1995; Cunningham et al., 1996; Fleishman & Mor, 1993; Marcus et al., 2000; Mor, 1993; Palacio, Shiboski, Yelin, Hessol, & Greenblatt, 1990; Stein & Mor, 1993; Stein et al., 2000). Individuals without insurance were often forced to choose between the cost of medical care and other basic needs, including going without clothing, food or housing to meet medical needs (Cunningham et al., 1999). Lack of insurance was also associated with missed medical appointments (Marcus et al., 2000).

In terms of social services, individuals with public insurance or no insurance have increased utilization of social services. Individuals with public insurance and no insurance are more likely to have a case manager (Fleishman et al., 1991; Heslin et al., 2001; Katz et al., 2001; London et al., 1998). Individuals with public insurance were also found to use more community based HIV services (London et al., 1998).

Care giving responsibilities for children as well as other individuals with HIV has consistently been associated with forgoing medical care for individuals living with HIV (Stein et al., 2000). For individuals with care giving responsibilities who used health care services, care giving was associated with a delay in initiating medical care for themselves (Shiboski et al., 1999; Stein et al., 2000). In a national study of women with HIV, care giving was associated with decreased need for mental health services as well as decreased use of psychotherapeutic medications (Schuman et al., 2001). African American children of HIV-positive parents were disproportionately under-enrolled in social services (Scott et al., 1995). Because of these findings, it was expected that individuals with care giving responsibilities had lower perceived health status and less client satisfaction with case management.

Housing situations of individuals living with HIV have been found to be associated with access to medical care and social services. Individuals who were unstably housed had lower levels of functional status as well as higher levels of emergency room utilization (Arno et al., 1996). Individuals who were stably housed had a greater number of ambulatory care visits (Arno et al., 1996). With regard to social services, individuals who were unstably housed were more likely to have at least one social service need (Katz et al., 2000). A nationally representative study found individuals without stable housing

were more likely to have unmet benefit advocacy and home health support needs than individuals with stable housing (Katz et al., 2000). However, even with increased social service needs, this same study found that housing situation was not associated with a changed in frequency of or need of contact with a case manager (Katz et al., 2000).

When looking at whether HIV-positive individuals live alone or with others, findings concerning which situation improves an individuals' health access are mixed. Living with other individuals was positively associated with having a primary care provider (Palacio et al., 1990). Women who lived alone were more likely to report a need for mental health services (Schuman et al., 2001). A study conducted earlier in the HIV epidemic found that stable housing was not related to unmet needs (Bonuck et al., 1996).

National data showed that having a competing need such as transportation, housing or food decreased access to health care services for HIV-positive individuals. Individuals with competing needs had increased emergency room use and increased delays in getting medical care (Cunningham et al., 1999; Cunningham, Hays et al., 1995). Competing needs were also associated with being less likely to be prescribed antiretroviral therapies (Cunningham et al., 1999). Furthermore, individuals with competing needs perceived the barriers to getting medical care as greater than individuals without competing needs (Cunningham et al., 1999). Cunningham (1999) found that many patients with severe HIV disease, put off care due to competing needs, demonstrating that disease severity played less of a role in seeking care than having other basic needs met. Having a regular source of HIV and general medical care, especially a private physician, was associated with improved utilization of medical care (Cunningham, Hays et al., 1995; Cunningham et al., 1996; Preston-Martin et al., 2002; Schuman et al., 2001; Stein et al., 2001; Turner et al., 2000). Though high level HIV care is often practiced in hos pital based clinics, having an HIV clinic as a site of primary care was associated with see ing an having an increased number of physicians as well as increased number of physician visits (Stein & Mor, 1993). Furthermore, patients seen in HIV clinics had dec reased hospital stays and shorter survival times after diagnosis (Hellinger & Fie ishman, 2001; Laine et al., 1998). Individuals cared for at private physician offices or Hosettings were more satisfied with their care than individuals seen at hospital clinics (Stein et al., 1993; Stein & Mor, 1993; Stone et al., 1995).

Population Characteristics: Need

Suppose were consistently predicted need of, and access to, care. Individuals with Suppose the symptoms needed more medical services, HIV self-care assistance and HIV home care (Weissman et al., 1995), as well as more social support services (Smith & Rapkin, 1995). Furthermore, individuals with greater number of symptoms were found to be less satisfied with access and interpersonal relationships with care providers (Stein et al., 1993). However, it is important to note that individuals with HIV-related symptoms were more likely to delay care (Turner et al., 2000)

For individuals living with HIV, stage of disease played a large role in access to care. Individuals with more advanced stages of HIV utilized more health care services, had



The adverse health experiences, and had greater needs for health care (Bonuck et al., 1996; Burnam et al., 2001; Hellinger & Fleishman, 2001; Keruly et al., 2002; Kilbourne et al., 2002; Laine et al., 1998; Montoya et al., 1997; Palacio et al., 1990; Schuman et al., 2001; Shapiro et al., 1999; Stein et al., 2000; Weissman et al., 1995). In early studies, the distinction between being HIV-positive without an AIDS diagnosis and having an AIDS diagnosis was used as a marker of stage of disease progression. This distinction was

Omen living with an AIDS diagnosis, as opposed to an HIV diagnosis, perceived the
i gma of the disease itself as barrier to medical care (Seals et al., 1995). Having an AIDS
i gnosis was found to be associated with being uninsured and having a greater number
f primary care visits and emergency room visits (Diaz et al., 1994; Fleishman et al.,
91; Knowlton et al., 2001; Palacio et al., 1990). In more recent studies of HIV, biologic
arkers such as viral load and CD4 cell counts have been used to stage disease
of gression. Using clinical markers for HIV disease progression removed a sense of
stigma and provided a continuous rather than dichotomous measure of stage of disease.
Individuals with low CD4 cell counts used more medications, (Gifford et al., 2002;
Keruly et al., 2002; Knowlton et al., 2001). While individuals with high CD4 cell counts

Stage of disease for individuals with HIV was associated with social service utilization. Individuals with more advanced stages of HIV were more likely to need, and to receive, case management services (Fleishman et al., 1991; Katz et al., 2001; Katz et al., 2000). Individuals with less advanced HIV disease were less likely to be able to get counseling and case management services (Montoya et al., 1997). Asymptomatic individuals had greater social service needs, yet were less likely to access social services because of the manner in which many social service organization were established (Burnam et al., 2001; Weissman et al., 1995).

yond stage of disease, comorbid conditions, including drug use and mental illness,
re associated with increased health care use as well as increased health care problems
sociated with HIV. Individuals with comorbidities had more and longer hospitalizations
an individuals with few or no diagnoses (Kim et al., 2001). However, when individuals
i th comorbid conditions were hospitalized for non-HIV related conditions their hospital
ys were shorter than when hospitalized for HIV-related conditions (Kim et al., 2001).
searchers found that comorbidity was associated with an increase in the number and
verity of HIV symptoms (Kilbourne et al., 2002).

i cit substance use played an important role in access to care for individuals with HIV.
travenous drug use (IDU), both current and past was found to be related to decreased
alth care utilization (Arno et al., 1996; Keruly et al., 2002; Knowlton et al., 2001; Mor,
93; Palacio et al., 1990; Shiboski et al., 1999; Turner et al., 2000). Individuals with a
tory of IDU were less likely to receive pharmaceutical treatment for HIV (Keruly et
2002; Mor, 1993). Enrollment in drug treatment programs improved access to
dical care. Specifically, individuals in drug treatment had more outpatient visits, a
ual source of care, and saw the same health care provider (Knowlton et al., 2001).

Individuals who were currently using illicit substances were more likely to be dissatisfied ith the quality of care they received (Stone et al., 1995). Several studies found that Substance use was not associated with problems accessing medical or social services (Magnus et al., 2001; Montoya et al., 1997; Schuman et al., 2001).

Image: A constraint of the services of the

Imber of perceived medical, emotional and social support needs was associated with
rollment in case management as well as frequency of contact with a case manager
Atz et al., 2001; Katz et al., 2000; London et al., 1998). The needs most often reported
ere related to health care services such as dental care, mental health and self care
onuck et al., 1996; Smith & Rapkin, 1995). The total number of needs was not
sociated with the number of unmet needs (Katz et al., 2000). The complexity of the
cial service needs, such as finding housing for clients when very little was available,
as found to be associated with greater unmet need (Smith & Rapkin, 1995).

Health Behavior

U se of case management by individuals who are HIV- positive was positively associated
i th access to medical and social services (Fleishman et al., 1991; Katz et al., 2001; Katz et al., 2000; Knowlton et al., 2001; London et al., 1998; Magnus et al., 2001; Thompson
al., 1998). In a national study of individuals with HIV, case management was
Sociated with medication adherence and reception of effective home health support
atz et al., 2001; Katz et al., 2000). Case management was associated with the
Creased likelihood of receiving antiretroviral therapies as well as complicated
Creased likelihood of receiving antiretroviral therapies as well as complicated
HIV-positive women found that case management was particularly effective in
Creasing access to consistent medical care. These studies found case management was
Sociated with improved retention in medical care, increased outpatient visits and the
bility to see the same primary care provider (Knowlton et al., 2001; Magnus et al., 2001; Magnus et al., 2001).

In number of social services used by individuals with HIV was positively associated
I th use of case management services. (Fleishman et al., 1991; Katz et al., 2001; London
al., 1998). Case management was also associated with fewer unmet social needs,
creased social needs over time, as well as improved quality of life (Katz et al., 2001;
atz et al., 2000; Nickel et al., 1996; Thompson et al., 1998). The use of case
anagement improves access to medical and social services.

In studies that examined the amount of case management received and described the i **r** tensity of case management service used, the average number of visits to a case anager in one month ranged from one to almost four visits (Fleishman et al., 1991; Thompson et al., 1998). Research indicated that the number of contacts with a case anager was positively correlated with the number of services needed by an HIVsitive individual and with the number of services provided by the case manager C IF Leishman et al., 1991; Thompson et al., 1998). Greater contact with a case manager Creased the number of unmet client needs (Katz et al., 2001). Frequency of contact **i** th a case manager was found to be positively associated with satisfaction with case anagement (Fleishman et al., 1991). While studies did assess the importance of having The quent and consistent contact with a case manager, no studies examined at the Toplications of having multiple case managers. It was expected that the greater number Section 1 with the past month would be positively associated with client-Torted case management need as well as clients satisfaction with case management S C rvices. It was also expected that clients with multiple case managers would have a E cater number of needs as well as greater satisfaction with case manager responses to ~ 1 i ent need.

Studies examining type of case management service used focused attention on the
 Ifferences in utilization of case management services rather than medical or social
 Utcomes. The median number of client visits being seen by case managers at
 Ommunity-based organizations was higher than the median number of visits for clients
 F clinic-based case managers (Fleishman et al., 1991). Proportions of clients who had

Contact with a case manager every month were higher for hospital-based and clinic-based
Case managers than for case managers practicing in community-based organizations
(Piette et al., 1990). The effectiveness of case managers in meeting clients needs was
Studied from the case manager perspective. Case managers at community-based
Case anizations reported more difficulty obtaining social welfare services while hospitalCase managers reported more difficulty obtaining volunteer, legal and housing
Crvices for clients (Piette et al., 1990). It was expected that clients who received case
Canagement at community-based organizations would have more visits with a case

The relationship between HIV medication use and survival time is well founded (Laine et ., 1998; Lenderking et al., 1994). Researchers also found a relationship between HIV
Catment and access to other medical services. A national study of HIV-positive women
Und that women using anti-retroviral medications were more likely to use
Sychotherapeutic medications than HIV-positive women who were not using antiTroviral medications (Schuman et al., 2001).

Outcomes

here have been no studies of client satisfaction with case management services. Most
dies that look at case management outcomes only examine unmet needs (Fleishman et
, 1991; Katz et al., 2001; Katz et al., 2000; Knowlton et al., 2001; London et al., 1998;
agnus et al., 2001; Thompson et al., 1998). However, client satisfaction with medical
are should be expected to mirror client satisfaction with HIV case management services.

C lient satisfaction with medical care has been widely studied among HIV-populations. **I I V**-positive individuals, like the general population, assess their medical care with a **i** gh degree of satisfaction for care provided by both physicians and nurses (Cleary, 1999; **C** l eary & Edgman-Levitan, 1997; Langner & Hutelmyer, 1995; Stone et al., 1995). **S a**tisfaction scores based on a scale similar in structure to that employed in this **i** ssertation ranged from 80% to 90% (Stone et al., 1995). Differences in satisfaction **I** irror differences in access. Women tend to be more dissatisfied with the quality of the edical care they receive compared to men (Stone et al., 1995). African Americans and The atinos reported being more dissatisfied with their health care than Caucasians (Siegel & aveis, 1997; Stone et al., 1995). Individuals with greater number of HIV symptoms reless satisfied with access and interpersonal relationships with care providers (Stein \leftarrow al., 1993). Individuals with more education were satisfied with the quality of the care **T A** ey received. How care is paid for and where a patient receives care also impacted Satisfaction. Individuals with Medicaid were least satisfied with their medical care, when ← ← mpared with individuals insured through public insurance and Medicare (Cunningham, **I** ays et al., 1995; Seals et al., 1995; Stein et al., 1993). Individuals who changed • Surance status from having private insurance to having no insurance, most often due to **1** • ss of employment and ineligibility for enrollment in public programs were most **d** i ssatisfied (Stein et al., 1993). Individuals cared for at private physician offices or HMO Settings were more satisfied with their care than individuals seen at hospital clinics (Stein et al., 1993; Stein & Mor, 1993; Stone et al., 1995). In a national study of HIV-positive **P**atients enrolled in health care services, client satisfaction scores were found to be high

across categories (Stein et al., 1993). It is expected that these relationships relating to satisfaction with medical services will be confirmed in this study for HIV case management services.

Few studies of people with HIV have examined self-perceived quality of health. Instead, most studies examined unmet needs and disease symptoms. Of those studies that did look at self-perceived health status, it was associated with sociodemographic characteristics as well as health related characteristics. In a national study of measurement of health status, racial minority groups rated their health status lower than the Caucasian population (Osmond, Vranizan, Schillinger, Stewart, & Bindman, 1996). In a qualitative study of African American and Puerto Rican patients in New York, participants were more likely to view their health as poor compared to other groups with HIV (Siegel & Raveis, 1997). Patients with more advanced HIV disease perceived their health status to be worse than individuals who were asymptomatic (Kilbourne et al., 2002). It was expected that these relationships will also appear in this study of self- perceived quality of health.

Perceived health status (quality of life and quality of health) and satisfaction with care were be associated (Sowell et al., 1997; Stone et al., 1995). In a study of individuals with HIV living in Massachusetts, individuals with higher levels of perceived health status were found to be more satisfied with the quality of care they received (Stone et al., 1995). For this reason, the relationship between health status and client satisfaction with HIV case management should be studied as an interaction. It was expected that people who

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had better perceived health status would be more likely to be satisfied with the case management services they received.

Progression of HIV and general overall health care experiences impacted how patients perceived their quality of life (Cleary et al., 1993; Holzemer & Wilson, ; Sousa, Holzemer, Henry, & Slaughter, 1999; Sowell et al., 1997; Weitz, 1991; Wilson, Hutchinson, & Holzemer, 1997). Wilson, Hutchinson and Holzemer (1997) found that HIV-positive individuals worked throughout the progression of their illness to maintain quality of life. The strategies that individuals with HIV developed to sustain a quality of life reflected the manner in which HIV disease progressed from asymptomatic to death (Wilson et al., 1997). A quantitative study of HIV-positive patients found similar patterns of disease experience and perceived quality of life. Self-perceived quality of life was associated with how a patient's health had been during the past month and how a patient felt on the day of the interview (Cleary et al., 1993). Having limitations to basic activities of daily living and increased symptoms were associated with a lower rating of quality of life (Cleary et al., 1993; Sowell et al., 1997). Receiving social supports and assistance with activities to improve health, specifically case management, improved the quality of life for individuals living with HIV (Nickel et al., 1996).

Improved health care utilization had been identified as an important service outcome of case management (Mor, 1993; Piette et al., 1992). While some studies looked specifically at delaying care (Turner et al., 2000), the more common outcomes of interest were either use of regular health care services and/or emergency room utilization (Arno et al., 1996;

Bonuck et al., 1996; Cunningham et al., 1999; Cunningham et al., 1996; Heslin et al., 2001). As discussed earlier in this chapter, the relationships between predisposing and enabling variables and health care utilization have been inconclusive, and often reflect the interaction between multiple characteristics. For example, in studies of HIV-positive women race was not associated with access to care (Magnus et al., 2001; Stein et al., 2001). Income, source of primary care, and insurance status have all been associated with health care utilization (Cunningham, Hays et al., 1995; Keruly et al., 2002; Montoya et al., 1997; Palacio et al., 1990; Turner et al., 2000; Weissman et al., 1997). With regard to HIV specific variables, stage of disease and HIV symptoms were both associated with utilization of regular medical care as well as increased emergency room use (Diaz et al., 1994; Fleishman et al., 1991; Kilbourne et al., 2002; Knowlton et al., 2001; Montoya et al., 1997; Palacio et al., 1990; Stein & Mor, 1993). Based on the literature, it was expected that people with vulnerable characteristics would have lower utilization of general health care services and greater emergency room use. Furthermore, it was expected that use of case management would be found to increase utilization of general health care services but decrease emergency room use.



CHAPTER IV

METHODS

This dissertation utilizes data from the Alameda County HIV Case Management Evaluation and Redesign project. Rani Eversley, Ph.D. served as the principal investigator for this project. Over the course of two years (1999-2000), the goal of this cross-sectional study was to examine the strengths and weaknesses in the HIV case management system and suggest modifications for improved outcomes. The project examined HIV case management agency policies, HIV case manager work, HIV case management client experiences and the relationship between HIV case clients and client outcomes in Alameda County. Questionnaire data were collected from HIV case management agency administrators, HIV case managers, and HIV case management clients.

Secondly, this project examined the utility and implementation of the Alameda County Quality Standards of Care for HIV Case Management. The evaluation project had two outcomes of note. The first was the institution of a county-wide protocol for HIV case managers in the form of an employee manual and the establishment of training sessions for the case managers working in Alameda County. The second was the development of a client case management manual that helped clients become oriented to the system of case management. Both of these outcomes were a direct result of the information found during the evaluation phase of the project. Unfortunately, a systemic redesign was not

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implemented. Reasons for this will be discussed in concluding chapters of this dissertation.

During the two years of the study, I served as the research coordinator for the project. I worked with Dr. Eversley to develop the survey instrument. As a member of the research team, I participated in weekly team meetings and also conducted interviews with participants. As the research coordinator, I developed the database and data entry system used in the project. I completed quality assurance checks on the data once it had been entered and prepared analyses needed for the county-wide evaluation. I also participated in Alameda County Ryan White CARE Act Title I and II Planning Council meetings as well as monthly meetings of care providers working on county-wide efforts during the Ryan White CARE Act Reauthorization process. While the Alameda County HIV Case Management Evaluation and Redesign project examined a wide range of issues including the structure of the case management agencies, the perceptions of effectiveness by case managers and the procedural issues within the county the helped or hindered service provision, I will focus on the experiences of the clients who participated in the study. These data are important in addressing how the allocation of funds is meeting the needs of the clients, the implicit goal of case management.

Specific Aims and Hypotheses

1)Aim: To describe and examine the relationship among predisposing characteristics, enabling characteristics and the self-perceived case management needs of HIV-positive individuals. <u>Hypothesis:</u> HIV-positive individuals who have care-giving roles will have higher case management needs than those without care-giving roles. Individuals with a history of homelessness and substance users will also have higher HIV case management needs than those without such vulnerable characteristics.

<u>2)Aim</u>: describe and examine the relationship among predisposing, enabling and need factors, utilization of HIV case management services, and consumer satisfaction with case management.

<u>Hypothesis:</u> Higher utilization of HIV case management services will be related in increased client satisfaction with case manager response to client need. HIV-positive individuals who have care giving roles will have lower satisfaction with case manager response to client need and the case manager relationship than those who are not caregivers, controlling for predisposing, enabling and need factors.

<u>3)Aim:</u> To describe and examine the relationship among predisposing, enabling and need factors, utilization of HIV case management services, and perceived health status. <u>Hypothesis:</u> Higher utilization of HIV case management services will be related to higher perception of general health and quality of life ratings. HIV-positive individuals who have care giving roles will have lower perceived quality of life and general health status than those who are not care-givers, controlling for predisposing, enabling and need factors.



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<u>4)Aim:</u> To describe and examine the relationship among predisposing, enabling and need factors, utilization of HIV case management services and utilization of health care services.

<u>Hypothesis:</u> Greater utilization of HIV case management services will be related to higher number of health care visits and decreased use of emergency services. HIVpositive individuals who have care giving roles will have lower utilization of heath care services and emergency room visits than those who are not care-givers, controlling for predisposing, enabling and need factors.

Research Setting: Alameda County

County Overview

Alameda County is an urban county situated on the Eastern shores of the San Francisco Bay. The county is bordered on the west by the San Francisco Bay reaching from Berkeley in the North to Hayward in the South. Alameda County, and Oakland in particular, have suffered the problems of urban flight by affluent residents during the past half century. The resulting situation is an urban center with high concentrations of poverty, higher unemployment rates and fewer economic resources than the surrounding communities of affluence with few reasons to enter the city (Scannell, 1999). With the economic boom of the past decade in Northern California, the county leadership has attempted to bring economic resources to Oakland as well as attract new residents to the county. The population of Alameda County is ethnically and socially diverse. The 2000 US Census accounted for 1,43,741 people living in Alameda County (US Census Bureau, 2001). Fifty-three percent of the county's population is of Caucasian descent, 16% is of African-American descent, 20% is of Hispanic descent and 22% is of Asian descent (US Census Bureau, 2001). Approximately 12% of the population lives below the poverty line (US Census Bureau, 2001).

HIV-Positive Population in Alameda County

In 1997, there were an estimated 2,708 people with AIDS in Alameda County (US Department of Health and Human Services, 2000). Alameda County Eligible Metropolitan Area (EMA) served 6,640 duplicated clients¹ in 1996 (US Department of Health and Human Services, 2000). Since 1993, people with AIDS living in Alameda County have accounted for 7% of California AIDS cases and 1% of AIDS cases in the United States (US Department of Health and Human Services, 2000).

In 1991, 74 % of cumulative AIDS cases in the Alameda County EMA were homosexual or bisexual males and 63% of the AIDS cases were white individuals (Marconi et al., 1994). In 1997, the proportion of AIDS cases who had a risk category of men who had sex with men, had dropped to 57% (US Department of Health and Human Services, 2000). For the same year, the proportion of white individuals who had AIDS dropped to 38% (US Department of Health and Human Services, 2000). The shift in the HIV

¹ Because clients may receive services at multiple case management agencies and each client at each sight is counted as a served individual when aggregate data is reported to the county, numbers provided by the county are often reported as duplicate clients. At the time of data collection the county was attempting to

population has created an ethnic distribution that looks closer to the national distribution of AIDS cases based on race/ethnicity than AIDS cases in California. With this shift has come an increase in problems associated with access to care for minority and low-income individuals.

Case Managers in Alameda County²

Eighteen HIV case managers completed the survey instrument distributed as part of the Alameda County HIV Case Management Evaluation and Redesign project. The case manager population was a diverse population in terms of gender, race, and sexual orientation. Fourteen of the case managers were women and the remaining four were men. Forty-four percent were Caucasian, 33% were African-American, 6% were Latino, 6% were Asian, and 12% were of other ethnic backgrounds. Eighty-three percent identified as heterosexual. The vast majority of case managers had at least a Bachelor's degree with one-third of the population reported earning a college degree and an additional 44% reported earning a graduate degree.

The HIV case manager population reported a long service in both the HIV community and with a particular agency. HIV case managers in Alameda County had been working with people with HIV for an average of six years with one case manager reporting working with the HIV population for 13 years. The mean number of years employed at the current HIV case management agency was three years and seven months.

develop a unique identification number of clients the would protect their confidentiality but streamline data reporting to the county and allow for better coordination of services between agencies.

² A more detailed description of the case managers and agencies was reported in Eversley, R. and Egorin, M.A. (2000). <u>Alameda County HIV Case Management Redesign Report.</u>

Most HIV case managers managed a case load above the recommended 50 clients (Health Resources and Services Administration, 1999; US Department of Health and Human Services, 1994). The number of clients carried in a case load ranged from less than five to 200. The mean number was 87 clients and the median number was 65 clients.

Case managers were asked to identify areas of effectiveness and barriers to providing services. HIV case managers felt most effective assisting clients with accessing food services, HIV medical care, and benefits. Accessing housing for active substance users and assisting clients with finding employment were identified as the areas where case managers felt least effective. Overall HIV case managers identified a moderate level of barriers to them providing services. Lack of clerical support and lack of time for coordinating care were identified as the two greatest barriers to providing services. These barriers, as well as large case loads, have been identified previously as reasons for case manager burn-out which often leads to leaving an agency or even the profession (Ross, 1993) Co-worker non-responsiveness and fears regarding personal safety in the work environment were seen as the least problematic.

Brief History of HIV in Alameda County

Alameda County has a long history of caring for people with HIV. Like San Francisco, Los Angeles and New York, Alameda County has had HIV cases since the earliest days of the epidemic. Most of these early cases were treated at public, county hospitals. As



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with most urban areas in the early 1980s, the earliest cases of HIV infection were a strain on the economic and medical resources of the county (Honey, 1988; Scannell, 1999).

Like San Francisco and New York, most people with HIV in Alameda County are still treated at county and public hospitals (Arno & Hughes, 1987; Scannell, 1999). But unlike San Francisco, Alameda County does not have an academic medical center located in the county and affiliated with the public hospitals. Though the Alameda County health care community does have a vast experience with HIV, the prestige associated with academic medical centers and the ability of academic medical centers to bring in high levels of supplemental funding through grants is often denied the HIV service community and in turn HIV-positive individuals (Benjamin, 1989; Benjamin et al., 1988; Jellinek, 1988). Many HIV-positive individuals in Alameda County seek care in San Francisco because of the great number of clinical trials existing in the county as well as the prestige associated with being treated at San Francisco General Hospital and the University of California, San Francisco.

Due to the history of HIV in Northern California, Alameda County HIV service providers often operate under the assumptions that their work is under appreciated on a local, state and federal level because they operate in the "shadow"³ of San Francisco. This "shadow" effect does come into play in the resources available to Alameda County. The San Francisco AIDS Foundation is an effective fundraising organization for AIDS services in

³ San Francisco and Alameda Counties are separated by the San Francisco Bay and connected via the 4.5 mile span bridge and the public transportation train system. From the downtown areas of both counties you can see the other city just across the bay. The closeness and distance between these two counties is reinforced through this dynamic.

the San Francisco Bay area. However, most funds raised stay in San Francisco rather than being distributed to surrounding counties. This is despite the fact that a significant portion of funds come from people living outside of San Francisco. In other words, donations, financial and material, are taken from local communities but not returned at the same level. Unfortunately, the strength of the San Francisco AIDS Foundation has created an environment where large-scale local fundraising efforts, such as an East Bay AIDS Walk, are not successful. The combination of these two factors results in local communitybased organizations and the HIV service providers in Alameda County being resentful of the success of San Francisco and adopting a martyr complex of providing services in an under-funded community.

Alameda County met the criteria for Title I funding in 1992 (Marconi et al., 1994). Contra Costa County was included in the establishment of the Eligible Metropolitan Area (EMA) to distribute Title I funds. Until 1994, the two counties managed Title I funds independently through separated planning councils (Kieler, Rundall, Saporta et al., 1996). During this time Alameda County administered 70% of the EMA funds, reflecting the greater number of AIDS cases and HIV services provided. Since 1994, the funds for Alameda County EMA, including Contra Costa County, have been administered through a single planning council with administrative support from Alameda County Department of Health. In 1998, the Alameda County EMA received \$5.9 million through Ryan White Care Act Title I funding . Of this, \$845 thousand, or 14%, was allocated for case management services and \$2.6 million, or 44%, was allocated for support services for people with HIV .



The Alameda County Planning Council is comprised of 23 members, of which 35% are people with AIDS (US Department of Health and Human Services, 2000). The planning council membership also includes leadership from community-based organizations, medical service providers and representatives from the county health department. Because of the conflicts of interests inherent in the composition and mission of the planning council, the Alameda County planning council has a long history of struggle and conflict. Though the planning council completes needs assessment and funds allocation annually as directed by the federal legislation, the process is full of controversy, resistance, and often power struggles (Kieler, Rundall, Saporta et al., 1996). In 1994, due to confusion of roles between the planning council members and the county health department as well as hostility among community-based organizations, the planning council was only able to secure 65% of its Title I funding grant (Kieler, Rundall, Saporta et al., 1996). Struggles concerning funding often lead to significant financial investment in consultants to perform evaluations of the system with hopes of noting the need for change. It should be noted that data for this dissertation project comes from a project initiated and funded based on political motivation of some members of the committee even though a similar evaluation of social services had been completed less than 2 years before the initiation of the project.

The Alameda County Department of Public Health actually distributes the funding to each agency and provides oversight of the Title I funds (Kieler, Rundall, & Saporta, 1996). This relationship is a result of the Department of Public Health acting as a proxy for the President of the Board of Supervisors of Alameda County, CEO of the EMA. The Office of AIDS and Communicable Diseases within the Department of Public Health offers administrative support as well as county oversight to the planning council. Because of overlapping roles and the perceived threats to the autonomy of the planning council, tensions often arise between the two groups (Kieler, Rundall, & Saporta, 1996). Tensions are further heightened by the fact that individual agencies that often have members on the planning council are frequently in conflict with the department. These hostilities are often destructive despite the fact that both organizations have the same goal of maintaining and improving the services available to people with HIV.

Subjects

The convenience sample consisted of 150 HIV-positive individuals from Alameda County, California. HIV case management clients were recruited to participate in the study through HIV case management agencies in Alameda County. Clients of case management were recruited from across the county and from various agencies receiving Ryan White CARE funding.

The study team used strategic sampling of clients based on ethnicity, gender, and geographic location. Because of this, the study cannot look at these factors as independent predictors of case management outcomes. Instead, these variables were used as control variables in all analyses. Due to the non-random nature of the data, this study has limited generalizability.



Table 1 presents data comparing the selected sample and the population of people using HIV case management services in Alameda County as reported by the county for the data- collection period. In the study, women and African-American clients were oversampled and Latinos were under-sampled. This over-sampling was included in the larger project research objectives to better understand the case management needs and barriers for these two populations, specific concerns for the Ryan White CARE Act Title II Planning Council of Alameda County.

	Compariso	Table 1 of Sample and Population Sample Overview n=150		Population Overview N=1,999	
Variable		%	n	%	Ν
Gender					
	Male	60.7	91	75	1,494
	Female	38	57	24	486
	Other	0.7	1	1	12
	Missing	0.07	1	0	7
Race					
	Caucasian	16.7	25	28	561
	African American	72.7	109	55	1,104
	Latino/a	3.3	5	11	228
	Asian or Pacific Islander	0.7	1	2	36
	Native American	1.3	2	2	34
	Other	0	0	3	67
	Missing	5.3	8		
Language (Primary)					
· - ·	English	96.7	145	90	1,798
	Spanish	1.3	2	5	95
	Other	0	0	1	26
	Missing	2	3	4	80

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Sample Size

The sample of HIV-positive individuals receiving case management was 150. This sample size was based on the limited country resources and the availability of participants. A power analysis was not conducted before data collection began. A posthoc power analysis was conducted and found that the sample size was sufficient for a significance level of 0.10 (Questa Research Associates, 2003; RAOsoft Inc., 2004).

The small sample size limits the complexity of the statistical models that can be utilized for investigation of HIV case management, quality of life, and satisfaction with services (Henry, 1990). Additionally, the sample size may be too small to identify significance differences.

Subject Recruitment

Subjects were recruited from case management agencies funded by Ryan White CARE Act monies administered by Alameda County Office of AIDS. A letter was distributed to all case management agencies notifying them of the study and asking for their participation in recruitment of participants. Agency directors were also asked if they would mind having interviews conducted at the agency. Research staff members then contacted agency staff to arrange recruitment of participants, timelines for recruitment and interview schedules. The research team made a concentrated effort to sample from agencies throughout the county. They also arranged recruitment and interviews at different times and days to draw from a wide range of case management clients. Notices describing the study were posted at agencies that agreed to participate. Research staff also went to HIV support groups to speak about the study. Interested clients registered to be contacted by the research team or selected specific interview times depending on the preference of the agency. All participation was voluntary. After giving written informed consent, structured face-to-face interviews were administered and subjects were compensated \$15 for participation.

Selection Criteria

To participate in the study, individuals needed to: 1) be HIV-positive; 2) be currently enrolled in HIV case management services; and 3) live in Alameda County. Participants were asked questions concerning eligibility when contacted to schedule an appointment or at the beginning of the interview when participants signed up for an appointment at the agency. Individuals were only eligible to participate once in the study even if they utilized services at multiple agencies from which participants were recruited. Participant contact lists were compared to prevent participants from being interviewed more than once.

Data Collection

Dr. Eversley, trained interviewers, or I conducted the face-to-face interviews for this study. Given that the use of ethnically and sexually-identified diverse HIV-positive interviewers has been noted to improve response rate and generate as honest answers as possible (Fowler et al., 1992), individuals with HIV and receiving services in Alameda County were hired as interviewers. These interviewers were able to access sites resistant



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to outside researchers as well as develop a rapport with clients who may have been reluctant to respond to individuals from outside the community.

A diverse team was recruited with hopes of reflecting the population of the county. The interview team consisted of four individuals- one African-American gay male, one Caucasian gay male, one African-American straight female and one Caucasian straight female. Data management quality was maintained through training at the beginning of data collection and by reviewing techniques at weekly staff meetings. The community interviewers were trained to use the survey instrument, administer informed consent, and to maintain confidentiality. During the training, interviewers were instructed in how to ensure that participants understood the questions and how to answer questions so as not to bias their responses. Interviewers conducted practice interviews with each other and were then helped to improve their interviewing technique. Further training and clarification were provided at weekly team meetings as needed.

The interview took 45 to 75 minutes to complete, depending on the health of the subject as well as the complexity of his or her responses. This difference in completion time was expected, based on the experiences of other studies of HIV-positive individuals (Fowler et al., 1992).

Variables of Interest

The following measures were gathered during structured interviews occurring with respondents between December 1999 and November 2000. These measures are a subset

of measures collected as part of a larger study on case management utilization in Alameda County. (See Appendix A for a copy of the full survey instrument).

Environment: Health Care System

No measures of the health care environment were collected during client interviews. Information about case management services and case management workers was collected through a separate survey process done as part of the larger study. All clients interviewed for this project received case management services in Alameda County. Clients received health care services primarily in Alameda County, though some clients also received health care services in Contra Costa and San Francisco Counties. The majority of clients received care from public hospitals through public insurance programs.

Population Characteristics: Predisposing

Demographics. The structured interview asked participants about age, ethnicity, and education. **Age** was recorded as current age and as a continuous variable. **Gender** was measured as a categorical variable (male, female and transgender). **Sexual Orientation** was measured as a categorical variable (heterosexual, gay/lesbian, bisexual, other). Gender was used as control variables because sample selection was not random.

Vulnerable domains. History of homelessness was analyzed as predisposing characteristics. **History of homelessness** was measured as a dichotomous variable. For individuals who had been homeless, the length of time homeless was collected in terms of the number months homeless as well as when the respondent was last homeless. There was no variance in **HIV status** among participants since being HIV-positive is an inclusion criteria for case management in Alameda County and hence an inclusion criteria for this study.

Social Structure. Race or Ethnic group was measured as a categorical variable. Due to sampling strategy used in the larger study, race or ethnic group was used as a control variable in all analyses. Education was recorded as number of years of education completed and was recoded to into categories of less than high school completion, high school degree, some college, and college degree or above. Current employment was measured as categorical variable. For the analyses in this dissertation employment was grouped as unemployed versus employed (full-time, part-time or student). Participants were asked about their current marital status, which was coded as categorical.

Population Characteristics: Enabling

Current monthly **income** was collected as a continuous variable with respondents being asked to round to the nearest \$100. Income data were used to identify participants living above or below the 2000 Federal **poverty line** for an individual, which was \$8,794. Participants were asked to identify their **source of primary HIV health care.** Text responses were then recoded into a categorical variable. These data were further transformed to examine types of care including private vs. public, clinic vs. private office, HMO vs. other and in-county vs. out-of-county. **Insurance** information was collected using a categorical measure and recoded into more general categories of private, public or no insurance coverage. To measure **housing**, participants were asked to identify their current residence and previous residence as a set of categorical responses. For analysis, the housing variable was recoded into stable (house, apartment or flat) vs. unstable housing (a friend or family member's house, single room occupancy hotel, transitional housing, halfway house, drug/alcohol center, shelter or on the street) situations. Participants were also asked how long they had been at their current residence. These responses were recorded as a number of months.

Two measures of **care giving status**, both dichotomous measures, were derived from other measures collected during the interview. The first measure, any care giving responsibilities, was based on participants' responses to questions regarding number of children, number of children under age 18 living with them, number of adult dependents including adult children, and number of dependent elderly. The second measure of care giving status, care giving responsibilities for children, was based on participant responses to questions regarding number of children and number of children under age 18 living with them

Vulnerable domains. A categorical measure of **public financial benefits**, as represented by public programs providing money to the participant, was collected. Benefit information was collected concerning SSI, GA or Cal Works, SSDI, SDI, AFDC, longterm disability and other sources identified by the participant. A dichotomous variable of **any public benefit** was created for these data. Participants were asked if they were



enrolled in **case management**, however, this was an inclusion criteria and no variance exists on this measure.

Population Characteristics: Need

HIV Stage of Disease. For purposes of this study, **stage of disease** was based on client rated acuity. Client-rated acuity was rated from level 1 (few or no HIV disease related symptoms and needing minimal support) to level 4 (end-stage disease and needing significant assistance). Those with the more advanced disease, levels 3 and 4, were combined for purposes of this dissertation. The proportion of people with end-stage disease in the sample was very small due to the nature of the sampling strategy.

Though this measure is not based on clinical outcomes such as CD4 or viral load measurements, it does provide an ordinal measurement of HIV stage of disease which is advantageous over a dichotomous measure such as AIDS diagnosis or not. Furthermore, the self-rated acuity scale was based on symptoms as well as functional status. This measure may better account for role limitations and individual illness experiences rather than a clinical number representing disease progression.

HIV Symptoms. HIV symptoms were assessed using a modification of The Sign and Symptom Checklist for Persons with HIV Disease (SSC-HIV) (Holzemer et al., 1999). Clients were asked to rate 57symptoms they may have been experiencing on the day of the interview. If clients were not experiencing a symptom, it was scored as zero. The scale is scored by summing the individual symptom rating scores. Twenty six items from the SSC-HIV are used to create subscales of HIV disease symptoms: malaise/weakness and fatigue (muscle ache, weakness, painful joints, fatigue, dry mouth, thirsty), confusion/ distress (difficulty concentrating, depression, memory loss, fear, anxiety, disorientation), fever/chills (fever, chills, day sweats, night sweats), gastrointestinal discomfort (loose stools, diarrhea, gas/bloating, abdominal pain), shortness of breath (shortness of breath at rest, wheezing, shortness of breath at activity), and nausea/vomiting (nausea, vomiting, lack of appetite). Two additional measures of female specific symptoms were added to the scale. There measures were yeast infections and menstrual irregularity. Self-reported symptoms have been found to be more sensitive to actual disease experience and are the recommended method of symptom measurement in HIV research (Justice, Rabeneck, Hays, Wu, & Bozzette, 1991; Reilly, Holzemer, Henry, Slaughter, & Portillo, 1997).

The SSC-HIV and its subscales had Chronbach's Alpha scores above 0.70. Table 2 displays how the SSC-HIV instrument performed in this study compared to reported performance.

An Examination of HIV Case Management 95

Table 2

Cronbach's Alpha for SSC-HIV

	Alpha in Present Study	Holzemer et al (1999)
Sample	HIV-postive case management clients	HIV-positive patients
Scale		
SSC-HIV	0.97	0.95
Subscale		
Malaise/Weakness/Fatigue	0.87	0.90
Confusion/Distress	0.87	0.90
Fever/Chills	0.82	0.85
Gastrointestinal discomfort	0.83	0.81
Shortness of breath	0.88	0.79
Nausea/vomiting	0.77	0.77
Female specific	0.73*	n/r

n/a= not applicable
n/r= not reported
* only for females in study

Comorbidities. In this analysis, measure of current **substance use** were considered. The dichotomous measure of any illicit drug use, except marijuana⁴, in the past month was used to identify a substance use comorbidity. **Mental health** history was collected using self-report of mental health visits. Clients who were seeing a mental health provider, taking medication for mental illness and/or were on disability due to a mental health were identified as having a mental health comorbidity.

HIV Case Management Perceived Needs. Participants are asked about case management services needed when enrolling in HIV case management. This

measurement strategy is similar to the measurement of case management and social need as a dichotomous measure used in a national study of individuals living with HIV (Katz et al., 2001). The participants were asked about needs in relation to the following: assistance with housing; utility bills; food services; employment needs; medical benefits programs; financial benefits programs; obtaining substance abuse treatment; HIV medical care; other medical care; home care; attendant care; hospice care; dental care; psychiatric care; and emotional counseling.

A summative measure of **total number of initial case management needs** was created for use in this dissertation. Need data were transformed into measures of **medical service needs** (HIV medical care, other medical care, home care, dental care, or psychiatric care) and **social service needs** (housing, utilities, food service, benefits, other financial needs, substance use treatment, attendant care, or counseling and emotional support).

Health Behavior: Use of Health Services

HIV Case Management Services Utilized. Several measures of case management services were collected. Participants were asked to name all agencies where they receive case management. Answers were recoded as categorical variable. This list of case management agencies were further transformed to measure **number of case management agencies** visited, and **site of case management** (clinic-based, communitybased or other). Clients were asked about the **length of time** they had been in each

⁴ Because of the prevalence of medicinal marijuana in the East Bay community and the questioned legality of such usage at the time of the study, the decision was made to not include marijuana use in the

agency. The longest time receiving services from any listed agency was used to identify the time in case management. Clients were asked the **number of HIV case management visits** they attended in the past month.

For individuals with care giving responsibilities for dependent children, dependent adults and/or caregivers, they were asked if direct **HIV case management for dependent(s)** had been received from the participant's case manager. Only 4% of client with care giving responsibilities reported receiving services for dependents. Therefore, this variable was not examined in this dissertation.

Medical Services Utilized. Participants were asked if they had a **primary care provider**; either a nurse or physician.

Outcomes: Health Status

Health Status. Participants completed the Medical Outcomes Survey 36 Item Short-form Health Survey for HIV (MOS) (Wu, Hays, Kelly, Malitz, & Bozzette, 1997). The more general SF-36 was developed by researchers at the RAND Corporation in an attempt to measure participant assessment of functioning and well-being (Wright, 1994; Wu et al., 1997). This measure was developed to be administered to individuals with a wide range of illnesses (Gill & Feinstein, 1994; Wright, 1994). The MOS, both general and HIVspecific, is an accepted and recommended standard measure of quality of life for individuals living with HIV (Fowler et al., 1992; Health Resources and Services Administration, 2000). The reliability and validity of the HIV-specific MOS in relation to the more general SF-36 has been proven in HIV-positive samples(Wu et al., 1997). The MOS includes 11 subscales (General Health Perceptions, Physical Function, Role Functions, Social Functions, Cognitive Function, Pain, Mental Health, Energy/Fatigue, Health Distress, Quality of Life, and Health Transition). For this dissertation the subscales of **general health perception** and **quality of life** were used as measure of health status.

The MOS and its subscales had Chronbach's Alpha scores above 0.70 except energy/fatigue. Table 3 displays how the MOS instrument performed in this study compared to reported performance in past studies.

	Alpha in Present Study	Cunningham et al (1995)	McHorney et al (1994)
Sample	HIV-postive case management clients	HIV-positive nonclinical trial patients	General patient population
Scale			
MOS	0.91	n/r	n/r
Subscale			
General Health Perception	0.82	0.79	0.78
Physical Health Function	0.87	0.84	0.93
Role Function	0.78	0.73	0.83
Social Function	n/a	n/a	n/a
Cognitive Function	0.89	0.84	n/r
Pain	n/a	n/a	n/a
Mental Health	0.80	0.84	0.90
Energy/Fatigue	0.40	0.85	0.87
Health Distress	0.91	n/r	0.84
Quality of Life	n/a	n/a	n/a
Health Transition	n/a	n/a	n/a

Table 3Cronbach's Alpha for MOS SF-26Alpha in PresentCunningham et alMcHor

Indicate subscales of interest

n/a= not applicable, single item scale n/r= not reported

Quality of Health. Participants were asked to rate their **overall health** on a Likert-type scale that ranged from excellent to poor. Though simple, this measure of self-perceived health has been used in many studies of health access for the general population and for individuals with HIV (Gill & Feinstein, 1994; Osmond et al., 1996; Pakenham, Dadds, & Terry, 1998). However, because of the high correlation between the MOS and this measure, this measure was not included in the dissertation analyses.

Outcomes: Client Satisfaction

Satisfaction with Case Management Services. Two measures of satisfaction were collected. The first measured client-evaluated satisfaction with case management services. Participants were asked to evaluate their case manager's response to each individual case management needs. A Likert-type scalewas used in which one (1) was ineffective and four (4) was very effective. The list of needs evaluated included assistance with housing, utility bills, food services, employment needs, medical benefits programs, financial benefits programs, obtaining substance abuse treatment, HIV medical care, other medical care, home care, attendant care, hospice care, dental care, psychiatric care, emotional counseling and housekeeping. Because case management evolves over time, participants were not limited to evaluating services needed only when they entered care. An overall summary score (mean score of services evaluated) was computed in the dissertation as a measure of case manager response to client need.

The second measure evaluated **client satisfaction of the case manager relationship**. Participants are asked to complete the HIV Case Management Satisfaction Survey (CMSS), a forty-six item scale was created based on qualitative interviews with HIV case management patients and developed specifically for the Alameda County HIV Case Management Evaluation and Redesign project. Other measures of client satisfaction of health services do not integrate client input or perspectives to assess satisfaction (Cleary, 1999, 2003; Cleary & Edgman-Levitan, 1997). The CMSS covers participants' perceptions of a case manager's knowledge of resources, skill with health problems, convenience of services, accessibility of services and interpersonal relationships. Clients were asked to rate each item using a Likert-type measurement were one (1) indicated not true and four (4) indicated very true. Because Likert-type scaling was used, it was appropriate to treat the scale as summative (McIver & Carmines, 1981).

For this dissertation, a 14-item subscale of the CMSS was used. Those questions related to the interpersonal relationship between the client and the case manager was included in the subscale while item related to service delivery and agency characteristics were excluded. The items included were my case manager seems burnt-out; my case manager has requested sexual favors for case management services; my case manager generally follows through with delivering promised services; my case manager has suggested that I offer them sexual favors; I feel assured by my case manager's professionalism; sometimes I am confused by what my case manager is going to take care of and what I am responsible for; my case manager is compassionate, my case manager is easy to contact in case of emergency; my case manager needs time to grieve; it helps that my case manager has personal experience with HIV; my case manager is attentive; my case manager promptly returns phone calls; sometimes my case manager seems to look at me as if I'm a burden; my case manager seems pressed for time; my case manager is judgemental; and my case manager is open to discussion out relationship. Inter-item reliability of the subscale was conducted using Cronbach's Alpha and individual items were checked using the item-removed Cronbach's Alpha calculation in SPSS. It was determined that no items from the original list needed to be removed based on these calculations. The inter-item reliability for the subscale was 0.87 above the standard of



0.70 to indicate internal reliability of the subscale (Carmines & Zeller, 1979; Knoke & Bohrnstedt, 1994).

Outcomes: Health Care Utilization

Clients were asked the number of health care visits they attended in the past month and the number of HIV medical care visits they attended in the past month. These continuous variables were summed to create an overall measure of **total health care visits attended**. Clients were asked the number of emergency room visits in the 6 months prior to the interview. A dichotomous variable of **any emergency room use in the prior six months** was created. Using client self-report of health care utilization for HIV-positive individuals has been found to be a valid measure of service use when compared to medical and insurance records (Weissman et al., 1996). Individuals with high rates of health care utilization, however, have been found to underreport usage (Weissman et al., 1996).

Data Management and Analysis

Data Management

A structured survey instrument was developed for the study. Interviewers read the survey questions and recorded the verbal answers given by participants on the survey instrument. The completed surveys were returned to the project on a weekly basis. Dr. Eversley or I reviewed the completed paper surveys and then gave them to a research staff member trained in data entry. Data were then entered in a Microsoft Excel spreadsheet based on a specific coding schema. Throughout the data entry process, entered data were routinely

checked against the paper surveys for accuracy and completeness. When data entry was completed, the Excel file was converted to an SPSS 10.0 file to allow for data cleaning, transformation and analyses. Following the conversion of the database from Excel to SPSS, a review of the two files was conducted to ensure that the conversion was successful.

Data were cleaned and descriptive statistics were examined for all study variables. Obvious outliers and other abnormalities were compared with original paper survey. Data entry mistakes were corrected and outliers were removed.

Data Analysis

Bivariate and multivariate descriptive analyses were conducted to address the research questions outlined in the specific aims and in accordance with the conceptual model described by Gelberg, Andersen and Leake (2000). Data analyses were conducted using SPSS 10.0. Based on a post-hoc power analysis to determine an appropriate significance level, a level of 0.10 or less was used (Questa Research Associates, 2003; RAOsoft Inc., 2004).

Analysis began with appropriate descriptive statistics (e.g., frequency, mean, variance, and proportion) for each variable to be used in the dissertation analyses. These data were useful in providing an overview of the data with a particular focus on case management utilization. To examine for multicollinearity, a correlation matrix of all independent variables with dependent variables and all independent variables with each other was generated. Where correlations above 0.60 exist, variables were transformed or removed from the subsequent analyses to protect against multicollinearity (Knoke & Bohrnstedt, 1994). (See Appendix B for correlation table)

Bi-variate analyses (e.g., chi-square, t-test, and ANOVA) were conducted to examine the relationships between predisposing (history of homelessness, substance use, mental health status, education, employment, marital status and number of children), enabling (caregiving status, income, source of primary care, housing, public benefits) and need (stage of sides, medication need, and HIV symptoms) and each outcome of interest.

Multivariate analyses were undertaken to examine each specific aim. The small sample size limited the number of independent variables included in each regression model (Paul, 2003). Each regression model used a standard set of twelve variables, except for the model for case management need where utilization variables were not included. Variables were selected based on the importance to the theoretical model and results from the correlation analyses conducted as part of the descriptive analyses for the dissertation. The predisposing variables selected were a history of homelessness and marital status. The enabling variables selected were income in relation to the poverty line and having a care role. The need variables selected were HIV level, number of HIV symptoms, having a drug comorbidity, and having a mental health comorbidity. The utilization variables selected were time in case management and number of case management agencies. Because the data were collected from a non-random sample, gender, and race/ethnic group were used as control variables in all analyses. All models used ordinary least

;

squares to estimate the model, except for the model of emergency room utilization, which used logistic regression. A significance level of 0.10 was used for all multivariate analyses.

Attempts were made to make the models used to examine the four specific aims as comparable with each other as possible. However, there were necessary changes due to the nature of specific dependent variables. Descriptions of each of the seven outcome variables are discussed below. If changes were made to the procedures presented above, the justification and specifics of these changes are noted.

 Aim: To describe and examine the relationship among predisposing characteristics, enabling characteristics and the self-perceived case management needs of HIVpositive individuals.

To examine Aim 1, total number of case management needs was used as the outcome variable. The possible range in needs was zero to thirteen services with a greater number of need indicating a higher need level. Because this aim examined initial number of needs, utilization variables were excluded from the OLS regression model estimating number of needs.

 Aim: To describe and examine the relationship between predisposing, enabling and need factors, the amount and type of HIV case management use and consumer satisfaction with case management. To examine Aim 2, two measures of clients satisfaction were used: 1) client-evaluated case manager response to client need and 2) client satisfaction of the case manager relationship. Client-evaluated response examined the average evaluated response by each client. Client satisfaction of the case manager relationship was measured using a selected subscale of relationships measures from the HIV Case Management Satisfaction Survey (CMSS). For both measures, a higher score indicates a higher level of satisfaction.

3) <u>Aim:</u> To describe and examine the relationship among predisposing, enabling and need factors, utilization of HIV case management services and perceived health status.

To examine Aim 3, two measures of self-perceived health status were used: 1) general health perception and 2) quality of life. Both measures are subscales of the MOS that was administered to clients during the interview. For both sub-scales, a higher score indicates a higher level of health status.

 Aim: To describe and examine the relationship among predisposing, enabling and need factors, utilization of HIV case management services and utilization of health care services. To examine Aim 4, two measures of health care utilization were used: 1) number of health care visits in the past 30 days and 2) emergency room use in the past six months. Health care visits was the total number of HIV and other physician or nurse visits attended. Emergency room use in the past six month was a dichotomous measure. Because of the nature of the outcome variable, a logistic regression model was used to estimate emergency room use. The model included the full twelve variables used in the other OLS regressions. All utilization data were client self-report.

Limitations

This dissertation attempts to address the complex relationships between HIV disease, care giving roles, HIV case management service, health status and client satisfaction with case management services. Though the study was constructed based on the limited resources of the larger project, the study design has limitations including the non-random sampling strategy, the small sample size, the cross-sectional nature of the data, change in environment during data collection, and the self-report of health status. Additionally, all of the data collected were quantitative measures recorded during a relatively short face-to-face interview. Therefore, many of the assertions made in the proposed analyses will not reflect the exact experience of each client or use the respondents words to answer the complex questions about the interaction of care giving roles, case management, health outcomes, and satisfaction with case management services.

The major limitation of this study is that it used a convenience sample of clients from Alameda County. This a non-random sample of clients enrolled in HIV case management was recruited from HIV case management agencies and HIV health care clinics in Alameda County. HIV-positive individuals not enrolled in case management services were not included in the study. Additionally, clients of case management agencies who were frequent users were more likely to see the recruitment flyers and/or be at the interview sites. Due to the non-random nature of the data, this study has limited generalizability even to the HIV-case management population of Alameda County. Focusing on clients at multiple agencies in Alameda County does offer a more representative picture of clients, the types of case management needs and case management services used than those studies of case management that focus on a single agency or a single type of services (e.g. hospital or community based) as occurs in much HIV case management research.

The sample represents 7.5% of the population of HIV positive individuals who received case management services in Alameda County during the time of the study. The sample size of 150 limits the complexity of the statistical models that can be utilized for investigation of HIV case management, quality of life and satisfaction with services (Henry, 1990). The small sample size may have been too small to identify significance differences. A power analysis was conducted and found that the sample size was sufficient for a significance level of 0.10 (Questa Research Associates, 2003; RAOsoft Inc., 2004). For a significance level of 0.05, the sample size would have to have been 228 individuals.

The data were collected from client interviews at a single point in time. Clients were asked historical information about their housing situations, substance use, adherence to medication and medical appointments as well as mental health conditions over the past month. The cross sectional nature of the data limits the ability to see how the health outcomes of the clients have changed over time and with the introduction or removal of HIV case management services. Due to the normal variations in HIV symptoms and well as medical needs for other health problems associated with HIV or other co-morbidities, measuring health outcomes as cross-sectional may not provide a full picture of the complicated nature of HIV health care as well as case management needs.

Data were collected during a period of economic expansion and relative prosperity in the San Francisco Bay area. The change in the environment between the beginning of data collection in 1999 and the end of data collection in 2000 cannot be accounted for due to the cross sectional nature of the data. The structural changes (decreased affordable housing, increased health care costs, increase in cost of housing and other living expenses as well as expanded employment opportunities) due to the changing environment might have impacted the needs of clients during the time of data collection. Though parts of the county environment may have shifted during the time of data collection, the structure of country services did not dramatically change nor did the amount of structure of local, state and federal funding for HIV case management.

Another complicating factor in the reliability of the data is that all medical information as well as retrospective behavioral data were self-reported by the respondents. There is the potential that the clients offered answers that were not representative of the behaviors they practiced because of the desire to offer an answer that would be acceptable to the interviewers. This positive response bias may prove to be important when looking at substance use behaviors where clients might under-report usage due to the stigma associated with substance use, especially in the arena of social service delivery. On the other hand, studies of individuals with HIV have found that client self-reporting of health conditions and of behaviors are rather reliable (Justice et al., 1991; Kauth, St. Lawrence, & Kelly, 1991).

Client interviews were conducted by a team of trained interviewers with weekly meetings to allow for additional training, trouble-shooting, and communication between the research team. However, no interviewer reliability testing occurred during the study. This is a potential source of bias as well as error in the study. Post-hoc tests showed no anomalies or pattern which would signify a problem between interviewers but reliability testing conducted during the study would have provided better certainty.

The outcome of client satisfaction with the case manager relationship is based on a nonstandardized measure of client satisfaction. The HIV Case Management Satisfaction Survey (CMSS) is a forty-six item measure generated from qualitative interviews with HIV case management patients in Alameda County and was developed for the Alameda County HIV Case Management Evaluation and Redesign project. The items used in the case manager relationship subscale also were not standardized. They did have face validity because selection was based on the content of the question. Appropriate statistical tests were conducted to ensure appropriate levels of subscale reliability.

However, the reliability of the larger scales as well as the generalizability of the scale to other populations is unknown.

CHAPTER V

RESULTS

This chapter presents the results of the analyses conducted to test a model of health care utilization for vulnerable populations based on the work of Gelberg, Andersen, and Leake (2000) with a focus on HIV-positive individuals, HIV case management and other vulnerable characteristics often associated with this population (Frankel et al., 1999). The chapter begins with a description of the predisposing, enabling, need, and case management utilization characteristics of the sample. Next, more detailed descriptions of the seven outcomes of interest are presented including bivariate analyses. The chapter concludes with a discussion of the seven regression models developed to predict case management needs, client satisfaction, health status, and health care utilization.

Description of the sample

One hundred and fifty HIV-positive individuals who were enrolled in case management in Alameda County participated in this study. Case management clients were one of three populations about whom data were collected during the Alameda County HIV Case Management Evaluation and Redesign project.⁵ Participants were recruited through information posted in case management agencies throughout the county. All interviews were conducted at participating agencies unless otherwise arranged by the researcher and subject with approval from the principal investigator. After giving written informed

⁵ Data about case managers activities and case management agency procedures were collected through census data collection. These data are not included in this dissertation project. As part of the larger research project, a sub-study of Latino/a mono-lingual and bi-lingual case management clients was

consent, structured face-to-face interviews were administered and subjects were compensated \$15 for participation. All interviews were conducted in English.

Predisposing Characteristics

Table 4 displays demographic information of the participants for predisposing variables. As discussed earlier in the conceptual model chapter, predisposing variables are individual characteristics including age, gender, and sexual orientation and social structure variables including education, ethnicity, and residential mobility. These variables are theoretically associated with the equitable distribution of health services but during the course of the study are characteristics with limited ability for change.

conducted. These data are not part of this dissertation because of the differences in the instrument and administration techniques.

Table 4Description of Predisposing Variables

=150

Variable	-150	Valid %	Ν	
Gender				
	Male	60.7	91	
	Female	38.0	57	
Sexual Orientatio	n ⁶			
	Heterosexual	46.7	70	
	Gay/lesbian/bisexual or other	52.1	76	
History of Home	lessness			
	Homeless during lifetime	58.7	88	
HIV Risk				
	Sex with an HIV+ individual	66.1	80	
	Shared needles	24.8	30	
	Other risk category or uncertain	9.1	11	
Race				
	Caucasian	17.6	25	
	African-American	82.4	117	
Education				
	Less than high school completion	22.4	33	
	High school completion	32	47	
	Some college	28.6	42	
	College degree or higher	17	25	
Employment				
	Employed (full-time, part-time or student)	14.9	22	
	Unemployed	85.1	126	
Marital Status				
	Married or partnered	24.7	37	
	Divorced, separated, widowed, or single	75.3	113	
		N	mean	range sd
Age (years)		148	41.77	(24-63) 8.11
Time Homeless (months)	83	19.83	(0.25-180) 35.65
Time in current p	rimary sexual relationship (months)	144	22.98	(0-204) 42.23

⁶ Italicized variables in all tables are for vulnerable characteristics as identified by Gelberg et al (2000).

Even with an over-sampling of women, six of ten participants were male. Over 80% of the participants were African-American. Just over half of the sample was gay, lesbian, or bi-sexual (52%). Men identified as gay or bi-sexual more often than women identified as lesbian or bi-sexual (77% vs.16%, p=0.00) and Caucasians identified as gay, lesbian, or bi-sexual more often than African-Americans (77% vs. 46%, p=0.01). Only a quarter of the sample was married or living in a marriage-like relationship. Over three-quarters of the sample completed high school and almost one in five earned a college degree or higher. Eighty-five percent of the sample was unemployed at the time of the study.

For vulnerable characteristics, six of ten respondents have been homeless during their lifetime. Of those who had been homeless, the modal time for homelessness was one year and the mean was just short of two years (19 months). There was no difference in experience of homelessness between males and females. African-American experienced homelessness more often than Caucasians (64% vs. 44%, p=0.07).

Enabling Characteristics

Table 5 displays demographic information of the participants enabling variables. Enabling variable are those individual characteristics that directly assist, or hinder, an individuals ability to utilize care. In accordance with the conceptual model, these variables include income, housing, competing needs, and case management.

Table 5Description of Enabling Variables

n=150	
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Variable	n=150	Valid %	Ν		
Income					
	Above poverty line	21.7	31		
	Below poverty line	78.3	112		
Stable Housing					
Studie Housing	Stable housing	78.7	111		
	Unstable housing	21.3	30		
Site of Care	Public	78.3	112		
	Private	21.7	31		
Health Insuranc					
	Medical	74.7	112		
	Medicare Private insurance	20 6.7	30 10		
	Filvate insurance	0.7	10		
Public Benefits					
	SSI	65.1	97		
	GA or CalWorks	4.7	7		
	SSDI	21.5	32		
	SDI	3.4	5		
	AFDC	2.0	3		
	LTD	6.0	9		
	Received any public benefit	90.6	135		
ADAP					
	Enrollment in ADAP	32.7	49		
Care giving	Any care giving role for children,				
	adult or elderly	48	72		
Case manageme	ent for dependent				
	Dependent received direct services from				
	case manager	1.3	2		
		NI			مما
		N	mean	range	sd
Monthly incom	e (dollars)	143	739	(0-2500)	360.71
Langth in ourse	nt residence (months)	145	33.86	(0.33-300)	43 70
Length in curre		145	55.00	(0.55-500)	43.17

700

The average monthly income of participants was below \$750 and the vast majority of people had income levels below the 2000 Federal poverty line. There were not statistically significant differences in income level by either gender or race and ethnic group.

As would be expected for a population with HIV, high rates of poverty, and receiving case management, enrollment in public benefits programs was high. Nine in ten people in the study participated in at least one public benefit program and 12% of the sample participated in two or more programs. The most frequent benefit program was SSI. Almost ninety-five percent of the sample was enrolled in either Medical or Medicare at the time of the study and one-third of the sample was enrolled in the AIDS Drug Assistance Program (ADAP).

Housing problems appear to be frequent among respondents to the survey. Over fifty percent of the sample reported a history of homelessness and one in thirteen reported being homeless at the time of the study. The average time homeless was just over one and a half years. Over three-quarters of the sample (79%) were in stable housing situations at the time of the study.

One-third of the sample was in a care-giving role at the time of the study. Thirty-seven percent of women were in a care-giving role compared to 18% of men (p=0.01). There was no difference in care-giving either by race and ethnic group or by marital status.

Need Characteristics

Need variables are those individual characteristics that reflect health care needs that are present as a person attempts to access care. These variables include illness level and comorbidities. In looking at health care utilization and outcomes of health status it is important to consider need variables as they are a measure of acuity. Table 6 displays demographic information of the participants for need variables except perceived case management needs which are presented in a later table.

	Table 6			
	N=150			
	Valid %	Ν		
HIV Level 7				
Level 1	31.7	46		
Level 2	44.8	65		
Levels 3 and 4	23.4	34		
Comorbidities				
Drug	14	21		
Mental health	66	99		
	N	mean	range	sd
HIV Symptoms	140	20.5	(1.0-57)	14.9

⁷ HIV stage is based on Alameda County HIV acuity level assessment. The description is as follows: level 1: I only need information, referrals, and minimal support. I am able to use medical care and adhere to medication regimens. I have minimal HIV symptoms.

level 2: I need information, referrals, emotional support, and sometimes assistance with follow through. I usually attend my medical appointment. I usually adhere to my medication regimens. I have some HIV symptoms.

level 3: I need a lot of assistance and emotional support to use information and referrals. I often have difficulty adhering to medical care and/or medication regimens. I have acute HIV symptoms or other significant health problems

The number of symptoms experienced by participants ranged from 1 to 57 with a modal number of 10 symptoms. The mean number of symptoms was 21. The most frequently reported symptoms were night sweats (67%), fatigue (65%) and depression (65%). Less than ten percent of respondents reported having jaundice (5%), Kapsoi Sacrcoma lesions (8%), yellow eyes (9%), and flushing (9%).

Symptoms reported by clients were consistent with self-perceived acuity level as measured by the study. Clients rated their health from few or no HIV disease related symptoms and needing minimal support (HIV level 1) to end-stage disease and needing significant assistance (HIV level 4). (Specific language for each acuity level is presented in footnote 8.) Clients perceived their health as being in good to moderate condition with few symptoms and limitations. Forty-five percent of the sample reported having some HIV symptoms (HIV level 2) and 32% of the sample reported having minimal HIV symptoms (HIV level 1). There was no difference in symptoms or HIV level by gender or race and ethnic group.

Two-thirds of the sample was identified as having a mental health comorbidity and fourteen percent with a drug comorbidity. Forty-four percent of the sample reported using marijuana but individuals who only used marijuana were not included in count of individuals with a drug comorbidity. Twelve individuals (8%) were identified as having both a mental health and drug comorbidity. There was no difference in drug or mental health comorbidity by gender or race and ethnic group.

level 4: I need home care and significant assistance with daily life tasks. I may need end-stage disease planning.

Case Management Needs

Table 7 presents case management needs of clients at the time of enrollment in services. These needs were examined separately from other need variables because this variable was identified as the specific reason for entering case management. This data was collected in retrospect and some differences between actual need and recalled need may exist. Additionally, because case management needs presumably evolved during the course of case management and disease experience these needs may not reflect the full spectrum of care needed. Even recognizing these potential limitations, case management need was high among clients.

Clients reported a wide range of needs from entering case management needing no services to needing all thirteen services. The average services needs reflect a relatively high level of needs with a mean of 4 services and the modes of 3 and 4 services. Almost all respondents (97%) reported having at least one social need and over half (57%) reported having at least one medical need. The most often reported need at the time of entering case management was assistance with food services (79%). Two-thirds of the sample reported entering case management services with a need for housing assistance. This could include assistance finding housing, accessing public housing programs, or finding housing vouchers.

Table 7
Description of Case Management Needs
N=150

	Valid %	Ν		
Reason for Entering Case Management ⁸				
Housing	66.7	100		
Utilities	56	84		
Food services	79.3	119		
Benefits	40	60		
Other financial services	19.3	29		
Substance use treatment	21.3	32		
HIV medical care	46.7	70		
Home, attendant or other medical care	19.6	29		
Dental care	19.3	29		
Psychiatric care or emotional support	60.8	90		
	Ν	mean	range	sd
Mean services needed	149	4.4	(0-13)	2.6

Table 8 presents differences in total number of initial case management needs for selected predisposing, enabling, and need characteristics⁹. Total number of initial case management needs was not found to be different for marital status and employment. There was a statistically significant difference for people with a history of homelessness (F= 6.13, p.=014). As would be expected, people with a history of homelessness have a greater number of initial case management needs than those without a history of homelessness (4.8 vs. 3.8).

⁸ These categories are not mutually exclusive. The majority of individuals have multiple case management needs.

⁹ Appendix B presents significant results of chi-square analyses for individual case management needs. For a county planning for the case management needs of vulnerable populations understanding not just differences in overall number of needs but individual needs is important. Differences by vulnerable characteristics appear for many of the need categories.

Table 8

Differences in Mean Number of Initial	Case Management Needs for Selected Variables

Variable		Mean
Predisposing		
History of Homelessness		
	Homeless during lifetime	4.82*
Education	Not homeless during lifetime	3.77
Education	Less than high school completion	
	Less than high school completion High school completion	
	Some college	
	College degree or higher	
Employment	conce degree of higher	
	Employed (full-time, part-time or student)	4.55
	Unemployed	4.41
Marital Status		4.41
	Married or partnered	4.03
	Divorced, separated, widowed, single	4.52
Enabling	, , , , , , , , , , , , , , , , , , , ,	1.52
Income		
	Above poverty line	3.94
	Below poverty line	4.47
Stable Housing		
	Stable housing	4.10
	Unstable housing	4.77
Site of Care		
	Public	4.46
	Private	4.43
Caregiving role		
	Any care giving role for children, adult, or elderly	4.74
	No care giving role	4.29
Need		
HIV Level		
	Level 1	3.47**
	Level 2	4.49
	Level 3 and 4	5.41
Drug Comorbidity		
	Yes	4.86
M A M M G M M	No	4.32
Mental Health Comorbidit	•	
	Yes	4.29
	No	4.60
t-test		
** significant at .01 level		

* significant at .05 level

significant at .10 level

No significant differences were found when looking at differences by enabling characteristics, including care giving role or income level.

There was a statistically significant difference for total number of initial case management needs by HIV level (F =6.04, p=.00). People with HIV level 1 entering case management report entering with 3.5 needs and people with HIV level 3 and 4 report entering with 5.4 needs. No other differences were detected based on need characteristics.

Additional bivariate analysis (not reported in table 5) showed a statistically significant difference between total number of initial case management needs by number of agencies. Individuals utilizing only one case management agency had an average of 3.5 initial needs, individuals utilizing two agencies had an average of 4.5 initial needs, and individuals utilizing three or more agencies had an average of 6.8 initial needs.

Case Management Utilization Variables

Table 9 displays case management utilization. These data reflect self-reported patterns of access case management and utilization of services throughout enrollment in case management services.

Almost three-quarter of participants identified receiving case management services from a community based organization. The mean time in case management was 42 months with one-third of clients receiving case management for more than three years. One in four clients had received case management for less than one year. While the majority (59%) of participants received case management from only one agency, one in five received case management from more than three agencies. Clients reported an average of just over one visit in the past month (1.3 visits).

While Table 7 displays initial case management needs, Table 9 displays the utilization of those services including services not identified as an initial need. This measure is a reflection that client needs may evolve over time. As a client's disease experience or life conditions change during their enrollment, the case management services received should shift as well. Another explanation for this evolution from initial needs to a full range of services is that a case manager helps the client understand what other services are available to meet his or her needs

	Valid %	Ν
Type of Case Management		
CBO based	73	103
Clinic based	27	38
Time in Case Management		
less than one year	23.4	30
one year to 2 years	22.7	29
2 years to 3 years	19.5	25
more than 3 years	34.4	44
Number of Case Management Agencies		
1 agency	58.9	83
2 agencies	19.9	28
3 or more agencies	21.3	30

N=150

Table 9 Description of Case Management Utilization

Table 9 Description of Case Management Utilization

Case Management
services used

	Housing	87	125		
	Utilities	84	121		
	Food services	94	138		
	Benefits	89	130		
	Other financial services	82	113		
	Substance Use Treatment	75	107		
	HIV Care	90	130		
	Home, attendant or other				
	medical care	81	111		
	Dental Care	76	108		
	Psychiatric care or emotional				
	support	90	127		
		Ν	mean	range	sd
Mean services use	d	150	10.2	(0-17)	3.9
Mean social case r	nanagement use	150	6.4	(0-8)	2.3
Mean medical case	e management use	145	3.8	(0-5)	1.7
Number of case m	anager visits in past 30 days	140	1.3	(0-9)	1.3
Time in Case Man	agement (months)	128	42.21	(1-240)	38.3

Clients utilized a large number of services during their tenure in case management. The mean number of services used was ten. Food services (94%), HIV care (90%), and emotional support (90%) were the most used services. Each category of service was used by over three-quarters of the sample. This high level of utilization reflects the large need for services among clients as well as the ability of case managers to identify and provide services to clients.

Description of Outcomes

Satisfaction with Case Management

Table 10 displays satisfaction with case management services and case manager relationship; these are the outcomes of interest for Specific Aim 2. The mean satisfaction with case management services was 2 on a scale of 1 (ineffective) to 4 (very effective). This value indicates that clients found case managers to be moderately effective in providing services. Clients were highly satisfied with their case manager relationships. The average evaluation was 44 out of a possible 64.

Table 10Description of Client Satisfaction OutcomesN=150

Satisfaction with case management services	N	mean	range	sd
	150	2	(0-4)	0.92
Satisfaction with case manager relationship	148	43.4	(0-61)	10.8

People who received case management services at multiple agencies were less satisfied with the services they received. This is probably a reflection of why they have sought services at multiple agencies. On the other hand, people receiving services at more than one agency were more satisfied with their case manager relationship.

The data suggest that vulnerable characteristics affect the evaluation of service efficacy and the relationship with a case manager. Statistically significant differences in rating of satisfaction with the case manager relationship was found for people with a history of homelessness (F=4.21, p=.042). People who were married or partnered expressed greater

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dissatisfaction with case management services than individuals who were divorced,

widowed, or single (F=3.15,p=0.08)

Differences in Client Satisfaction for Selected Variables				
			Satisfaction with case	
Variable		management services	manager relationship	
Presdisposing				
History of Homelessness				
	Homeless during lifetime	2.08	44.92*	
	Not homeless during lifetime	1.95	41.23	
Employment				
	Employed (full-time, part-time or student)	2.15	42.48	
	Unemployed (run mine, part mine of station)	2.00	43.57	
Marital Status	Chemployed	2.00	10.01	
Marian Status	Married or partnered	1.79#	41.08	
	Divorced, separated, widowed, single	2.10	44.18	
Enabling	Divoleed, separated, widowed, single	2.10	44.10	
Income				
meome	Above poverty line	2.07	43.48	
	Below poverty line	2.07	43.80	
Stable Housing	Below poverty line	2.04	45.00	
Stable Housing	Carble boundary	2.03	42.83	
	Stable housing			
	Unstable housing	2.13	43.89	
Site of Care	D.11	0.07		
	Public	2.07	44.42	
	Private	1.92	42.03	
Caregiving role				
	Any care giving role for children, adult, or elderly	1.92	46.91*	
	-	2.05	42.45	
NT	No care giving role	2.05	42.43	
Need				
HIV Level	T . 11	1.07	42.01	
	Level 1	1.96	43.91	
	Level 2	2.17	43.45	
	Level 3 and 4	1.86	44.03	
Drug Comorbidity		6 40 tot	.	
	Yes	2.10**	34.71**	
	No	1.54	44.84	
Mental Health Comorbidi	-			
	Yes	2.22**	43.70	
	No	1.65	42.82	
ANOVA or T-test				
AA 1 10 1 1011 1				

Table 11 Differences in Client Satisfaction for Selected Variable

** significant at .01 level

* significant at .05 level

significant at .10 level

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Statistically significant differences in the rating of satisfaction with the case manager relationship were found for people in a care giving role (F=4.51, p=.036) with people in a care giving role reporting a higher level of satisfaction. No other differences by enabling characteristics were found to be significant for satisfaction with case manager relationship and no enabling characteristics were significant for satisfaction with case manager management services.

People with drug and mental health comorbidities were more satisfied with the case management services they received than those without comorobidities (F=6.84, p=.010 and F=14.0, p=.000 respectively). However, people with a drug comorbidity were less satisfied with their case manager relationship (F=17.55, p=.000).

Health Status

Table 12 displays health status outcomes. For the MOS and its subscales, a higher score indicates better health (Wu et al., 1997). Clients reported mean general health perception score of 13.5 and a mean quality of life score of 3.3.

Table 12Description of Health Status OutcomesN=150N

MOS general health perception	N 150		range (2-25)	sd 4.9
MOS quality of life	149	3.3	(1-5)	1.1

Table 13 presents differences in health status for selected predisposing, need, and enabling characteristics. Individuals who were married or partnered reported higher general health perception scores than individuals who were divorced, widowed, or single (F=5.262, p=0.02). No significant differences were found based on employment or history of homelessness.

While no difference in quality of life was found for individuals with a care giving role, differences were found for general health perception (F=12.88, p.=.000). People with a care giving role reported a lower general health perception with a score of 11.1 as opposed to a score of 14.4 for people with no care giving role. Differences in quality of life were detected based on stable housing (F=2.83, p.=.095) with individuals living in stable housing reporting higher quality of life than those individuals living in unstable housing situations.

Individuals with vulnerable characteristics reported lower levels of quality of life and general health perception. Differences in quality of life were detected based HIV level (F=11.13, p.=.000), mental health comorbidity (F=3.78, p.=.054), and drug comorbidity (F=8.074, p.=.005). Differences in general health perception were found based on HIV level (F=10.12, p.=.000) and mental health comorbidity (F=3.54, p.=.062).

Variable		Quality of Life Mean	General Health Perception Mean	
Predisposing				
History of Homelessness				
	Homeless during lifetime	3.36	13.44	
	Not homeless during lifetime	3.30	13.64	
Employment				
	Employed (full-time, part-time			
	or student)	3.32	12.95	
	Unemployed	3.33	13.65	
Marital Status				
	Married or partnered Divorced, separated, widowed,	3.51	15.11*	
	single	3.28	13.02	
Enabling	-			
Income				
	Above poverty line	3.32	13.77	
	Below poverty line	3.31	13.55	
Stable Housing				
	Stable housing	3.41#	13.87	
	Unstable housing	3.03	12.30	
Site of Care				
	Public	3.35	13.51	
	Private	3.32	13.10	
Caregiving role				
	Any care giving role for			
	children, adult, or elderly	3.09	11.09**	
	No care giving role	3.40	14.39	
Need				
HIV Level				
	Level 1	3.78**	15.93**	
	Level 2	3.34	13.08	
	Level 3 and 4	2.68	11.44	
Drug Comorbidity				
	Yes	2.70**	12.62	
	No	3.43	13.68	
Mental Health Comorbidity				
	Yes	3.21#	13.00#	
	No	3.58	14.57	

 Table 13

 Differences in Health Status for Selected Variables

ANOVA or T-test

** significant at .01 level

* significant at .05 level

significant at .10 level

Health Care Utilization

Table 14 displays two measures of health care utilization: number of health care visits in the past month and number of emergency room visits in the past six months. Clients had a mean of 3 health care visits over the past month with a range between one and fourteen visits. Over half of the sample (55%) had attended between 1 and 3 health care appointments in the past thirty days with less than one in ten individuals (9%) not attending any appointments.

Table 14Description of Utilization OutcomesN=150

Number of health care visits in past 30 days	N 142	mean 3	range (0-14)	sd 2.1
Number of ER visits in past 6 months	123	0.6	(0-8)	1.3

The measure of health care visits is a composite measure of general health care visits and HIV-specific visits. When the two types of health care visits are examined separately, it was found that the mean number of visits for general health care was 1.64 (sd=1.37, range 0-12) and for HIV-specific care was 1.4 (sd=.98, range 0-5). The modal number of visits for both types was one visit in the past 30 days with over half of the sample having one visit. Utilization rates were high with only nine percent of the sample having no general health care visit in the past 30 days and twelve percent of the sample having no HIV visit in the past 30 days. These numbers also reflect a high rate of utilization of both types of care with 44% of the sample attending one HIV visit and one general health care visit in the past month.

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One hundred and forty-two individuals identified a primary care doctor or nurse and one hundred and forty-three individuals identified a medical clinic, hospital, or doctor's office as a regular source of care. Having a regular source of care allows clients to have a site of care that is better suited for routine health care and for health care that manages disease over multiple visits. Such utilization might prevent clients from delaying care and therefore causing an individual to need emergency services. It might also explain why few differences in health care visits were found in the bivariate analyses presented in Table 15.

Variable		Mean
Predisposing		
History of Homelessness		
	Homeless during lifetime	3.24
	Not homeless during lifetime	2.70
Employment		
	Employed (full-time, part-time or student)	2.44
	Unemployed	3.11
Marital Status		
	Married or partnered	4.00*
	Divorced, separated, widowed, single	2.72
Enabling		
Income		
	Above poverty line	2.43#
	Below poverty line	3.20
Stable Housing		
	Stable housing	3.16
	Unstable housing	3.00
Site of Care	-	
	Public	3.17
	Private	2.63
Caregiving role		
	Any care giving role for children, adult, or	
	elderly	3.15
	No care giving role	2.97

 Table 15

 Differences in Health Care Visits in the Past 30 Days for Selected Variables

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Dif	ferences in Health Care Visits in the Past 30	Days for Selected Variables
Need		-
HIV Level		
	Level 1	2.67
	Level 2	3.00
	Level 3 and 4	3.50
Drug Comorbidity	/	
	Yes	2.94
	No	3.04
Mental Health Co	morbidity	
	Yes	3.16
	No	2.77

Table 15

ANOVA and t-test

** significant at .01 level

* significant at .05 level

significant at .10 level

Married or partnered individuals attended more health care visits in the past 30 days than individuals who were divorced, single, or widowed (F=10.30, p=0.00). No other predisposing variables were found to be significant.

Individuals living above the poverty line attended fewer health care visits than individuals living below the poverty line (F=3.05, p=0.08). No other enabling characteristics were found to be significant. Additionally, no need characteristics were found to be significant.

Compared to what would be expected of a low-income, predominately minority sample, emergency room utilization was very low (Cunningham, Hays et al., 1995; Cunningham et al., 1996; Kilbourne et al., 2002; Weissman et al., 1997). Table 16 displays differences in emergency room utilization. Only 31 clients (25%) used emergency services in the six months prior to being interviewed. Of those who did use services, the mean number of

visits was 2.4 and modal number of visits was 1. This low utilization might reflect the success of case management to have clients access regular sources of care. Utilization of emergency room services was statistically different for people who had a history of homelessness as compared to those individual with no history of homelessness $(x^2=5.05, p=0.03)$. No other statistically significant differences for emergency room utilization based on predisposing or enabling characteristics, including by care giving role, were detected.

As would be expected, emergency room utilization was higher for people with greater HIV acuity. People who evaluated their HIV level at one or two visited the emergency room less than once in the past six month while people who evaluated their HIV level at three or four visited the emergency room on average ($x^2=14.38$, p=0.00). Additionally, having a drug comorbidity increased utilization of emergency medical services ($x^2=10.38$, p=0.00).

A bivariate analyses (not reported in Table 16) found that the fewer number of case management agencies a client utilizes the lower the emergency room utilization. People who received services at three or more case management agencies had an average of 1.24 emergency room visits in six month as opposed to those who received services at one or two agencies who visited the emergency room less than once (.33 and .67 respectively). This difference was significant at the .01 level.

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Table 16				
Differences Emergency Room Utilization	in Past Six Months for Selected Variables			
N	21			

Variable		Ν	Valid %
Presdisposing			
History of Homelessness			
	Homeless during lifetime	23*	74
	Not homeless during lifetime	8	26
Employment			
	Employed (full-time, part-time or student)	5	16
	Unemployed	26	84
Marital Status			
	Married or partnered	6	19
	Divorced, separated, widowed, single	25	81
Enabling			
Income			
	Above poverty line	6	19
	Below poverty line	25	81
Stable Housing			
	Stable housing	22	79
	Unstable housing	6	21
Site of Care			
	Public	22	73
	Private	8	27
Caregiving role			
	Any care giving role for children, adult, or	0	21
	elderly	9	31
	No care giving role	20	69
<i>Need</i> HIV Level			
HIV Level	Level I	6**	21
	Level 1 Level 2	9	31
	Level 2 Level 3 and 4	14	48
Drug Comorhiditu	Level 5 and 4	14	40
Drug Comorbidity	Yes	0 **	29
	No	22	29 71
Mental Health Comorbidit		22	71
Mental realth Comorbidi	Yes	23	74
	No	2 <i>3</i> 8	26
	140	o	20

Chi-square test

** significant at .01 level

* significant at .05 level

significant at .10 level

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Regression Models ^{10,11}

In this section, results of seven regression models are presented. Each model was estimated using ordinary least squares regression, with the exception of emergency room utilization, which was modeled using logistic regression. Each regression model used a standard set of twelve variables, except for the model for initial case management need where utilization variables were excluded. Variables were selected based on the importance to the theoretical model and results from the correlation analyses conducted as part of the descriptive analyses for the dissertation. The predisposing variables selected were a history of homelessness and marital status. The enabling variables selected were income in relation to the poverty line and having a care role. The need variables selected were HIV level, number of HIV symptoms, having a drug comorbidity, and having a mental health comorbidity. The utilization variables selected were time in case management and number of case management agencies. Because the data were collected from a non-random sample, gender, and race/ethnic group were used as control variables in all analyses. A significance level of 0.10 was used for all multivariate analyses.

The discussion of the four specific aims begins with a presentation of the aim and the hypothesis that was tested in the analysis. Results of each of the seven regression models are presented and discussed before a review of the findings in light of the hypothesis. A

¹⁰ A correlation matrix (see Appendix B) was created to examine the variables for high correlation and issues of multicollinearity. Based on these analyses, sexual orientation was excluded from the model because of high correlation with gender. Additionally, health care setting and insurance were excluded because of high correlation with the living below the poverty line as well as each other.

¹¹ Because selection of the sample was not random and there was an over-sampling of African-American and female clients, gender and race or ethnic group were included in all models as control variables. Coefficients and standard errors for these variables are not presented in the descriptions below.

broader discussion of the findings with relation to previous literature is presented in the discussion chapter.

Aim 1: Case Management Needs

<u>Aim</u>: To describe and examine the relationship among predisposing characteristics, enabling characteristics and the self-perceived case management needs of, HIV-positive individuals living in Alameda County, particularly those individuals with HIV who are in care-giving roles.

<u>Hypothesis</u>: HIV-positive individuals who have care-giving roles will have increased case management needs. Individuals with other vulnerable characteristics such as homelessness and substance use will have similar HIV case management use and HIV case management need patterns.

Table 17 displays the ordinary least squares regression model for total number of case management needs. The total number of initial case management needs was examined as the outcome of interest for the first specific aim of this dissertation. The possible range in needs was zero to thirteen services with a greater number of need indicating a higher need level. The model includes select predisposing, enabling, and need variables. Because this aim examined initial number of needs, utilization variables were excluded from the OLS regression model estimating number of needs.

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Table 17OLS Regression EstimatingTotal Number of Initial Case Management NeedsN=115

	B ¹²		se
Coefficient			
Constant		2.63	(0.90)
Predisposing			
History of Homelessness		1.25 **	(0.46)
Married or Partnered		-0.40	(0.491)
Enabling			
Poverty line		-0.22	(0.53)
Care giving role		0.03	(0.50)
Need			
HIV Level		0.108	(0.32)
Total number of symptoms		0.07 **	(0.02)
Drug comorbidity		0.15	(0.61)
Mental health comorbidity		-0.47	(0.47)
Control			
Male		-0.37	(.45)
African-American or other minority		0.07	(.58)
Model fit			
R ²		0.25	
Adjusted R ²		0.18	

** significant at .01 level

* significant at .05 level

significant at .10 level

Eight independent variables were entered into the model for initial case management needs, accounting for 18% of the total variance. In this model only two variables were significant. The vulnerable characteristics of history of homelessness was significant at the p=0.01 level and positively associated with increased initial case management needs.

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¹² All reporting of OLS regression results use unstandarized betas and standard errors.

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Being married or partnered was not predictive of initial case management needs. No enabling variables were predictive of initial case management needs.

The only need variable predictive of initial case management needs was total number of symptoms. An increased number of symptoms was positively associated with an increased number of initial case management needs. On the other hand, self-rated HIV acuity level was not associated with initial number of case management needs. Neither a mental health comorbidity or a drug comorbidity was associated with initial case management needs.

It was hypothesized that HIV-positive individuals who have care-giving roles would have increased case management needs. Furthermore, individuals with other vulnerable characteristics such as homelessness and substance use would have similar HIV case management use and HIV case management need patterns. Based on the results of OLS regression model, total case management needs were not predicted by having a care-giving role. The vulnerable characteristics of history of homelessness and total number of HIV symptoms were positively associated with case management needs. Other vulnerable characteristics, including having a drug comorbidity or mental health comorbidity were not predictive of initial HIV case management needs.

Aim 2: Client Satisfaction

<u>Aim:</u> To describe and examine the relationship among predisposing, enabling and need factors, utilization of HIV case management services, and consumer satisfaction with

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case management as measured by case manager response to client need and client satisfaction with the case manager relationship.

<u>Hypothesis:</u> Increased utilization of HIV case management services will be related to increased client satisfaction with case management services and client satisfaction with the case manager relationship. HIV-positive individuals who have care giving roles will have decreased satisfaction with case manager response to client need and the case manager relationship, controlling for predisposing, enabling and need factors.

Table 18 displays the model summary for the ordinary least squares regression for client satisfaction with case management services and Table 19 displays the model summary for client satisfaction with case manager relationship.

Client-evaluated response examined the average evaluated response by each client. The mean satisfaction with case management services was 2 on a scale of 1 (ineffective) to 4 (very effective). This value indicates that clients found case managers to be moderately effective in providing services. A higher score indicates a higher level of satisfaction.

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Table 18OLS Regression EstimatingClient Satisfaction with Case Management ServicesN=104

	В		se
Coefficient			
Constant		2.45	(0.39)
Predisposing			
History of Homelessness		.00	(0.18)
Married or Partnered		-0.37 *	(0.18)
Enabling			
Poverty line		-0.08	(0.20)
Care giving role		-0.21	(0.18)
Need			
HIV Level		-0.11	(0.12)
Total number of symptoms		0.00	(0.01)
Drug comorbidity		-0.38#	(0.23)
Mental health comorbidity		0.57 **	(0.17)
Utilization			
Time in case management		0.03	(0.07)
Number of case management agencies		-0.21 *	(0.10)
Control			
Male		-0.20	(0.17)
African-American or other minority		0.12	(0.21)
Model fit			
R ²		0.29	
Adjusted R ²		0.20	
** significant at .01 level			

* significant at .05 level

significant at .10 level

Ten independent variables were entered into the model for satisfaction with case

management services, accounting for 29% of the total variance. In this model, four

variables were significant.

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Being married or partnered was predictive of lower satisfaction scores. A history of homelessness was not predictive of satisfaction. No enabling characteristics were significant in the model of client satisfaction with case management services.

Vulnerable characteristics related to comorbid conditions were significant in the model of client satisfaction with case management services. Having a mental health comorbidity was positively related level of satisfaction while having a drug comorbidity was negatively related. HIV self-rated acuity and number of HIV symptoms were not related to satisfaction with case management services.

Receiving services from a greater number of case management agencies was negatively related to level of satisfaction with case management services. This finding could be interpreted as dissatisfied clients look for services at more agencies. On the other hand, the hassle associated with attending multiple agencies may affect how clients see their services.

Client satisfaction of the case manager relationship, as presented in Table 19, was measured using subscale of relationships measures from the HIV Case Management Satisfaction Survey (CMSS). Clients were highly satisfied with their case manager relationships. The average evaluation was 44 out of a possible 64. A higher score indicates a higher level of satisfaction.

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Table 19OLS Regression EstimatingClient Satisfaction with Case Manager Relationship

N=104

	В		se
Coefficient			
Constant		41.64	(4.75)
Predisposing			
History of homelessness		0.21	(2.02)
Married or partnered		-4.26 *	(2.02)
		-4.20	(2.08)
Enabling			
Poverty line		1.10	(2.35)
Care giving role		2.16	(2.21)
Need		1 40	(1 1 7)
HIV Level		-1.40	(1.47)
Total number of symptoms		-0.01	(0.07)
Drug comorbidity		-5.91 *	(2.81)
Mental health comorbidity		-0.74	(2.15)
Utilization			
Time in case management		0.21	(0.81)
Number of case management agencies		2.57 *	(1.14)
Control			
Male		3.89	(1.98)
African-American or other minority		1.67	(2.34)
Model fit			
R ²		0.22	
Adjusted R ²		0.22	
Aujusicu K		0.09	
** significant at .01 level			

* significant at .05 level

significant at .10 level

The model for satisfaction with case manager relationship accounted for 9% of the total

variance. In this model, three variables were significant.

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Client satisfaction with the case manager relationship was lower for individuals who are married or partnered. This relationship is similar to the findings for clients satisfaction with services and may reflect a high expectation for people who receive emotional and social support from a spouse or partner. History of homelessness is not associated with client satisfaction with the case manager relationship.

As was found for client satisfaction with services, neither enabling variable was predictive of client satisfaction with the case manager relationship.

Having a drug comorbidity was negatively associated with satisfaction with case manager relationship. This finding is similar to the satisfaction with services. HIV self-rated acuity and number of symptoms were not associated with client satisfaction. No other need variables were significant predictors of client satisfaction with the case manager relationship.

In opposition to the findings for satisfaction with services, the number of HIV case management agencies was positively associated with satisfaction with case manager relationship. The difference may be explained by clients who continue to use multiple agencies if they are satisfied with the relationship even if they are not satisfied with the services they received. On the other hand, the more people a client feels are invested in his or her care the more satisfied they are with these relationships, regardless of quality of services.

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It was hypothesized that increased utilization of HIV case management services would be related in increased satisfaction with case management services and satisfaction with the case manager relationship. Additionally, it was hypothesized that HIV-positive individuals with care giving roles and vulnerable charactertistics will have decreased satisfaction. Number of case management agencies was positively associated with the case manager relationship and negatively associated with client satisfaction with case management services. This mixed finding seems to indicate a more complicated process of satisfaction than had originally been expected. Having a care-giving role was not predictive of client satisfaction with case management services or the case manager relationship. With respect to vulnerable characteristics, having a mental health comorbidity was positively associated with client satisfaction with services while having a drug comorbidity was negatively associated with client satisfaction with the case manager relationship and with case management services.

Aim 3: Health Status

<u>Aim</u>: To describe and examine the relationship among predisposing, enabling and need factors, utilization of HIV case management services and perceived health status as measured by general health perception and quality of life.

<u>Hypothesis:</u> Increased utilization of HIV case management services will be related to increased health status as measured by general health perception and quality of life. HIV-

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positive individuals who have care giving roles will have lower perceived quality of life and general health status, controlling for predisposing, enabling and need factors.

Table 20 displays the model summary for the ordinary least squares regression general health perception and Table 21 displays the model summary for quality of life. Both measures are subscales of the MOS administered to clients during the interview. For both sub-scales, a higher score indicates a higher level of health status. In both models, the independent variables were entered into the model based on correlation analyses and importance to theoretical model.

Ten independent variables were entered into the model for general health perception, accounting for 26% of the total variance. In this model, four variables were significant. Being married or partnered was positively related to general health perception.

As was hypothesized, being in a care-giving role was predictive for general health perception. Individuals with a care giving role reported lower general health perception. Income in relation to the poverty line was not associated with general health perception.

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Table 20OLS Regression Estimating
General Health Perception
N=104

	В	se
Coefficient		
Constant	17.58	(2.18)
Predisposing		
History of homelessness	-0.82	(0.95)
Married or partnered	2.36 *	(0.97)
Enabling		
Poverty line	1.09	(1.07)
Care giving role	-3.44 **	(0.99)
Need		
HIV Level	-1.09	(0.68)
Total number of symptoms	-0.08 *	(0.03)
Drug comorbidity	-1.32	(1.26)
Mental health comorbidity	-1.70#	(0.94)
Utilization		
Time in case management	-0.01	(0.36)
Number of case management agencies	0.61	(0.53)
Control		
Male	-0.77	(0.90)
African-American or other minority	1.59	(1.15)
Model fit		
R ²	0.35	
Adjusted R ²	0.26	
** significant at 01 level		

** significant at .01 level* significant at .05 level# significant at .10 level

Total number of symptoms was negatively associated with general health perception.

However, HIV self-rated acuity was not associated with general health perception. This discordant finding points to the difference between the role of symptoms and the larger

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concept of illness experience on health perceptions. Having a mental health comorbidity negatively affected general health perception. A drug comorbidity did not affect general health perception. No case management utilization variables were associated with general health perception.

Ten independent variables were entered into the model for quality of life, accounting for 22% of the total variance. In this model, two variables were significant. A higher HIV level indicating a more critical self-assessed disease acuity was associated with a lower quality of life. As would be expected, having a drug comorbidity negatively affected quality of life. The need variables of number of HIV symptoms and mental health comorbidity were not statistically predictive of quality of life. No other variables were predictive including income in relation to the poverty line, or either HIV case management utilization variable.

It was hypothesized that increased utilization of HIV case management services would be related to higher evaluation of general health perception and quality of life. Additionally, HIV-positive individuals who have care giving roles and other vulnerable characteristics will have lower perceived quality of life and general health status. No case management variables were related to either measure of health status. As hypothesized, having a care giving role was negatively associated with general health perception. However, a care giving role was not associated with quality of life. Total number of HIV symptoms was negatively associated with general health perception. Quality of life was negatively associated with general health perception.

Table 21 OLS Regression Estimating Quality of Life N=103

	В		se
Coefficient			
Constant		3.63	(0.53)
Predisposing			
History of homelessness		-0.08	(0.23)
Married or partnered		0.14	(0.24)
Enabling			
Poverty line		0.09	(0.26)
Care giving role		-0.27	(0.24)
Need			
HIV Level		-0.56 **	(0.17)
Total number of symptoms		0.00	(0.01)
Drug comorbidity		-0.93 *	(0.32)
Mental health comorbidity		0.03	(0.23)
Utilization			
Time in case management		0.09	(0.09)
Number of case management agencies		0.21	(0.13)
Control			
Male		-0.20	(0.22)
African-American or other minority		0.44	(0.28)
Model fit			
R ²		0.31	
Adjusted R ²		0.22	

** significant at .01 level

* significant at .05 level # significant at .10 level

Aim 4: Health Care Utilization

Aim: To describe and examine the relationship among predisposing, enabling and need

factors, utilization of HIV case management services and utilization of health care

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services as measured by number of health care visits in past 30 days and emergency room utilization in past six months.

<u>Hypothesis:</u> Increased utilization of HIV case management services will be related to increased health care visits and decreased use of emergency services. HIV-positive individuals who have care giving roles will have lower utilization of heath care services and emergency room visits, controlling for predisposing, enabling and need factors.

Table 22 displays the model summary for the ordinary least squares regression for health care visits in the past 30 days and Table 23 displays the model summary for the logistic regression predicting emergency room visits in the past six months. In both models, the independent variables were entered into the model based correlation analyses and importance to theoretical model.

Health care visits measured the total number of HIV and other physician or nurse visits attended.Clients had a mean of 3 health care visits over the past month with a range between one and fourteen visits. Over half of the sample (55%) had attended between 1 and 3 health care appointments in the past thirty days with less that one in ten individuals (9%) not attending any appointments. All utilization data were client self-reported

Table 22OLS Regression EstimatingNumber of Health Care Visits in Past 30 Days

N=99

	В		se
Coefficient			
Constant		2.10	(1.07)
Des dise site -			
Predisposing		0.70	(0.47)
History of homelessness		-0.78	(0.47)
Married or partnered		1.37 **	(0.48)
Enabling			
Poverty line		-0.86	(0.54)
Care giving role		-0.35	(0.49)
Need			
HIV Level		0.33	(0.34)
Total number of symptoms		0.00	(0.02)
Drug comorbidity		0.60	(0.64)
Mental health comorbidity		0.12	(0.47)
Utilization			
Time in case management		-0.02	(0.18)
Number of case management agencies		-0.40	(0.27)
Control			
Male		0.34	(0, 44)
			(0.44)
African-American or other minority		0.63	(0.56)
Model fit			
R ²		0.19	
Adjusted R ²		0.08	

** significant at .01 level* significant at .05 level# significant at .10 level

Ten independent variables were entered into the model predicting number of health care

visits in the past 30 days accounting for 8% of the total variance. In this model, only

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being married or partnered was significant. This finding was positively associated with having a health care visit in the past 30 days.

Client reported emergency room use in the past six month was examined as a dichotomous measure of use or no use. Only 31 individuals used emergency services in the past six months. Because of the nature of the outcome variable, a logistic regression model was used to estimate emergency room use.

Ten independent variables were entered into a logistic regression model predicting emergency room visits in the past six months, accounting for 29% of the total variance. In this model, three variables were statistically significant.

Having a history of homelessness predicted emergency room use. Individuals with vulnerable characteristics would be expected to have higher emergency room utilization. Being married or partnered did not predict emergency room use.

Having a drug comorbidity was predictive of emergency room use. Because reason for emergency room use was not collected, there is no way to determine if the emergency room use was related to HIV, drug use, or other health care needs. However, no other need variables were predictive of use.

Table 23Logistic Regression EstimatingEmergency Room Use in Past Six Months

N=87

Coefficient	I
	I
Constant -4.87 (1.68)	
Predisposing	
History of homelessness 1.45 # (0.83)	ł
Married or partnered -1.14 (0.82)	(
Enabling	
Poverty line -0.93 (0.85)	,
Care giving role 0.89 (0.73)	
Need	
HIV Level 0.12 (0.53)	
Total number of symptoms0.02(0.02)	
Drug comorbidity 2.39* (1.08)	
Mental health comorbidity1.04(0.69)	
Utilization	
Time in case management 0.18 (0.26)	
Number of case management agencies0.78 *(0.37)	
Control	
Male -0.32 (0.67)	
African-American or other minority-0.78(0.79)	ļ
Model fit	
Cox and Snell R2 0.29	
Nagelkerke R ² 0.42	
** significant at .01 level	
* significant at .05 level	

significant at .10 level

The number of case management agencies was associated with emergency room

utilization. This may reflect that clients with multiple agencies are less like to have their

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care coordinated. There are other possible explanations that may not have been fully explored due to the limited model.

It was hypothesized that increased utilization of HIV case management services would be related to increased health care visits and decreased use of emergency services. In addition, HIV-positive individuals who have care giving roles and other vulnerable characteristics will have lower utilization of heath care services and increased emergency room visits. Number of case management agencies predicted emergency room use but not health care visits. Time in case management and number of case management agencies was not associated with either measure of health care utilization. Having a care giving role was not predictive of health care utilization as measured by number of health care visits or emergency room use. The vulnerable characteristics of a history of homelessness and having a drug comorbidity were predictive of increased emergency room use.

Conclusions

Case management was less predictive than had been expected. Of the seven regression models presented in this chapter, time in case management was not significant in any model. Number of case management agencies was predictive in only three of the models. The data begins to show the affects of case management but the sampling strategy, model and the measures that were used limit the full understanding of case management services in Alameda County In future research, more precise and specific measures of case management intensity and length should be employed.

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Clients in Alameda County have high utilization of routine health care services and low emergency room use. Over 50% of the sample reported an initial case management need for HIV medical care. But at the time of the study, 90% of the sample had primary care provider and attended regular health care visits. While case management services may not be predictive of current level of health care utilization, it does appear that the services are addressing medical needs and assisting clients in entering into and sustaining medical care.

The analysis of health behaviors and utilization for an HIV-positive, low-income sample benefited from the inclusion of vulnerable characteristics in the Andersen Model. Comorbid condition were significant in many of the models. Drug comorbiditiy and mental health comorbidity predicted different outcomes, which were often divergent. In the future, the inclusion of a wider range of comorbid conditions would allow researchers to better understand the constellation of health care needs for HIV-positive individuals.

A history of homelessness was predictive of several outcomes. Early in the study, this variable was not expected to have the impact that is did. The long-term implications of experiencing homelessness and other vulnerable characteristics such as drug use, competing needs, and use of public benefits should be investigated further. This area of research would allow tolook at the legacy of experiences that are known to decrease access to health care and reduce health status.

The vulnerable enabling characteristics of income in relation to the poverty line and having a care giving role were not as relevant to the model as other vulnerable characteristics. Living below the poverty line was not predictive of any of the outcomes of interest. Having a care role was predictive of only general health perception. However, theoretically these two variables were important to the model. Future research should examine in greater detail why these variables were not of greater importance.

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CHAPTER VI

DISCUSSION

Previous studies of case management primarily examined large national data sets (Bozzette et al., 1998; Bozzette et al., 2001; Cunningham et al., 1999), demonstration projects (Fleishman, 1998; Fleishman et al., 1991; Piette et al., 1990; Piette et al., 1992), or agency specific findings (Cunningham, Hays et al., 1995; Kuehnert et al., 1998; Mercier & Racine, 1995; Sonsel, 1998; Taylor-Brown et al., 1998; Weissman et al., 1995). While nationally representative sampling allows for an understanding of case management throughout the United States, the true effectiveness of local case management practices are hidden in such analyses. Because case management systems, including federally funded programs such as the Ryan White CARE Act Title II-funded case management, are structured differently in each local context it is important to focus research attention on local systems to better understand if case management services continue to reap the benefits touted in research from the beginning of the HIV epidemic (Arno, 1986; Arno & Hughes, 1987; Benjamin et al., 1988; Jellinek, 1988).

This dissertation utilizes data from the Alameda County HIV Case Management Evaluation and Redesign Project, a two-year study aimed at examining the strengths and weaknesses in the Alameda County HIV case management system. The Ryan White CARE Act Title I and II Planning Council (the Planning Council) contracted this study to examine the efficacy of HIV case management in Alameda County and to recommend new procedures for improving outcomes. The project examined a wide range of issues

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including the structure of the case management agencies, the perceptions of effectiveness by case managers and the procedural issues within the county that helped or hindered service provision. Of particular interest to the Planning Council were recommendations for procedural changes at the agency level, case manager training, and information about satisfaction of clients with HIV case management. There was a perception that clients were withdrawing from services because of dissatisfaction and the Planning Council wanted to better understand this phenomenon prior to the next funding cycle.

This dissertation focuses on the experiences of English-speaking clients receiving HIV case management in Alameda County. This dissertation examines the predictors of case management needs, satisfaction with HIV case management, health status, and health care utilization using a variation of the vulnerable populations behavioral model developed by Gelberg, Andersen, and Leake (2000). The findings indicate that specific predisposing, enabling, need, and health behavior variables affect how clients perceive their needs, evaluate their satisfaction with case management, appraise their health status, and utilize medical service. Findings indicate that utilization of case management services has limited impact on the studied outcomes of interest.

Review of Methods and Sample

One hundred and fifty HIV-positive individuals receiving HIV case management services in Alameda County participated in the English-language client survey. Clients were recruited from case management agencies with strategic sampling of clients based on gender, ethnicity, and geographic location. The sample accounted for 7.5% of clients

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receiving case management services in Alameda County during the duration of the study. Due to the nature of the recruitment, the sample was non-random and therefore has limited generalizability to the larger HIV-positive population in Alameda County.

Vulnerable characteristics were widespread in the sample with all individuals in the study were HIV-positive. Over 80% of the participants were African-American. Approximately half of the sample identified as gay, lesbian, or bi-sexual. Over 50% of the sample reported a history of homelessness and one in 13 reported being homeless at the time of the study. One-third of the sample was in a care-giving role at the time of the study. Two-thirds of the sample was identified as having a mental health comorbidity and fourteen percent with a drug comorbidity.

The average monthly income of participants was below \$750 and the vast majority of people had income levels below the 2000 Federal poverty line. Eighty-five percent of the sample was unemployed at the time of the study.

As would be expected with for a population with HIV, high rates of poverty and case management needs, enrollment in public benefits programs was high. Nine in ten people in the study participated in at least one public benefit program and 12% of the sample participated in two or more programs. Housing problems appear to be frequent among respondents to the survey.

The breadth of the model was limited due to the small sample size. Each regression model was limited to twelve independent variables (Paul, 2003). A standard set of variables was selected based on the importance to the theoretical model and results from the correlation analyses conducted as part of the descriptive analyses for the dissertation. The model was limited to: two predisposing variables, a history of homelessness and marital status; three enabling variables, income in relation to the poverty line and having a care-giving role; four need variables, HIV level, number of HIV symptoms, having a drug comorbidity, and having a mental health comorbidity; and two case management utilization variables, time in case management and number of case management agencies. Because of the sampling strategy, gender and race and ethnicity were controlled for in all regression analyses but not investigated as independent variables that are potentially predictive of case management needs, client satisfaction, health status, and health care utilization.

Meaning of Findings

An Overview of Case Management Findings

Since all participants were enrolled in case management services, it was not possible to examine differences enrollment in case management make to meeting clients needs, health status, or utilization. However, the survey instrument included measures for case management type, frequency of case management visits, length time in case management services, and number of case management agencies. Length of time in case management and number of case management agencies were selected for inclusion in regression

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analyses because these measures were markers for quantity of services used with sufficient variability.

Clients in the sample attended regular case management appointments. Individuals on average had visited a case manger 1.3 times in the past month with a range of zero to nine visits. Over 80% of the sample had attended at least one case management appointment in the past month while 17% had no visit. (A detailed discussion of HIV case management utilization is presented later in this chapter.)

The results on satisfaction and service duplication are mixed. Clients enrolled at multiple agencies are more satisfied with their case manager relationship and less satisfied with the services they received. An increased number of case management agencies was positively associated with satisfaction with case manager relationship. The personal relationships may be what is sustaining the service duplication. If clients like their individual case managers they may be more likely to continue pursuing services at multiple agencies even if this requires additional energy and time. Multiple case managers may also provide a full complement of social and emotional supports that make the overall case management process appear in a better light.

On the other hand, utilization of an increased number of agencies predicted a decreased satisfaction with services. No other studies have looked at the effect of duplication of services on satisfaction. Individuals may enroll in multiple case management agencies because their needs are not being met at one. This study was unable to answer if this

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dissatisfaction is a result of service duplication or a reason for it. In their study of client perceptions of case management, Fleishman, Peitte and Mor (1991) posit that the nature of case management work and large case loads make case managers hard to access and many outside services difficult to get for clients. However, these are aspects of the case managers job that are rarely seen by clients and hence they are more likely to perceive a negative experience rather than structural issues related to their job.

In focus groups, clients reported the importance of having a long-term relationship with case manager in helping them feel integrated into the health care and social service systems (Eversley & Egorin, 2000b). However, time in case management did not predict any of the outcomes of interest. Upon reflection, this measure was not sensitive to changes that occur once a client is enrolled in case management services for longer periods of time. It is important that studies continue to examine how case management changes over time as well as how long-term case management affects the outcomes for clients. In this dissertation, collecting data from case management records would have allowed researchers to examine how services changed over time. If the study had collected longitudinal data rather than cross-sectional data, perhaps differences in case management overtime would have been noticed. In previous studies that utilized longitudinal data, clients appeared to drift in and out of services and well as have different levels of needs at different points in time (Katz et al., 2001; London et al., 1998).

Another reason why time in case management was not predictive of changes in health status or health care utilization is that case management may be most effective in the first three to six months and not in the longer enrollment periods. During the initial periods in case management is when most of a clients needs should be addressed and when entry into additional resources should be secured. Studies of shorter time periods have found that the most significant changes in utilization and behavior change occur in the first three months (Coffey, 2003; Sorensen et al., 2003). The moving in and out of services found in previous studies may be a reflection of this process of using case management to manage short-term issues and then moving out of services when no other service needs exist (Katz et al., 2001; London et al., 1998). If clients have long-term needs for case management due to substance use or mental health comorbidities, then perhaps these issues are best addressed by other health professionals or case managers and not by HIV case managers.

One argument in support of case management is for the improved access and coordination of care. One would like to think, based on the findings of this dissertation, that use of case management leads to more consistent use of health care services. However, it could be argued that those individuals who are most likely to use regular medical services are also more likely to utilize case management. The structure of this dissertation does not allow for the study of this potential reverse explanation.

The influence of case management on health status and health services utilization is limited. The strong support for case management based on economic savings of reducing expensive emergency care experienced early in the epidemic may not continue as the nature of HIV care and the types of case management services continue to shift. The reason to continue to support case management might have more to do with meeting a larger group of social needs that are less related to HIV disease experience and more towards helping adjust for economic disenfranchisement of the HIV population.

Case Management Need

Many studies have looked at the unmet needs of clients (Cunningham et al., 1999; Fleishman et al., 1991; Katz et al., 2001; Katz et al., 2000; Piette et al., 1990; Smith & Rapkin, 1995) but perhaps a more interesting question is what service needs bring clients to case management. Or put another way, what are the case management needs of clients at the time of enrollment? This dissertation was able to answer this question because clients were asked about the initial case management needs. Participants reported a high level of need with the average individual needing four services at the time of enrolling in case management with a range of zero to thirteen needs. This high level of need is consistent with previous studies for low income individuals with HIV and need for case management services (Arno et al., 1996; Fleishman & Mor, 1993; Fleishman et al., 1991; Katz et al., 2001; Katz et al., 2000; London et al., 1998; Smith & Rapkin, 1995).

More than 90% of participants reported having at least one social need at the time of enrollment in case management with the most requested need being food services and housing. Over fifty percent reported having at least one medical need. This might reflect that medical needs are easier for primary health care providers or HIV-specialist to manage and therefore medical needs are less prevalent in the population since these issues presumably can be addressed in a non-case management setting. (A further discussion of case management is presented later in this chapter.) This supposition is supported by the frequent comments of HIV care providers in Alameda County who mentioned that part of their job as providing care coordination services (Egorin & Eversley, 2000; Eversley & Egorin, 2000a).

The high reported need for specific services reflects a requirement of case management to access special programs designed to assist HIV-positive individuals. In Alameda County during the study period, one agency was given full distribution rights for transportation vouchers and other agencies were seen as "controlling" food and utilities assistance programs for the county. Therefore, case management acts as "gateway" to services that clients should be able to access without the bureaucracy of enrollment. Alternatively, clients might report a full spectrum of needs in an attempt to be seen as being "worthy" of services and the time needed to execute a full case management plan. However, if this pattern were prevalent in the sample, it would be expected that a higher number of initial needs would be reported.

Food services were the most frequently reported initial case management need with four of every five participants identifying it. This is about 20% higher than found in the San Francisco Ryan White CARE Act Eligible Metropolitan Area (EMA) where the 57% of respondents reporting a food need (Katz et al., 1997). In Alameda County, food services included food vouchers for local grocery stores as well as food distribution programs.

Several participants identified a case manager associated with Project Open Hand, a local
 ommunity-based organization that provides groceries and hot meals to HIV-individuals.
 Having a basic need such as food left unfulfilled directly impacts the quality of life and general well being of clients. In the HIV Cost and Service Utilization Study (HCSUS) sample, HIV-positive individuals went without food, along with other subsistence needs, because of a completing medical care need (Cunningham et al., 1999). This decision did not always favor medical care needs, individuals reported forgoing medical care because of a completing food need (Cunningham et al., 1999).

Two-third of respondents reported having an initial need for housing services and almost 90% reported using housing services during their case management career. In addition, one in five participants lived in an unstable housing situation. This high level of need for housing services is not surprising as this study was conducted during a time when economic growth in the San Francisco Bay area placed strain on the housing stock of the area. Alameda County and Oakland, in particular, experienced a rapid regentrification process as upper-middle class individuals looked for "affordable" housing and the city worked to attract over 100,000 new residents¹³. Over the course of the two-year period of the study, the incidence of people having difficulty finding housing or being "renovated out¹⁴" of rental units increased. In concert with this process was the increased cost of

¹³ With the economic boom of the late 1990s and the early 2000s, Oakland began to experience revitalization. This process was assisted when Mayor Jerry Brown announced his goal of brining 100,000 new residents to the city. The implication of this plan, and subsequent development that occurred, was that these new residents were to be desirable upper-middle class individuals. There was limited investment in services for the existing population, which was disproportionately African-American and living at, or below, the poverty line compared to the rest of Alameda County.

¹⁴ As rental prices increased and neighborhoods gentrified, many landlords renovated or otherwise improved apartments and houses. This process allowed landlords to work around rent control and eviction laws. During the renovations, renters were asked to leave the property and most often placed in an unstable

Living associated with increased rents that then put pressure on other needs such as food and transportation.

This high level of housing need is an unfortunate result of environmental conditions often beyond a case manager's or client's control. Housing services have traditionally been a problem area for case managers trying to link to outside services (Mercier & Racine, 1995; Piette et al., 1990; Wright et al., 1993). However, having problems with housing related to a more complicated set of case management needs. As Katz et al (2000) found, people with unstable housing situations needed increased number of other social services including assistance with benefits. In this study, while no differences in initial number of needs based on current housing situation, people with a history of homelessness had a need level that was higher than those without a history of homelessness.

Six out of ten individuals had an initial need for psychiatric services or emotional support. This level of needs is consistent with the findings for the San Francisco EMA, where seventy percent of individuals reported needing mental health services(Katz et al., 1997). In comparison with the high levels of need found in the Bay Area, the nationally representative HCSUS data revealed that one-third of the sample needed emotional support or assistance (Katz et al., 2000).

Even though 90% of individuals reported having a usual source of case management at the time of the study, 46% needed HIV medical care when entering case management.

housing situation, such as staying with friends, in an SRO hotel, or in a shelter. Many of these residents never moved back to the property because while they were given the right of first refusal, the increased

Initial need for HIV medical services demonstrates how even with the availability of Services in the local community, individuals with HIV need assistance with access the Care. This finding seems to point to the importance of case management in helping clients access medical care and then maintain regular contact with health care providers.

Forty percent of clients needed benefits assistance and 20% needed other financial services. In the HCSUS sample, forty-three percent of individuals needed benefits assistance (Katz et al., 2000). In a sample of San Francisco EMA clients, over half reported need financial assistance with food, housing or clothing (Katz et al., 1997). While our study did not ask what the other financial services were for, these studies support a high level the finding that financial services are import to case management delivery.

The rules of Medicaid and Medicare often create long waiting periods prior to enrollment in public insurance programs for people with HIV (Mor, 1993). The means testing used for Medicaid eligibility may mean that if people are still employed part-time, or receiving Social Security Disability Insurance, they may not be eligible for public insurance. For Medicare, people need to be eligible for disability based an AIDS diagnosis or other disease. It is estimated that it takes a minimum of 29 months once an individual has been identified as being disabled and eligible for Social Security Disability Insurance to receive Medicare (Levi, 1998). With early HIV diagnosis as well as longer survival rates for people living with HIV, an AIDS diagnosis may be delayed by many years. Twenty-one percent of individuals initially needed assistance with substance use treatment. This level of needs is approximately twice the national need of 10% as found in HCSUS (Katz et al., 2000). Substance use treatment is a service that requires a case manager coordinate with outside services and often these services are in limited supply (Katz et al., 1997; Marx, Katz, Park, & Gurley, 1997; Piette et al., 1990). As a result, even if one in five clients enter with a substance use treatment need, the chances of this need going unmet is rather high.

One in five clients needed home care when entering case management. This level of need is similar to that found in the HCSUS sample where 17% of individuals needed home care services (Katz et al., 2000). The need for home care probably reflects a client's need for regular assistance at a later stage of disease. Since most of the people in the sample rated their acuity at a lower level, these needs may have been more prevelant in a sample with a greater proportion with more severe limitations on activities of daily living and a greater number of symptoms.

Dental health care was needed by 20% of individuals. Since coverage of dental care is not as wide spread, or standard, as medical coverage, it was surprising that dental care was seldom identified as an initial care management needs. However, national studies report similar levels of need with 20% of the HCSUS sample and 9% the AIDS Cost and Service Utilization Study, the predecessor to HCSUS, sample reporting a need for with dental services (Bonuck et al., 1996; Marcus et al., 2000). To examine the predictors of total number of initial case management needs, an ordinary least squares (OLS) regression model was developed. Independent variables were selected based on importance to the theoretical model and correlation analyses. The model included the following variables: predisposing variables of a history of homelessness and marital status; enabling variables of income in relation to the poverty line and having a care role; and need variables of HIV level, number of HIV symptoms, having a drug comorbidity, and having a mental health comorbidity. It was hypothesized that HIV-positive individuals who have care-giving roles would have increased case management needs. Furthermore, individuals with other vulnerable characteristics such as history of homelessness and substance use will have similar HIV case management use and HIV case management need patterns.

The predictors of initial case management needs were found to reflect previously published literature for the two significant independent variables. Having a history of homelessness was predictive of increased number of initial case management needs. This is in keeping with previous studies of housing situations for people with HIV that found unstable housing to be associated with increased number of social service needs (Cunningham et al., 1999; Fleishman et al., 1991; Katz et al., 2001; Katz et al., 2000; Katz et al., 1997).

HIV symptoms were predictive of number of case management needs. This is in keeping with previous studies of HIV acuity and care needs (Bonuck et al., 1996; Katz et al., 2001; Smith & Rapkin, 1995; Weissman et al., 1995). In the HCSUS sample, individuals

with a more advanced stage of HIV disease were more likely to have case management needs than individuals with less advanced HIV to which they were compared (Katz et al., 2001). Increased number of HIV symptoms may lead to economic changes that generate a need for HIV case management services. Mor (1993) points to structural issues that change when people are diagnosed with HIV and as their disease progresses to AIDS or symptomatic HIV. Most striking in the change in employment and health insurance that occur after a person is diagnosed with HIV. Such changes might lead to increased needs for both medical and social services.

Of particular interest for this dissertation were the care-giving roles by HIV-positive individuals, a vulnerable characteristic in the conceptual model. Having such a role was not found to be associated with case management needs. This contradicts earlier findings (Stein et al., 2000) that showed care-giving to be associated with increased need for medical services. It also contradicts studies (Schuman et al., 2001) showing the decreased need for mental health services for people with care-giving roles.

Utilization of Case Management Services in Alameda County

All individuals in the sample were enrolled in case management at the time of the interview. The range of time enrolled in case management at the time of the interview was one month to twenty years with a mean of 42 months and a median of 36 months. Approximately a quarter of the sample had been in case management for less than one year and an additional 23% had been in services for between one and two years. A third of participants had been in case management for more than three years.

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Forty percent of the sample received services at two or more HIV case management agencies and 20% of the sample received services at three or more agencies. This difference probably reflects the different nature of the service delivery systems. In Alameda County, certain community-based organizations are given the responsibility for distributing supplemental food and transportation vouchers. At these agencies clients are required to enter into case management to receive such vouchers even if a case manager at another HIV case management agency has referred them to the distributing agency and these are the only services they are receiving. Clients perceive such bureaucratic experiences negatively and from an economic perspective such service duplication is a waste of resources. The duplication of services reported in the dissertation sample was higher than had been found in the Robert Wood Johnson Foundation demonstration projects where 10% of clients had multiple case managers (Fleishman et al., 1991). Because the dissertation study focused on HIV case management, the level of service duplication may actually be higher as clients potentially receive other types of case management that were not covered in this study.

Individuals on average visited a case manger 1.3 times in the past month with a range of zero to nine visits. Fifty-six percent of the sample had one visit in the past month while 17% had no visits and 25% had two or more. While less than 20% of clients in either group saw a case manager more than four times in a month. Katz and colleagues (2000) found similar levels of contact with case managers among HCSUS participants. Individuals receiving case management as part of the Robert Wood Johnson Foundation

AIDS Health Services Program on average attended one case management appoint per month with 20% of the clients having no case manager contact (Fleishman et al., 1991). This regular care for clients in Alameda County may be a result of having a strong relationship with a case manager and feeling the time investment receiving services is worthwhile. However, frequent contact with a case manager probably reflects the requirement that a client meet with a case manager to receive services and benefits that are distributed monthly (e.g., transportation and food vouchers). This monthly meeting allows case management agencies to report high levels of regular service provision and therefore continue to receive funding.

Client Satisfaction

Clients rated the services they received and the relationship with their case manager with a low to moderate degree of satisfaction. These ratings were lower than expected as high levels of satisfaction with medical and social services have been consistently reported by people with HIV who have a case manager (Fleishman et al., 1991; Langner & Hutelmyer, 1995; Stein et al., 1993; Stone et al., 1995). However, the concern of the Planning Council about client satisfaction with HIV case management supported the findings of the client interviews.

To understand the differences between services and the case manager relationship, two measures of satisfaction were examined. The two measures were not highly correlated. The difference in the regression models seem to point to variation the results of the Ordinary Least Squares regression models continue to support the notion that case management satisfaction is not exclusively satisfaction with services or satisfaction with the relationship but rather a subtle balance between the two.

Clients were asked to evaluate their satisfaction with individual case management needs between ineffective (1) and very effective (4). The list of needs evaluated were the same as those asked about as initial needs. Because case management evolves over time, participants were not limited to evaluating services needed only when they entered care. An overall summary score was computed in the dissertation as a measure of case manager response to client need. The mean score for case management service satisfaction was two (2), which is below an expected average of 2.5, and indicates a low level of satisfaction. However, on the scale a response of two indicated services were "usually effective."

Participants are asked to complete the HIV Case Management Satisfaction Survey (CMSS), a 46-item scale that was created based on qualitative interviews with HIV case management patients and developed specifically for the Alameda County HIV Case Management Evaluation and Redesign project. This scale, while not standardized, addressed concerns about the inclusion of clients perspective that have been raised by other researchers of satisfaction with care (Cleary, 1999; Cleary & Edgman-Levitan, 1997). Clients were asked to rate each item using a Likert-type measurement where one (1) indicated not true and four (4) indicated very true. For this dissertation, a 16-item subscale of the CMSS was used. Those questions related to the interpersonal relationship between the client and the case manager was included in the subscale while item related to service delivery and agency characteristics were excluded. The average evaluation of client satisfaction with the case manager relationship was 44 out of a possible 64. This is an approval rating of 66% indicating a low to moderate level of satisfaction. In a study of patient ratings of quality, which employed a similar type of scale to the one used in this dissertation, clients reported a satisfaction level of 87% or 26 out of a potential 30 points (Stone et al., 1995).

To examine the predictors of client satisfaction, an OLS regression model was developed. Independent variables were selected based on importance to the theoretical model and correlation analyses. The model included the following variables: predisposing variables of a history of homelessness and marital status; enabling variables of income in relation to the poverty line and having a care-giving role; need variables of HIV level, number of HIV symptoms, having a drug comorbidity, and having a mental health comorbidity; and utilization variables of time in case management and number of case management agencies. It was hypothesized that increased utilization of HIV case management services will be related in increased client satisfaction with case management services and client satisfaction with the case manager relationship. It was also hypothesized that HIVpositive individuals who have care-giving roles will have decreased satisfaction with case manager response to client need and the case manager relationship, controlling for predisposing, enabling and need factors.

An increase in the number of case management agencies a client received services from was significantly associated with decreased satisfaction. While frequency of contact with case manager has been found to increase satisfaction with services (Fleishman et al., 1991) no studies have looked at the implication of using multiple case management agencies to meet client needs. Perhaps this is because most studies look at case management as a complete process, often provided by a single agency in a community rather than at fragmented system such as that which exists in Alameda County. Or perhaps for researchers the duplication of service seems anathema to the notion of case management as a unifying and coordinated process. Do the findings of this dissertation reflect the displeasure of needing to "shop" for services or do they reflect displeasure in a system that does not coordinate care as much as distribute benefits?

Clients reported a low degree of satisfaction with case management services that was not in keeping with the findings of medical care and case management which have a bias towards very high levels of satisfaction (Fleishman et al., 1991; Langner & Hutelmyer, 1995; Stein & Mor, 1993; Stone et al., 1995). For example, the Robert Wood Johnson Foundation AIDS Health Service Project clients enrolled in the demonstration project generally were satisfied with both their case managers and the services they received (Fleishman et al., 1991). While community-based organization clients tended to be more dissatisfied in their evaluations the proportion of clients who were dissatisfied was relatively small (Fleishman et al., 1991).

In considering how people rated their satisfaction with both services and the relationship with a case manager, it is important to consider that case management services entitled people with HIV to services that are not readily available to the general public. It should be remembered that clients might be hesitant to complain because they are satisfied with the services just being available. Do clients think that by complaining about a "bonus" services it makes them "ungrateful?" An alternative explanation is the people hold public benefit programs, such as case management provided by the county, in low esteem and these low expectations of case management bias their evaluations. Or perhaps in a less optimistic perspective, the services are being provided with only a low degree of efficacy.

In general, clients reported a moderate degree of satisfaction with their case manager relationship. This finding is in keeping with qualitative data collected during the larger study where clients expressed a high degree of respect for, and personal involvement with, their case managers but were not always happy with the amount of time and attention provided. Clients reported feeling disappointed and abandoned when the case manager left an agency, which occurs often due to high turnover rates.

Health Status

Participants completed the Medical Outcomes Survey 36-Item Short-form Health Survey for HIV (MOS) (Wu et al., 1997). The MOS is an accepted and recommended standard measure of quality of life for individuals living with HIV (Cunningham, Bozzette, Hays, Kanouse, & Shapiro, 1995; Fowler et al., 1992; Health Resources and Services Administration, 2000; Wright, 1994; Wu et al., 1997). For this dissertation the MOS subscales of general health perception and quality of life were used to measure health status. The inter-item reliability for the general health perception subscale in this dissertation were comparable to previously published studies (Cunningham, Bozzette et al., 1995; McHorney, Ware, Lu, & Sherbourne, 1994). The quality of life subscale was a one-item subscale so such a statistical test was not appropriate. Clients reported relatively high levels of health status.

To examine the predictors of health status, an OLS regression model was developed. Independent variables were selected based on importance to the theoretical model and correlation analyses. The model included the following variables: predisposing variables of a history of homelessness and marital status; enabling variables of income in relation to the poverty line and having a care role; need variables of HIV level, number of HIV symptoms, having a drug comorbidity, and having a mental health comorbidity; and utilization variables of time in case management and number of case management agencies. It was hypothesized that increased utilization of HIV case management services will be related to increased health status as measured by general health perception and quality of life. It was also hypothesized that HIV-positive individuals who have caregiving roles will have lower perceived quality of life and general health status, controlling for predisposing, enabling and need factors.

This dissertation study found that case management services had no relation to increased perception of health perception or quality of life. These findings directly contradict the original hypothesis. One potential explanation is that with a chronic illness such as HIV, general health outcomes are not affected by the services provided through HIV case management. Because of this, a different measure of health status may have offered a better insight into the role of case management and health status. The hypotheses were

not supported when examining the relationship between care-roles and quality of life. Having a care-role was associated with decreased health perception but was not associated with quality of life.

An increase in the total number of symptoms was associated with decreased health perception. While this finding is consistent with earlier studies of HIV acuity and health status (Kilbourne et al., 2002; Sowell et al., 1997), the total number of symptoms was not associated with a decrease in the quality of life. On the other hand HIV level, measured as self-perceived acuity, was associated with decreased quality of life. This is consistent with research on disease progression and quality of life (Cleary et al., 1993; Holzemer & Wilson, 1995; Sousa et al., 1999; Sowell et al., 1997; Weitz, 1991; Wilson et al., 1997). While patients develop strategies to maintain a certain degree of quality of life throughout the disease spectrum (Wilson et al., 1997), research has shown that decreased ability to complete activities of daily living, due to illness, is associated with lower quality of life (Cleary et al., 1993; Sowell et al., 1997). Because increases in HIV level and symptoms had discordant relationships with the outcomes of interest this seems to point to the subtle but important differences in measures of health status, acuity, and symptoms. These differences have important clinical and research significance as HIV care and case management look to "managing disease."

Health Care Utilization

Over 90% of the sample identified a primary care provider and medical clinic, hospital, or doctor's office as a regular source of care. Having a regular source of care allows

clients to have a site of care that is well suited for routine health care and for health care that manages disease over multiple visits. Such utilization might prevent clients from delaying care and therefore needing emergency services.

The measure of health care visits used in this dissertation was a composite measure of general health care visits and HIV-specific visits. Clients had a mean of three health care visits over the past month with a range between one and fourteen visits. Utilization of health care visits was high with less than one in ten individuals (9%) not attending any appointments. The modal number of visits for both general health care and HIV-specific care was one visit in the past 30 days.

Married or partnered individuals attended more health care visits in the past 30 days than individuals who were divorced, single, or widowed. Individuals living above the poverty line attended fewer health care visits than individuals living below the poverty line

Only 31 clients (25%) used emergency services in the six months prior to being interviewed. Compared to what would be expected of a low-income, predominately minority sample, emergency room utilization was very low (Cunningham, Hays et al., 1995; Cunningham et al., 1996; Kilbourne et al., 2002; Weissman et al., 1997). Of those who did use services, the mean number of visits was 2.4 and modal number of visits was one. Utilization of emergency room services was statistically different for people who had a history of homelessness as compared to those individual with no history of homelessness. As would be expected, emergency room utilization was higher for people with greater HIV acuity. Having a drug comorbidity increased utilization of emergency medical services. A bivariate analyses found that the fewer number of case management agencies a client utilizes the lower the emergency room utilization.

To examine the predictors of health care utilization, an OLS regression model was developed for number of health care visits. Because emergency room utilization was measured as a dichotomous variable, a logistic regression model was developed for utilization of emergency room services. Independent variables were selected based on importance to the theoretical model and correlation analyses. Both models included the following variables: predisposing variables of a history of homelessness and marital status; enabling variables of income in relation to the poverty line and having a care role; need variables of HIV level, number of HIV symptoms, having a drug comorbidity, and having a mental health comorbidity; and utilization variables of time in case management and number of case management agencies. It was hypothesized that increased utilization of HIV case management services would be related to increased health care visits and decreased use of emergency services. It was also hypothesized that HIV-positive individuals who have care-giving roles will have lower utilization of heath care services and emergency room visits, controlling for predisposing, enabling and need factors.

As opposed to the research hypothesis for emergency room utilization, having a care role was not associated with utilization of emergency room services nor was either of the case management utilization measures. When examining use patterns of people in care roles who had emergency room utilization, there were no statistically significant differences in either the full regression model or bivariate analyses comparing those with, and without, care roles.

A potential explanation for the lack of significant findings in relation to case management might be the low utilization rates of emergency services by the clients interviewed. The mean number of visits to the emergency room in the past six-month was less than one with only 31 clients (25%) utilizing emergency services. Even among these individuals the average number of visits was 2.4 during a six-month period. Because previous literature notes high emergency service use for people living below the poverty line, of African-American decent, with public insurance or low educational attainment (Cunningham, Hays et al., 1995; Fleishman & Mor, 1993; Mor, 1993), it might be argued that case management actually is impacting the use of these services but because all participants were using such services infrequently the effect was not measurable.

The low emergency room utilization may be related to the high rates of having a usual source of care among the sample. Over 90% of the sample identified a primary care provider. In previous literature, a usual source of care reduced emergency room utilization (Cunningham, Hays et al., 1995; Mor, 1993).

Robert Wood Johnson Foundation AIDS Services Health Project clients using hospital clinics for their site of care had more physician visits in the three months prior to study and to have lower likelihood of using the emergency room for care (Mor, 1993). Mor (1993)notes that utilization of health care services does not necessarily equal higher quality of care, especially in the case of hospital-based clinics where the continuity of care is not the same as in a private physician's office (Mor, 1993).

The low utilization of emergency room services in Alameda County may be an artifact of the difficulty in receiving emergency care in the County and have nothing to do with having a source of usual care or case management. Most emergency care in Alameda County is provided through Highland Hospital. The county emergency department is not known for providing timely and comprehensive care. Therefore, people may avoid using services all together rather than enter into a potentially arduous process.

Case management was initially supported because it was shown to reduce the utilization of expensive inpatient medical care and increase the use of outpatient services (Arno, 1986; Arno & Hughes, 1987; Benjamin et al., 1988). But as the nature of HIV care has changed, the role of case management must have shifted as well. In this dissertation study, no utilization of case management services variable was associated with health care utilization. One potential explanation is that case management clients have little variability in their medical appointment attendance and low utilization of emergency services. A question this dissertation was unable to answer, but is still worth considering, is do the utilization patterns reflect a specific experience of clients in case management or do the utilization patterns reflect larger social forces that can not be mitigated by case management?

Sociological Implications

Refining the Behavioral Model for Vulnerable Populations

The high level of explained variance for all of the regression models employed in this dissertation support the use of a modified version of the Behavioral Model for Vulnerable Populations (Gelberg et al., 2000) for understanding health care utilization by HIV-positive individuals. This model builds on earlier models developed by Andersen, Aday, Newman, and colleagues that focused attention on the general population but did not attempt to address the unique access issues experienced by communities traditionally disenfranchised in America (Aday & Andersen, 1974, 1978, 1981; Andersen, 1968, 1995; Andersen & Aday, 1978; Andersen et al., 1983; Andersen & Newman, 1973). The Vulnerable Population model allows for a better understanding of the nuances of care and the barriers of care for these populations.

Findings from this dissertation suggest that studies including vulnerable characteristics in the model should not examine exclusively current status but collect historical data. The inclusion of a history of homelessness in the regression models generated surprising results. A more comprehensive list of historical characteristics include incarceration, unemployment, domestic violence, and immigration status. The development of a historical category could provide useful insight into how individuals utilized services and evaluate their health based on habits and perceptions developed as a result of these experiences. For example, are people with a history of lack of insurance more likely to use emergency services because this is a health care delivery mode they have learned how to use?

In the examination of HIV-positive individuals, as well as other vulnerable populations, comorbid conditions should be included in the model. Having a drug use comorbidity and a mental health comorbidity repeatedly were significant predictors in the regression models employed for this dissertation. It is worth developing subcategories of comorbid condition based on the etiology of the disease. For example, drug use would be considered a behavioral comorbid condition and breast cancer would be considered a physiological comorbid condition.

The model put forward by Gelberg, Andersen, and Leake (2000) focuses on the utilization of health care services as the determinant of health outcomes. In the original model, case management is identified as an enabling characteristic. This placement implies that case management services, along with other social services, does not have the same potential impact on health status and quality as medical care. This dissertation deviated from the original model by examining case management in place of more traditional forms of medical care as a predictor. The lack of statistically significant findings for the intervention of interest, case management, might point to a shift that is needed in understanding the full model. From this research, it could be argues that the role case management with the emphasis on advocacy and care coordination needs to be further integrated into the model under the category of health utilization. This revision of

the model for vulnerable populations would reflect a more coordinated system of health care delivery. This is the type of system that the Ryan White CARE Act and other funding mechanisms expect when directing resources not only to medical services but social services as well.

Lessons Learned

This dissertation project achieved what sociological work is supposed to; it made a contribution to the phenomenon being studied. For this project, the contribution came in the form of training materials and proposed changes to Alameda County's HIV case management programs. At the same time, this dissertation, like all research projects, offers many places for hindsight about the methodology and study implementation. Many of these points became apparent as I worked with data to answer the question about the role of case management in Alameda County and as I looked at the generalizability of the project. Even with the suggestions that will be made in this section, I recognize that many of them were not possible given the structural and resource limitations of the project.

Sampling

The dissertation study employed a convenience sample of 150 individuals enrolled in Ryan White CARE Act funded case management. The study would have benefited from the use of a better sampling strategy and a larger sample size. The results of this dissertation have limited generalizability because of the non-random nature of the study. The complexity of the predictive model used in this dissertation was limited due to the sample size. The use of a random sample of all HIV-positive individuals in the county would have allowed for a comparison of clients receiving case management and those who were not receiving services. The true effect of case management as delivered in Alameda County potentially would be been measured if this sampling strategy was undertaken. The limiting of samples to people currently enrolled in HIV care is a common problem with access to care studies(McKinney & Marconi, 2002).

If a county-wide random sample was not possible, random sample of clients receiving case management services in the county would have been the next best option. Having a random sample of case management clients would have allowed for generalizability to the county and stronger statistical models that included race and gender. Potentially, a random sample of case management clients would have provided a better distribution of clients between clinic-based and community-based organizations. This information might have shown differences in the nature of case management based on the type of agency, which did not appear in the results of this dissertations. Additionally, a random sample of clients. This data would have allowed for an understanding of how clients living in urban settings such as Oakland compare to clients living in more suburban settings such as Hayward.

Ideally, a larger sample would have been collected and a more complex model of case management and health outcomes could have been constructed. Because the sample size was only 150 the regression model was limited to twelve independent variables (Paul, 2003). In a post-hoc power analysis, a sample size over 263 was recommended based on the size of the HIV case management population in Alameda County. If the full HIV population had been entered into this model, the ideal sample size would have been even higher.

Measures

At the beginning of the research project, no scale in the published literature measured the case manager relationship in a multi-dimensional manner. Based on qualitative data collected as part of the instrument development process the HIV Case Management Satisfaction Survey (CMSS) was developed to specifically examine case management services, agencies, and relationships as perceived by clients. This dissertation employed a 14-item sub-scale of the CMSS, which offered a high level of internal consistency and face-validity. This subscale was included as an outcome of interest because, in focus groups and interviews with clients, it was apparent that this relationship was an important component of the case management experience as well as the perception of the efficacy of services (Eversley & Egorin, 2000b). More research needs to be conducted on the interpersonal dynamics of clients and case managers. This measure should be tested in a larger sample to see if the sample levels of internal validity exist. Also, the measure should be tested outside of Alameda County to see if there is generalizability of the measure to the larger HIV population.

The measures of case management need included in this dissertation study did not allow for an understanding of how client case management needs change over time. The study

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also asked clients to evaluate a range of services they received even if these were not initial needs. From this measure, a proxy measure of developing need could be employed. However, this proxy measure would be limited because we do not know if clients initiated service request or if these services were delivered initially because of a case manager perceived need. In the end, this proxy measure was not included in the model because of the measurement ambiguity. The question was structured so that clients could be reporting their own experience of services or their perception of services available in the county. While this information is useful for the goals of the larger project, it did not seem appropriate for this dissertation. A future study needs to develop a more precise measure of case management need and how needs evolve over time.

The study collected information about initial HIV care management needs which offer limited insight to what draws clients to case management. A measure of what spurred the decision to enter case management would have been useful. Potential questions that could have been answered by this additional measure include were clients forced to enter case management to receive services?; do clients enter case management on the recommendation of a health care provider?; and do case management agencies provide any outreach into the community for people before they become clients?

Because the process of case management is a dynamic one, additional measures of need and need fulfillment might have been useful. Questions for each need category asking if clients ever had this need, if clients' needs was met, and how long it took to resolve would have allowed for more precision in understanding the case management process. While increasing participant burden, these additional data would have allowed for a more robust understanding of the full spectrum of case management care.

Methodological Changes

All data was collected via client self-report. While client recall for short periods of time has been found to be reliable (Justice et al., 1991; Kauth et al., 1991), the longer-term recall is not as reliable. The data concerning initial needs may have been biased because of problems with recall. If the resources had been available, a chart review of clients' case management records would have allowed for additional measures of needs and services received. By conducting a chart review, it would have been possible to examine the number of client visits required to address specific needs as well as see if needs reappeared during the course of case management. Chart review would also allow for a more accurate measure of appointment attendance and number of needs. In both of these areas, there was the potential for over- or under-reporting by a participant wanting to give an answer he or she deemed more appropriate than the truth.

Another manner for understanding how case management services are received would have been linking clients and case managers into dyads. In the study of care-giving and case management by London, LeBlanc, and Aneshensel (1998), the use of dyads provided a more complex picture of the needs and utilization of services for both the HIV-positive individual and the caregiver. The dyads in this study were the informal caregiver and the person with HIV. London and colleagues did not match these pairing to case managers. Rather the researchers studied the case management needs of both patients and care givers to see how services changed over time as well as difference in levels of need based on the care-giving relationships. Building on this data collection strategy, dyads of clients and case managers would have allowed for an examination of the concordance between a client's perception of services received and a case manager's report of services delivered. Future studies would benefit from examining both sides of the client-case manager relationship and the differences in perception of how and which services are delivered during HIV case management.

Future Directions

Study of Case Management

HIV case management should remain an area of study as long as economic and human resources are directed to this form of service delivery. As the emphasis on case management moves towards solving structural and personal barriers to care, social support, and other subsistence needs (i.e., food and housing), the research on HIV case management needs to become more refined. HIV case management research should move beyond looking at unmet needs and health care utilization to a full complement of outcomes including satisfaction, client skill development, and the case management process.

One of the implicit reasons for case management is to have clients develop skills so that they need fewer case management services while working to meet their current needs. This goal implies a level of client education and skill development. Future studies should develop measures and methodologies to allow for the study of client education and independence.

Few studies have examined HIV case management from a systems perspective. Future case management research should examine how HIV case management is integrated into HIV care. A comparison of different models of case management delivery and different local systems would allow for a better understanding of case management practices and service integration. Comparative research would move beyond current case management research, which tends to focus on the individual client experience or on individual agency practices. By engaging in institutional level analysis, the application of HIV case management and a more global perspective will inform the improvement of the services.

Economic analysis of HIV case management should remain a field of research that informs future HIV case management funding on the federal, state, and local levels. Early studies championed HIV case management for the cost savings that it produced. As the treatment and care of HIV has evolved so has the role of case management. The new economic analyses should focus on spending per client as well as spending per service category to look at where the current needs are as well as where spending could be restructured.

Continued Research on Vulnerable Populations

The validity of the Behavioral Model for Vulnerable Populations should be tested on a larger, more diverse sample of HIV-positive individuals. The model offers important

modifications to the Behavioral Model of Health Services Utilization, often referred to as the Andersen Model. While several nationally representative data sets have been analyzed in accordance with the Andersen Model (Bozzette et al., 1998; Cunningham et al., 1999; Cunningham, Hays et al., 1995), these data, in addition to robust data sources yet to be developed, offer the potential to better examine nuances of the health experiences of vulnerable populations by including vulnerable characteristics into the data analyses.

The predictive role having a history of homelessness played in accessing health services, health status and satisfaction with care was surprising. While extensive research has been conducted on individuals who are homeless at the time of data collection (Cousineau, 1997; Gelberg, Gallagher, Andersen, & Koegel, 1997; Gelberg, Linn, Usatine, & Smith, 1990; Mercier & Racine, 1995), little research has been done about the long-term effects of experiencing homelessness or other sources of instability. Future research should look at the long-term implications of vulnerable characteristics including homelessness, unemployment, incarceration, drug use, competing needs, and use of public benefits before current study period. It would be worthwhile to include such measures in future versions of national data collection efforts such as the National Health Interview Survey (NHIS) and the Medical Expenditure Panel Survey (MEPS) for the general US population and the HIV Cost and Service Utilization Study (HCSUS) for HIV-positive populations.

Focusing on Family Case Management and Gender Issues

The original intent of this dissertation was to examine the role of care-giving, specifically the care roles of women, in utilizing case management services and the health related outcomes. Due to sample limitations this research was not possible. In the sample, while almost half of participants provided care to another individual, only two individuals received case management services for their dependent child or adult. Many clients noted that such services were available for children and their care givers through Children's Hospital's Title IV-funded case management program. However, clients caring for adult dependents or clients who did not know about, or could not access, the Children's Hospital program were at a disadvantage for receiving services. Future research should look at the differences between those who receive case management in the general community setting and those individuals enrolled in special family based case management programs, such as Ryan White CARE Act Title IV programs.

Expanding and Improving the Client Satisfaction with Case Manager Relationship Scale Based on qualitative data collected as part of the larger project, I believe the relationship with a case manager is a key factor for client continuing with case management, attending appointments, and engaging fully in the case management process. A new scale of satisfaction with case management was developed for the project, and a subscale was used in this dissertation. This measure has the advantage of using client perspectives to measure satisfaction with a wide variety of case management components and as Cleary and Edgman-Levitan (1997) note client perspectives are rarely include in satisfaction measures. Future research should further validate this new scale and work to develop additional measures of the client-case manager relationship that could be generalized to other HIV case management systems and to the more general case management community.

Conclusions

The lack of statistically significant findings supporting the role of case management in health care utilization should not overshadow the results of this research and the larger project from which the data came. The project outcomes of client and case manager training were of benefit for all those who were involved with the process. While it is unknown if these efforts will be sustained given current budgetary constraints and changes in the Planning Council direction, creating a sense of community and an arena for discussion was important. Additionally, the training materials provided to the county offer excellent resources for future training efforts.

With respect to this dissertation study, clients who are receiving case management services have moderate to low levels of satisfaction with both the case management services and their relationship with a specific case manager. The study also found that HIV-positive individuals receiving case management services in Alameda County had low utilization of emergency services. These findings do address the initial concerns of the Planning Council that HIV case management services were not meeting the expectation of clients. The effectiveness of the case management system and the larger health care delivery system of Alameda County is limited by the current fragmented structure. The county should work towards an integrated system that would better use the

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Appendix A Client Instrument _____ Interviewer Initials
____ Date
____ Alameda County Resident
Case Management Client

Time Begun _____ Time Ended _____

Client Instrument HIV Case Management in Alameda County

I. Demographics and Social Factors

- 1. What is your current age? _____
- 2. What is your gender identification? (choose one)
- __ Male
- __ Female
- ___ Transgender
- ____ Male to Female
- ___ Female to Male
- ___ Other _____

3. With which racial or ethnic group do you most closely identify?

- __ Caucasian
- ___ African-American
- ___ Latino/a
- ___ Asian or Pacific Islander
- ___ Native American
- ___ Other ethnic background _____

4. What language do you speak most often at home?

- ___ English
- ___ Spanish
- ___ Cantonese
- ___ Mandarin
- ___ Tagalog
- ____Other ______

5. How many years of education you have completed?_____

clues: High school=12 and College=16

6. Are you presently employed?

- ___ Yes, full time
- ___Yes, part time
- ____Yes, occasional labor
- ___ Yes, volunteer work
- ___ Yes, enrolled in a stipend program
- ___ No, unemployed
- ____ No, retraining program

7. Are unable to work full or part time due to a disability?

- __ Yes
- ___ No

8. To the nearest \$100, What is your current monthly income?

9. Do you receive money for any of the following services?

- __ SSI
- __ GA or Cal Works
- __ SSDI
- ___ SDI
- ___ AFDC
- ___ Long Term Disability
- __Other _____

10. Where do you currently receive your primary health care for HIV disease?_____

11. Do you receive health care including alternative and complimentary therapies from any other sources (doctors, clinics, hospitals etc.)?

__Yes __No

12. If yes, where do you receive other health care?_____

13. What is (are) the most likely way(s) that you became infected with HIV? (Check all that apply)

- ___ Sex with a man who was HIV+
- ___ Sex with a woman who was HIV+
- ___ Shared needles with a person who was HIV+
- ____Blood transfusion or other medical procedures
- ___ Uncertain
- ___Other : Please specify

II. Health Insurance

1. How do you currently pay for your health care?(check all that apply)

- ____ Medicaid or MediCal
- ___ Medicare
- ___ Military/Veterans Administration
- ___ Private Insurance (self/spouse/significant other)
- ___ Clinical drug trial
- ___ Self pay
- __ Other. Please specify: _____

2. Does your health care program pay for part or all of your HIV medication? ____ All ___ Part ___ None

3. Do you receive free medications from a drug assistance program (such as ADAP)?___ Yes ___ No

4. Do you receive free medications from a clinical drug trial? ___Yes ___No

5. Are there medications you need that you cannot afford?

III. Relationships and Family

1. Which sexual orientation do you most closely identify with?

- ___ Heterosexual
- __ Gay
- ___ Lesbian
- __ Bisexual
- ___ Undecided
- ___ Other _____

2 What is your present marital status?

- ____ Married or domestic partner relationship
- ___ Divorced or separated from spouse or partner
- ___ Widowed
- ___ Single, never married or partnered

3. Are you currently in a primary sexual relationship?

- ___Yes
- ___ No (skip to question 5)

4. If yes, how long have you been in this primary relationship?

._____

5. Do you have any children from any relationship?

- __Yes
- ___ No (skip to question 8)

6. If yes, how many children do you have? _____

7. What is the age and gender of each child. Do they currently live with you.

Age	Gender	Do they live with you?		
		yes	no	

8. How many total children, including children who are not yours, under the age of 18 live with you?

(if 0 skip to question 11)

9. Besides your child(ren), What is the age, gender and relationship of each child living with you

Age	Gender	Relationship

10. Have any of the dependent children under the age of 18 that you take care of received any help from your HIV case manager?

__Yes

___ No

Please describe the help they received

11. Do you take care of any dependent adults over the age of 18 including adult children?

__ Yes

____ No (skip to question 14)

12. If yes, please describe age, gender and relationship?

	es, preuse c	action age, genaer and r
Age	Gender	Relationship

13. Have any of the dependent adults over the age of 18 who you take care of received any help from your HIV case manager? ___ Yes___ No

Please describe the help they received

14. Do you take care of any dependent elders (over the age of 65)?

(Please note is care is shared with other family members.)

- __ Yes
- ___ No (skip to question 17)

15. If yes, please list age, gender and relationship of each elder.

Age	Gender	Relationship	

16. Have any of the dependent elders over the age of 65 who you take care of received any help from your HIV case manager?

- __Yes
- ___ No

Please describe the help they received

17. Do you have a care-giver (a family member, partner, or friend who assists you with the activities of daily living?

- ___ Yes
- ____ No (skip to next section)

19. Does your care-giver receive any services from your HIV case manager?

- __ Yes
- ___ No

Please describe the help they received

IV. Housing Status

1. Please describe where you currently live (choose one)

- ____ House, apartment, or flat
- ____ A friend or family member's house apartment or flat
- ____ Single room occupancy hotel
- ____ Transitional housing
- ____ Halfway house or drug/alcohol center
- ____ Shelter
- ___On the street, in a park, in a car, or in an abandoned building
- ___ Hospital
- ___ Jail
- ___ Other _____

2. What is the current zip code of your residence or the area where you currently live?_____

3. How long have you have been living in your current residence?

4. Is your home accessible to caregivers and other service providers?

- __ Yes
- ___ No

5. Prior to this residence, please describe where you lived

- ____ House, apartment, or flat
- ____ A friend or family member's house apartment or flat
- ____ Single room occupancy hotel
- ____ Transitional housing
- ____ Halfway house or drug/alcohol center
- ___ Shelter
- ___On the street, in a park, in a car, or in an abandoned building
- ___ Hospital
- ___ Jail
- ___ Other _____

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6. Have you ever been homeless?

__ Yes

No (skip to next section)

7. When were you last homeless? _____

8. For how long were you homeless? _____

V. HIV Case Management

1. Are you currently receiving HIV case management?

__Yes __No

2. Where are you or where have you received case management in Alameda County?

Please list each agency, length of time in case management and if you are currently receiving case management from this agency.

	Agency	Length of time	Cur	rently
			rece	eiving
			ser	vices
1			yes	no
2			yes	no
3			yes	no
4			yes	no
5			yes	no

If you have stopped using HIV case management at any of these sites, please describe why you stopped?

3. Which of the following reason lead to your stopping use of HIV case management at any agency?

- __Case manager left
- ___ I had difficulty scheduling appointments
- ___ I no longer needed services.
- ___ I moved from the area.
- ___ I had difficulties receiving needed services.
- ____ My case was terminated by the agency.
- ___ I felt misunderstood or mistreated by the staff.
- ____ There was too many bureaucratic procedures.

(for example: paperwork, meetings or other time consuming procedures.)

____I felt that the staff did not respond to my needs.

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4. Please describe what happened in each of the above incidents.

5. Which of the following did you need when you started to see your HIV case manager?

- 5a. __ Housing
- 5b. __ Utilities
- 5c. __ Food services
- 5d. ___ Benefits (for example MediCal, SSDI)
- 5e. __ Other financial needs
- 5f. ____ Substance abuse treatment
- 5g. __ HIV medical care
- 5h. __ Other medical care
- 5i. ___ Home care
- 5j. ___ Attendant Care
- 5k. __ Dental care
- 51. __ Psychiatric care
- 5m. ___ Counseling and emotional support

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6. Using the following scale please describe how helpful your HIV case manager was in each of the following categories? (Note if they do not apply (NA))

housing	Very effective 4	Usually effective 3	Moderately effective 2	Ineffective 1
utilities (bills)	4	3	2	1
food services	4	3	2	1
benefits	4	3	2	1
employment	4	3	2	1
other financial needs	4	3	2	1
substance abuse treatment	4	3	2	1
HIV medical care	4	3	2	1
other medical care (non-HIV-related)	4	3	2	1
home care	4	3	2	1
attendant care	4	3	2	1
hospice care	4	3	2	1
dental care	4	3	2	1
psychiatric care (for mental ill	ness) 4	3	2	1
care for cognitive disorders (dementia)	4	3	2	1
counseling (for emotional supp	oort) 4	3	2	1
housekeeping	4	3	2	1

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7. Which of the following symptoms has your HIV case manager or nurse case manager helped you to address?

Symptom	Have you had the symptom	Have you addressed this with you case manager	How did your case manager address the symptom? 1) treatment or direct intervention 2) teach self care 3) refer to primary care
Day sweats			
Night sweats			
Fever			
Chills			
Weakness			
Muscle aches			
Fatigue			
Painful joints			
Difficulty			
concentrating			
Disorientation			
Memory loss			
Vomiting	_		
Nausea			
Lack of appetite			
Anxiety			
Depression			
Fear			
Shortness of breath at			
rest	-	ļ	
Shortness of breath			
with activity			
Wheezing			
Gas/ Bloating			
Dry mouth			
Thirst			
Abdominal pain			

Symptom	Have you had the symptom	Have you addressed this with you case manager	How did your case manager address the symptom? 1) treatment or direct intervention 2) teach self care 3) refer to primary care
Coughing			
Blood in sputom			
Constipation			
Weight loss			
Sore Throat			
Difficulty Swallowing			
Mouth Ulcers			
Sore/bleeding gums			
Thrush			
Insomnia			
Dizziness			
Headaches			
Blurred Vision			
Seizures/tremors			
Numbness/tingling			
Nosebleeds			
Easy Bruising			
Yellow Eyes			
Yellow Skin (jaundice)			
Flushing			
Swollen Glands			
Swollen Feet			
Skin Rashes			
Itchy Skin			
Shingles			
Herpes			
K.S.Lesions			
Heart Racing			
Chest Pain			
Yeast Infections			
Menstrual Irregularity			

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Client Satisfaction

	Not True	Somew hat True	True	Very True	
1 My case manager helps me to obtain benefits or entitlements.	1	2	3	4	N A
2 My case manager delivers services in a timely fashion.	1	2	3	4	N
3 My case manager assists me to pay for medication (enroll in ADAP).	1	2	3	4	A N A
4 My case manager seems burnt-out.	1	2	3	4	N
5 My case manager has requested sexual favors for case management services.	1	2	3	4	A N A
6 My case manager generally follows through with delivering promised services.	1	2	3	4	N A
7 My case manager has suggested that I offer them sexual favors.	1	2	3	4	N A
8 My case manager offers me assistance with medical needs.	1	2	3	4	N A
9 My case manager has informed me of services I did not know were available.	1	2	3	4	N A
10 My case manager's agency is located close to my home.	1	2	3	4	N A
11 I sometimes have to wait in line for case management services.	1	2	3	4	N A
12 I feel assured by my case managers professionalism.	1	2	3	4	N A

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	Not True	Somew hat True	True	Very True	
13 Sometimes, I am confused by what my case manager is going to take care of and what I am responsible for.	1	2	3	4	N A
14 My case manager's agency offers transportation.	1	2	3	4	N
15 My case manager is compassionate.	1	2	3	4	A N
16 My case manager has assisted me with hospital costs.	1	2	3	4	A N
17 My case manager is sometimes late in delivering services.	1	2	3	4	A N A
18 My case manager puts me in touch with support groups.	1	2	3	4	N A
19 My case manager's agency does not give the option of making appointments for certain services.	1	2	3	4	N A
20 My case manager assists me to find ways to take my medication on a regular basis.	1	2	3	4	N A
21 My case manager's agency is open at convenient times.	1	2	3	4	N
22 My case manager's agency or office is physically accessible (wheel chair accessible).	1	2	3	4	A N A
23 My case manager is easy to contact in case of emergency.	1	2	3	4	N A
24 I sometimes have to wait more than an hour for case management services.	1	2	3	4	N A

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	Not True	Somew hat True	True	Very True	
25 My case manager's agency seems understaffed.	1	2	3	4	N A
26 My case manager needs time to grieve.	1	2	3	4	Ν
27 My case manager offers home visits.	1	2	3	4	A N
28 My case manager provides assistance with medical bills.	1	2	3	4	A N A
29 I am generally seen within 15 minutes of arriving at my case manager's office.	1	2	3	4	N A
30 My case manager assists me to obtain medication.	1	2	3	4	N
31 My case manager assists me with sorting out confusing or overwhelming situations.	1	2	3	4	A N A
32 I feel a sense of stigma at my case manager's office.	1	2	3	4	N
33 My case manager works closely with my primary health care provider.	1	2	3	4	A N A
34 My case manager's agency is convenient for parking.	1	2	3	4	N
35 It helps that my case manager has personal experience with HIV.	1	2	3	4	A N A
36 My case manager helps me to rebuild my credit rating.	1	2	3	4	N
37 My case manager is attentive.	1	2	3	4	A N
38 My case manager promptly returns phone calls.	1	2	3	4	A N A

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	Not True	Somew hat True	True	Very True	
39 Sometimes my case manager seems to look at me as if I'm a burden.	1	2	3	4	N A
40 My case manager seems pressed for time.	1	2	3	4	N A
41 My case manager assists me with power of attorney in case I become too disabled to speak for myself.	1	2	3	4	N A
42 My case manager's agency is convenient to bus and BART lines.	1	2	3	4	
43 I fear that I may lose services from my case manager if I complain.	1	2	3	4	
44 My case manager is judgmental.	1	2	3	4	
45 My case manager is open to discussing problems in our relationship.	1	2	3	4	
46 I am afraid of stepping on toes when talking to staff at my case manager's agency.	1	2	3	4	N A

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VI. HIV Disease Experience

1. Please describe your current needs from HIV case management?

2. Which of the following levels of need best describes your relation to HIV and other health issues? _____

- A I only need information, referrals and minimal support. I am able to use medical care and adhere to medication regimens. I have minimal HIV symptoms.
- B I need information, referrals, emotional support and sometimes assistance to with follow through. I usually attend my medical appointment. I usually adhere to medication regimens. I have some HIV symptoms.
- C I need a lot of assistance and emotional support to use information and referrals. I often have difficulty adhering to medical care and/ or medication regimens. I have acute HIV symptoms or other significant health problems.
- D I need home care and significant assistance with daily life tasks. I may need end-stage disease planning.
- 3. Overall, how would you rate your health? Would you say it is:
- ___ Excellent
- ___ Very good
- ___ Good
- ___ Fair
- ___ Poor

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VII. Substance Use/Abuse

1. Have you used alcohol or drugs in the past month?

__Yes

___ No (skip to question 4)

2. How often have you had a drink containing alcohol-a glass of beer, wine, a mixed drink or any kind of alcoholic beverage- in the last 30 days?

- ___ Daily
- ___ Nearly everyday
- ____ 3 or 4 times a week
- ___Once or twice a week
- ___ 2 or 3 times a month
- __ Once a month
- ___ Never

3. During the past 30 days, how often have you had 5 or more drinks of alcohol in a row, that is, within a couple of hours?

- __ Daily
- ___ Nearly everyday
- ____ 3 or 4 times a week
- ___Once or twice a week
- ____2 or 3 times a month
- ___Once a month
- ___ Never

4.Do you currently use any marijuana?

___Yes ___No

4A. If yes, how many days in the past month (0-30 days) did you use marijuana?

4B. How many times per day did you use marijuana? _____

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5. Do you currently use cocaine (powder, crack, or freebase)? ___Yes ___No

5A. If yes, how many days in the past month (0-30 days) did you use cocaine or crack? _____

5B. How many times per day did you use cocaine or crack?

5C. If you used cocaine in the past 30 days, did you inject or shoot it into your veins, under your skin or into a muscle? __Yes __ No

6. Do you currently use heroin?

__Yes __No

6A.If yes, how many days in the past month (0-30 days) did you use heroin? _____

6B. How many times per day did you use heroin? _____

6C. If you used heroin in the past 30 days, did you inject or shoot it into your veins, under your skin or into a muscle? __Yes __ No

7. Do you currently used amphetamines (speed, crank, crystal uppers)? ___ Yes __ No

7A. If yes, how many days in the past month (0-30 days) did you use amphetamines? _____

7B. How many times per day did you use amphetamines?

7C. If you used amphetamines in the past 30 days, did you inject or shoot it into your veins, under your skin or into a muscle? __Yes __ No 8. Do you currently use inhalants (poppers)? ___ Yes ___ No

If yes, how many days in the past month (0-30 days) did you use inhalants? _____

How many times per day did you use inhalants? _____

Skip to question 11 if no drug use in past month

9. In the past month, did you use more than one substance at a time?

__Yes

__ No

If yes, which substances did you combine?

10. If yes, how many times did you combine these substances?

 Per day______

 Per week______

11. Are you currently in methadone treatment? __ Yes __ No

12. Have you ever been in methadone treatment? ___ Yes ___ No

13. Are you in recovery from drug and/or alcohol abuse?

__ Yes

____ No (skip to next section)

14. If yes, are you currently abstinent with regard to drugs and/or alcohol?

- ___Yes
- ___No

15. If yes, how long have you been in recovery? _____

16. If yes, how long did you use drugs or alcohol prior to recovery

VIII. Mental Health Status

1. Have you ever seen a psychiatrist, psychologist or therapist?

__Yes

__No

- 2. Do you current see a psychiatrist, psychologist or therapist
- __Yes
- ___ No

3. How many times have you been treated for any psychological or emotional problems?

_____ times in hospital

_____ times as an outpatient or private patient

4. Do you receive a pension (SSI, SSD) for psychiatric or emotional disability?

__Yes _ No

In the past 30 days have you experienced any of the following (that was not a result of alcohol or drug use)?

1. Experienced serious depression? Yes _____ No_____

2. Experienced serious anxiety or tension? Yes _____ No_____

3. Experienced hallucinations? Yes _____ No_____

- 4. Experienced trouble with understanding, remembering or concentrating? Yes _____ No_____
- 5. Experienced difficulty with controlling violent behavior? Yes _____ No_____

6. Experienced serious thoughts of suicide? Yes _____ No_____

7. Have taken medication for a psychological or emotional problem? Yes _____ No_____

8. How much have you been bothered by these psychological or emotional problem?_____

9. How important to you is treatment for these psychological or emotional problems?_____

IX. Brief Symptom Inventory

Below is a list of problems people sometimes have. Please read each on carefully and circle the number to the right that describes how much that problem has distressed or bothered you during the past 7 days including today. Circle one number for each problem and do not skip any items.

0= not at all 1= a little bit 2= moderately 3= quite a bit 4= extremely

Nervousness or shakiness	0	1	2	3	4
Faintness or dizziness	0	1	2	3	4
The idea that someone else can control your thoughts	0	1	2	3	4
Feeling others are to blame for most of your troubles	0	1	2	3	4
trouble remembering things	0	1	2	3	4
Feeling easily annoyed or irritated	0	1	2	3	4
Pains in heart or chest	0	1	2	3	4
Feeling afraid in open spaces or on the streets	0	1	2	3	4
Thoughts of ending your life	0	1	2	3	4
Feeling that most people cannot be trusted	0	1	2	3	4
Poor appetite	0	1	2	3	4
Suddenly scared for no reason	0	1	2	3	4
Temper outbursts that you can not control	0	1	2	3	4
Feeling lonely when you are with people	0	1	2	3	4
Feeling blocked in getting things done	0	1	2	3	4
Feeling lonely	0	1	2	3	4
Feeling blue	0	1	2	3	4
Feeling no interests in things	0	1	2	3	4
Feeling fearful	0	1	2	3	4
Your feelings being easily hurt	0	1	2	3	4
Feeling that people are unfriendly or dislike you	0	1	2	3	4
Feeling inferior to others	0	1	2	3	4
Nausea or upset stomach	0	1	2	3	4
Feeling that you are watched or talked about by others	0	1	2	3	4
Trouble falling asleep	0	1	2	3	4
Having to check and trouble check what you do	0	1	2	3	4
Difficulty making decisions	0	1	2	3	4

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0= not at all 1= a little bit 2= moderately 3= quite a bit 4= extremely

Feeling afraid to travel on buses, subways or trains	0	1	2	3	4
Trouble getting your breath	0	1	2	3	4
Hot or cold spells	0	1	2	3	4
Having to avoid certain things, places, or activities because they frighten you	0	1	2	3	4
Numbness or tingling in parts of your body	0	1	2	3	4
Your mind going blank	0	1	2	3	4
The idea you should be punished for your sins	0	1	2	3	4
Feeling hopeless about the future	0	1	2	3	4
Trouble concentrating	0	1	2	3	4
Feeling weak in parts of your body	0	1	2	3	4
Feeling tense of keyed up	0	1	2	3	4
Thoughts of death or dying	0	1	2	3	4
Having urges to beat, injure or harm someone	0	1	2	3	4
Having urges to break or smash things	0	1	2	3	4
Feeling very self-conscious with others	0	1	2	3	4
Feeling uneasy in crowds, such as shopping or at a movie	0	1	2	3	4
Never feeling close to another person	0	1	2	3	4
Spells of terror or panic	0	1	2	3	4
Getting into frequent arguments	0	1	2	3	4
Feeling nervous when you are left alone	0	1	2	3	4
Others not giving you proper credit for your achievements	0	1	2	3	4
Feeling so restless you can't sit still	0	1	2	3	4
Feelings of worthlessness	0	1	2	3	4
Feeling that people will take advantage of you if you let them	0	1	2	3	4
Feelings of guilt	0	1	2	3	4
The idea that something is wrong in your mind.	0	1	2	3	4

X. Personal Strengths

Sometimes people discover things about themselves when they are faced with serious illness. On a 1 to 4 scale how much do each of the following qualities describe you.

	Very m	uch, some	what n	ot very much	not at
1. I have become more aware of my inner strengths.		1	2	3	4
2. I have become more self confident.		1	2	3	4
3. I have gotten a better idea of what is important in life.	1	2	3	4	
4. I have grown as a person.		1	2	3	4

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On a 1 to 4 scale how much do each of the following qualities describe you. Very much, somewhat not very much not at all

1. I feel that I have a number of good qualities.	1	2	3	4
2. I feel that I am able to do things as well as other people.	1	2	3	4
3. I feel that I do not have much to be proud of.	1	2	3	4
4. I take a positive attitude. towards myself	1	2	3	4
5. On the whole I am satisfied with myself.	1	2	3	4
6. I certainly feel useless at times.	1	2	3	4
7. At times I feel like a failure.	1	2	3	4
8. There is no way that I can solve some of the problems I have.	1	2	3	4
9. Sometimes I feel like I have been pushed around by life.	1	2	3	4
10. I have little control over the things that happen to me.	l	2	3	4
11. I can do just about anything I set my mind to do.	1	2	3	4
12. I feel helpless in dealing with the problems of life.	1	2	3	4
13. What happens to me in the future mostly depends on me.	1	2	3	4
14. There is little I can do to change the important things in my life.	1	2	3	4

XI. Medication History

1. Have you ever been prescribed medication for treatment of HIV?

- ___Yes
- ____ No (skip to next section)

2. Are you currently taking medication for treatment of HIV?

- ___Yes
- ____ No (skip to next section)

3. Complete the chart below for all medication you are presently taking or prescribed to take.

Medication Name	HIV or Non-HIV related	How often do you have to take this medication?

4. When was the last time you skipped any doses of your anti-viral medications?

- ___ Within the past 4 days
- ____ With in the past 2 weeks
- ___ 2-4 weeks ago
- ____1-3 months ago
- ____ More than 3 months ago
- ____ Never(skip to next section)

	Never	Rarely	Sometimes	Often
Were away from home or traveling	0	1	2	3
Were busy with other things	0	1	2	3
Simply forgot	0	1	2	3
Had too many pills to take	0	1	2	3
Wanted to avoid side effects	0	1	2	3
Didn't want others to notice you	0	1	2	3
taking medication				
Had a change in you daily routine	0	1	2	3
Felt the drug was too toxic	0	1	2	3
Fell asleep or slept through dose	0	1	2	3
time				
Felt ill or sick from side effects	0	1	2	3
Felt depressed or overwhelmed	0	1	2	3
Had problem taking pills at	0	1	2	3
specified times(with food, on				
empty stomach, etc.)				

5. How often have you missed taking you medications because you:

XII. Quality of Life

1.In general, would you say your health is

- ___ Excellent
- ___ Very good
- ___ Good
- ___ Fair
- ___ Poor

2. How much bodily pain have you generally had during the past 4 weeks?

- ___ None
- ___ Very mild
- ___ Mild
- ___ Moderate
- ___ Severe
- ___ Very severe

3. During the past 4 weeks, how much pain interfered with your normal work (including both work outside the home and housework)?

- ___ Not at all
- ___ A little bit
- ___ Moderately
- ___ Quite a bit
- ___ Extremely

4. The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

- a. The kinds or amounts of vigorous activities you can do, like lifting heavy objects, running or participating in strenuous sports.
- ___ Yes, limited a lot
- ____Yes, limited a little
- ____No, not limited at all

b. The kinds or amounts of moderate activities you can do like moving a table, carrying groceries or bowling.

- _ Yes, limited a lot
- ____Yes, limited a little
- ___ No, not limited at all

c. Walking uphill or climbing (a few flights of stairs)

- ___ Yes, limited a lot
- ___ Yes, limited a little
- ___ No, not limited at all

d. Bending, lifting or stooping.

- ___ Yes, limited a lot
- ___ Yes, limited a little
- ____ No, not limited at all

e. Walking one block.

- ____Yes, limited a lot
- ___ Yes, limited a little
- ____No, not limited at all

f. Eating, dressing, bathing, or using the toilet

- ___ Yes, limited a lot
- ___ Yes, limited a little
- ____No, not limited at all

5. Does your health keep you from working at a job, doping work around the house or going to school?

- __Yes
- ___ No

6.Have you been unable to do certain kinds or amounts of work, housework or schoolwork because of your health?

- ___Yes
- ___ No

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For each of the following questions, please check the answer that comes closest to the way you have been feeling during the past 4 weeks.

7. How much of the time during the past 4 weeks, has your health limited your social activities (like visiting friends or relatives)?

__ All 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

8. How much of the time during the past 4 weeks:

- 1 = All the time
- 2= Most of the time
- 3 = A good bit of the time
- 4= Some of the time
- 5 = A little of the time
- 6= None of the time

____a. Have you been a very nervous person?

____ b. Have you felt calm and peaceful?

____ c. Have you felt downhearted and blue?

____ d. Have you been a happy person?

____e. Have you felt so down in the dumps that nothing could cheer you up?

9. How often during the past 4 weeks:

1 = All the time

- 2= Most of the time
- 3 = A good bit of the time
- 4= Some of the time
- 5 = A little of the time
- 6= None of the time

____a. Did you feel full of pep?

___ b. Did you feel worn out?

____ c. Did you feel tired?

____ d. Did you have enough energy to do the things you wanted to?

____e. Did you feel weighed down by your health problems?

____f. Were you discouraged by your health problems?

____ g. Did you feel despair over your health problems?

___h. Were you afraid because of your health problems?

10. How much time during the past 4 weeks:

- l = All the time
- 2 = Most of the time
- 3 = A good bit of the time

4 = Some of the time

5 = A little of the time

6 = None of the time

____a. Did you have difficulty reasoning and solving problems, for example, making plans, making decisions, learning new things?

_____ b. Did you forget things that happened recently, for example, where you put things and when you had appointments?

____ c. Did you have trouble keeping your attention on any activity for long?

_____ d. Did you have difficulty doing activities involving concentration and thinking?

11. Please check the answer that best describes where each of the following statements is true or false for you?

	Definite ly true	Most ly true	Don't know	Mostly false	Definit ely false
I am somewhat ill					
I am as healthy as anybody I					
know					
My health is excellent					
I have been feeling bad lately					

12. How has the quality of your life been during the past 4 weeks? That is, how have things been going for you?

- ____ Very well; could hardly be better.
- ___ Pretty good.
- ___ Good and bad parts about equal.
- ___ Pretty bad.
- ____ Very bad; could hardly be worse.

13. How would you rate your physical health and emotional condition now compared to 4 weeks ago.

- ____ Much better.
- ___ A little better
- ____ About the same
- ____ A little worse
- ____ Much worse

XIII. Primary Care

1. Do you currently have a primary care physician or nurse? ___Yes___No

2. At what clinic or hospital do you see this person?

3. If you do not currently have a primary care medical provider, please briefly explain why

4. During the last month, how many health care visits were scheduled for you? _____

How many did you attend? _____

5. a During the last month, how many HIV care appointments were scheduled for you? _____

5b. How many did you attend? _____

6a. During the last month, how many HIV case management appointments were scheduled for you?

6b. How many did you attend? _____

7. In the past 6 months, how many times have you visited the ER?

8. What symptoms brought you to the ER?

9. Besides the ER and doctors offices, do you receive health care from any other source (e.g. other health plan, alternative health practitioner, health van)?

__Yes

___ No

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Appendix B Correlation Matrix

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Age Gender Stable vs unstable housing History of homelessness Agency type Total number of agencies Time in case management Total number of case management needs Total number of case management needs Total number of social case management needs Mean satisfaction with case management services Mean satisfaction with case manager Client satisfaction subscale HIV Level Health accuity MOS general health perceptions MOS quality of life Health care visits HIV care visits Case management visits Emergency room visits Care giving role Total number of symptoms Sexual orientation Mental health comorbidity Drug comorbidity Poverty line Martial status Primary care setting	Gender -0.083	Stable vs unstable housing -0.146 0.051	History of homelessn ess -0.011 -0.07 0.181	Agency type -0.011 -0.113 -0.018 0.224
Poverty line				
Primary care setting Level of education				
Sum of case management services used				
Sum of medical case management services used Sum of social case management services used				
-				

	Total number of agencies	Time in case management	Total number of case management needs	Total number of medical case management needs
Age	0.063	0.137	0.1	0.127
Gender	0.033	0.168	0.02	0.031
Stable vs unstable housing	0.045	-0.003	-0.113	-0.035
History of homelessness	-0.154	-0.033	-0.201	-0.149
Agency type	0.006	-0.096	-0.055	-0.15
Total number of agencies		0.082	0.519	0.569
Time in case management			0.183	0.092
Total number of case management needs				0.838
Total number of medical case management needs				
Total number of social case management needs				
Mean satisfaction with case management services				
Mean satisfaction with case manager				
Client satisfaction subscale				
HIV Level				
Health accuity				
MOS general health perceptions				
MOS quality of life				
Health care visits				
HIV care visits				
Case management visits				
Emergency room visits				
Care giving role				
Total number of symptoms				
Sexual orientation				
Mental health comorbidity				
Drug comorbidity				
Poverty line				
Martial status				
Primary care setting				
Level of education				
Sum of case management services used				

Sum of readical case management services used

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Age	HIV Level 0.059	Health accuity 0.107	MOS general health perceptions -0.09	MOS quality of life 0.044
Gender	-0.051	-0.021	0	-0.01
Stable vs unstable housing	-0.1	-0.104	0.132	0.142
History of homelessness	-0.183	-0.138	0.02	-0.027
Agency type	-0.047	0.018	0.187	0.164
Total number of agencies	-0.033	0.006	0.006	0.087
Time in case management	0.064	0.103	-0.095	-0.02
Total number of case management needs	0.304	0.089	-0.228	-0.075
Total number of medical case management needs	0.227	0.084	-0.243	-0.102
Total number of social case management needs	0.26	0.076	-0.167	-0.038
Mean satisfaction with case management services	-0.011	-0.007	-0.005	0.075
Mean satisfaction with case manager	0.04	0.075	-0.174	0.147
Client satisfaction subscale	0.015	-0.029	-0.03	0.078
HIV Level		0.4	-0.372	-0.382
Health accuity			-0.636	-0.413
MOS general health perceptions				0.477
MOS quality of life				
Health care visits				
HIV care visits				
Case management visits				
Emergency room visits				
Care giving role				
Total number of symptoms				
Sexual orientation				
Mental health comorbidity				
Drug comorbidity				
Poverty line				
Martial status				
Primary care setting				
Level of education				
Current and a management can icon upod				

Sum of case management services used

Sum of medical case management services used

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			Case	
	Health	HIV care	management	Emergency
	care visits	visits	visits	room visits
Age	-0.075	-0.107	-0.07	0.11
Gender	0.049	0.051	0.044	-0.061
Stable vs unstable housing	0.036	0.031	-0.013	-0.058
History of homelessness	-0.109	-0.089	-0.067	-0.24
Agency type	-0.142	-0.004	-0.067	-0.217
Total number of agencies	-0.064	-0.036	0.155	0.276
Time in case management	0.031	0.122	-0.046	0.245
Total number of case management needs	-0.002	-0.069	0.118	0.213
Total number of medical case management needs	-0.001	-0.118	0.077	0.285
Total number of social case management needs	-0.001	-0.014	0.123	0.11
Mean satisfaction with case management services	0.109	0.259	0.014	-0.101
Mean satisfaction with case manager	0.015	0.163	0.015	0.203
Client satisfaction subscale	0.021	-0.031	0.121	-0.018
HIV Level	0.128	0.133	0.035	0.296
Health accuity	-0.032	0.017	0.044	0.162
MOS general health perceptions	0.018	-0.018	-0.13	-0.327
MOS quality of life	-0.042	0.098	-0.075	-0.209
Health care visits		0.55	-0.014	0.286
HIV care visits			0.084	0.185
Case management visits				-0.061
Emergency room visits				
Care giving role				
Total number of symptoms				
Sexual orientation				
Mental health comorbidity				
Drug comorbidity				
Poverty line				
Martial status				
Primary care setting				
Level of education				
Sum of case management services used				
Sum of medical case management services used				
Cum of appial appa management continue upod				

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		Total		Mental
	Care	number of	Sexual	health
	giving role	symptoms	orientation	comorbidity
Age	-0.142	-0.022	-0.003	-0.087
Gender	-0.22	-0.002	-0.603	-0.101
Stable vs unstable housing	0.11	-0.196	-0.012	0.11
History of homelessness	0.047	0.029	-0.07	-0.09
Agency type	-0.178	-0.147	0.102	-0.004
Total number of agencies	0.092	0.279	-0.056	-0.167
Time in case management	-0.073	0.118	-0.135	-0.03
Total number of case management needs	0.079	0.441	-0.104	-0.057
Total number of medical case management needs	0.069	0.488	-0.158	-0.022
Total number of social case management needs	0.07	0.308	-0.041	-0.071
Mean satisfaction with case management services	-0.062	-0.172	0.049	0.294
Mean satisfaction with case manager	0.038	0.128	-0.026	0.059
Client satisfaction subscale	0.181	0.113	-0.009	0.039
HIV Level	0.223	0.437	0.041	0.091
Health accuity	0.209	0.29	0.077	0.107
MOS general health perceptions	-0.297	-0.409	-0.018	-0.153
MOS quality of life	-0.119	-0.193	0.068	-0.158
Health care visits	-0.032	0.113	-0.022	0.058
HIV care visits	-0.041	0.027	-0.117	0.125
Case management visits	0.12	0.143	-0.113	0.058
Emergency room visits	0.005	0.299	0.048	0.062
Care giving role		0.155	0.233	-0.042
Total number of symptoms			0.011	0
Sexual orientation				0.059
Mental health comorbidity				
Drug comorbidity				
Poverty line				
Martial status				
Primon (poro potting				

Primary care setting

Level of education

Sum of case management services used

Sum of medical case management services used

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				Primary
	Drug	Poverty	Martial	care
	comorbidity	line	status	setting
Age	-0.031	-0.058	-0.071	-0.133
Gender	0.126	-0.081	0.14	-0.201
Stable vs unstable housing	-0.075	0.129	0.098	-0.111
History of homelessness	0.055	0.236	-0.024	-0.293
Agency type	-0.07	-0.065	0.058	0.234
Total number of agencies	0.037	0.007	0.064	0.122
Time in case management	0.191	-0.072	-0.012	-0.048
Total number of case management needs	0.073	-0.09	-0.083	0.02
Total number of medical case management needs	0.103	-0.03	-0.077	0.024
Total number of social case management needs	0.034	-0.114	-0.07	0.013
Mean satisfaction with case management services	-0.21	0.014	-0.144	0.157
Mean satisfaction with case manager	-0.136	0.089	-0.126	0.052
Client satisfaction subscale	-0.328	-0.013	-0.124	0.077
HIV Level	0.094	0.065	-0.029	-0.098
Health accuity	-0.069	-0.057	-0.141	-0.018
MOS general health perceptions	-0.076	0.019	0.185	0.008
MOS quality of life	0.228	0.006	0.093	-0.011
Health care visits	0.061	-0.169	0.184	0.149
HIV care visits	0.087	-0.067	0.288	0.2
Case management visits	-0.187	-0.081	0.084	0.114
Emergency room visits	0.263	0.024	0.012	0.047
Care giving role	-0.127	0.213	0.118	-0.056
Total number of symptoms	0.111	0.012	-0.066	-0.006
Sexual orientation	-0.103	0.057	0.008	0.241
Mental health comorbidity	-0.075	0.079	0.019	0.17
Drug comorbidity		0.044	-0.008	-0.122
Poverty line			0.056	-0.162
Martial status				-0.056
Primary care setting				
Level of education				
Sum of case management services used				
Sum of medical case management services used				

Sum of medical case management services used

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	Levelof		Sum of medical case management	Sum of social case	
		services used	-	•	Race
Age	0.039	-0.101	-0.089	-0.085	-0.061
Gender	0.133	-0.058	-0.07	-0.05	-0.225
Stable vs unstable housing	-0.043	-0.025	0.03	-0.061	-0.049
History of homelessness	0.209	-0.187	-0.148	-0.212	-0.154
Agency type	-0.026	0.079	0.057	0.125	0.326
Total number of agencies	-0.023	-0.308	-0.361	-0.27	0.025
Time in case management	-0.132	0.044	-0.032	0.075	0.02
Total number of case management needs	0.033	0.166	-0.008	0.223	0.029
Total number of medical case management needs	0.02	-0.021	-0.098	-0.016	-0.035
Total number of social case management needs	0.036	0.273	0.063	0.358	0.073
Mean satisfaction with case management services	0.046	0.399	0.579	0.38	0.024
Mean satisfaction with case manager	0.101	0.254	0.239	0.246	-0.057
Client satisfaction subscale	0.095	0.155	0.15	0.134	-0.039
HIV Level	-0.191	0.156	0.154	0.129	0.148
Health accuity	-0.109	0.156	0.101	0.19	0.028
MOS general health perceptions	0.109	-0.215	-0.156	-0.203	0.095
MOS quality of life	0.158	-0.217	-0.178	-0.189	0.139
Health care visits	-0.106	-0.042	0.045	-0.087	0.046
HIV care visits	-0.141	0.145	0.231	0.094	0.093
Case management visits	-0.074	0.129	0.111	0.118	0.001
Emergency room visits	-0.087	-0.031	0.004	-0.083	-0.011
Care giving role	-0.106	0.004	-0.024	0.016	-0.022
Total number of symptoms	0.003	-0.005	-0.028	-0.018	-0.029
Sexual orientation	-0.189	-0.038	0.002	-0.029	0.229
Mental health comorbidity	-0.175	0.366	0.393	0.336	-0.089
Drug comorbidity	-0.079	-0.077	-0.064	-0.107	-0.016
Poverty line	0.204	-0.016	0.066	-0.075	-0.108
Martial status	-0.101	-0.034	0.012	-0.071	-0.156
Primary care setting	-0.261	0.096	0.132	0.085	0.197
Level of education		-0.216	-0.212	-0.187	-0.115
Sum of case management services used			0.929	0.963	-0.06
Sum of medical case management services used				0.787	-0.049
Sum of social case management services used					-0.038

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Appendix C Table of Significant Chi-Square Results for Individual Needs

	Housing (5a) X ² p.	g (5a) <i>p</i> .	Utilities (5b) X ² p.	s (5b) <i>p</i> .	Food Services (5c) χ^2 p.	rices (5c) p.
Gender Sexual orientation History of homelessness Stable vs unstable housing HIV Level Medicare enrollment Medical Enrollment	13.001 6.242	0 0.012			5.911	0.015
ADAP Private vs public hospital Long term disability benefits SSI benefits SSDI benefits	2.814	0.093	4.188	0.041	4.792 7.382 8.216 5.616	0.029 0.007 0.004 0.018
SUI benefits Drug Use Drug comorbidity Mental health comorbidity Total number of case management agencies Number of agencies (1, 2 or 3+) Type of agency (CBO vs Clinic) Time with agency	5.977	0.05				

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	Benefits (5d)	:s (5d)	Other financial needs (5e)	seds (5e)	Substand treatmo	Substance abuse treatment (5f)
Gender	X ² 8.165	p. 0.017	X²	ġ	X ² D.	đ
Sexual orientation						
History of homelessness					2.611	0.106
stable vs unstable nousing HIV Level	9.266	0.026			7.336	0.062
Medicare enrollment						
Medical Enrollment						
ADAP			4.01	0.045	3.886	0.049
Private vs public hospital						
Long term disability benefits	5.746	0.017				
SSI benefits						
SSDI benefits SDI henefits						
Drug Use						
Drug comorbidity					13.844	0
Mental health comorbidity			5.644	0.018	3.242	0.072
Total number of case management						
Number of agencies (1, 2 or 3+)	7.336	0.026	14.841	0.001	17.325	0
Type of agency (CBO vs Clinic)					3.21	0.073
Time with agency					11.049	0.011

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	HIV medical care (5g)	l care (5g)	Other medical care (5h)	al care (5h)	Homo			
Gender	X ²	ק	X²	b.	X ²	χ^2 p .	Attendant χ^2	Attendant care (5j) χ^2 p.
Sexual orientation	2.652	iii						•
History of homelessness	4.018	0.045					3.335	0.068
Stable vs unstable housing	3.821	0.051			0110	010 0		
HIV Level	9.599	0.022			0.140	0.076		
Medicare enrollment	2.82	0.093			10.01	0.002		
Medical Enrollment								
ADAP	3.916	0.048						
Private vs public hospital								
Long term disability benefits								
SSI benefits								
SSDI benefits								
SDI benefits								
Drug Use								
Drug comorbidity					2 624	100		
Mental health comorbidity					100.0	/cn.n	5.413	0.02
Total number of case management								
agencies								
Number of agencies (1, 2 or 3+) Type of agency (CBO vs Clinic)	16.478 4.645	0 0.031	42.757	0	10.94	0.004		
l ime with agency	7.909	0.048						

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	Dental Care (5k) X ² p.	are (5k) <i>p</i> .	Psychiatri X ²	Psychiatric care (5l) X ²	Counseling and emotional support (5m) X ² <i>p</i> .	ing and ipport (5m) <i>p</i> .
Gender Sexual orientation History of homelessness Stable vs unstable housing	3.465	0.063	3.071	0.08		
Medicare enrollment Medical Enrollment ADAP						
Private vs public hospital Long term disability benefits SSI benefits SSDI benefits						
SDI benefits Drug Use Drug comorbidity Mental health comorbidity Total number of case management	2.889	0.089				
agencies Number of agencies (1, 2 or 3+) Type of agency (CBO vs Clinic) Time with agency	20.242 3.128	0 0.077	15.128	0.001	6.648	0.084

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