

CHAIN 2007-2a Report



Satisfaction and Dissatisfaction with Medical Services and Primary Medical Provider

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HRSA Contract H89HA00015
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C.H.A.I.N. REPORT

ACKNOWLEDGMENTS

A Technical Review Team (TRT) provides oversight for the CHAIN Project. In addition to Peter Messeri, PhD, Angela Aidala, PhD, and Gunjeong Lee, PhD of Columbia University's Mailman School of Public Health, TRT members include Mary Ann Chiasson, DrPH, Public Health Solutions, Inc. (Chair); Fabienne Laraque, MD, MPH, Care, Treatment, and Housing; Jan Carl Park, MPA, Nina Rothschild, DrPH, Office of AIDS Policy and Community Planning; Mary Irvine, DrPH, Monique-Nicole Anthony, MPH, and Clarissa Silva, MSW, Research and Evaluation; Daniel Waglein, MD, Public Health Practice; Anthony Santella, DrPH, Policy, Planning, and Implementation; JoAnn Hilger, Ryan White Program; Julie Lehane, PhD, Westchester County Department of Health; and Roberta Scheinmann, MPH, Public Health Solutions.

This research was supported by a grant from the New York City Department of Health and Mental Hygiene as part of its Ryan White grant number H89 HA 0016-17 from the US Health Resources and Services Administration (HRSA), HIV/AIDS Bureau, with the support of the HIV Health and Human Services Planning Council. Its contents are solely the responsibility of the researchers and do not necessarily represent the official views of the US Health Resources and Services Administration, the City of New York, or Public Health Solutions, Inc.

INTRODUCTION

With the transformation of HIV infection into a long-term illness, medical care is an even larger part of the lives of persons living with HIV/AIDS. Regular visits for monitoring disease process, and managing medications and side-effects, as well as co-occurring conditions, are basic to HIV care (AIDS Institute, 2007). Continuity of care and adherence to treatment regimen are critical for patients to achieve the maximum benefit of effective HIV treatment. Research has shown that satisfaction with care is associated with positive attitudes toward treatment, treatment adherence, appropriate utilization of health care services, continuity of care, and improved health and quality of life outcomes (Chesney, 2000; Fuertes et al. 2007; Godin et al. 2005; Rodriguez et al. 2007). Some studies have found an association between satisfaction with medical care and reduced sex and drug risk behaviors among HIV positive persons (CDC 2003; Burke et al. 2002). Patient satisfaction with care is increasingly seen as a quality of care indicator for persons living with HIV/AIDS, along with measures of essential medical care and treatment processes (AHRQ, 2009; Rapkin et al, 2008; Wu et al, 2000).

This report explores the extent to which a diverse sample of people living with HIV/AIDS (PLWHA) in New York City and the Tri-County region of Westchester, Putnam, and Rockland counties are satisfied with their HIV primary medical care provider and medical services they receive. We examine information provided by multiple interviews conducted with CHAIN study participants between 2002 and 2007. Where appropriate, we compare findings on current patterns of satisfaction and dissatisfaction with an earlier CHAIN investigation of satisfaction among PLWHA in New York City, interviewed in 1994-1998 (Lekas & Aidala, 1998). Information for this earlier time period is not available for the Tri-County region.

We use quantitative data in the form of answers to specific questions asking study participants to rate their satisfaction with providers and services, as well as qualitative data from open-ended questions asking them to explain in their own words their experiences with medical services. An important part of the report is based on content analysis of the statements CHAIN study participants offered regarding specific service encounters and their experiences with the service delivery system more generally.

Our study addresses the following questions: 1) What are rates of satisfaction and dissatisfaction with HIV primary medical care provider, and with specific medical services received? 2) Are there differences in satisfaction with HIV primary medical care provider by patient characteristics, or by characteristics of providers or service settings? 3) What are the reasons given by study participants who report dissatisfaction with their primary medical care provider? 4) What is the relative influence of patient, provider, and service setting characteristics on dissatisfaction with HIV primary medical care provider in New York City and in the Tri-County Region?

KEY FINDINGS

- The overwhelming majority of participants consistently reported high rates of satisfaction with their HIV primary medical care provider. Across all waves of interviewing, 80% or more of all respondents reported being completely satisfied with their primary care physician or other medical provider.

- At each wave of interviewing, in both New York City and the Tri-County region, the highest levels of dissatisfaction with medical services were associated with emergency room visits and inpatient hospital stays.
- Satisfaction/dissatisfaction with HIV primary medical care provider was not associated with patient sociodemographic characteristics (gender, age, race/ethnicity, education, income), risk exposure group, or current health status indicated by CD4 count. In New York City, rates of dissatisfaction were higher among active drug users compared to non-users, and among persons with lower mental health functioning compared to those with higher mental health scores. Area of residence was associated with dissatisfaction among Tri-County PLWHA, with greater dissatisfaction seen in residents of suburban Westchester and Putnam County.
- The quality of patient-provider relationship consistently has been the primary factor determining satisfaction or dissatisfaction with a medical provider. Patients who perceived that their physician spent enough time with them, understood them, and showed interest and concern for their well-being during medical visits were those most likely to be completely satisfied with their HIV primary medical care.
- Satisfaction or dissatisfaction with HIV primary medical care provider was also related to organizational features of medical care systems. Patients were more satisfied with primary care that was comprehensive, that met clinical practice standards, and that did not require long waits to see a physician. Limited ability to choose one's medical provider was associated with greater dissatisfaction.
- Content analysis of narrative descriptions of reasons for dissatisfaction with medical care revealed four major thematic areas of concern: 1) patient-provider relationship or communication issues; 2) perception of limited competence of the provider to address specific medical concerns and solve problems; 3) problems with the organization of services at the clinic or medical facility; and 4) poor outcomes of medical treatment or care. Consistent with findings from the quantitative analysis, the majority of CHAIN participants who were dissatisfied with care described provider relationship issues.

METHODS

Study Samples

Data on satisfaction and dissatisfaction with medical providers and services were obtained through interviews with the two current CHAIN cohorts of HIV-infected individuals residing in New York City and the Tri-County region north of New York City which includes Westchester, Putnam, and Rockland Counties.

NYC Cohort. Data for this study come from three rounds of interviews with the 2002 NYC cohort which was sampled and recruited following a protocol designed to yield a broadly representative sample of people living with HIV or AIDS in the five boroughs of New York City. A two-step sampling procedure was followed. A listing of over 2000 eligible recruitment sites was created from all NYC HIV service providers where earlier CHAIN study participants reported receiving medical

or social services. Service providers were randomly selected from this list, stratified by type of agency (medical versus social service agency) and borough. With the assistance of agency staff, clients were randomly selected from agency client rosters or through an onsite sequential recruitment procedure. Recruitment was conducted at 34 sites between July 2002 and December 2003, and baseline interviews were completed with 684 clients. A small sample (n=25) of HIV-positive individuals unconnected to medical care were contacted through outreach activities and completed shorter interviews. Nine of these completed the full CHAIN questionnaire and are included in the study cohort.¹ Extensive in-person interviews have been conducted approximately yearly by trained community interviewers.

Table 1 compares the 2002 CHAIN cohort of 693 individuals with contemporaneous New York City HIV/AIDS epidemiology data and a duplicated count of Ryan White CARE Act-funded encounters. The gender and ethnic composition of the NYC cohort is similar to the AIDS and HIV epidemiology data with the exception of the substantial under representation of white males and the corresponding greater concentration of African American and Latino males. The cohort's gender and ethnic makeup closely tracks the profile of clients using Ryan White CARE Act services for the fiscal year starting in March 2001. Details about sample recruitment and representativeness of the NYC samples have been discussed elsewhere (Lee, et al. 2004).

Tri-County Cohort. The Tri-County cohort was recruited using the same sampling and recruitment protocol used for the New York City cohort. Recruitment was conducted in a random selection of 28 agencies in Westchester, Rockland and Putnam Counties. Baseline surveys were completed by 398 individuals between November 2001 and November 2002, with yearly follow-up assessments. The cohort was augmented with recruitment of 84 individuals, who were interviewed for the first time during the third round of interviews. Table 2 shows that compared to the gender and ethnic composition of surviving AIDS cases in Tri-County at the end of 2000, females in the Tri-County cohort were over represented, but ethnic composition within gender closely approximated the AIDS case data. An earlier CHAIN report discussed in detail Tri-County recruitment and sample representativeness (Abramson & Bennett, 2002). In the Tri-County and New York City CHAIN samples, PLWHA who receive their medical care in private doctors' offices and who have no need for social services are under-represented in the CHAIN study samples.

Measures

Satisfaction

At each round of interviews, study participants were asked to define their HIV primary medical care provider with the question: "Is there one doctor, nurse, or other medical provider whom you consider to be in charge of your overall HIV health care now, at the present time?" A service or practice group could be defined by the respondent as his or her primary provider. Questions followed about experiences with this provider and overall level of satisfaction with care received. Answers were reported on a four point scale: "very satisfied, somewhat satisfied, somewhat dissatisfied, or very dissatisfied." In addition to questions about HIV primary medical care provider, CHAIN respondents who reported any use of 14 different types of medical services (e.g. inpatient hospital stay, outpatient visit, ER visit, mental health counseling, etc) in the past six months were asked if they were satisfied with services received, using the same four point satisfaction scale.

Table 1. Sample Representativeness, NYC HIV/AIDS Cases and CHAIN Cohort

	NYC Persons Living with AIDS, as of 6/30/03 ¹		NYC Persons Living with HIV, as of 6/30/03 ¹		Ryan White CARE Act Encounters, 3/2001 - 2/2002 ²		CHAIN 2002 Cohort 6/2002-6/2004	
	Female	Male	Female	Male	Female	Male	Female	Male ³
Total N	15,753 (28%)	39,765 (72%)	10,104 (35%)	18,995 (65%)	10,765 (39%)	16,962 (61%)	278 (40%)	415 (60%)
White	11%	25%	8%	30%	9%	8%	6%	10%
Black	56%	40%	58%	36%	53%	53%	62%	47%
Latino	33%	32%	31%	30%	37%	37%	31%	41%
Other	1%	2%	3%	4%	2%	2%	<1% (1)	2%

¹ Source: Personal correspondence, HIV Epidemiology Program, Department of Health and Mental Hygiene, the City of New York

² Source: HIV CARE Services. Data represent a duplicated count of first time encounters with Ryan White CARE Services in FY11, March 2001 - February 2002.

³ Seven transgender cases in transition are included in male category.

Table 2. Sample Representativeness, Tri-County AIDS Cases and CHAIN Cohort

	Tri-County Surviving AIDS Cases, 12/31/00 ¹		Tri-County CHAIN Cohort	
	Male	Female	Male	Female
n	1429	748	204	194
White	27%	18%	27%	14%
Black	50%	60%	43%	57%
Latino	22%	22%	29%	26%
Other	<1%	<1%	1%	3%

¹ Source: New York State Department of Health, Bureau of HIV/AIDS Epidemiology

For this report, the last three categories of the satisfaction answer scale are collapsed in order to measure the percentage of clients who reported anything other than complete satisfaction; the term ‘dissatisfied’ should be understood to include anyone less than completely satisfied. Dichotomizing responses in this manner is appropriate given the well-documented tendency for lower SES patients to skew responses to standardized satisfaction questions in favor of ‘acquiescence’ or expressing satisfaction regardless of what may be substantive concerns (Crow et al., 2002; Ware, 1978). Classification of responses in this manner also facilitates cross-study comparisons (Aidala & Lekas, 1998).

The CHAIN interview also asked persons who answered that they were ‘somewhat’ or ‘very’ dissatisfied to describe their reasons for dissatisfaction with the question “Could you briefly describe why you were dissatisfied?” Answers were recorded verbatim and coded for thematic content. These

narrative descriptions provide detail regarding reasons for satisfaction and dissatisfaction not captured by the single quantitative score.

Patient Experiences of Providers and Features of Medical Practice

Questionnaire data also provided information about providers and specific features of the care system. CHAIN participants were asked about waiting time to see their physician or provider, and whether they had a choice of HIV primary care provider. Other questions asked about respondents' perceptions of their encounters with care providers such as whether their medical provider spent enough time with them, seemed to understand them, and showed interest in and concern for them. Medical specialization of provider (HIV or infectious disease specialist vs other) and location of medical practice (HHC hospital clinic, voluntary hospital clinic, community clinic, private practice office, social service or drug treatment agency) were coded based on respondent description, cross-validated by checking provider names in service directory or licensure listings.

Quality of Care

We also collected information to characterize HIV medical care in terms of adequacy and comprehensiveness. We determined appropriate medical care for HIV based on interview data assessing whether minimum practice standards were met with regard to recommended number of outpatient visits, receipt of diagnostic services such as CD4 T-cell counts and viral loads, and drug therapies. Standards for HIV medical care were obtained from those promulgated by the New York State Department of Health (NYS DOH) AIDS Institute (2003, 2007). We also developed a separate measure of "comprehensive primary care" based on patient report of care characterized by coordination (single doctor or medical person "in charge of overall HIV care"), comprehensiveness (indicated by the provision of "routine check-ups, vaccinations, and medical tests" as well as being a place they could go for "information or advice about a health concern") and access (whether the provider or covering service would be available 24/7 in case of a medical emergency). These features of coordination, comprehensiveness, and access have been established by the Institute of Medicine as characteristics of good primary care (IOM, 1994; 1996) upon which patients can reliably report (Flocke, 1997).

FINDINGS

Satisfaction and Dissatisfaction with Medical Services Received

Tables 3 and 4 show rates of satisfaction and dissatisfaction by provider or visit type for New York City and Tri-County CHAIN participants. We examine satisfaction rankings from three interview periods in New York City (2002 to 2007) and four interview periods in the Tri-County region (2001 - 2007). The "n" reported in parentheses in the tables indicates the total number of respondents who reported being very satisfied or less than completely satisfied (dissatisfied) for each service area. Numbers differ depending upon how many total participants reported using that service during the period under review. Note that these are cross-sectional rates of dissatisfaction among respondents who had used a particular service during a given time period. Differences cannot be attributed to change in quality of a service over time since different patients with perhaps differing needs may be among those reporting.

Table 3. Satisfaction and Dissatisfaction with Medical Services in New York City

	Wave 1 2002-2003 (n=693)	Wave 2 2004-2005 (n=548)	Wave 3 2006-2007 (n=481)
<i>Total number interviewed n=</i>	% (n)	% (n)	% (n)
Primary Provider for HIV Medical Care ¹			
Very Satisfied	79.6 (535)	81.3 (443)	82.4 (392)
Not Completely Satisfied	20.4 (137)	17.4 (102)	17.7 (84)
Private Doctor's Office Visit			
Very Satisfied	84.3 (43)	86.2 (25)	87.5 (21)
Not Completely Satisfied	13.7 (7)	13.8 (4)	12.5 (3)
Hospital Clinic Visit			
Very Satisfied	81.7 (452)	82.6 (361)	84.4 (340)
Not Completely Satisfied	17.9 (99)	17.4 (76)	15.4 (62)
Community Clinic Visit			
Very Satisfied	83.3 (90)	72.6 (69)	86.3 (69)
Not Completely Satisfied	16.8 (18)	26.4 (25)	13.8 (11)
Women's Gyn/ Family Planning			
Very Satisfied	79.2 (160)	81.0 (119)	na
Not Completely Satisfied	19.3 (39)	19.0 (28)	
Mobile Medical Unit Visit			
Very Satisfied	66.7 (2)	40.0 (2)	50.0 (2)
Not Completely Satisfied	33.3 (1)	60.0 (3)	50.0 (2)
Medical Practitioner Visit ²			
Very Satisfied	81.2 (147)	83.1 (162)	75.9 (164)
Not Completely Satisfied	18.2 (33)	14.9 (29)	23.6 (51)
Nursing Home/Residential Care			
Very Satisfied	57.1 (16)	53.8 (7)	63.2 (12)
Not Completely Satisfied	42.9 (12)	46.2 (6)	36.9 (7)
Home Health Care			
Very Satisfied	75.4 (46)	79.6 (43)	72.5 (37)
Not Completely Satisfied	21.3 (13)	20.4 (11)	27.4 (14)
Dental Services			
Very Satisfied	68.3 (198)	76.4 (165)	69.5 (157)
Not Completely Satisfied	31.0 (90)	22.6 (49)	29.2 (66)
Alternative Therapy Visit ³			
Very Satisfied	93.4 (85)	93.3 (70)	80.6 (54)
Not Completely Satisfied	6.6 (6)	6.7 (5)	17.9 (12)
Inpatient Hospital Stay			
Very Satisfied	67.2 (88)	64.1 (75)	61.7 (66)
Not Completely Satisfied	31.3 (41)	35.0 (41)	37.4 (40)
Emergency Room Visit			
Very Satisfied	52.7 (118)	54.3 (101)	50.6 (82)
Not Completely Satisfied	45.1 (101)	45.1 (84)	49.4 (80)
Mental Health Professional⁴			
Very Satisfied	81.7 (174)	82.7 (182)	79.1 (144)
Not Completely Satisfied	17.3 (37)	13.6 (30)	19.9 (36)
Drug/Alcohol Treatment⁵			
Very Satisfied	78.4 (80)	63.6 (49)	76.2 (64)
Not Completely Satisfied	16.7 (17)	31.2 (24)	23.9 (20)

1. Primary medical provider for HIV care regardless of service setting.

2. Visit to an optometrist, chiropractor, foot doctor, or nutritionist.

3. Treatment from herbalist, acupuncturist, massage therapist, practitioner of holistic medicine.

4. Visit to a psychiatrist, psychologist, therapist, clinical social worker.

5. Professional drug treatment including inpatient, outpatient, detox, methadone maintenance, and residential.

Table 4. Satisfaction and Dissatisfaction with Medical Services in Tri-County Region

<i>Total number interviewed n=</i>	Wave 1 2001-2002 (n=382)	Wave 2 2003-2004 (n=315)	Wave 3 2005-2006 (n=340)	Wave 4 2005-2007 (n=235)
	% (n)	% (n)	% (n)	% (n)
Primary Provider for HIV Medical Care ¹				
Very Satisfied	82.4 (313)	85.6 (268)	86.9 (292)	82.5 (193)
Not Completely Satisfied	17.6 (67)	14.0 (44)	13.1 (44)	16.7 (39)
Private Doctor's Office Visit				
Very Satisfied	83.1 (64)	73.1 (57)	87.3 (55)	85.1 (40)
Not Completely Satisfied	16.9 (13)	26.9 (21)	12.7 (8)	14.9 (7)
Hospital Clinics				
Very Satisfied	81.1 (197)	84.8 (167)	85.8 (200)	84.5 (142)
Not Completely Satisfied	18.9 (46)	14.7 (29)	14.2 (33)	15.5 (26)
Community Clinics				
Very Satisfied	71.6 (68)	79.8 (67)	70.7 (53)	64.9 (37)
Not Completely Satisfied	28.4 (27)	20.2 (17)	29.3 (22)	35.1 (20)
Women's Gyn/ Family Planning				
Very Satisfied	76.5 (104)	88.5 (77)	87.5 (14)	na
Not Completely Satisfied	23.5 (32)	10.3 (9)	12.5 (2)	
Mobile Medical Unit				
Very Satisfied	93.8 (15)	88.9 (16)	52.9 (9)	87.5 (7)
Not Completely Satisfied	6.3 (1)	11.1 (2)	47.1 (8)	12.5 (1)
Medical Practitioner Visit ²				
Very Satisfied	82.1 (92)	76.8 (109)	73.7 (101)	64.7 (55)
Not Completely Satisfied	17.9 (20)	22.5 (32)	26.3 (36)	35.3 (30)
Nursing Home/Residential Care				
Very Satisfied	72.7 (8)	27.3 (3)	50.0 (7)	44.4 (4)
Not Completely Satisfied	27.3 (3)	72.7 (8)	50.0 (7)	55.6 (5)
Home Health Care				
Very Satisfied	57.1 (20)	85.7 (24)	75.8 (25)	87.5 (21)
Not Completely Satisfied	42.9 (15)	14.3 (4)	24.2 (8)	12.5 (3)
Dental Services				
Very Satisfied	73.1 (147)	75.3 (134)	75.4 (129)	76.1 (89)
Not Completely Satisfied	26.4 (53)	24.7 (44)	24.6 (42)	23.9 (28)
Alternative Therapy Visit ³				
Very Satisfied	80.6 (25)	84.0 (21)	83.3 (20)	84.6 (11)
Not Completely Satisfied	19.3 (6)	16.0 (4)	16.7 (4)	15.4 (2)
Inpatient Hospital Stay				
Very Satisfied	46.6 (41)	66.1 (39)	66.7 (48)	59.1 (26)
Not Completely Satisfied	53.4 (47)	33.9 (20)	33.3 (24)	40.9 (18)
Emergency Room Visit				
Very Satisfied	47.1 (65)	48.1 (51)	54.2 (64)	53.3 (40)
Not Completely Satisfied	52.9 (73)	51.9 (55)	45.8 (54)	46.6 (35)
Mental Health Professional⁴				
Very Satisfied	74.6 (62)	75.0 (57)	62.0 (62)	76.4(42)
Not Completely Satisfied	25.4(21)	25.0 (19)	38.0 (38)	23.6(13)
Drug/Alcohol Treatment⁵				
Very Satisfied	65.1 (28)	57.7 (15)	79.3 (23)	66.7 (20)
Not Completely Satisfied	34.9 (15)	42.3 (11)	20.7 (6)	33.3 (10)

1. Primary medical provider for HIV care regardless of service setting.

2. Visit to an optometrist, chiropractor, foot doctor, or nutritionist.

3. Treatment from herbalist, acupuncturist, massage therapist, or practitioner of holistic medicine.

4. Visit to a psychiatrist, psychologist, therapist, clinical social worker.

5. Professional drug treatment including inpatient, outpatient, detox, methadone maintenance, and residential.

Note that the first row refers to the specific medical professional (e.g. physician) named as the participants primary medical provider for HIV medical care regardless of service setting. Other table entries refer to any care received in a specific type of service setting (e.g. community clinic) or a specific type of service (e.g. dental services, drug treatment).

Regarding types of service settings, in New York City very high rates of satisfaction were found among those who had one or more visits to a private (office based) physician for medical care as well as those who received care in a hospital based clinic or community clinic setting. Rates of being 'very satisfied' with medical care received in any of these settings are over 80% in all waves of interviewing with the exception of the 2004-2005 reports on community clinic visits. Women who reported visits for gynecological or family planning services tended similarly to be very satisfied with services received. Tri-County participants were also very satisfied with care received in hospital based clinics and during gynecological or family planning visits (77% - 89% completely satisfied) as well as with private office based care (73%- 87%% completely satisfied). Care received in community clinic settings was rated lower by Tri-County residents. Over one-third (35%) of CHAIN participants who visited a community clinic for care in Westchester, Putnam, or Rockland counties during 2005-2007 were less than completely satisfied with the care they received.

Treatment received from an alternative or complementary health care provider or healer has consistently received high satisfaction ratings from PLWHA in both New York City and the Tri-County region. About 14% of New Yorkers and 8-10% of Tri County residents reported visits with an herbalist, acupuncturist, massage therapist, or practioner of holistic medicine during the six months prior to their interview, and almost all were very satisfied with the care or treatments received.

On the other end of the spectrum, at each wave of interviewing, emergency room visits and inpatient hospital stays provoked the highest levels of dissatisfaction. Emergency rooms left close to half of the patients who visited them dissatisfied with the encounter (45- 49% dissatisfied among New Yorkers and 46-53% in Tri-County). At least one-third and upwards of 50% of patients who spent one or more nights in the hospital were less than completely satisfied with the care they received there. Dissatisfaction with inpatient care was higher in the Tri-County region than among PLWHA reporting on hospital stays in New York City.

Rates of dissatisfaction were lower but still substantial among New York City respondents who had used home health care and drug treatment services (17-31%). Rates of dissatisfaction in both these service areas were higher among Tri-County participants than in NYC but seem to have declined in recent years. In Tri-County, dissatisfaction with home health care was much higher in 2001-02 (43% dissatisfied) than among those using this service in 2005-07 (13% dissatisfied). It is not possible to tell from the data at hand whether this represents a change in home care services in the region, a change in the expectations of persons using the service at different time periods, or simply random variation since the number using the service has been relatively small. We do not have Tri-County data from earlier periods to enable longer over time comparisons.

Differences in rates of dissatisfaction for each medical service area evaluated by CHAIN study participants are summarized in graphic form in Figure 1 and Figure 2. Information from the most recent interview period (2006-2007) is presented. Note that only services rated by twenty or more PLWHA are included here.

Figure 1: Dissatisfaction with Medical Services in NYC - Percent Less than Completely Satisfied with Service Received Past Six Months (2006-2007)

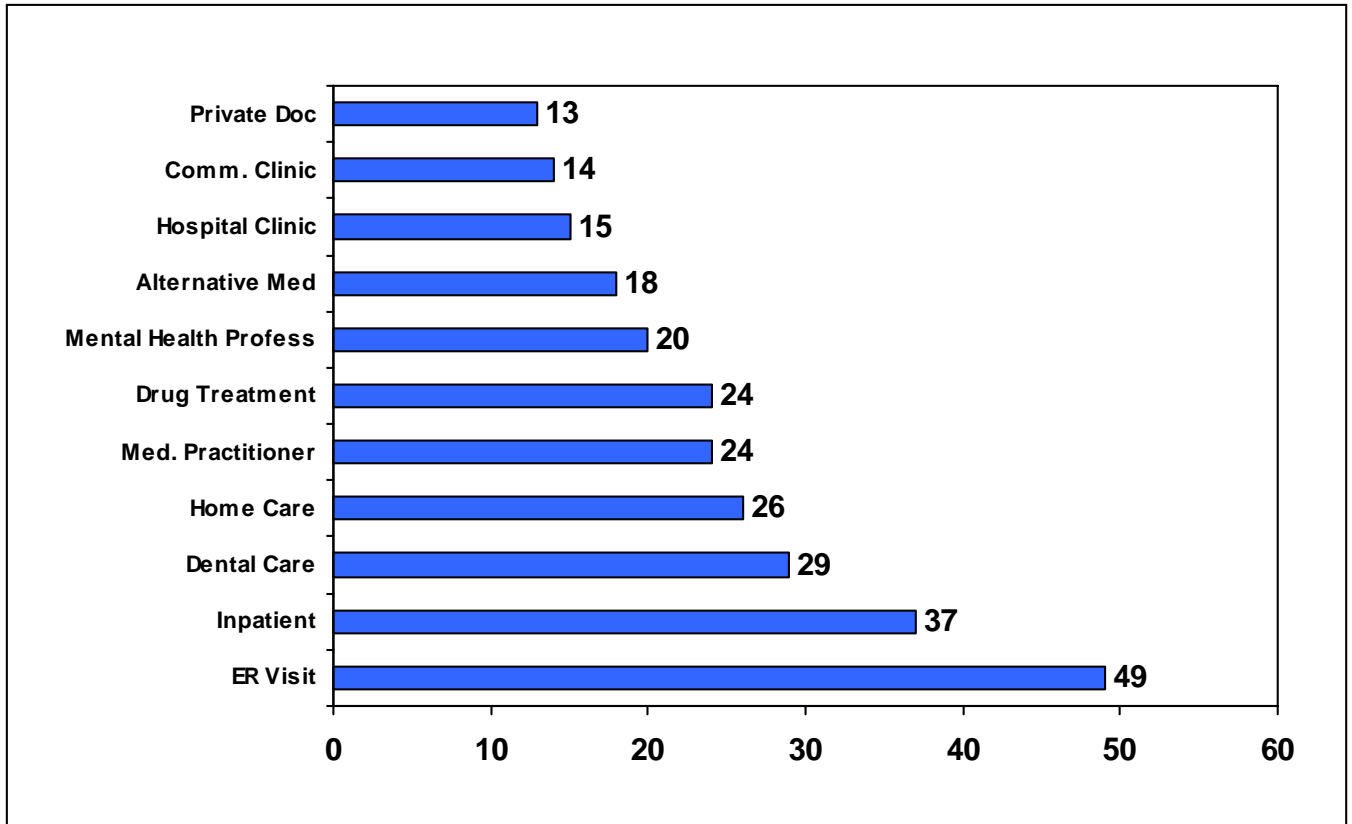
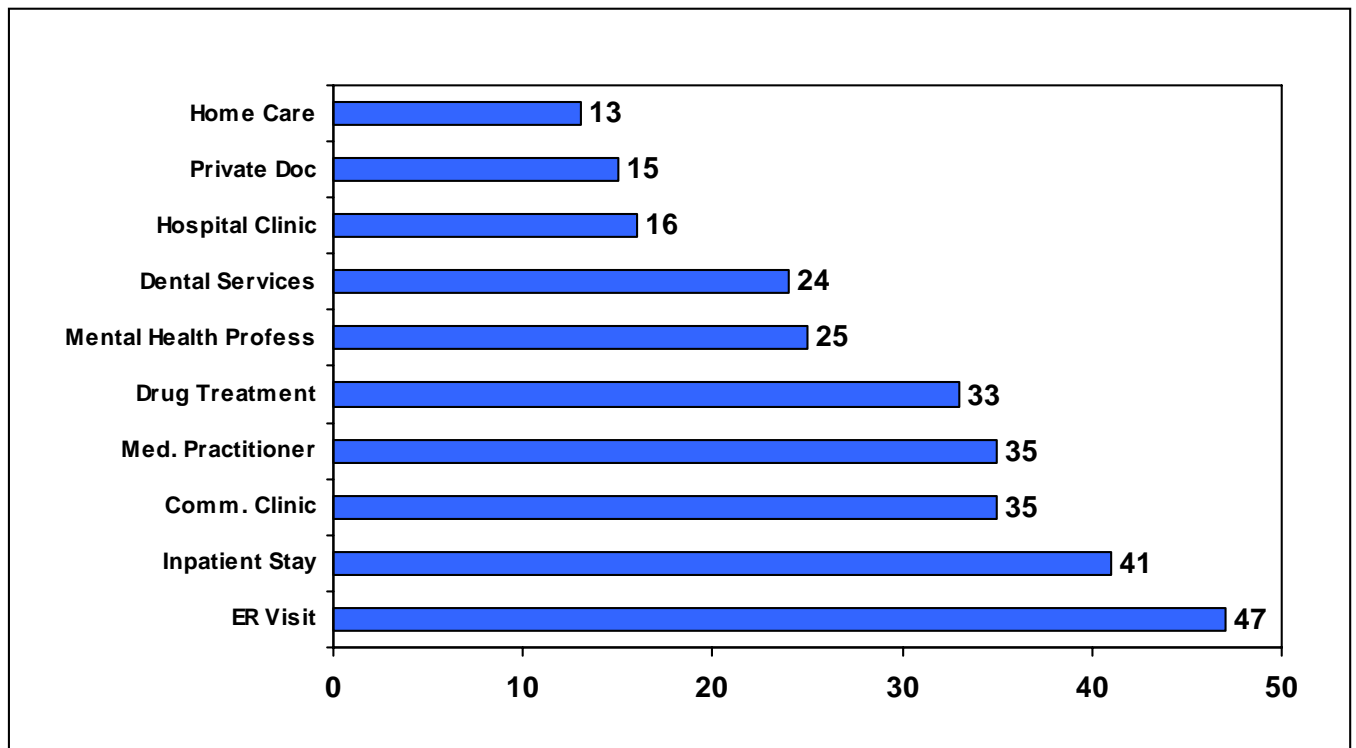


Figure 2: Dissatisfaction with Medical Services in Tri-County - Percent Less than Completely Satisfied with Service Received Past Six Months (2006-2007)



Services with High Rates of Dissatisfaction: ER Visits and Hospital Stays

Content analysis of respondents' narrative explanations of their dissatisfaction with emergency room visits and hospital stays revealed a set of criteria that respondents used when evaluating medical services more generally. Statements were transcribed verbatim and coded for recurrent themes, letting categories and patterns emerge from the investigation. Across all areas examined, reasons given for dissatisfaction with medical services could be classified into four broad categories: 1) reasons related to organizational and other service-setting factors; 2) reasons related to patient-provider interaction and communication; 3) reasons related to perceived competency of the provider to address specific health needs; and 4) reasons associated with the outcome or results of the services received.

Regarding emergency room care, respondents complained about long waits to be seen by a provider, a factor associated with the organization of ERs. Many respondents, however, described the long waits as a manifestation of a lack of caring for patients. Statements such as "Because they are too long, and don't care if you are all right," or "They are too slow and do not care if you are in pain," were given by both NYC and Tri-County respondents as reasons for dissatisfaction with ER visits. Some who were dissatisfied emphasized poor treatment in general by medical providers in terms of lack of caring and disrespect: "They treat you like you're a no name kind of person," or in some instances, lack of privacy protection: "They have no consideration talking about my status in front of everyone there."

Some respondents evaluated their care as inappropriate or stated that the poor outcome of their visit to the emergency room was their source of dissatisfaction. Respondents mentioned that they were not diagnosed properly, physical symptoms were not addressed properly, or that physical pain was not alleviated. One of our study participants, for example, complained that "They were just guessing . . . no x-rays, no bandage, they were just guessing." It should be emphasized that high rates of dissatisfaction with hospital emergency rooms usually were not a reflection of the overall quality of care in hospital settings, since the same respondents who complained about a hospital's ER often reported high rates of satisfaction with other departments and services offered by the same hospital. In the words of one respondent, "The hospital clinic is great but the emergency room is not good."

Inpatient hospital care was another service area with relatively high rates of dissatisfaction. Poor patient-provider interaction and communication was the primary reason accounting for dissatisfaction. Lack of information was one type of poor communication - e.g. "They never told me anything or explained anything." Experiences of disrespect were also described: "They treated me like I was infectious. The first day they did not even come to see me. They treated me like if I had tuberculosis." Patients also described nurses who were indifferent or disrespectful. Some participants who were hospitalized expressed concern that some doctors lacked the knowledge for dealing with their complex medical conditions: "They made a lot of mistakes with me." Reasons for dissatisfaction with hospital stays also included environmental and organizational aspects of the inpatient stay such as unclean rooms, too few support staff, and poor food service.

Satisfaction and Dissatisfaction with HIV Primary Medical Care Provider

In addition to evaluating different types of medical services and different types of service settings, a separate set of questions asked all CHAIN respondents about their perceptions of the specific person or practice team who was their current HIV primary medical care provider, regardless of service setting. Almost all (96% - 100%) of CHAIN participants reported a primary care provider. The following analyses examine in more detail the specific medical provider named by respondents as "in charge of my overall HIV medical care."

Table 5. Dissatisfaction with HIV Primary Medical Care Provider by Patient Characteristics

Dissatisfaction with HIV Primary Medical Provider ¹				
	In New York City 2006-2007		In Tri-County 2005-2007	
	N	% Dissatisfied	N	% Dissatisfied
Total Sample	481	18%	235	17%
Gender				
Female	214	17%	127	14%
Male	260	18%	106	21%
Age				
20-34	20	25%	11	18%
35-49	251	18%	115	14%
50+	210	16%	108	20%
Race/Ethnicity				
White Non-Hispanic	44	16%	41	24%
Black Non-Hispanic	250	15%	130	17%
Hispanic/Latino	180	21%	50	12%
Other	7	43%	5	20%
Foreign Born				
No	364	16%	207	18%
Yes	117	22%	27	11%
Education				
Less than HS	187	15%	95	15%
HS/GED	213	19%	65	15%
More than HS/GED	81	19%	72	21%
Income				
Less than \$10,000 yearly	373	18%	129	17%
\$10,000+ yearly	104	17%	98	15%
Risk Exposure Group				
MSM	86	17%	31	16%
IDU	187	20%	88	22%
MSM + IDU	52	19%	9	12%
Heterosexual/Other	156	15%	106	12%
CD4 cells/mm³				
0-200	89	20%	43	16%
201-500	213	21%	99	17%
Above 500	170	12%	68	18%
Mental Health				
Very low MH score	115	24% *	67	23%
Higher MH score	366	16%	167	15%
Substance Abuse				
Current Problem Drug Use	137	26% **	30	21%
Problem use > 6 months ago	246	14%	134	17%
Never Problem Drug Use	98	14%	70	14%
NYC Residence				
Bronx	116	19%	--	--
Brooklyn	148	20%	--	--
Manhattan	115	18%	--	--
Queens	62	13%	--	--
Staten Island	24	13%	--	--
Tri-County Residence				
Urban Westchester	--	--	138	12% *
Suburban Westchester/ Putnam	--	--	63	26%
Rockland	--	--	30	17%

*** p<=.001, **p<=.01, *p<=.05

1. Less than completely satisfied. Row percentages shown.

As discussed above, in the most recent interview period, over 80% of PLWHA in both New York City and the Tri-County region were completely satisfied with their HIV primary medical care provider; only 18% expressed any dissatisfaction (Tables 3 and 4). We found few differences in satisfaction with provider by gender, race/ethnicity, risk exposure group or other individual patient characteristics (Table 5). 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 lower-income patients. However, when we divided the study participants into those whose individual annual income was less than \$10,000 and those whose income equaled or exceeded \$10,000, we found no consistent relationship between income and satisfaction with primary medical care provider.

In New York City, the only client characteristics associated with elevated rates of dissatisfaction with primary medical provider were mental health functioning and history of substance use. Participants with lower mental health functioning scores and those who were currently using drugs were more likely to be less than completely satisfied with their primary medical care provider. In Tri-County, geographic area of residence was the only patient characteristic associated with differential rates of dissatisfaction. Participants from suburban Westchester or Putnam County were more often dissatisfied with their current medical care provider (26%) compared with those in urban Westchester (12%) or Rockland (17%).

We also examined the association between provider characteristics and satisfaction/ dissatisfaction with one's HIV primary medical provider, as well as organizational or service-setting features of medical care (Table 6). In addition to medical specialization of provider (HIV or infectious disease specialist vs other) and location of medical practice (hospital clinic, private practice office, etc), we examined characteristics of care in terms of comprehensiveness of primary care and whether or not care received met minimum clinic practice standards. Consistent with prior CHAIN research, in the most recent assessment period, these characteristics of the service setting and patient provider relations were more strongly associated with patient satisfaction than any individual patient characteristics.

There were, however, some differences between PLWHA living in New York City and those in the Tri-County area. In New York City, CHAIN respondents who experienced their medical care as coordinated, comprehensive and accessible, were more satisfied than respondents whose care lacked one or more of these features. Respondents not receiving care that met basic clinical practice standards for HIV in terms of numbers of visits for out-patient care and receipt of basic diagnostic services (AIDS Institute, 2003) were more likely to be dissatisfied with their provider. Lack of choice regarding medical provider and a longer waiting time to see the doctor were also associated with dissatisfaction. Neither specialization of provider nor location of medical practice were associated with differential rates of dissatisfaction among NYC participants. In the Tri-County region, waiting time to see the doctor, and having a doctor who was not an HIV or infectious disease specialist were associated with higher rates of dissatisfaction. Comprehensiveness of care and meeting minimum clinical practice standards for visits and procedures were less important.

In both New York City and the Tri-County Region, dissatisfaction with HIV primary medical care provider was most strongly associated with low scores on the patient-provider relationship scale. The majority of CHAIN study participants reported that their provider spent enough time with them, understood them well, and was very concerned about them. The relationship between these dimensions of perceived patient-provider relationship and patient satisfaction is very apparent. Among both cohorts, 60% - 70% of respondents who did not feel that their provider spent enough time with them and did not experience understanding and concern, were dissatisfied with the medical care they received from him or her. In contrast, only 5% of individuals who described their provider positively with regard to these dimensions of patient-provider relationship were dissatisfied with their care (Table 6).

Table 6. Dissatisfaction with HIV Primary Medical Care Provider by Selected Provider and Service Setting Characteristics

Dissatisfaction with HIV Primary Medical Provider ¹				
	In New York City 2006–2007		In Tri-County 2005-2007	
	N	% Dissatisfied	N	% Dissatisfied
Total Sample	472	18%	229	17%
Medical Specialization				
HIV or Infectious Disease Specialist	334	17%	127	12%*
Other	138	19%	102	23%
Location of Medical Practice				
HHC Hospital Clinic	71	14%	na	na
Voluntary Hospital Clinic	285	18%	149	13%
Community Clinic	59	17%	51	25%
Private Practice Office	21	14%	23	17%
Social Service/ Drug Treatment Agency	31	23%	3	33%
Adequate Clinical Care				
Meets minimum clinical practice standards ²	344	15%*	186	15%
Other	128	23%	43	23%
Comprehensive Primary Care				
Care coordinated, comprehensive, and accessible for emergency	224	10%***	193	16%
Lacks one or more feature	248	24%	36	22%
Choice of Medical Provider³				
Choice of medical provider	387	15%***	184	16%
Limited choice of provider	32	38%	38	18%
Waiting time				
< 30 min to see doctor	221	12%**	139	12%*
30+ min to see doctor	251	22%	90	23%
Patient-Provider Relationship				
Shows concern, understands problems, and spends enough time with patient	380	5%***	182	5%***
Lacks one or more feature	92	70%	47	60%

*** p<=.001, **p<=.01, *p<=.05

1. Less than completely satisfied . Row percentages shown.

2. Based on patient report of receipt of recommended number of outpatient visits, appropriate diagnostic tests and drug therapies as indicated, following New York State AIDS Institute recommendations.

3. Patient report of open or restricted choice of provider, regardless of reason for limitation of choice. Data not available for all respondents; most recent interview data shown

Reasons for Dissatisfaction with HIV Primary Medical Provider

Content analysis of participants' narrative descriptions regarding their primary medical care providers further supports findings from the quantitative analysis. Answers to open-ended questions asking for reasons for dissatisfaction among those who expressed dissatisfaction were recorded verbatim by interviewers and subsequently coded . The same four broad thematic areas emerged from the analysis of dissatisfaction with primary care provider as were apparent in descriptions of dissatisfaction with ER and hospital stays: 1) patient-provider relationships and communication; 2) perceived provider competence to address the full range of patient needs; 3) the organization of services or characteristics of the medical facility or service setting; and 4) poor or disappointing outcomes of medical treatment or care. Table 7 shows the percentage of respondents who mentioned each type of reason in their reported

reasons for dissatisfaction. Data are pooled from all interview periods. Note that multiple responses are possible within the same interview period (multiple reasons to be dissatisfied with the same provider) as well as across interview periods (being dissatisfied with different providers visited at different times). However, very few respondents were dissatisfied with their primary care provider at more than one interview period.

More than any specific feature of care or treatment outcome, patients tended to be dissatisfied with their providers if they felt that the patient-provider interaction was poor. A good rapport between the patient and the provider, however the patient defined it, contributed to high satisfaction. Physicians who provided explanations about illnesses and medications, inspired trust in their patients, spent time examining their patients, were accessible to their patients, were attentive and listened to their patients' fears and concerns, and empathized with their patients, received high marks from the CHAIN study participants. On the other hand, a majority of patients who were dissatisfied with their primary care physician gave as their primary reason poor patient-provider relationship and communication (62% of New York City PLWHA who were dissatisfied and 53% of the dissatisfied in Tri-County).

General characterizations such as “nasty attitude,” “in it only for the money,” “thinks he is some kind of God” and “she don’t listen,” fall under this category. Complaints about poor provider interaction often focused on lack of concern or lack of awareness of the medical provider for the patient as a “whole person.” Often this was expressed in terms of not taking enough time during medical visits. In the words of one patient, “He always seems in a rush and does not have time to sit down and explain anything...he needs to be more sensitive to his patients.” Another complained, “I don’t think she is concerned about me at all. When I go to my appointments, she look at the computer and tell me how I feel... Then she rush me out.” Other respondents connected lack of good patient-provider interaction and communication with an emphasis on medications: “She’s not concerned at all. All she can talk about are the medications. She don’t work with me to solve any problems with my medications,” and “He doesn’t care about my emotions. How I feel. He is only interested in giving me prescriptions.” Less often individuals attribute what they see as uncaring treatment to physician attitudes toward substance use, mental health issues, or sexuality. Statements such as, “He lets his personal opinions about drug use interfere with my care,” and “She’s too busy getting into my head, trying to be my shrink instead of taking care of me,” and “because of your past they judge you,” are examples of patient perceptions of differential treatment. While it is not possible with the data at hand to determine the basis of such perceptions, the quantitative data do show higher rates of dissatisfaction among patients who were actively using drugs and/or who had lower mental health functioning scores (see Table 5).

In addition to issues and concerns raised about patient-provider relationship and communication, approximately 40% of respondents give reasons for dissatisfaction that best fit the coding category of “perceived provider competence.” It is important to note that there were very few mentions of misdiagnoses or wrong medications prescribed. In addition, few respondents indicated that their physician was not up to date regarding newer HIV treatment regimens - fewer than during earlier times, before widespread adoption of antiretrovirals. Competency issues in more recent years more often referred to concerns about comorbid conditions, or “what problems are causing other problems.” In some instances, specific chronic illnesses were referenced, “...Every time I tell her I have problems with my asthma or my diabetes she wants to send me to the emergency room. It is not serious enough to go to the emergency room. She is my PCP,” or “Like when I need a prescription for Celebrex she says I have to go to orthopedics.” More often respondents expressed dissatisfaction with what they felt was a too narrow focus on HIV disease. This criticism was reflected in statements such as “...[only] HIV status, all other

Table 7. Reasons Given for Dissatisfaction with Medical Provider by PLWHA in New York City and the Tri-County Region

	% Who Gave Reason Among the Most Dissatisfied	
	New York City 2006-2007	Tri-County 2005-2007
n=	(82)	(66)
REASONS FOR DISSATISFACTION¹		
Patient -Provider Relationship and Communication Individual doctor or medical provider lack of concern, poor communication, poor quality of interaction	62%	53%
Perceived Provider Competence to Address Needs Individual doctor or medical provider not competent to address all concerns, solve problems	39%	38%
Organization of Services Problems with organization of services, characteristics of the clinic, medical facility, or service setting	26%	36%
Outcomes of Medical Care Poor outcomes of medical treatment or care, needs not met, problem(s) not solved	40%	21%

Note: Themes emerging from content analysis of narrative descriptions of reasons for dissatisfaction with primary medical care provider among those who expressed dissatisfaction. Answers to question: "Could you briefly explain why you were dissatisfied." Pooled data from all interview periods. Multiple responses possible within the same interview period (multiple reasons dissatisfied with the same provider) as well as across interview periods (being dissatisfied with different providers visited at different times).

ailments she has no concern whatsoever," or "He needs to know that everything is not HIV related - there are other issues like menopause and he doesn't understand."

Another theme that emerged from analysis of reasons for dissatisfaction with HIV primary medical care provider referred to the organization of services or characteristics of the medical facility or service setting. In some instances the issue of "not enough time" with the physician was blamed on the facility. Other complaints referred to overall organization of services at the clinic or care center, such as, "I felt it was like a meat market: 'NEXT, NEXT'" and "It's the whole system and how it works... I feel that when I do have a complaint it will affect my services and also that I just feel like a number..." Persons dissatisfied with medical services in Tri-County were more likely than dissatisfied participants in New York City to have reported problems with organization of services as their reason for dissatisfaction (36% compared to 26%). The reverse pattern holds for the final theme that emerged from the dissatisfaction analysis: dissatisfaction due to patient experience of poor outcomes of medical treatment or care. Patients in New York City are more likely than those in Tri-County to give reasons such as, "I don't feel she is helping me," or "I'm in pain and not being treated for it," or "Because I still have the problems that I ask him for help with" (Table 7).

Analysis of Multiple Influences on Dissatisfaction with Primary Medical Care Provider

We next examine the relative importance of patient characteristics, provider characteristics, and organizational features of health service organizations as predictors of dissatisfaction with HIV primary medical care provider. Table 8 presents the results of separate analyses conducted for both New York City and Tri-County. Each interview completed provided an opportunity to observe the relationship between personal and provider characteristics and satisfaction/ dissatisfaction with care. Models examine socio-demographics (gender, age, education, income, race/ethnicity); risk exposure group (MSM, IDU); health and treatment status (physical functioning score, AIDS diagnosed, on HAART); comorbidities (recent hard drug use, low mental health functioning, other chronic disease); characteristics of health services organization (provider is an HIV or infectious disease specialist, respondent has a choice of medical provider, usual waiting time to see provider is under 30 minutes, primary care is coordinated, comprehensive and accessible for emergency); and “good” patient - provider relationship (provider takes enough time, is understanding, and shows concern). Multivariate cross-sectional time series logistic regression models were constructed using generalized estimation equation (GEE) random effects procedures to adjust standard errors of the estimates of the regression coefficients to account for the dependency among multiple observations contributed by the same individual.

In New York City, the odds of dissatisfaction with primary medical provider are higher for persons with low mental health functioning than for persons with higher mental health scores (AOR 1.77, CI 1.07,2.94). Physical health functioning also shows an inverse relationship with dissatisfaction: those with higher scores indicating better functioning were less likely to be dissatisfied (i.e. were more satisfied with their care). Individuals on HAART were less likely to be dissatisfied with their provider, as were patients who reported that the usual waiting time to see their provider was less than 30 minutes. In the Tri-County Region, a history of injecting drug use is associated with higher odds of dissatisfaction with HIV primary care provider. Having a choice of medical provider, and receipt of comprehensive primary care are each associated with lower odds of dissatisfaction (Table 8).

The strongest predictor of dissatisfaction with medical provider among both NYC and Tri-County CHAIN participants is patient-provider relationship. The odds that individuals who indicate “good” patient-provider relationship and communication are dissatisfied with their provider are negligible compared to those without such a relationship (AOR 0.01, CI 0.00,0.01) Another way to state this finding is that the odds that individuals with a good patient-provider relationship are completely satisfied with their primary medical care are over 100 times greater than the odds among study participants who report that their relationship with their doctor is lacking one or more of these features, controlling for patient characteristics and organizational features of primary care. Taken together these findings from the quantitative analysis are consistent with the in-depth content analysis of CHAIN study participants' narratives which clearly indicate that the quality of the patient-provider relationship is the primary factor determining patients' satisfaction or dissatisfaction with HIV primary medical care.

SUMMARY

The present report shows that CHAIN study samples of individuals living with HIV/AIDS in the New York City and in the Tri-County region for the most part have been very satisfied with medical services received and with their HIV primary medical care provider. For all interview periods, both

Table 8: Predictors of PLWHA Dissatisfaction¹ with HIV Primary Medical Care Provider in New York City and Tri-County Region

	New York City		Tri-County	
	AOR	CI	AOR	CI
Demographics				
Male	0.90	(0.48, 1.67)	1.01	(0.54, 1.89)
Age ²	1.00	(0.97, 1.04)	0.98	(0.95, 1.01)
Education ³	1.01	(0.91, 1.11)	1.04	(0.93, 1.15)
Income < \$7500 yr	1.52	(0.87, 2.65)	0.46	(0.20, 1.03)#
Black	1.10	(0.48, 2.48)	1.64	(0.83, 3.23)
Latino	1.10	(0.47, 2.58)	1.00	(0.47, 2.13)
Risk Exposure Group⁴				
Ever MSM	1.16	(0.57, 2.37)	0.94	(0.42, 2.12)
Ever IDU	0.77	(0.43, 1.37)	2.38	(1.30, 4.34)**
Comorbidities				
Recent problem drug use ⁵	1.24	(0.72, 2.12)	1.13	(0.59, 2.18)
Low mental health score (< 37.0) ⁶	1.77	(1.07, 2.94)*	1.03	(0.62, 1.71)
Other chronic illness ⁷	0.49	(0.21, 1.15)#	1.03	(0.50, 2.13)
Health & Treatment Status				
Good physical health functioning ⁸	0.98	(0.95, 1.00)*	0.99	(0.96, 1.01)
On HAART	0.59	(0.36, 0.96)*	1.03	(0.61, 1.73)
AIDS diagnosed ⁹	0.97	(0.59, 1.62)	0.77	(0.43, 1.37)
Characteristics of Health Care Service				
Provider HIV or infectious disease specialist	0.89	(0.52, 1.51)	0.74	(0.44, 1.24)
Choice of medical provider	1.08	(0.50, 2.34)	0.31	(0.17, 0.56)***
Usual waiting time to see provider < 30 min	0.53	(0.33, 0.85)**	0.61	(0.38, 1.01)#
Primary care is coordinated, comprehensive, & accessible for emergency	0.63	(0.39, 1.01)#	0.60	(0.36, 1.00)*
Patient/Provider relationship				
Provider shows concern, understands problems, & spends enough time with patient	0.01	(0.00, 0.01)***	0.02	(0.01, 0.04)***

NYC: n = 598 respondents, 1460 observations; Tri-County : n= 379 respondents, 1070 observations.

Bold typeface: p ≤ .05. * p ≤ .001, **p ≤ .01, *p ≤ .05 # p ≤ .10**

1. 'Dissatisfaction' is defined as less than complete satisfaction
2. Continuous variable.
3. Years of education.
4. Reference category, heterosexual/ other.
5. Any heroin, cocaine, crack, methamphetamine use or problem drinking (CAGE) past six months.
6. MOS-SF12v2 mental health summary score. 1= below mean score seen in psychiatric inpatient populations.
7. Asthma, other pulmonary/breathing problems, hypertension, heart problems, diabetes, arthritis, high cholesterol, chronic sinusitis, hepatitis C.
8. MOS-SF12v2 physical health functioning summary score. High score indicates better functioning.
9. Self-report that a doctor told respondent that he/she had "clinically diagnosed AIDS," or CD4 ever below 200.

in New York City and in the Tri-County region, 80% or more of study participants reported being “very satisfied” with their HIV primary medical care provider. High rates of satisfaction are consistent with findings from prior CHAIN studies and other research that has found levels of satisfaction tend to be high, regardless of different characteristics and quality of services offered (for recent review see Sofaer & Firminger, 2005). Nonetheless, there is much to be gained from the minority of patients who express dissatisfaction, revealing insights about characteristics of providers and service settings that likely affect care, treatment, and outcomes for larger numbers of persons living with HIV/AIDS who are non-adherent, dropout of care or change providers often.

Consistent with earlier CHAIN reports, emergency room visits and inpatient care have the highest rates of dissatisfaction (see also Wilson et al. 2002). Part of the stark difference in patient evaluation of acute care services is likely due to characteristics of treatment in such settings, such as long waiting times, overextended staff, and limited interaction with providers. It is also likely that care provided in inpatient and emergency room settings contrasts sharply with HIV primary care, delivered for the most part by medical personnel who have specialized training, knowledge and experience that provides both medical and cultural competency to address the multiple needs of persons less well served by conventional medical care systems due to lack of income, substance use histories and/or sexual minority status. Other studies have shown that clinician characteristics such as specialized training and experience are associated with the quality of care received and with patient satisfaction among patients with HIV infection (Kitahata et al., 2003; Landon et al., 2002; Sullivan et al., 2000).

Also consistent with earlier CHAIN reports and with published results of other studies, the quality of patient-provider relationship is the most significant factor determining satisfaction or dissatisfaction with medical services and with primary medical care provider. Beyond the experience of satisfaction or dissatisfaction, the entwining of satisfaction, patient-provider relationship, and medical care quality is consistently shown in the literature to be a correlate of patient engagement and maintenance in care, and clinical care outcomes. Engagement in care – most frequently measured by adherence to therapeutic regimens, including taking medications, following provider advice, and keeping appointments -- is facilitated by good rapport and adequate communication between patient and physician or other medical provider (Bakken et al., 2000; Abel and Painter, 2003; Roberts, 2002; Ding et al., 2008; Barlett et al., 1984; Bogart et al., 2004).

Commenting on the link between patient-provider rapport and prescriptive care, for example, Fuertes et al.(2007) find that “when patients and doctors are ‘partnered allies’ in patient-centered treatment, lines of communication between them are established and utilized, trust is enhanced, and patients are more likely to see the value of the treatment and to feel more capable of adhering to treatment regimens” (Fuertes et al., 2007). Furthermore, good communication not only supports patients’ overall satisfaction with medical care and their engagement with their care, but extended patient-provider alliances can also result in better physician knowledge of the patient which can make an even greater contribution to maintenance in care and good clinical outcomes. As Ding et al. have observed, “The effective use of medical and support services probably requires a provider who knows each patient...For most patients, such a relationship may develop naturally as a result of regular interactions. For other patients, it may be necessary to take a more proactive approach” (Ding et al., 2008).

Despite the well-documented relationship in which patient satisfaction, patient-provider relationship, and medical care are enmeshed, many CHAIN respondents in both New York City and the Tri-County region reported that providers do not spend sufficient time with patients for them to understand and participate

in treatment decisions. Other research has shown a similar pattern. For example, work done on PLWHA patient perspectives by Davis-Michaud et al.(2004) has demonstrated patients' desire for effective communication in order to motivate and support their adherence to medical regimens. Complaints from their respondents are similar to descriptions of reasons for dissatisfaction heard among CHAIN Study participants: "Unfortunately doctors don't sit down and talk to you. A lot of them assume that you are just going to take the medications or just assume that you have educated yourself on what you are taking" (Davis-Michaud et al. 2004). Whether due to increased client flow necessary to meet cost considerations, or the preference of individual physicians, the issue of insufficient time spent with patients should be an area of further investigation. Given the importance of regular monitoring of HIV clinical status and appropriate treatment and adherence to antiretroviral regimens, as well as complexities introduced by co-occurring conditions, the patient-provider relationship among persons living with HIV/AIDS has become even more significant.

Endnote

¹ *It is appropriate to include PLWHA who were unconnected to HIV primary medical care at baseline or at some other point during the study period since they may use other services although not in regular medical care. Persons unconnected to care at baseline were in care by the third wave of interviewing which is the time period we focus on in the report. It is also the case that other individuals who were 'connected' at baseline dropped out of care during a subsequent interview period. To be consistent, across reports we include in the overall sample those unconnected to care at any point during the study period, but the questionnaire is designed so that they are not reporting on services that they have not used, or treatments they have not received, during the specific time period under investigation.*

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