Satisfaction and Dissatisfaction with Medical and Social Services among Persons Living with HIV in New York City

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SATISFACTION AND DISSATISFACTION
WITH MEDICAL AND SOCIAL SERVICES

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I. INTRODUCTION

This report explores the extent to which a representative sample of people living with HIV in New York City are satisfied with the medical and social services they receive from public and private agencies in New York City. Both quantitative and qualitative analyses were conducted, using data from four rounds of interviews (data collected from 1994 through 1997), for examining the CHAIN study participants' satisfaction with medical and social services and their reasons for satisfaction or dissatisfaction with the service delivery system.

One of the main findings of the literature on patient satisfaction is that reported satisfaction tends to be high regardless of the objective quality of services offered (Ellis, 1987; Goldfield and Nash, 1995). The overall satisfaction rates from the CHAIN study show the same pattern. For example, in Wave 4, 81% of the study participants reported being "very satisfied" with their primary medical provider, while 60% of them were "very satisfied" with their case manager. Furthermore, rates of satisfaction remain high throughout all four waves of the study. This report, by analyzing characteristics of service experience as well as direct measures of satisfaction, attempts to discover the factors contributing to the high rates of satisfaction with services.

Satisfaction with medical and social services, at times, reflects the clients' perception of the patient-provider relationship, and at times their rating as consumers of concrete aspects of the service system, that is, their judgment of specific features of services they receive. The CHAIN interview includes questions regarding both these aspects of care. For example, CHAIN study participants were asked if they thought that their medical provider showed interest and concern for them. Study participants were also asked to assess as consumers specific features of their medical care such as whether their medical provider offers "routine check-ups, vaccinations and medical tests." An analysis of both sets of questions was carried out in order to understand respondents' reasons for satisfaction or dissatisfaction with care. Differences in satisfaction according to client characteristics (such as, gender, race/ethnicity, risk and stage of illness), as well as differences associated with types of service delivery setting (such as, public versus private agencies) were also examined.

This report uses both quantitative data in the form of answers to check-list type of answers to questions about satisfaction, as well as qualitative, open-ended answers to questions asking study participants to explain their experiences with medical and social services in their own words. An important part of the report is based on in-depth content analysis of the open-ended statements study participants offered regarding specific service encounters and their experiences with the service delivery system more generally. To better understand what might contribute to dissatisfaction, a special analysis was conducted of the most problematic service areas, that is those that consistently had the lowest satisfaction rates. In addition, we conducted an in-depth analysis of the sub-set of study participants who remained consistently
dissatisfied with their medical or social services throughout all four waves of interviewing. According to the literature, patients' physical and mental health (Hall et al. 1993; Wyshak and Barsky 1995), the patients' sociodemographic characteristics (Hall and Dornan, 1988) and the quality of interaction and of communication between patients and providers (Bertakis et al., 1995) are among the main factors determining patient satisfaction. All of these factors were taken into consideration in the interpretation of the respondents' narrative descriptions of their encounters with service providers.
Key Findings

- CHAIN study participants across all four waves of data collection and regardless of their background characteristics, tend to be more satisfied with the medical care system than with the social service system.

- The overwhelming majority of participants reported high rates of satisfaction with both their primary medical provider and with their case manager, although satisfaction with the case manager is lower.

- The quality of the patient-provider relationship is the primary factor determining satisfaction or dissatisfaction with a medical provider. Patients who perceive that their physician spends enough time with them, understands what is bothering them, and shows interest and concern for their well-being are those most likely to be very satisfied with their medical care. A good patient-provider interaction and communication is more strongly related to patient satisfaction than several care features characterizing the medical service setting, such as, comprehensiveness and accessibility of care.

- In each wave of interviews, the highest levels of dissatisfaction with medical services are associated with emergency room visits, inpatient hospital stays and home health care although rates of dissatisfaction in each of these service areas declined over time. Clients tend to give relatively high satisfaction ratings to mental health services; drug treatment services are rated much lower.

- Satisfaction with social services is related to both the process of getting assistance (the steps involved, treatment by providers etc.) as well as to the outcome of one's attempt to get assistance, whether or not problems get resolved.

- Housing and financial services elicit the most dissatisfaction from study participants among all social service areas. This pattern has remained the same across all waves.

- Client descriptions of why they are satisfied or dissatisfied with social service providers indicate that the availability of expanded service options, and case managers who “more assertively” advocate for their clients are factors associated with increased satisfaction.

II. THE CHAIN SURVEY AND DATA

The Columbia School of Public Health is responsible for conducting the CHAIN Project surveys and reporting on findings from the survey data in collaboration with the New York City Department of Health, the Medical and Health Research Association of New York City, Inc. (MHRA) and the Mayor's Office of AIDS and Policy Coordination. The purpose of this study
is to provide longitudinal information on study participants' needs for health and human services, their use of health care and social service organizations, their satisfaction with services, and the impact of these services on change in physical, mental and social well being. This information is specifically prepared for the NYC HIV Health and Human Services Planning Council of New York to assess the full spectrum of services for HIV infected persons in NYC. The study was undertaken through a subcontract from MHRA with the authorization of the NYC Department of Health and the HIV Planning Council.

Sample and Interviews

The CHAIN Project followed a recruitment procedure designed to yield a broadly representative sample of people living with HIV in New York City. Study recruitment was conducted in 43 agencies that were selected to equally represent medical care and social service sites that were and were not recipients of Title I grants. At 30 sites, staff contacted a random sample of clients. Clients who indicated an interest in participating were contacted by CHAIN staff and interviews arranged. An open enrollment procedure was implemented at the remaining 13 agencies. All eligible clients present on a small number of recruitment days were invited by agency providers and CHAIN staff to participate in the study. Interviews were scheduled with interested clients. A total of 648 individuals recruited from participating agencies completed baseline interviews. This sample was supplemented with 48 interviews conducted with individuals who were outside or only marginally connected to HIV medical and social services (the Unconnected). These individuals were contacted at outreach sites and through nominations from CHAIN participants. More detailed information on sampling strategy and recruitment may be obtained upon request from MHRA (CHAIN Technical Report #1).

Subsequent interviews were conducted at approximately 6-9 month intervals. At Time 2, follow-up interviews were completed with 568 participants, 480 were completed at Time 3, and 420 at Time 4. The Time 4 interviews were done from October 1996 to September 1997 and completed cases (N= 420) represent 82% of the original cohort who have not died or moved away from New York City. Fewer than 3% of study participants have refused to participate in the follow-up interviews.

All CHAIN interviews are conducted in person in English or in Spanish by trained interviewers. Interviews last approximately 2 hours and topics include sociodemographic characteristics, access and use of medical and social services, and quality of life.

Measures of Satisfaction / Dissatisfaction

At each round of interviews, study participants were asked about their overall satisfaction with a whole array of different kinds of medical and social services. Answers were reported on a four-point scale: “very satisfied, somewhat satisfied, somewhat dissatisfied, or very dissatisfied”. For presentation purposes, the last three categories were collapsed in order to measure the percentage of clients reporting anything other than complete satisfaction with agency services.
Throughout this report, “less than complete satisfaction” and “dissatisfaction” will be used interchangeably.

In addition, as mentioned earlier, at each wave of interviews, study participants were asked a battery of questions referring to both their perceptions of the patient-provider relationship, and to specific aspects of their medical care which allowed them to rate the care system as consumers. Specifically, the CHAIN interview includes questions about respondents' perceptions of their encounters with the medical care system such as whether they think that their medical provider spends enough time with them, whether they feel that their medical provider understood what was bothering them, and whether their medical provider showed interest and concern for them.

We also included in the interview questions designed to elicit study participants' ratings of specific features of the care system such as how long do they have to wait to see their medical provider, whether their provider offers preventive care as expressed in the provision of routine check-ups, vaccinations, and medical tests, whether they can receive information or advice about a health concern from their provider, and finally, whether they have access to their provider 24 hours a day, in case of a medical emergency. A similar set of questions referring to the study participants' case manager was also asked. The ability to choose their medical provider and case manager, and the reasons accounting for lack of choice were also examined as features of care clients received.

III. FINDINGS

A. Satisfaction and Dissatisfaction with Medical and Social Services: Summary of Quantitative Analysis

A series of analyses examined answers to direct questions about level of satisfaction or dissatisfaction with their primary medical provider, with inpatient, outpatient and emergency room visits, as well as other type of medical service encounters clients may have had during the six months prior to each interview. Satisfaction/dissatisfaction was also examined for mental health and drug treatment services and any services received in ten social service areas (financial assistance, housing, transportation etc.) The full results of these analyses are presented in tabular form in the Appendix. These tables summarize the extent to which respondents are not completely satisfied with medical and social services received from the agency with which they had the most recent contact. We analyzed data from all four waves, but we present for comparison data from the baseline survey (conducted in 1994-95) and the most recent wave of interviewing, (Time 4, conducted 1996-97). When reviewing these tables note that the "n" reported in parentheses in the tables indicates the total number of respondents that answered the satisfaction question for each type of service area.

As the tables in the Appendix indicate, in general, dissatisfaction with medical services tends to be less pronounced than dissatisfaction with social services. Regarding specific type of service within the medical services area, across all 4 waves, the majority of respondents reported
being satisfied with their primary medical provider. Specifically, 73% in Wave 1 and 82% in Wave 4 reported being very satisfied with their primary medical provider. High rates of satisfaction (73% - 79%) were found among those who had one or more visit to a visit to a private (office based) physician for medical care and those who visited a mental health provider regardless of practice setting (77% satisfied). Clients also tended to be very satisfied with their support group, if they had one. Seventy five percent in Wave 1 and 83% of respondents in Wave 4 reported complete satisfaction with their support groups.

On the other end of the continuum, at each wave of interviewing, emergency room visits, inpatient hospital stays, drug treatment programs and home health care seem to provoke the highest levels of dissatisfaction. In each wave of interviewing, emergency rooms left more than half of the patients who visited them dissatisfied with the encounter. Dissatisfaction with inpatient care ranged from 46% of participants in Wave 1 to 37% in Wave 4. Rates of dissatisfaction with drug treatment programs ranged from 40% in Wave 1 to 29% in Wave 4. Dissatisfaction with dissatisfaction with home health care ranged from 51% of those who used this service at baseline to 31% of those receiving home care at the time of Wave 4 interviews. In all these service areas, rates of dissatisfaction have declined over time; however, at the most recent study period, sizeable proportions of consumers are dissatisfied with services they receive in these areas (see Tables in Appendix).

Regarding social services, assistance with housing and financial problems was criticized more frequently than any other type of social services. In each wave of interviewing, at least 60% of those who sought assistance with housing problems were dissatisfied with the help they received. More than half (54% to 72%) of clients who sought services for help with financial problems were dissatisfied with agency or provider response to their needs. Dissatisfaction with assistance received to meet needs for food, meals or nutritional services is also high, ranging from 63% in Wave 1 to 60% in the fourth wave. Dissatisfaction for transportation services was even higher; the percentage in both waves was 67%.

Across all waves, satisfaction rates with one's primary case manager are high, for example, in Wave 1 76% of all clients reported being very satisfied with their case manager and in Wave 4 two thirds of clients reported this level of satisfaction. Moreover, the overwhelming majority of respondents feel that they have a choice of case manager: 68% in Wave I and 69% in Wave 4 felt they had such a choice.

Across all service areas, the satisfied/ dissatisfied question showed few differences by client characteristics such as gender, race/ethnicity, risk group, or stage of illness. Other research suggests that patients with higher incomes tend to hold their medical providers to higher standards of care, are harder to please, and consequently tend to report dissatisfaction more frequently than low-income patients (Ross et al. 1995). However, when we divided the study participants into those whose individual annual income is less than $10,000 and those whose income equals or exceeds $10,000 we again found no consistent relationship with
the quantitative measure of satisfaction/ dissatisfaction\(^1\) (See Appendix for Tables).

These quantitative analysis facilitated identification of the most problematic service areas across all waves (those with the highest rates of dissatisfaction) which directed our in-depth analysis of the open-ended statements to identify specific reasons for dissatisfaction and satisfaction. The next section consists of an examination of respondents’ reasons for satisfaction or dissatisfaction with medical services, mental health services and drug treatment programs.

**B. Satisfaction and Dissatisfaction with Medical, Mental Health, and Drug Treatment Services:**

**Summary of Qualitative Analysis**

All clients who expressed any dissatisfaction with a service were asked why they were dissatisfied. An analysis of the content of the statements respondents made when explaining their reasons for dissatisfaction with these service areas revealed a set of criteria patients use when evaluating the medical care system. We classified the reasons for dissatisfaction with medical services in three categories: **environmental reasons**, related to the organizational and other service-setting characteristics of a medical facility; reasons related to **patient-provider interaction and communication**; and reasons associated with the results of the medical services rendered which we labeled **outcome reasons**.

1. **Medical Service Areas With High Rates of Dissatisfaction**

\(^1\) We selected the $10,000 benchmark based on HRA’s maximum allowable low income criterion of $810 per month ($9,720 annually).
Emergency room visits. The quantitative analysis showed that emergency room encounters engender relatively high rates of client dissatisfaction. Qualitative analysis of reasons given for dissatisfaction point to environmental reasons such as the long wait to be seen by a provider, a factor associated with the organization of ERs, as the main reasons for dissatisfaction with emergency room services. An analysis of three hundred Wave 1 interviews revealed that out of 74 patients who reported being anything less than “very satisfied” with the care they received in emergency rooms, 42% attributed their dissatisfaction to long waits. Another twenty two percent of these 74 dissatisfied patients stated that the poor outcome of their visit to the emergency room is their source of dissatisfaction. Respondents mentioned that their physical symptoms were not addressed properly or that physical pain was not alleviated. One of our study participants, for example, complained about her visit to the ER because she “had to return to the hospital after they sent me home because my lung collapsed.” Another stated that the doctors at the ER “didn't want to give me medication for what was wrong with me. They told me it could go away by itself.” Eighteen percent of these dissatisfied patients recounted instances of poor interaction with medical providers in emergency rooms. Their encounters with physicians and nurses left these study participants with the impression that their providers were not concerned about their well being. It should be emphasized that high rates of dissatisfaction with hospital emergency rooms usually are not a reflection of the overall quality of care of hospitals, since the same respondents who complained about a hospital’s ER often reported high rates of satisfaction with all other departments and services offered by the same hospital.

Inpatient hospital care is another service areas with relative high rates of dissatisfaction. Poor patient-provider interaction and communication was the primary reason accounting for dissatisfaction with both these service areas. An in-depth analysis of the narratives the first three hundred interviews conducted at Wave 1 revealed that 65% out of 31 respondents who were dissatisfied with their inpatient stay attributed their dissatisfaction to their interaction with their medical providers. Encounters with doctors during hospitalization left respondents with the feeling that these doctors often lack the necessary knowledge for dealing with HIV/AIDS and are not concerned about their patients. I have to fight with my doctor sometimes to get various services...The doctors aren't specialists at my clinic,” one patient explained. Another patient complained that his doctor's attitude made him feel like a “guinea pig” and gave him the impression that he lacks the necessary medical expertise. Lack of concern was manifested by not spending enough time with their patients, while lack of knowledge was reflected in the patient's perception that the doctor was unable to offer adequate information about his condition. Among reasons for dissatisfaction with hospital stays, patients also listed nurses who were overworked, indifferent or disrespectful. Environmental and organizational aspects of inpatient stay were also recognized as sources of dissatisfaction. Unclean hospital rooms, unsavory hospital meals,

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1 The remaining fourteen study participants dissatisfied with their visit to the ER either did not explain their reasons for dissatisfaction, or provided a general statement such as “I do not like hospitals which could not be classified in any of the categories.”
overcrowded hospitals, waiting time for nurses-response, and hospital procedures for informing the patients about test results were mentioned by 8 of these 31 patients dissatisfied with their inpatient stay.

Home health care is a third area of medical services with high rates of dissatisfaction. Study participants explained that their dissatisfaction in this area stems from both the interaction with the nurse's aides or paid home care provider as well as from the poor outcome of their services. To a large extent, boundary problems account for our respondents' dissatisfaction. For example, nurse’s aides refuse to perform light housekeeping when asked because they do not believe it is part of their job description. Housekeepers and nurse's aides are sometimes perceived as invading their clients privacy, as one client put it, “the nurse takes over my home.” Additionally, housekeepers were characterized as being “lazy” and nurse's aides as being inexperienced. Respondents also complained about the organizational set-up of home health care agencies. In particular, they complained that the person providing the home services is constantly changing. Ensuring continuity of care was the request voiced by clients who reported dissatisfaction with the ever-changing home health aides.

2. Medical Service Areas With High Rates of Satisfaction

On the check-list satisfaction questions, primary medical providers, especially private physicians, received high satisfaction ratings across all four waves of interviewing. The qualitative analysis of patient experiences with providers suggests some aspects of medical care that underlay reasons for satisfaction.

Primary Care Provider. An in-depth analysis of the content of the participants' narratives regarding their primary providers and private physicians indicates that even when patients are satisfied with specific features of medical care offered by their providers they tend to be dissatisfied with their providers if they feel that the patient-provider interaction is poor. A good rapport between the patient and the provider, however the patient defines it, contributes to high satisfaction. Physicians who provide explanations about illnesses and medications, inspire trust in their patients, spend time examining their patients, are accessible to their patients almost any time, are attentive and listen to their patients' fears and concerns, and who empathize with their patients received high marks from the CHAIN study participants. "The [provider] is doing his job and the important thing is that he understands and he is caring, one female patient remarked. Another patient praised his doctor, "She is very nice. Every time that I feel sick, I page her and I explain what I have felt and she tells me what I have to do: like go to a hospital or take some other medication." At the other end of the spectrum, one patient defined the unconcerned physician by stating "No interaction, no explanation for medications, he gave me medication without informing me of side effects." Another explained "My

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3 A distribution of the reasons for dissatisfaction with home health services is not provided because in our analysis we combined the narratives from different sections of the interview that touched on this service area.
provider doesn't pay enough attention to my care. I don't trust his decision about medication. We don't have a good working relationship." The majority of patients who were dissatisfied with their primary physician, across waves, reported a poor patient-provider relationship, despite giving high marks to them for providing specific aspects of care mentioned earlier, such as, routine check-ups, information about a health concern and being able to call 24-hours a day in case of a medical emergency.

3. Mental Health Services

Mental health providers left most of the study participants very satisfied in all four waves. An analysis of respondents' experiences with their mental health providers (psychiatrists, psychologists, therapists) indicates that, once again, a good rapport with the provider is the primary reason for satisfaction. "I feel we relate well and he seems very concerned" was how one respondent described his provider, while another explained that her provider "Takes time to talk and listen; he gets involved, helps and asks how the medication [anti-depressants] is making you feel." In contrast, mental health providers who attracted criticism by patients were described as being unable to inspire "trust", as "not spending enough time" with their patients, and lacking "commitment and concern." "Going through the motions" was how a male client described his psychotherapist's lack of concern; "I have that number feeling" was how another patient described his encounter with his therapist.

HIV Support Groups. It is noteworthy that patients dissatisfied with their mental health providers often resort to HIV support groups, who also left most of the study participants "very satisfied", in all four waves. Content analysis of open-ended statements demonstrate that support groups offer participants the opportunity to share their concerns and hopes with others similarly infected and affected by the disease. Participants seem to find this opportunity invaluable. As one woman characteristically said, "It was nice finally to come in contact with those who are going through what I am going through," while another referred to his HIV-support group as "a second home." Support groups provide both emotional and instrumental support to their participants. An analysis of long-term drug users among 50 study participants demonstrated that HIV-support groups oftentimes function as alcohol/drug abuse support groups (such as Alcoholic Anonymous and Narcotics Anonymous) strengthening participants' sobriety, as well as providing support for other challenges facing people living with HIV.

4. Dissatisfaction with Drug Treatment

Drug treatment programs. Once again, dissatisfaction stemmed primarily from the poor quality of interaction and lack of communication with the drug counselors. An analysis of the 132 Wave 2 interviews with respondents who were currently enrolled in or in the last six months had attended some type of drug treatment program revealed that 37% of the 52 respondents who reported dissatisfaction experienced a lack of rapport and understanding with their counselors. Twenty one percent of these 52 respondents linked their dissatisfaction to environmental factors, and
specifically, to the setting of methadone maintenance programs offering methadone but no counseling, and as one program participant said “holding you methadone-hostage.” Some drug/alcohol counselors were perceived as “unconcerned and insensitive”. One respondent confessed, “My counselor is a little cold, sometimes I think he doesn’t care.” This contrasts with clients who express satisfaction with their drug treatment who report good counselors described as “a friend”, or somebody who “cares and works with those willing to get clean.”

C. Analysis of Multiple Influences on Patients' Satisfaction with their Primary Medical Provider.

The literature shows that essential to most definitions of “good” primary care are, dimensions of coordination of care, comprehensiveness, and access to the service system (Flocke et al. 1995). Characterizations of the patient-provider relationship along dimensions such as the patients' perception of the provider's understanding and concern for him or her as an individual also influence patients' ratings of the medical provider (Bertakis et al., 1995). As the qualitative analysis demonstrated, all these themes are found in patient narrative descriptions about what they like and do not like about their medical care. The CHAIN survey has specific questions that can be used as indicators of these dimensions or aspects of care and a multi-variate quantitative analysis was conducted to examine the extent to which characteristics of the delivery of primary care and/or the patient-provider relationship are associated with patient satisfaction.

A summary measure was calculated comprised of answers to questions that could be used as indicators of the extent to which study participants experienced primary care as coordinated (“Is there a single doctor or medical provider whom you consider in charge of your overall medical care”), comprehensive (“Is there somewhere you can go for routine check-ups or medical tests” and “someone you could go to for information or advice about a health concern”) and accessible (“Is there someone you could call up 24 hours a day in case of a medical emergency”). It must be emphasized that the single items used do not claim to address the full complexity of these features of care, but they can be taken as indicators of characteristics of care likely to affect patient satisfaction. Likewise, a measure of the patient-provider relationship was created by answers to three questions about patients' perceptions of the quality of their interaction and communication with their provider: their assessment of whether their provider spends enough time with them, how well their provider understood what was bothering them and how much interest and concern for them the provider has demonstrated.

The following tables present data from Wave 1 because the baseline data

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4 The remaining twenty respondents did not explain their reasons for dissatisfaction with the drug treatment programs they attended.
set provides a larger case base and constitutes a more representative sample. A larger case base allows an examination of the joint effects of multiple influences, including client background characteristics as well as characteristics of the service delivery system. The smaller case base available in the most recent round of interviews provides too few cases for important subsets of clients (e.g., white women who were dissatisfied, problem drug users of color, etc) to allow for reliable statistical generalizations. However, an analysis using Wave 4 data indicated the same overall patterns of satisfaction and dissatisfaction with the primary care system. This section of the report constitutes an attempt to find general patterns that underlay reasons for satisfaction and dissatisfaction with services, and these general principles are not affected by the recency of interviews.

Characteristics of Primary Care. Table 7 shows that organizational and service-setting features of primary care are indeed associated with satisfaction or dissatisfaction with one's medical provider among persons living with HIV/AIDS.

Table 7. Organizational Features of Primary Care and Patient Satisfaction with Medical Provider

<table>
<thead>
<tr>
<th>Score on Index of Characteristics of Good Primary Care</th>
<th>Score=0</th>
<th>Score=1</th>
<th>Score=2</th>
<th>Score=3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Score=0: Care is NOT coordinated, comprehensive or accessible (n=32)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Score=1: 1 feature of good primary care present (n=49)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Score=2: 2 features of good primary care present (n=253)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Score=3: All 3 features of good primary care present (n=314)</td>
<td></td>
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</tr>
</tbody>
</table>

| Completely satisfied with medical provider | 53% | 43% | 66% | 86% |
| Less than completely satisfied, dissatisfied with medical provider | 47% | 57% | 34% | 14% |

We can see that relatively few study participants have medical care that is neither coordinated, comprehensive, or accessible (using the indicators specified above). There are only 32 individuals out of 648 (5%) with a source of care who score "0" on the scale. Another 49 (8%) of respondents had one feature of good primary care as measured by the scale. However, in both these groups, satisfaction with their medical provider is much lower (53% and 43% respectively) than among other respondents, especially among
CHAIN respondents whose medical care was coordinated, comprehensive and accessible, as they experienced it.

Patient-Provider Relationship. As Table 8 clearly illustrates, relatively few persons living with HIV/AIDS in New York City are cared for by providers with low scores on the patient-provider relationship scale. In fact, the great majority of CHAIN study participants, that is, 65% (419/648) score "3" on the scale, indicating that they perceive that their provider spends enough time with them, understands them very well, and is very concerned about them. The relationship between these dimensions of perceived patient-provider relationship and patient satisfaction is very clear. Almost all (94%) of the individuals who describe their current provider in these ways are satisfied with him or her. In stark contrast only 6% of respondents who do not feel their provider spends enough time with them and do not experience understanding and concern, are satisfied with the care they have received.

Table 8. Features of Patient-Provider Relationship and Patient Satisfaction

<table>
<thead>
<tr>
<th>Score on Index of Characteristics of Patient-Provider Relationship</th>
<th>Score = 0 Provider does NOT spend enough time, understand patient well, or show great concern (n=49)</th>
<th>Score = 1 1 feature of good patient - provider relationship present (n=67)</th>
<th>Score = 2 2 features of good patient - provider relationship present (n=113)</th>
<th>Score = 3 All 3 features of good patient - provider relationship (n=419)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Completely satisfied with medical provider</td>
<td>6%</td>
<td>21%</td>
<td>58%</td>
<td>94%</td>
</tr>
<tr>
<td>Less than completely satisfied, dissatisfied with medical provider</td>
<td>94%</td>
<td>79%</td>
<td>42%</td>
<td>6%</td>
</tr>
</tbody>
</table>
Waiting time. Drawing on existing research literature as well as on the in-depth analysis of CHAIN interviews, we are led to examine "waiting time", that is, the time a client has to spend between his or her scheduled appointment and the time that he or she is actually seen by a provider, as an additional source of satisfaction or dissatisfaction with medical care. The mean waiting time to see one's provider among CHAIN study participants is approximately 45 minutes; however, "typical" times of up to four hours were reported by some respondents. There is a direct relationship between waiting time and satisfaction with medical provider. Among clients who waited on average 30 minutes or less, 78% were completely satisfied with their current medical care. Individuals who typically waited more than 30 minutes had lower rates of satisfaction; 64% were completely satisfied and 36% less than completely satisfied with their doctor or other primary medical person (Table 9).

Choice of medical provider. There is also a relationship between being able to choose a medical provider and high rates of satisfaction with one's medical care. Patients who have a choice can change their provider and therefore, they find and stay with one they approve (Ellis, 1987). More than three-fourths of CHAIN study participants, across all four waves, feel they have a choice of providers. However, among the minority of individuals who feel they have no choice, rates of satisfaction with care are much lower. Only 37% of people who report limited choice of providers are completely satisfied with their provider compared to 83% of participants who have choice and report that they could change providers if they wanted to (Table 9). Type of insurance coverage, lack of information, and the mode of operation of the medical system which just assigns physicians to patients were the most frequently mentioned factors confining participants' choice of primary physician. Since the overwhelming majority of respondents (approximately four fifths) are covered by Medicaid, when they mention coverage as a confining factors they almost invariably refer to their Medicaid coverage. As more clients enroll in Medicaid managed care plans, it will be interesting to see whether this relationship between Medicaid coverage and limited choice of medical provider is affected. When study participants mention "lack of information" as a confining factor they refer to both not knowing the process by which one changes his or her provider and to whether they have the right to request such a change. Once again, information from the Wave 5 interviews on knowledge of one's rights as a patient will further enhance our understanding of the relationship between lack of information and choice of provider.
Table 9. Patient Satisfaction by Waiting Time and Choice of Medical Provider

<table>
<thead>
<tr>
<th>Waiting time typically 30 min or less (n=406)</th>
<th>Waiting time typically 30+ min. (n=239)</th>
<th>Have choice of medical provider (n=480)</th>
<th>No choice of medical provider (n=148)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Completely satisfied with medical provider</td>
<td>79%</td>
<td>83%</td>
<td>37%</td>
</tr>
<tr>
<td>Less than completely satisfied, dissatisfied with medical provider</td>
<td>22%</td>
<td>17%</td>
<td>43%</td>
</tr>
</tbody>
</table>

x² 14.215, p=.000  
x² 92.885, p=.000

In order to examine the relative importance of all of these variables: 1. characteristics of primary care (coordinated, comprehensive, accessible), 2. the perceived patient-provider relationship (taking enough time, understanding, showing concern), 3. waiting time, 4. choice of medical provider, and 5. clients' background characteristics (including being a problem drug user and type of insurance coverage) these variables were entered in a logistic regression analysis, a technique that allows the examination of several possible predictors and the isolation of the effects of each factor while controlling for all other variables in the model. (See Figure 1) "Good" (i.e., coordinated, comprehensive, and accessible) primary care, a patient-provider relationship characterized by understanding and concern, the ability to choose providers, and being white are all significantly associated with patient satisfaction. Waiting time was not significant, once the other variables were controlled for. Among the variables tested, the strongest predictor of patient satisfaction is the nature of the patient-provider relationship.
Individuals who report that their medical provider takes enough time with them, understands very well what was bothering them and seemed very concerned about their well being are over 23 times more likely to be completely satisfied with their medical care than study participants who report that their relationship with their doctor or other medical person is lacking one or more of these features, even controlling for characteristics of primary care and perceived choice of medical provider (data not shown).
Figure 1. What Predicts Patient Satisfaction with HIV Medical Care

QUESTION: What factors contribute to patient’s being “very satisfied” with his or her primary HIV medical provider?

Possible explaining factors...

<table>
<thead>
<tr>
<th>Individual Characteristics and Health Status and Characteristics of Health Care Delivery and Characteristics of Patient/Provider Relationship</th>
</tr>
</thead>
<tbody>
<tr>
<td>C Gender C Physical Health Functioning Score C Has choice of medical provider C Current provider shows concern, understands problems &amp; spends enough time with patient</td>
</tr>
<tr>
<td>C Race/ Ethnicity C Problem drug user C Usual waiting time to see provider &lt; 30 min</td>
</tr>
<tr>
<td>C Public insurance or no insurance C Primary care is coordinated, comprehensive &amp; 24 hr access</td>
</tr>
</tbody>
</table>

ANSWER: The following characteristics or measures were associated with being “very satisfied” with medical provider:

Explaining factors:

<table>
<thead>
<tr>
<th>Individual Characteristics and Health status and Characteristics of Health Care Delivery and Characteristics of Patient/Provider Relationship</th>
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<tr>
<td>C Race/ethnicity # C Has choice of medical provider*** C Current provider shows concern, understands problems &amp; spends enough time with patient***</td>
</tr>
<tr>
<td>C Primary care is coordinated, comprehensive &amp; 24 hr access**</td>
</tr>
</tbody>
</table>

# p < .10   *p < .05   **p < .01   ***p < .001
The findings from the above quantitative analysis are consistent with the in-depth content analysis of the CHAIN study participants' narratives which clearly indicates that the quality of the patient-provider relationship is the primary factor determining patients' satisfaction with medical care. The next section of the report consists of two vignettes of CHAIN study participants who were consistently, in all four waves, dissatisfied with their medical provider. An in-depth analysis of participants' profiles allows them to express their experiences with the medical system in their own words.

D. Profiles of CHAIN Study Participants Consistently Dissatisfied with their Medical Provider

Across the four waves of interviews, 40 respondents remained consistently dissatisfied with their medical provider. Sixty seven percent were men and the remaining were women. Almost half were white (42%), one quarter were black (25%) and the remaining were Latinos. The great majority (60%) were diagnosed with AIDS, and the remaining 40% was equally split between HIV asymptomatic and HIV symptomatic patients. Finally, 42% were problem drug users, 22% were men who have sex with men and problem drug users, and respondents who fell in the other two risk categories, that is, men who have sex with men with no history of problem drug use, and heterosexual and other, each constituted 18% of this sub-group of consistently dissatisfied patients. Following are two vignettes that provide illustrative examples of the type of difficulties that clients who are consistently dissatisfied with their medical care discuss in their CHAIN study interviews.

The first vignette is that of a 39-year old white woman who at Wave 1 is receiving medical care in a big public hospital and expressing her dissatisfaction with her medical provider: "I wasn't interested in the medicine he was trying to make me take .. he doesn't spend enough time with me and he doesn't understand me." The woman went on narrating her experience as a patient by saying that she stopped going to this hospital because her provider "Was just pumping medications into me. He would not listen to my point of view about medical care." In the next two waves, this woman has moved to a general public clinic and she remains dissatisfied with her provider although satisfied with the clinic as a whole. In the most recent wave, this female patient is attending the same clinic but has no regular doctor. The way she defines her system of medical care is expressed in the following statement: "I don't want to bother with doctors.... They are all the same. They tell you anything. They don't take time to explain anything. I participate in studies (clinical trials) to maintain my health. I just keep track of my T-cells."

A second case involves a male black patient whose reasons for dissatisfaction with his medical provider echo themes heard in many other
client interviews. In the first round of interviews he was 40 years old and was receiving care in a big public hospital. He attributed his dissatisfaction to the fact that his provider does not spend enough time with him: "He doesn't do any physical exam. He just writes prescriptions. I waited for an hour to see him and he only saw me for two minutes. He doesn't care for his patients." In all subsequent waves, this dissatisfied male patient is attending the same hospital and having the same medical provider. As he explained he did not change hospitals because he thought that Medicaid would not cover services in another facility. In the last round of interviews, this respondent linked his dissatisfaction to lack of the provider's availability and concern "I can never see him the day I need to see him. I need someone to be there when I need him... someone who cares."

These two profiles illustrate that the interaction between patient and physician is one of the aspects of care patients tend to assess carefully during their medical visit. It is interesting to note that many patients, despite being dissatisfied with their medical care are reluctant to change their medical provider The biggest danger with dissatisfied patients is that they might decide to stop seeking medical care all together as illustrated by a 33 year old black respondent who explained, “The hospital kept changing my doctor, so I became discouraged about going to see any doctor.”

E. Satisfaction and Dissatisfaction with Social Services and Case Managers.

As the quantative analysis showed, across all four waves, the services related to housing, finances, food and transportation had the highest rates of dissatisfaction among CHAIN study participants, while services which provide legal assistance left most of them relatively satisfied. The narrative descriptions of the reasons for dissatisfaction reported by study participants, can be classified in two categories: those related to the process of getting social services and those related to the outcome of their attempt to get social services.

1. Social Service Areas with High Rates of Dissatisfaction.

Housing Services. An analysis of the rates of resolution of housing problems indicates that, in all waves, close to one third of housing problems are either resolved or a great deal of progress towards resolution is accomplished. Moreover, as previous CHAIN reports on housing problems argues most clients who reported a housing problem in Wave I had their problem resolved by Wave 3 (Update Report #5). These findings dovetail with the findings from an analysis of the narratives of dissatisfaction with social services in which study participants attributed their lack of satisfaction mostly to the process of receiving
housing services and secondly to the poor outcome of agency efforts to assist them.

Most of the respondents who claimed to be dissatisfied with the process of receiving housing assistance criticized the bureaucratic character of housing agencies, and quite a few attributed their dissatisfaction with housing service agencies to delays in providing assistance. An in-depth analysis of 300 Wave 1 interviews indicated of the 120 clients who were less than completely satisfied with housing services, 25% associated their dissatisfaction with the bureaucratic nature of agencies, while 17% with delays in getting assistance. "I lost three apartments while waiting for this agency to do the process for the money needed for rent", one client explained. A bureaucratic error, for instance, resulted in one respondent's rent money being sent to the wrong landlord, "I am in court with my landlord.... my worker fouled up my case." was how the respondent described the mix up. Twenty two percent of these 120 disgruntled clients complained about the lack of useful information regarding their housing benefits and the location of appropriate housing. Seven percent of these dissatisfied respondents spoke of the lack of communication and rapport with the case manager, social worker or other agency employee they contacted. One respondent provided the following remark when describing the poor rapport between clients and service providers: "It's like they [providers] think they are on a pedestal and anyone who needs help is not worthy." Housing providers were perceived as being "not supportive" and "lacking understanding," and some respondents suggested that housing agencies should offer better incentives in order to attract "qualified and dedicated" employees.

Dissatisfaction also stemmed from the poor outcome of housing assistance. Seventeen percent of the 120 respondents who were dissatisfied with housing services clients reported that their attempt to get housing assistance led to poor results: not getting adequate housing, housing subsidy, or quality of housing desired by the client. Primarily systemic factors, such as the inadequate amounts of rental subsidies for people with HIV/AIDS, the features of the housing market in New York City (housing shortage and high rent prices), long waiting lists for low-income and specialized AIDS housing, the discriminatory practices of landlords, the lack of cooperation among housing agencies, and once again, the bureaucratic nature of some housing agencies are seen to contribute to poor housing outcomes.

5. Satisfaction with professional help with emotional problems, as reported in the social services area, is high, ranging from 65% in Wave 1 to 74% in Wave 4. In our earlier analysis of satisfaction with mental health services we combined findings from sections we will not engage into farther analysis of this service area.

Financial Assistance. An examination of the rates of resolution or of great deal of progress toward resolution of financial problems across
waves reveals that the rate has increased somewhat from 14% in Wave 1 to 22% in Wave 4. Still, most study participants who need financial assistance claim to be disenchanted by the poor process of receiving financial services and many are dissatisfied with the poor outcome of their efforts to get help. An analysis of 300 narratives demonstrated that out of 84 respondents dissatisfied with financial assistance, 54% complained about the process characterizing the service system, while the remaining 46% reported poor outcome as a source of dissatisfaction.

In addition, an analysis of the respondents’ reasons for dissatisfaction with several other service areas (e.g. food and transportation) that lack of money underlies most of the problems in those social service areas. Study participants' reports of dissatisfaction with financial services often refer to how the lack of money influences the quality of their nutrition, as well as to how it bars access to transportation. Respondents explained that they cannot afford good food and mass transportation: "I need a better diet, but it costs too much," one man characteristically mentioned. Another complained that "I don't even have money to go to my medical appointments."

Approximately half of the 84 respondents dissatisfied with the financial assistance they have received are aware that the financial benefits they are eligible for are limited, and therefore realize that the providers of financial services are not always to blame for their lack of financial resources. However, in some instances, the system by which financial benefits are delivered was criticized for being sluggish, inefficient, and fragmented. "I have applied for SSI and have been waiting to hear what’s going on, that was one year ago," one respondent reported. Both public and private service agencies catering to the needs of people with HIV/AIDS and of low-income people in general were labeled as inefficient due to their inadequate, overworked personnel and their lack of interorganizational cooperation. Study participants have experienced the fragmentation of the service system. "Communication among providers is poor", a participant who has problems getting financial benefits explained, and another mentioned that she had to "run back and forth between agencies" to get financial assistance. Receiving the "runaround" through the maze of agencies was a major complaint underlying dissatisfaction with all types of social services.

Food and Transportation. Most of the dissatisfaction in the area of food and transportation as mentioned earlier, was associated with not having enough money for buying quality food and using mass transportation. In the area of transportation, however, almost one third of the dissatisfaction was attributed to the way ambulette services operate. Complaints about delays and having to request an ambulette a day or two in advance, prevents many respondents from using these services. One patient stated "They (ambulette agency) made you wait too long; one or two hours," while another blamed the hospital clinic for the transportation delays, "The
clinics don't schedule the transportation properly."

2. Social Service Areas with High Rates of Satisfaction

Legal services. The service area with the most consistent relatively high rates of client satisfaction was legal services. For each of four study waves, the majority of study participants who sought legal services were very satisfied with the help they received. This is a relatively high rating when compared to the other social service areas. A content analysis of 300 clients' narratives reveals that 62 clients request legal assistance but for a variety of situations, not all associated with being HIV positive. For example, study participants ask for legal assistance in getting custody of their children, or filing for a divorce, drafting a will or fending off an eviction. Of the 34 respondents who reported being very satisfied with the legal services they accessed, 70% linked their satisfaction to a positive outcome of their attempt to get legal assistance; the remaining 30% linked their satisfaction to receiving useful information. At the other end of the spectrum, 64% of 28 dissatisfied clients associated their dissatisfaction primarily with being ambivalent about seeking professional assistance in the first place. It is significant that almost one-third of clients with legal problems choose to eschew professional help, yet those who do seek agency or provider assistance have much higher rates of problem resolution.

3. Satisfaction and Dissatisfaction with Case Managers

As shown in the quantitative analysis, across all waves, satisfaction rates with case managers are consistently high. An analysis of the respondents' statements on case managers provided definitions of a "good" case manager versus a "bad" one. The literature suggests that "assertive case management," that is, management provided by vigilant case managers who follow up on the clients, are well informed about their clients' benefits, and make sure that their clients receive the assistance they are entitled to, contributes to resolution of some social service problems (Korr and Joseph, 1995). CHAIN study participants evaluated both their encounters with their case manager and the outcome of their overall services. Respondents seem to appreciate a good rapport with their case manager as much as a positive outcome in securing services. Case managers who are responsive to their clients' needs, who provide useful information, and who are personable and understanding were defined as "good case managers". "She [case manager] really does help. She doesn't say one thing and then do another. She's always there in a time of need," one client explained. Given the fluidity of case managers' job responsibilities, it was interesting to discover that study participants appreciated those case managers who they perceived as "going beyond their duty." As one male respondent said, "When I'm depressed I call her... she helps me out in a lot of ways." Another study participant whose housing problems were resolved by his case manager stated: "She [case manager]
At the other end of the spectrum, respondents criticized case managers whom they perceived as unconcerned or disrespectful as well as those who were unable to provide some assistance. "My case manager is rude and he doesn't know enough about services. We don't get along well, he isn't helpful and I complained to his supervisor" one male client said, echoing the experience of a number of respondents.

The following section presents the experiences of two clients who were, in all four waves, dissatisfied with social services. An in-depth review of each of their discussions during CHAIN interviews provides vignettes that illustrate common experiences among those persistently dissatisfied with social services.

F. Profiles of CHAIN Study Participants Consistently Dissatisfied with Social Services

Throughout all four waves of interviews, 25 study participants remained consistently dissatisfied with the help they received or attempted to obtain from a variety of social service agencies. Men were significantly over represented in this group of hard core dissatisfied clients (72%) when compared to women. All ethnic/racial groups were almost equally represented in this group, as were risk groups. Individuals with AIDS were disproportionately represented in this group (72%) when compared to HIV symptomatic (20%) and HIV asymptomatic (8%) clients.

The first vignette describes a 38 year-old Latino man who at baseline interview is struggling with serious service needs - doubled-up with relatives and friends and moving from place to place this respondent needs to find housing, as well as get health coverage, and financial benefits. The way this client recounted his numerous encounters with a variety of public social service agencies clearly explains his reasons for dissatisfaction: "It was difficult for me to understand the social services system. I was treated very badly. My case manager doesn't have time for me. He has not been able to even get information about a housing application and so I am still homeless." In the last two waves, the respondent stated that he has his own place. However, an intervention by a legal agency was necessary to prevent eviction, and he expressed dissatisfaction with the poor condition of his apartment and with the way in which he is treated by social service employees: "They show no compassion, no respect." Moreover, the client is discouraged and has given up on asking for professional help with his housing problems: "It would be so hard for me to go and find someone to help me. I don't have the energy."

Our second case study is a 44 year old white man. At the first interview,
he began recounting his experiences with the social services system, "You have no choice of case manager. You take what they give you when you walk through the door and mine is a complete waste of time." He had resorted to three different case managers in both public and private agencies in his attempt to get an apartment in an elevator building because his failing health prevented him from living in a six-floor walk-up. After loosing his rent subsidy and food stamps, due to a bureaucratic error, he summarized his view of the social service system in the following way: "Working through the system is what I would change. Private agencies don't have enough money and city agencies ask for so much paperwork!" In the last three waves, we find that the respondent has moved into an appropriate building fitting his physical needs, but now is encountering a new problem: his health coverage has been discontinued. "I was given the runaround. I couldn't resolve the issue over the phone. My case manager doesn't know his job and doesn't care." was how he described his attempt to get his medical benefits reinstated.

These profiles indicate that social service needs are usually interwoven and require a dedicated and knowledgeable case manager as well as other agency staff to help clients with complicated problems. However, regardless of whether social problems are resolved or not, study participants still appreciate being treated with respect and understanding. Like with medical providers, clients appear reluctant to change case managers even when they are not satisfied with their assistance. The reason underlying this hesitation could be the fear of being labeled a "bad client", as a 32 year old male respondent described, "If you fight for your rights, you get labeled as a bad client."

IV. SUMMARY

The present report demonstrates that individuals living with HIV/AIDS in New York City tend to express greater satisfaction with the medical than with the social service delivery system. Primary medical providers, private physicians, mental health providers and support groups had the highest rates of satisfaction, while emergency rooms, inpatient care, drug treatment programs and home health care services had the highest rates of dissatisfaction. The quality of the patient-provider relationship was the most significant factor determining satisfaction with medical services. A good rapport and adequate communication with one's medical provider is the aspect of care valued the most by patients and may even influence their decision to continue seeking medical care. Given the new treatments for HIV now available and the importance of adherence to these treatments, this relationship with one's provider becomes even more significant and needs further exploration. Social service agencies, particularly the ones offering assistance with housing, financial, food and transportation problems, have room for improvement according to the CHAIN participants. By their own reports, respondents often found both the experience of
getting services and the outcome of social services wanting.
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