

CHAIN Update Report #44



Latino Populations in the CHAIN Cohort

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ACKNOWLEDGMENTS	4
1. INTRODUCTION.....	5
2. KEY FINDINGS	6
3. BACKGROUND TO ANALYSIS	7
3.1. BACKGROUND: TERMINOLOGY AND HISTORY	7
3.2. BACKGROUND: THEORETICAL UNDERSTANDINGS	8
4. METHODS	10
4.1. THE CHAIN PROJECT	10
4.2. ANALYTIC ISSUES.....	12
4.3. LIMITATIONS OF ANALYSIS AND INTERPRETATION	13
5. LATINOS IN THE CHAIN COHORT	14
5.1. COMPARISON TO NYC HIV/AIDS CASES.....	14
5.2. WHO ARE THE LATINOS IN THE CHAIN COHORT?	15
5.2.1. <i>Latinos in New York City and the CHAIN cohort</i>	16
5.2.2. <i>Latinos in the CHAIN cohort</i>	17
5.2.3. <i>The special case of Puerto Ricans</i>	19
6. RESOURCES AND SERVICES	20
6.1. BASIC DEMOGRAPHIC AND MIGRATION PATTERNS.....	20
6.2. HEALTH BACKGROUND	23
6.3 HIV-RELATED MEDICAL SERVICE USE	24
6.4. DRUG USE AND SERVICES	25
6.5. SEXUAL BEHAVIOR AND IDENTITY.....	27
6.6. MENTAL HEALTH AND MENTAL HEALTH SERVICES.....	28
6.7. FAMILY AND KIN RESOURCES – SOCIAL SUPPORT AND BURDEN	30
6.8. PATHWAYS TO HIV CARE	31
6.9. SERVICE COORDINATION	33
6.10. FINANCIAL AND ECONOMIC RESOURCES AND USE.....	35
7. UNMET NEEDS AND THE FUTURE.....	37
7.1. EXPRESSED NEEDS	37
7.2. BARRIERS TO CARE.....	38
7.3. LOOKING AT THE FUTURE IN NYC	40
8. CONCLUSIONS.....	43
REFERENCES.....	45

FIGURES AND TABLES

No.	Title	Page
4.2.1.	Self-defined race/ethnic distribution, CHAIN cohort	12
4.2.2.	Analytic decision tree, classification by race/ethnicity	12
5.1.1.	Comparison by race/ethnicity, CHAIN cohort and NYC living AIDS cases compared	14
5.1.2.	Racial/ethnic distribution of CHAIN respondents, by borough	15
5.2.1.	Distribution by origin, Latino populations of U.S., NYC, and CHAIN cohort	16
5.2.2.	Comparison of Other Latino and Puerto Rican populations	18
6.1.1.	Age distribution at study entry	20
6.1.2.	Puerto Ricans and Other Latinos born on U.S. Mainland, by age group	21
6.1.3.	Major demographic differences	22
6.2.1.	Health background	23
6.3.1.	HIV medical care, HIV primary care, and ER use	24
6.3.2.	Other medical services use	25
6.4.1.	Drug use and treatment history	26
6.4.2.	Injection drug users as percentage of CHAIN cohort and of NYC AIDS cases through 2001	27
6.5.1.	Identification as member of sexual minority	28
6.5.2.	Lifetime same-sex sexual activity.	28
6.6.	Mental health needs and current treatment use	29
6.7.	Family and network resources	30
6.8.1.	Site of diagnostic HIV test	32
6.8.2.	Reasons for entering HIV care	33
6.9.	Use of service coordination resources	34
6.10.1.	Economic resources' in respondents' households	35
6.10.2.	Type of insurance	36
6.10.3.	Economic and educational background in respondents' households. . . .	36
6.10.4.	Housing needs and resources	37
7.1.	Needs for further help	38
7.2.1.	Experience with barriers to HIV-related services	40
7.2.2.	Experience with barriers to HIV-related services, contd.	40
7.3.1.	Numerical racial/ethnic distribution of CHAIN cohort, by age group. . . .	41
7.3.2.	CHAIN cohort at study entry, by race/ethnicity and Latino subpopulations	42

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1. INTRODUCTION

Latinos represent a large and growing proportion of the population of New York, the NYC HIV-infected and AIDS cases, and consequently of the CHAIN cohort. Their importance stems not only from their large numbers now, but from the probability of increases in their numbers – especially at younger ages – in the future. Understanding different segments of the CHAIN cohort and the population of HIV-infected New Yorkers they represent is an important step in understanding the existing population and service utilization, and an even more important step in planning for the future.

It is beyond the resources and scope of this report to attempt to make causal connections between characteristics and service utilization, given the limited type of data available and the complexities of the role of racial and ethnic differences in many of these areas. There is an extensive research literature on the role of racial and ethnic differences in health and disease, and in utilization of care and services. Beyond the fact that differences exist, there is little consensus on how, why, and what their effects are. Further, generalizations between a moderate sized sample and the larger population must be made with extreme caution.

There are particular difficulties in interpreting racial and ethnic differences in services utilization, especially in the area of HIV services. We have no data on the level of HIV infection (and consequent need for services) in the population at large. Differences in use of services may result from differences in need for services, or from differences in access to services, or both. Further, we might not expect to see large racial and ethnic differences in services use among the HIV infected: the risk behaviors that contribute to HIV infection as well as the distinctive challenges of living with HIV may make the infected more similar to each other than to their larger population groups of origin.

Rather than attempting an explanatory analysis (which would be severely limited by the absence of data on either citizenship or language use in the cohort), this report attempts to identify key points of similarity and difference of the Latinos to White and Black-identified populations in the CHAIN study, as a means of situating the Latino population in a larger context. We point to differences in pathways to treatment and services that may influence eventual outcomes, and concentrate on identifying those characteristics of the Latino segment of the cohort and population that are both reasonably consistent with established research both inside and outside the HIV field and can form a background for understanding past and future analytic findings that include Latino status as an important element. We also compare the two major parts of the Latino subpopulation in the CHAIN cohort – those of Puerto Rican background vs. those of other Latino background – on the same dimensions as those on which we compare Latinos to Whites and Blacks. Where appropriate, we note similarities to other findings about Latino status within existing CHAIN reports.

2. KEY FINDINGS

1. Approximately 31% of the CHAIN cohort identify themselves as Latino, similar to the proportion of Latinos within the diagnosed NYC AIDS cases.
2. Respondents who identified themselves as Puerto Rican make up 81% of the total Latinos (N=316) in the CHAIN cohort. This is a far larger proportion than Puerto Ricans contribute to the overall NYC Latino population. This numerical dominance of people of Puerto Rican background in the CHAIN cohort, and in turn the unique place of Puerto Ricans in the U.S. and New York City – explain many of the characteristics of “Latinos” in the existing CHAIN cohort, and mean that most of the findings should not be generalized beyond HIV-infected people of Puerto Rican background in New York.
3. Many of the characteristics of the Latino portion (with the exception of the non-Puerto Rican, Other Latino subpopulation) of the cohort are consistent with the longer and more intense history of drug use and injection among the Latino portion when compared to the Black and especially the White portions.
4. Latinos in the cohort differ little from Whites and even less so from Blacks in having some type of insurance and in high levels of current use of basic HIV care and use of HIV-specific resources such as Division of AIDS Services and Income Support (now HASA, HIV/AIDS Services Administration) programs, suggesting the important contributions of Ryan White-funded services in reducing disparities in basic HIV care. Disparities are more prominent in use of primary care, emergency rooms, and auxiliary and alternative medical services.
5. Differences in pathways to HIV diagnosis, and in need for and use of other types of services, reflect the lower lifetime socio-economic status of most Blacks and Puerto Rican Latinos, especially their greater tendency to have a background in drug use.
6. Latinos display the poorest health status (both HIV-specific and general) at study entrance, because of both their longer time since diagnosis (than Blacks) and greater burden of pre-HIV-diagnosis health problems (than both Blacks and Whites).
7. A smaller group of non-Puerto Rican Latinos differs noticeably from Puerto Ricans within the CHAIN cohort, in age, sex, birthplace, same-sex orientation, history of drug use, background resources, access to and use of benefit programs, and disease stage. Except for their younger age, they are more similar to the Whites within the cohort than to the Puerto Rican Latinos.
8. All groups cite financial and housing needs as the major unmet needs. However, needs-tested benefit programs play a larger role in meeting needs among Latinos than among Blacks or (especially) Whites. Expressed barriers to services reflect differences in length of time since diagnosis, producing differing lengths of time to have experienced barriers.

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9. The only area in which Puerto Ricans do not differ from Other Latinos – but both do differ from both Whites and Blacks in the cohort – is in the presence of a gap between mental health symptoms and use of mental health services. This gap is far larger than among Blacks or Whites in the cohort, and has been noted in other studies of Latino mental health services utilization.
 10. The younger age of Other Latinos (compared to Puerto Ricans) combined with their greater likelihood of being born outside the Mainland U.S. and the growing Latino immigration to New York, suggest that a smaller “second epidemic” may develop among New York Latinos, one that more closely resembles the MSM-dominated epidemic of the 1980s than the more drug-related epidemic of today.

3. BACKGROUND TO ANALYSIS

3.1. BACKGROUND: TERMINOLOGY AND HISTORY

Defining “Latino” for analytic purposes is not straightforward. Surveys of the Latino population point to the fact that what we think of as Latinos have been identified as a separate group in Census and related federal documents for only some 30 years, and classification systems vary between sources and across time. In fact, data on the “Latino” or “Hispanic” population as a separate group did not appear in Census and many other government documents until the 1970s or even later (Bean and Tienda 1987).

Although we use the term “Latino” in this report because of its inclusiveness and consistency with other CHAIN reports, it is important to understand what we mean by “Latino” populations, especially as other terminologies (most often “Hispanic”) are used in many governmental documents, including those of the U.S. Census and many NYC agencies.¹ “Latino” is a term generally used to describe people of origins in Latin America, and focuses on a common place of origin. “Hispanic” is a slightly more inclusive term based on language use, which may include natives of Spain and other non-Latin-American Spanish-speaking countries. It is important to note that while we usually think of White and Black as “races,” Latino (or Hispanic) is not a race (assumed to indicate similar genetic background). It is an ethnicity, based in commonalities of background, culture, and expression. Latinos (who are often racially mixed) can be either Black or White, or refuse to accept either label. Many, especially in the earlier generations of immigrants, think of themselves not so much as Latinos (a pan-Latin identity) but in terms of their specific country of origin (“Dominican,” “Mexican-American,” etc.).

“Latinos” are not necessarily “immigrants” (a term referring to those born outside the U.S.) although many are. Some Latino populations have lived in the Mainland U.S. for centuries, as in parts of the Southwest. Others have arrived in the U.S. and/or New

¹ For discussions of these issues and the choices to be made in how to operationalize “Latino” in research, see the discussions in Del Pinal and Singer (1997), Marín and Marin (1991) and Bean and Tienda (1987).

York City area only in recent years. There are substantial differences among Latino-origin groups not only by national origin, but by length in this country and/or generations in this country (Bean and Tienda 1987; Del Pinal and Singer 1996).

Characteristically, immigration is a selective process: those willing to leave their country for another are not completely representative of their population of origin. They are usually more motivated (by a desire for improvement or survival), younger, and more likely to be male, especially in the early waves of immigration. The original immigrant generation expends its energies on work and/or learning English and getting established. Their children, who belong in both worlds, are subject to a different set of stresses, at the same time that they have different opportunities open to them. As a result, generational status, or “vintage” is an important determinant of behavior and service utilization among immigrants populations generally.

3.2. BACKGROUND: THEORETICAL UNDERSTANDINGS

Understanding the roots of what we see as racial or ethnic differences in health behavior or health outcomes or service utilization is a complex task, one that goes beyond documenting group differences in knowledge of health and treatment. There are several factors, alone or in combination, that may produce differences in behavior, utilization or outcomes. Observed differences may be based in one or more underlying differences in:

1. **Population composition.** Racial or ethnic groups may differ in their composition, in some way that affects the probability of contracting a disease or condition (and thus the need for services for it). For example, Florida often leads the states in use of certain health services, because a relatively large proportion of the Florida population is composed of retirees – older people who have more health problems that require services. In studies of HIV-infected populations, many differences may be related to the age, gender, and type of risk behavior represented in the populations, more than to differences in knowledge or cultural differences. If population composition is important, we might expect to see differences between White and both Black and Latino, based on their differences in transmission behavior or route (greater proportion of drug injector v. MSM, for example) and the differences in gender (proportion male) associated with racial and ethnic differences.
2. **Legal and structural barriers that affect groups differently.** Differences in health conditions and service use may reflect eligibility for services, affected by a variety of legal and structural barriers. Legal barriers may include statutory eligibility for services based on residence in a city or county, citizenship status, or possession of proper documentation. Other barriers may be less legal and more structural in nature: lack of insurance or adequate transportation, for example. If these were important, we would expect to see differences in health and services based on factors such as citizenship status, place of residence, or insurance status.

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3. **Economic and social resources available.** There are often group differences in the resources people bring to care-seeking and service utilization. These include education, employment and financial resources, knowledge of and connections to available services, and the burdens imposed by individual and group histories of discrimination and stigma. For example, an increasing body of research finds racial or ethnic differences in service utilization related to group differences in availability or type of health insurance. If resources were important, we would expect to see broad similarities between Latinos and Blacks, based on the generally lower level of educational and economic resources in both groups when compared to Whites.
 4. **Cultural orientations**, meaning ways of thinking and behaving that are common to members of a particular population. These can affect health behavior, outcomes, and services use through several mechanisms. If these were important, we would expect to see broad similarities in behavior across an entire racial/ethnic group that is thought to share basic elements of a culture. In the current case, we would expect to see major differences between Latinos and both Blacks and Whites, based on their different histories and immigration background, combined with relatively minor differences within the Latino group. Some of the common ways cultural orientations may be important in health and service use include:
 - a. **Interpretation of symptoms and need for care.** One of the most common cultural orientations is how people of different cultural backgrounds interpret particular symptoms and the type of care that is appropriate for them, which in turn influences whether and how they actually seek and use care. Studies of health-care often refer to such concepts as “health beliefs.”
 - b. **Language barriers.** Fluency in English can be a major hindrance to knowledge of illness states and to accessing care for them. Latino populations are distinctive in their common historical background in Spanish language, but there is major variability in everyday use of Spanish, and in proficiency in English. These variations often coincide with generational lines, as younger generations learn English from an early age, while older generations may never do so.
 - c. **Acculturation.** In studies of immigrants, it is common to see health and other beliefs differ by degree of “acculturation,” or the absorption of new outlooks and cultural norms from the host culture, and discarding of old ones. Facility in English is part of acculturation to life in the U.S., and lack of it can be a serious structural barrier to health services. If acculturation were a major influence, we would expect to see differences between groups based on how long they had been in this country, as well as by facility in English. A key limitation of the “acculturation” approach to understanding health care is that indicators of acculturation (such as English-language facility) often overlap with indicators of higher education and income, which may be more important to actual health behavior (Arcia et al. 2001).

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- d. **Forms of social interaction.** Cultural orientations include general ways of behaving and of dealing with other people. Latino cultural patterns are often said to include valuing close family relationships, respect for the individual, and a preference for relatively smooth routine social interactions (Marín and Marín 1991).

This report presents a three-group comparison (White / Black / Latino) rather than two-group (Latino / non-Latino) because of the complexity of the factors involved. We would expect Black and Latino members of the cohort to be more similar to each other than either to the White members for two major reasons:

1. Population-composition differences across racial subgroups. Although the face of the epidemic in NYC is changing, IDU and Heterosexual-transmission cases continue to dominate among both Black and Latino cases while MSM-transmission cases remain the largest group among the White cases. These differences in composition along behavioral dimensions have consequences for access to and use of services.
2. Resource differences in the population. Blacks and Latinos, relative to the White population, are more likely to suffer from lower income, education, and other outcomes of historical and current discrimination. These historically consistent differences affect the types of risk behavior an individual is likely to be exposed to, as well as resources (informational, social, economic among others) that an individual brings to seeking and using care once infected.

The comparison of Latinos to both Whites and Blacks separately allows us to isolate characteristics that are unique to Latinos, rather than simply outcomes of a history of poverty and discrimination that Latinos generally share with Blacks.

4. METHODS

4.1. THE CHAIN PROJECT

The Mailman School of Public Health at Columbia University is responsible for conducting the CHAIN Project surveys and reporting on findings from the survey data in collaboration with the NYC Department of Health and the Medical and Health Research Association of New York City, Inc. (MHRA). 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 physical, mental and social well being. This information is specifically prepared for the NYC HIV Health and Human Services Planning Council 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.

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 so that there would be roughly equal numbers of medical care and social services sites and representation from sites that were and were not recipients of Title I grants. At 30 sites, staff contacted a random sample of clients. The names of clients who indicated an interest in participating were turned over to CHAIN staff for interviews. A sequential 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 CHAIN study. Interviews were then scheduled with interested clients. A total of 648 individuals recruited from participating agencies completed baseline interviews. The agency-based sample was supplemented with 50 interviews conducted with HIV+ individuals with little or no connection to medical and social services. 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, 1995).

Subsequent interviews have been conducted at approximately 6 to 12 month intervals. In an effort to replenish the CHAIN sample (which had lost a number of participants to death and other factors), in 1998 an additional 268 individuals were added to the study, using the same agency and community sources. These individuals constituted the "refresher" sample. Taken together, the original and refresher cohorts provide 968 individuals with comparable data collected at their entrance to the study.

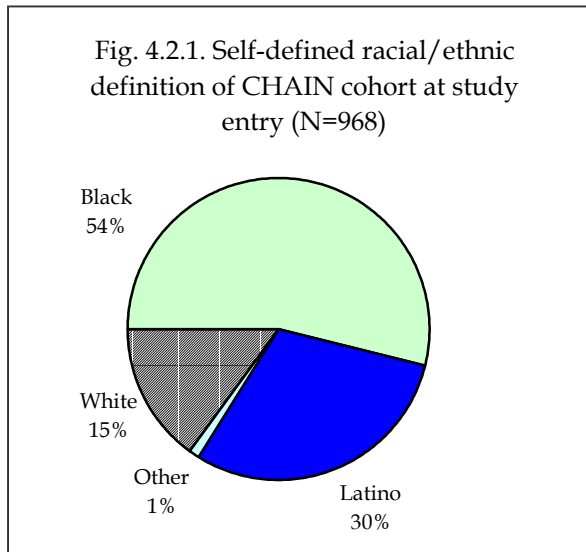
All CHAIN interviews are conducted in person by interviewers recruited from communities throughout New York City and trained specifically for the study. Interviewers are matched to respondents as much as possible with regard to gender and race/ethnicity. Approximately one-third of the field staff are themselves HIV positive. Interview topics include sociodemographic characteristics, the full range of experiences with access and use of medical and social services, and quality of life. At each round of interviews participants are asked about their current living situation, their recent health and social services utilization, and perceptions of quality and satisfaction with that utilization.

For this report, except where otherwise noted, we use 957 of the full number of 968 baseline interviews collected in 1994 and 1998.² Tables generally show two sets of comparisons, with a p-value for each: first the three major groups (White, Black, Latino) of the overall cohort are compared, and then the two Latino subpopulations (Puerto Rican and Other Latino) are compared.

² Minor discrepancies are attributable to missing data for particular variables; larger discrepancies are most often due to a question having been added or dropped between 1994 and 1998 intake waves.

4.2. ANALYTIC ISSUES

Sample. Only 1% of the overall sample identified themselves as something “Other” than White, Black or Latino. We have excluded the “others” from this analysis because of their small numbers, for a total of 957 self-identified as White, Black, or Latino analyzed here.



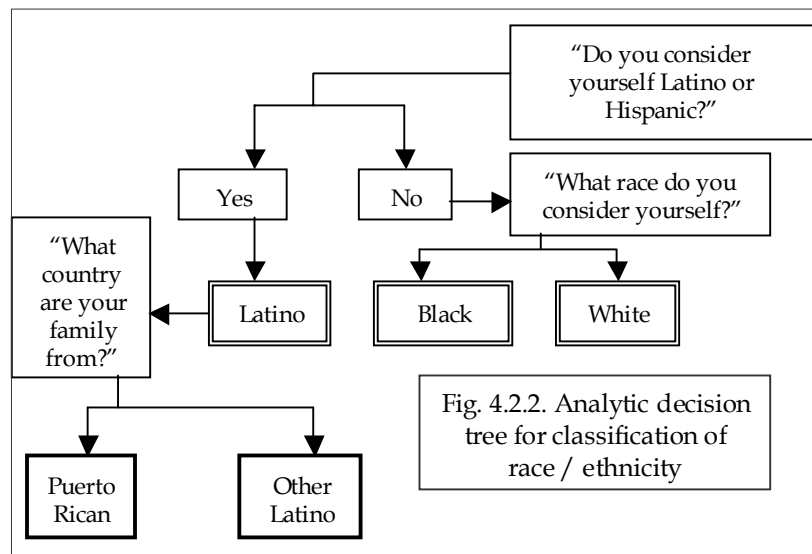
Defining “Latino.”

There are several methods of defining who “Latinos” are (see discussion in Marín and Marín 1991), and each has consequences for analysis. Based on our interest in finding commonalities based on similarities of background, we have used a method based on self-identification rather than one based on classification by the researchers. We divided respondents into categories as follows.

First, we looked at responses to a question about “do you consider yourself Hispanic or Latino?” Anyone who

answered “yes” was classified as Latino, whatever their response to the preceding question, “what race do you consider yourself”.³ The remainder (those who did not identify themselves as Latino), were classified as Black or White or Other on the basis of their response to the question on race. Thus, although people identifying themselves as “Latino or Hispanic” may also have identified themselves as being of Black or White “race,” They are

categorized only as Latino/Hispanic for this analysis. This procedure yields a categorization roughly equivalent to that seen in many government documents, which divide respondents into categories of Latino/Hispanic, (non-Latino) Black and (non-Latino) White. We then subdivided the Latinos into those of Puerto Rican vs. other Latino



³ In fact, only a very few of those who identified themselves as Latino selected White or Black as their race.

backgrounds on the basis of a question about “what country are your family from?” Those who indicated mixed ancestry were asked which they felt “closer to.” (See Fig. 4.2.2.)

Presentation of findings. Because of their relatively small numbers, we have combined the non-Puerto Rican Latinos into a single group (“Other Latinos”) for comparative purposes, although this disguises what is doubtless considerable diversity among them.

4.3. LIMITATIONS OF ANALYSIS AND INTERPRETATION

There are major limitations in our ability to describe aspects of the Latino portion of the CHAIN cohort. Two of these are data limitations of the baseline questionnaire, which lacks questions on two important areas:

1. **Citizenship and immigration status.** This represents an important structural barrier to accessing some types of care, chiefly those related to benefits and financial assistance. These items were deliberately not included in the CHAIN instrument because their potentially invasive nature might damage the trust and rapport necessary to the study. We have instead approached this topic indirectly, through analysis of the items about place of birth.
2. **Language use.** We have no measure of facility in, or routine use, of English and Spanish. Language use may represent a structural and resource barrier to services if the person cannot communicate adequately with service personnel, or a translator cannot be found. It also represents an important measure of exposure to and ease in, a dominantly English-speaking society with the educational and employment opportunities it offers.

Caution is also necessary in generalizing from the findings presented here to the larger populations the CHAIN sample represents, because of sampling considerations.

1. **Sample size.** The sample is modest relative to the population it represents (over 40,000 individuals living with AIDS in NYC), and may not be an accurate reflection of the real population differences, especially in more detailed areas.
2. **Sample recruitment.**
 - a. Because of the relatively small sample and modest number of agencies at which it was recruited, apparent differences in the sample between racial or ethnic groups may actually reflect unknown differences between locations and agencies where the sample was drawn, more than real differences between the populations they represent.
 - b. The CHAIN sample is recruited mainly through medical and social service agencies, few of which are completely bilingual and often have few if any Spanish-speaking staff. This means that Latinos without some

command of English are less likely to be represented in a services-recruited sample.

5. LATINOS IN THE CHAIN COHORT

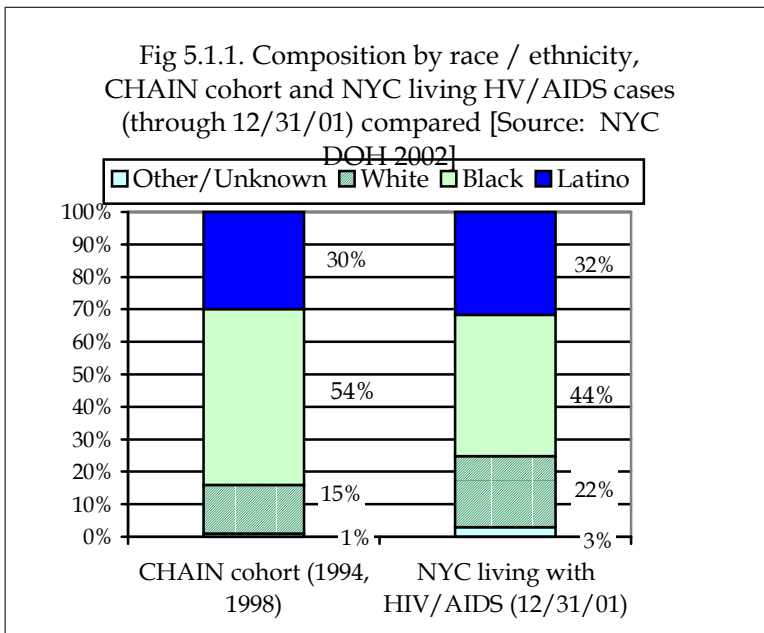
In this section we describe the makeup of the Latino portion of the CHAIN cohort, and compare it to the composition of the Latino population of the U.S. and New York City, and to New York’s reported AIDS cases.

5.1. Comparison to NYC HIV/AIDS cases

Some 30% of the overall CHAIN cohort are of Latino origin, as defined by their answers to a question about whether they are of Latino origin. This pattern has been relatively stable across CHAIN subcohorts: 32% of the original 1994 cohort, and 26% of the 1998 “refresher” cohort were Latinos.

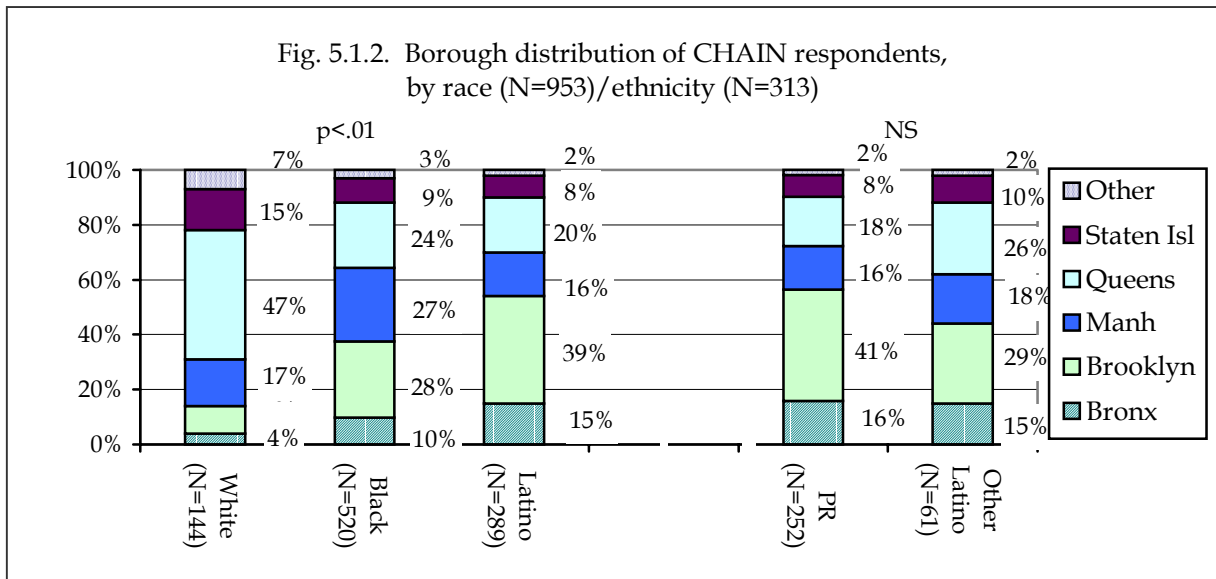
The proportion of Latinos in the CHAIN cohort (recruited 1994-98) is similar to their proportion in the NYC population living with HIV or AIDS a few years later (N=57,297 as of 12/31/01 according to the NYC Department of Health 2002): 30% of the overall CHAIN cohort reported themselves as Latino, while 32% of the cumulative total living with HIV/AIDS in NYC were Latino.⁴ Although the data are not exactly comparable because of the slightly different collection dates, it is sufficient to allow us to conclude that the racial/ethnic makeup of the CHAIN cohort is comparable to that of the NYC

AIDS/HIV cases.



⁴ The CHAIN cohort and NYC living-with-HIV/AIDS surveillance figures are not completely comparable because of their slightly different data collection dates. Another (probably very small) difference may be in classification: NYCDHMH uses the categorization “Hispanic” while we use “Latino.”

We also examined the distribution of borough of residence within the CHAIN sample. Although represented in all boroughs, a larger proportion of the CHAIN cohort's Latinos



is found in three outlying boroughs than is the CHAIN cohort as a whole. That is, 15% of the cohort's Latinos live in the Bronx while only 11% of the total sample lives there, 39% of the Latinos live in Brooklyn compared to 28% of the total sample, and 15% on Staten Island compared to 9% of the total sample. These figures for the overall Latino category reflect the dominantly Puerto Rican makeup of the group. Interestingly, the distribution by borough of Other Latinos mirrors very closely the distribution of the total cohort.⁵

5.2. WHO ARE THE LATINOS IN THE CHAIN COHORT?

New York has always been a "city of immigrants," but rarely more than today. According to the NYC Department of City Planning (2002), the Census 2000 found that 36% of New Yorkers were born outside the U.S., an increase from the 28% born outside the U.S. on the 1990 census. This proportion of foreign-born in the population is the highest since 1910, when 41% of New Yorkers were foreign born. Of the foreign-born in 2000, 53% were born in Latin America (including Mexico and the Caribbean), making Latinos the largest proportion of immigrants in New York. Including both foreign- and U.S.-born, 27% of New York's population identified themselves as being of "Hispanic origin," for the first time overtaking Blacks as a percentage of the population second only to the 35% "non-Hispanic Whites" (NYC Department of City Planning 2001). This growth has not been simply as a proportion of the population. New York's absolute population grew by over 600,000 between 1990 and 2000 censuses, and over half of that increase was accounted for by growth in Hispanic population.

⁵ The total cohort is distributed as: 101 or 11% in the Bronx, 271 or 28% in Brooklyn, 210 or 22% in Manhattan, 248 or 26% in Queens, 90 or 9% on Staten Island, 33 or 4% Elsewhere.

At the same time that Latinos have grown in both absolute numbers and as a proportion of the population, their origins have changed dramatically. Although still very different from the overall U.S. Latino population, New York’s Latino population has begun to change in directions that make it more similar to the U.S. Latino population, but are extremely new to New York. This section briefly reviews and contrasts the makeup of the Latino portions of the U.S. population, New York City population, and CHAIN cohort.

5.2.1. Latinos in New York City and the CHAIN cohort

New York’s Latino population has historically been made up mainly of people from the Caribbean islands: Cuba, the Dominican Republic, and most of all, Puerto Rico. In its “Caribbean Latino” flavor, NYC and its surrounding area differ from the overall U.S. Latino population’s makeup. While Puerto Ricans contribute only a modest 11% of the national Latino population, they have long been the dominant Latino group in NYC (and still represent approximately one-third of NYC’s Latino population), as so much of Puerto Rican migration has been concentrated in the NYC area.

The analysis of Latino populations in the CHAIN cohort is dominantly that of Puerto Rican Latinos, as they dominate the HIV-infected population in services from which the CHAIN study is drawn. Respondents who identified themselves as wholly or partly Puerto Rican make up 81% of the total Latinos (N=316) in the CHAIN cohort. This is a far larger proportion (in fact, over twice as large) than Puerto Ricans contribute to the overall NYC Latino population. The CHAIN study may not be an accurate reflection of the expanding non-Puerto Rican Latino population in NYC, about whose HIV prevalence and service needs very little is known.

Table 5.2.1. Distribution of Latino population by origin, NYC and CHAIN cohort

Origin	Group as percentage of Latino population in	
	NYC Census 2000	CHAIN cohort (1994-1998)
Puerto Rican	37%	81%
Dominican	19%	4%
Cuban	2%	2%
Mexican	9%	1%
Central and South American	15%	7%
Hispanic/Latino undefined	19%	5%

Sources: NYC Dept. of City Planning 2001; CHAIN data

Only a few decades ago, “Latino” or “Hispanic” and “Puerto Rican” were almost synonymous in NYC, so large was the Puerto Rican proportion of the Latino population. But as a result of the immigration reforms of 1965 (which lifted long-standing immigration quotas for Western Hemisphere nations), total immigration from Latin America has increased dramatically, and changed the face of Latino New York. Even in

1990, Puerto Ricans made up only 50% of the Census Bureau's count of the Latino population in New York City, and by 2000 this share had shrunk to 37%. Increasing streams of immigration have come from the Dominican Republic and, even more recently, Central America and Mexico. According to a NYC Department of Health and Mental Hygiene (Forlenza 2002) analysis of cumulative foreign-born AIDS cases in New York, immigrants from Haiti remain the largest contributor to immigrant AIDS cases, followed by immigrants from the Dominican Republic and then from Cuba.

The differences between the CHAIN cohort's Latino members and NYC's Latino population have important consequences for analysis and interpretation. Generalizing from existing studies (including CHAIN) of NYC's Latino AIDS cases -- which have been dominantly Puerto Rican in background -- to other, especially newer immigrant, NYC Latino populations with HIV, requires caution. We will see later that the Puerto Ricans who make up the vast bulk of the Latino CHAIN subpopulation differ in important ways from those of other Latino backgrounds in CHAIN.

5.2.2. Latinos in the CHAIN cohort

The difference between the shape of the Latino population of New York and that of CHAIN cohort may be attributed to several factors, alone or in combination. We lack the data to evaluate these explanations, and present them as background.

1. ***Lower need for services.*** Other Latinos in New York may have lower rates of HIV prevalence than their Puerto Rican counterparts, need services less, and be less likely to be captured in a services-based sample.
2. ***Less access to services.*** We would expect Other Latinos, with their lower exposure to U.S. institutions, as well as structural (citizenship-based) barriers to care, to be less able to access HIV-related services, services if they did need them. While many health-related services are accessible to any NYC resident without regard to citizenship or documentation status, these are not the only factors affecting access to and use of services. Shedlin and Shulman's study (2002) of selected recent non-Puerto Rican Latino immigrant groups (Dominican, Central American, Mexican) in the Greater NYC Eligible Metropolitan Area (NYC plus Westchester, Putnam, and Rockland Counties) does not establish a number of Latino immigrants in need of services, but points to a number of characteristics that might limit their representation in service agencies even if infected. For illustrative purposes, we have summarized some of their observations (as well as spelled out the implied contrast to Puerto Ricans) below.
3. ***People living with HIV are very different from other members of their racial/ethnic group.*** While the parent populations may differ, we cannot assume that those differences extend to the infected members of different populations in any consistent or predictable way.

Fig. 5.2.2. Comparison of Other Latino and Puerto Ricans' potential service barriers

Barrier to care:	Other Latinos:	Puerto Ricans:
Legal status	May be: U.S. citizen (by birth or naturalization); non-citizen (documented or undocumented).	U.S. citizens at birth.
Migration to NYC	Peaked in 1980s or later, still continuing in large numbers. Limited by visa eligibility.	Peaked in 1950s, continues with some return. No legal limitations.
Age-sex profile	More likely to be young, male, because of selectivity of emigration.	Relatively similar to general NYC population.
Geographic background	Often from rural area in sending country.	Generally urban, especially in U.S.
Employment	May be limited by: lack of documentation, education, and/or U.S. educational credentials. Often in multiple jobs, frequently off-books.	Limited by education, but more likely to be in job offering salary and benefits.
Access to government-funded benefits (financial, health care)	May not be eligible at all (most financial benefit programs), based on immigration status or lack of documentation. Often lack knowledge of eligibility for health care programs. Legally eligible for many health care programs, may not be eligible for programs (for example Medicaid) that help access health care.	Barriers no different than other U.S. citizens.
History of service utilization	Little tradition of use of health care or social services in home countries. Reluctance to use services here because of immigration concerns..	Longer exposure to U.S. health care system. No legal or immigration-related barriers to care.
Language barriers	Variable; education often in Spanish more than or rather than English.	Minor; large proportion educated totally or partially in English, have English-speaking children or relatives to translate.
Pathways to HIV services 1. Formal 2. Informal	1. Few agencies specifically serving newer immigrant Latinos. 2. Fewer kin / friends employed in or familiar with pathways.	1. More agencies founded by and for Puerto Ricans and older immigration waves. 2. More kin / friends employed in or familiar with pathways.
Substance use patterns	Alcohol, some non-injected drug use, little injection use.	Longer exposure to urban patterns, drug use and especially injection relatively more common. More opportunity to access services through drug treatment system.
Sexual behavior and identity patterns	Great stigma around MSM behavior and identity.	More exposure to U.S. patterns, less stigma around MSM behavior, identity. More able to access services through MSM networks, services.

5.2.3. The special case of Puerto Ricans.

Why should we assume that people of Puerto Rican background are more likely to both need and access HIV-related services than their Other Latino counterparts?

At the national level, the Latino population as a whole is even more disadvantaged than the Black population, in terms of such resources as education and income. However, of all the major Latino population groups in the U.S., those of Puerto Rican background are consistently the lowest in economic and social indicators; they are on average often closer to American-born Blacks than to other Latino groups, such as Mexicans or particularly Cubans (Bean and Tienda 1987), whose immigration history and current position are quite different from that of Puerto Ricans.

The distinctiveness of Puerto Ricans among U.S. and New York Latinos is a result of one thing. Puerto Rico's history, linked to the U.S. for almost a century, means that whether born in New York or Puerto Rico, Puerto Ricans are by definition American citizens at birth. This affects several factors related to potential *need* for services:

1. ***Population composition.*** Puerto Ricans can and do travel freely to and from Puerto Rico. The fact that they do not have to secure passports or visas and can travel and bring families easily also means that there is less selectivity in Puerto Rican immigration to New York; entire families may migrate with or follow the original migrant very quickly. The age-sex and household-composition profile of Puerto Ricans is more similar to that of the general population than is the case with Other Latinos.
2. ***Distinctive stressors.*** A large proportion of Puerto Rican New Yorkers has been born and grown up on the Mainland or migrated to and from Puerto Rico. They suffer the stresses of biculturalism and bilingualism, never being fully at home in either "world," discrimination against them in New York, and exposure to risk behavior (especially sexual and drug-use) that their migrant parents or grandparents lacked.

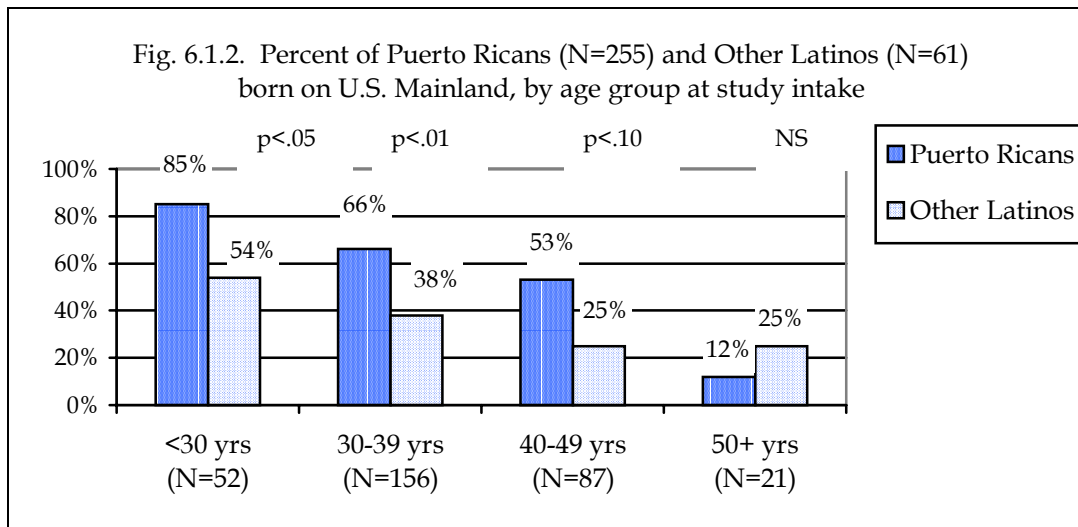
At the same time, their U.S. citizenship has given Puerto Ricans have some distinctive advantages over their Other Latino counterparts in finding out about and *using* needed services.

1. ***Absence of legal barriers.*** Puerto Ricans in New York are entitled to the same benefits and services as other American citizens; limitations on access are on the basis of resource or personal characteristics.
2. ***Cultural orientations and skills.*** Puerto Ricans are exposed to a great deal of Mainland culture and often English-language education even before they arrive in New York, as the result of a century of close ties to the U.S. and frequent migration back and forth.

have been infected (or at least diagnosed and entered services) at younger ages, and because it has consequences for the future shape of the population in services, and its service needs.

A second key factor in service use is that far larger proportions of White or Black cohort members were born in the U.S. (Mainland) than were Latinos, presumably giving most Whites and Blacks facility in English from a young age, as well as a U.S.-style education and exposure to contemporary U.S. services and behavioral patterns. This is not surprising, as Puerto Rican immigration to the mainland has been ongoing for some 50 years and may have peaked over the long term, but still continues.

However, Puerto Ricans and Other Latinos *also* differ significantly in place of birth. A much larger proportion of the Puerto Rican Latinos in the cohort were born in the U.S. (Mainland) than is the case with Other Latinos. This generalization holds for the groups as a whole, and within all but the oldest 10-year age range.⁶ This suggests greater ease



for Puerto Ricans in accessing services as well as exposure to conditions that create need for services.

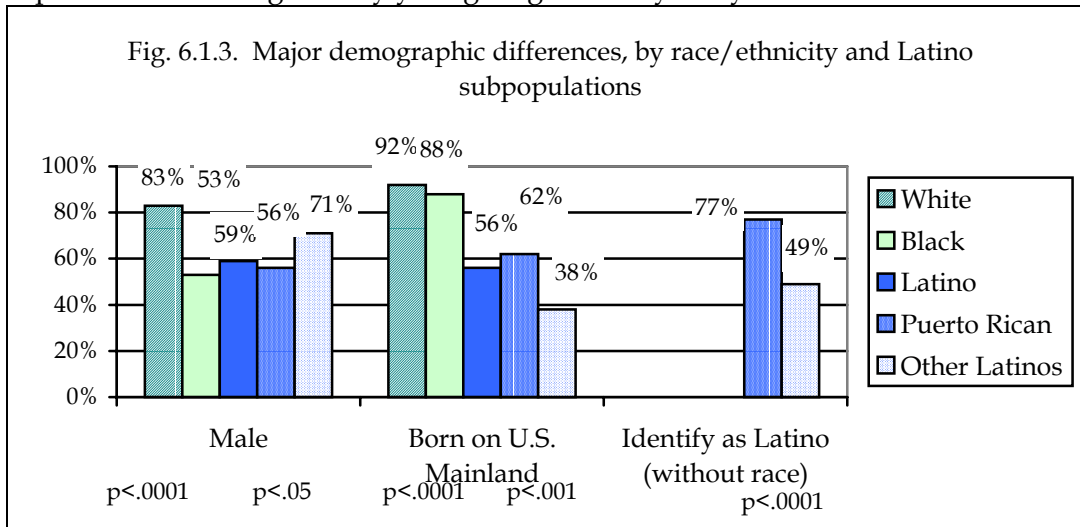
While we have no data on their citizenship, an unknown proportion of the Other Latinos who were born outside the U.S. are certainly either naturalized citizens or non-citizens, statuses which may have reduced both their exposure to U.S. norms and their ability (in terms of both legal and knowledge barriers) to access services.

Neither the Puerto Ricans nor the Other Latinos are particularly recent migrants to New York. Of those (Puerto Rican and Other Latino) born outside the U.S. Mainland, only a small number report having come to the mainland after 1990, and the distribution of arrivals across decade ranges is relatively even. The fact that there are few recent (post-

⁶ The exception is those 50 or more years of age, who are in any case a small enough number that the differences can easily be by chance rather than a reflection of a real underlying population difference.

1990) immigrants in the cohort suggests that it generally takes some years after arrival to require and/or access services. It also suggests that the assimilation of these groups into the HIV-services stream may be a steady, if slow, process.

Other Latinos in the cohort have started migrating to the U.S. historically later than their Puerto Rican counterparts. Reflecting the earlier start of large-scale Puerto Rican migration to the Mainland, the mean year of arrival for CHAIN's Puerto Ricans was 1968, and the earliest year of arrival 1942. In contrast, the earliest Other Latino arrival in the cohort was a full 10 years later, in 1952, and the mean year of arrival 1978 (reflecting the large growth in Western Hemisphere immigration to the U.S. after quotas were lifted in 1965). This later start of migration to New York by Other Latinos offers a partial explanation of their generally younger age at study entry.



Service need and utilization may also be affected by population composition, specifically gender. Reflecting the greater dominance of MSM transmission among White AIDS cases in New York generally, the White members of the CHAIN sample are significantly more likely than the Blacks or Latinos to be male. Slightly less expected is the fact that the Other Latino group includes a significantly higher proportion male than does the Puerto Rican group of Latinos. This may reflect a combination of the general pattern of earlier waves of migrants to be men, and differences in sexuality between Puerto Ricans and Other Latinos, reflected in differing proportions of MSM cases.

A final difference related to immigration pattern is that of Latino identity. "Latino" is an identity forged largely in the U.S., where it is a contrast to *non*-Latino groups. We use it here as an indirect measure of acculturation, as it reflects a cultural orientation about oneself. Immigrant populations often identify more with their country of origin than with other groups to whom they are culturally related. Reflecting their greater longevity on the Mainland, the Puerto Ricans are significantly more likely to have rejected choosing a White or Black "race" (and instead identified as "Latino" or "Hispanic") than

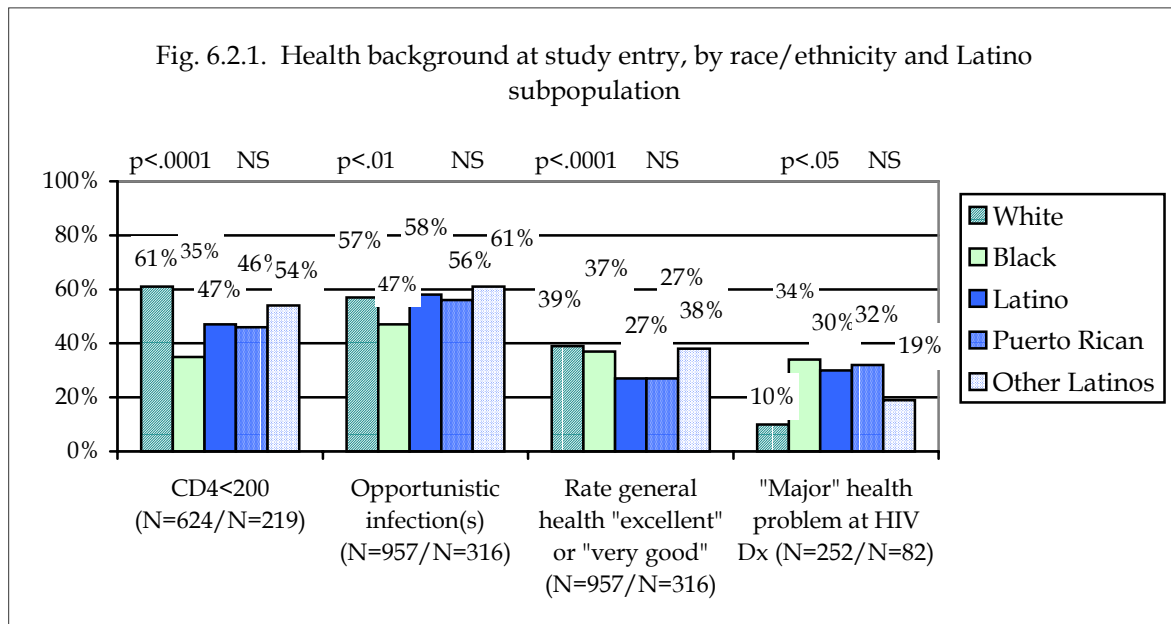
were the Other Latinos. Among the Other Latinos, a larger minority than among the Puerto Ricans selected a non-Latino identity -- most often Black.⁷

6.2. HEALTH BACKGROUND

Are there current inter-group differences in HIV-related health status? If so, they might (as a reflection of “need”) explain group differences in actual service utilization. A prior history of poorer general (non-HIV) health might also help explain differences in current health and service use.

By two “objective” measures, Latinos’ HIV-related health at study entry was roughly comparable to that of Whites, and measurably worse than that of Blacks. The higher proportions of the White and Latino groups with (self-reported) CD4 cell counts below 200 and the proportion reporting having already had one or more opportunistic infections, both markers of a more advanced HIV infection, both point in this direction, as does the proportion (not shown) reporting an actual AIDS diagnosis.

The picture differs somewhat when we examine more subjective measures. Although their health status is roughly similar to that of Whites on HIV-related objective measures, Latinos are significantly less likely than Whites or Blacks to describe their



“general health” as “excellent” or “very good” (as opposed to “fair” or “poor”). Some of the perceived lower overall health status of Latinos at study entry may be attributable to pre-existing poorer general health, or perhaps partially to cultural differences around perception and expression of health and disease. They (along with Blacks) are significantly more likely than Whites to describe themselves as having had “major” health problems (as oppose to “minor” or “no” health problems) at the time they were

⁷ This probably reflects the fact that Dominicans – who are often Black – are the largest non-Puerto Rican Latino group in the sample.

first diagnosed with HIV, suggesting that they brought poorer *pre-existing* health status with them when they entered HIV care. This is consistent with later findings.

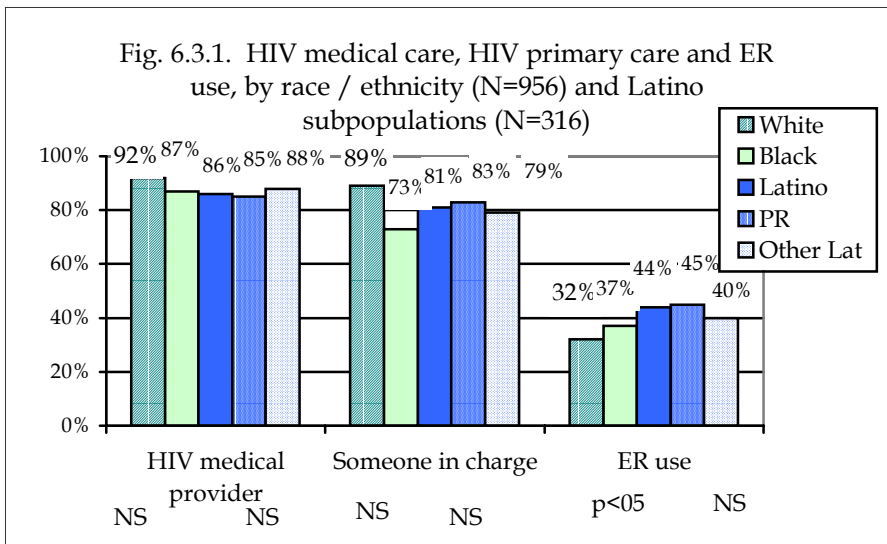
Although the differences are not statistically significant, the Other Latinos show a distinctive pattern relative to the Puerto Ricans: poorer HIV health status, combined with better overall self-rated health status and fewer pre-existing general health problems. This is consistent with the Other Latinos' younger age and lower rates of drug use, providing fewer opportunities for general health problems to develop.

It is striking that, relative to Puerto Ricans, Other Latinos show worse HIV-related health (low CD4 cells and Opportunistic Infections). However, they rate their overall health higher. This is probably the result of fewer major health problems at time of HIV diagnosis, itself partially an outcome of Other Latinos' younger ages as well as differences in background and lifestyle factors.

So far, we have pointed to a pattern in which Latinos are younger, and entered HIV care with more pre-existing health problems. This is an important population composition difference among the groups: we would expect them, in general, to need a larger number of services. The following sections examine service utilization at study entry.

6.3 HIV-RELATED MEDICAL SERVICE USE

What kinds of HIV-related medical services are cohort members using at study entrance? Are there any patterns of inter-group difference in utilization, and could they be related to



differences in health status, or are other factors more important?

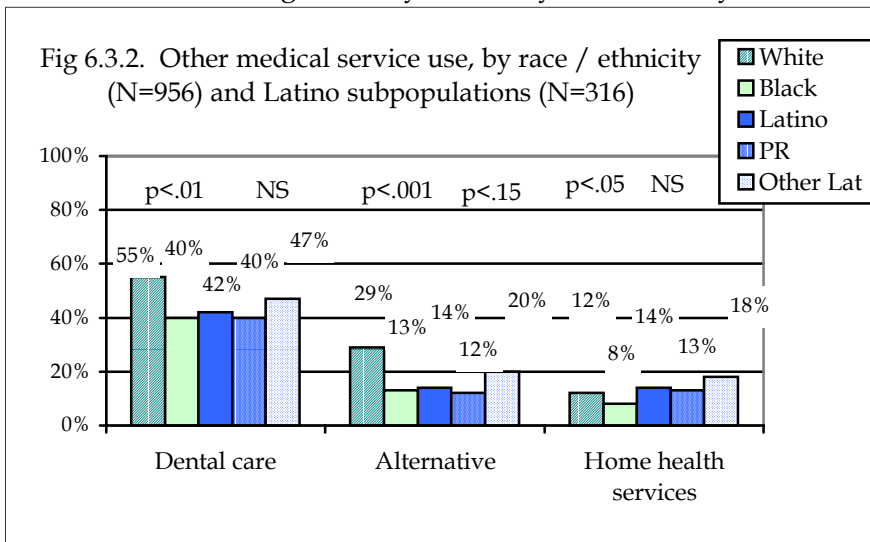
There are no significant differences among groups in the proportion having an HIV medical provider at time of study entrance. This is consistent with prior CHAIN reports showing a

convergence in services utilization over time, and can be attributed at least partly to the role of the CARE Act in expanding the availability of HIV care.

However, both Black and Latino subgroups are somewhat less likely to have a primary provider ("someone in charge of your overall HIV condition"). This in spite of a broad similarity in need: all groups are roughly similar in the percentage (approximately 25%

across groups) having been an inpatient in the period before study entry, inpatient care being a type of use relatively insensitive to convenience or continuity of care factors, and determined largely by objective medical need. Despite this similarity of medical need, Blacks and Latinos were -- probably as a result of lower use of what we might term "HIV primary care," -- significantly more likely to have used emergency rooms as a source of care (whether for HIV-related or other care cannot be easily determined) in the period preceding first interview.

There are no significant differences in the proportions of groups saying that they were satisfied with their care in each of these areas. There are, however, significant differences in use of other medical services, chiefly dental care and alternative medical services, both of which are significantly less likely to be used by Blacks and Latinos than by



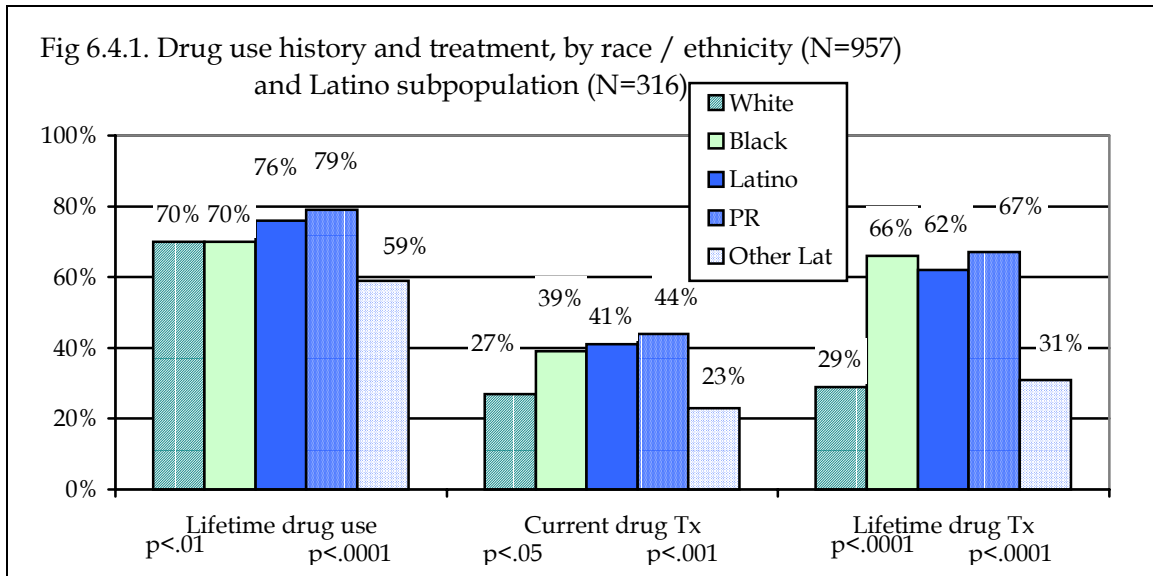
Whites. The somewhat greater use of home health services by Whites and Latinos is probably explained by a compositional factor: the more advanced disease stage that occurs more commonly in these groups than among Blacks.

Two areas in which there are significant differences in utilization are in the areas of drug treatment and mental health services. The reasons differ by type of service, and the next sections explore some possible reasons.

6.4. DRUG USE AND SERVICES

Differences within the CHAIN cohort often reflect demographic differences, or differences in time since disease onset, both compositional factors. However, a third major compositional factor, and one that explains many utilization differences, is a difference in history of injection and other drug use across groups.

A history of serious drug use, and especially of current drug use has been shown by a number of studies, both elsewhere in the U.S. (Chitwood et al. 1999) and in NYC (Weiss, Kluger and McCoy 2000) and specifically within the CHAIN cohort (Sotheran and Lee 2001; Sotheran, Lee, and Aidala 2002) to be related to poorer health, to lower use of almost any medical or social service, and to a distinctive set of barriers to use of services. We would expect groups with higher indicators of drug use to show lower utilization of health services despite their poorer health and higher need.



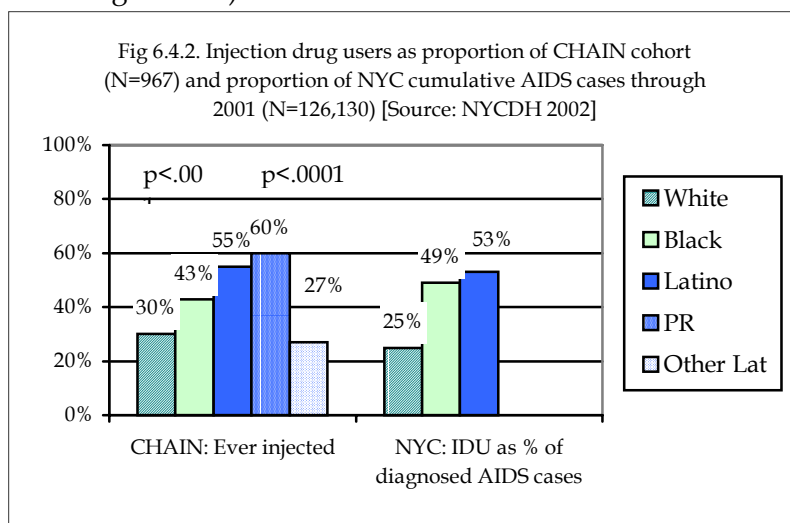
Examining drug use generally, Latinos (whether Puerto Rican or Other Latino) are somewhat more likely to report a history of lifetime drug use, despite the fact that they are on the average the youngest of the three major groups. However, when we examine three other drug use indicators that more accurately measure *intensity* of drug use, we see that Latinos are significantly more likely to have been higher-intensity and high-risk users and potentially experienced more severe personal and health problems related to their drug use. First, both Blacks and Latinos are significantly more likely to have been “Current” drug users when enrolled in the study⁸. Second, they are significantly more likely than the Whites to report current use of drug treatment as well as lifetime history of some drug or alcohol treatment, an important indicator of severity of drug problems. Finally, the Latinos are significantly more likely to report a history of *injecting* drug use, with all the potential attendant health and personal problems.

Especially when compared to Puerto Ricans but also when compared to all other groups, Other Latinos are significantly less likely to manifest a history of drug involvement on all of these indicators. They are also, however, the youngest of the groups and have had fewer years of adulthood to develop drug use problems.

⁸ These categories are based on dividing an individual’s use into time periods. For purposes of analysis, we divided the sample into:

- “Never” users reported either no lifetime use of crack, cocaine, or heroin at all, or fewer than 5 lifetime uses. In practical terms, fewer than 5 uses qualifies as experimental usage, so these behaviorally similar to and merged into “never” users.
- “Lifetime” drug users may belong to either of the following groups:
- “Past” users reported more than 5 lifetime uses of crack, cocaine, or heroin, suggestive of an ongoing past pattern of use, but *no* use within the 6 month period preceding baseline interview.
 - “Current” users are those with 5 or more lifetime uses of crack, cocaine, or heroin, and who have *continued* (or perhaps reverted) to use during the 6 months preceding interview.

There are significant inter-group differences in history of drug injection, an indicator of importance both for transmission risk and for health complications. Comparing the percentage of CHAIN respondents who reported ever in their lifetime injecting a drug with the percentage of NYC AIDS cases attributed to injection drug use, the patterns are remarkably similar. In the CHAIN sample, Whites are significantly less likely to have a This is consistent with NYC cumulative AIDS surveillance, which reports 31% of Latino (“Hispanic”) diagnosed cases and 42% of Black diagnosed cases through June 2001 to be from IDU background, contrasted to 25% of White cases. It is also consistent with epidemiological studies that show higher rates of substance use diagnoses among Latinos in the U.S. than among Latinos in their native countries or Whites in the U.S. These are thought to be a byproduct of the stress of migration, acculturation, and relatively disadvantaged position socioeconomically within the U.S. population (Vega and Alegria 2001).



A history of drug use (especially injected drug use) is in turn a major population composition factor affecting co-existing conditions, pathways into care, and service utilization. This history operates both through the types of settings and institutions the individual is exposed to, and through stigma and discrimination

within health care. Most of the utilization patterns found in Latinos are compositional in origin, attributable to the relatively high proportions among them with a history of past or current drug use.

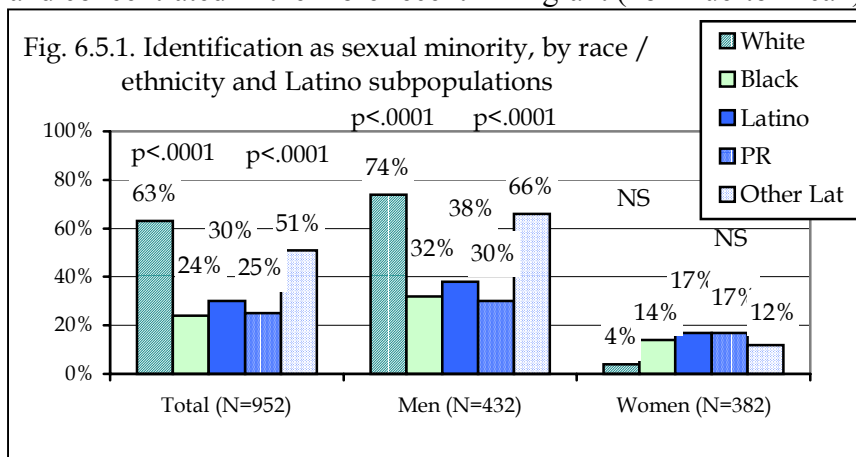
6.5. SEXUAL BEHAVIOR AND IDENTITY

Sexual behavior and identity can also be regarded as an important aspect of composition, as they influence access to resources (usually through differences in social networks), and the operations of discrimination and stigma. We examined sexuality with two different measures.

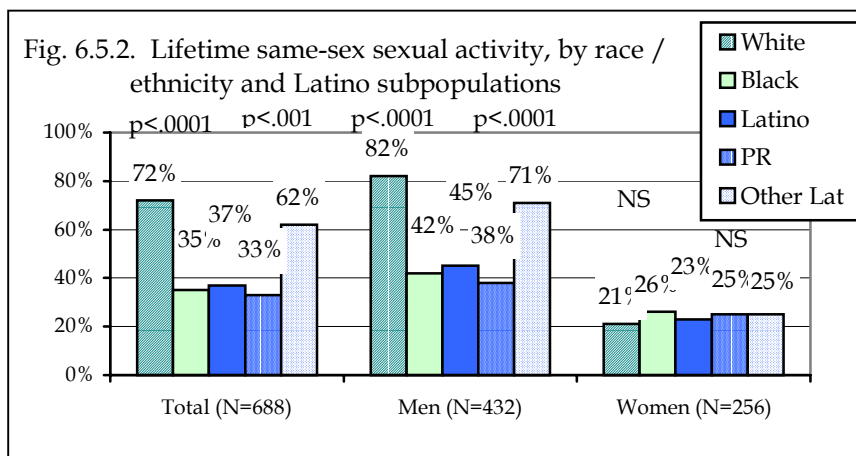
1. *Identity.* Whether respondent identified as a member of “sexual minority” by choosing “Homosexual,” “Bisexual,” or “Other” status as opposed to “Heterosexual” on a question specifically asking about identity.
2. *Behavior.* Reporting any same-sex sexual activity over the respondent’s entire lifetime. Data (not shown) on same-sex sexual activity over the 6 months

preceding interview fall into the same patterns as those for lifetime activity, and are not presented here.

In both cases, we looked at the total sample, and then broke it down into men v. women, as these patterns can be expected to differ by gender. It is not surprising that whether measured as identity or behavior (which shows an almost identical pattern to identity), White men are significantly more likely to have same-sex orientations: the epidemic appears to have entered New York first through White MSMs. However, it is quite striking that Other Latinos are significantly more likely than Puerto Ricans to be oriented to other men. In fact, they are second only to the White men in this respect. This fact, combined with the lower prevalence of histories of injection drug use among Other Latino men, suggests that there may be a small “second” and very different epidemic among Latino men, one that is younger, less related to drug injection, more homosexual, and concentrated in the more recent immigrant (non-Puerto Rican) groups.



Probably as a consequence of their generally younger age and greater likelihood of having immigrated to New York, the Other Latinos are significantly less likely to report having had a partner at the time they were diagnosed with HIV, and thus lack both the support and the burdens that a partnership may entail.



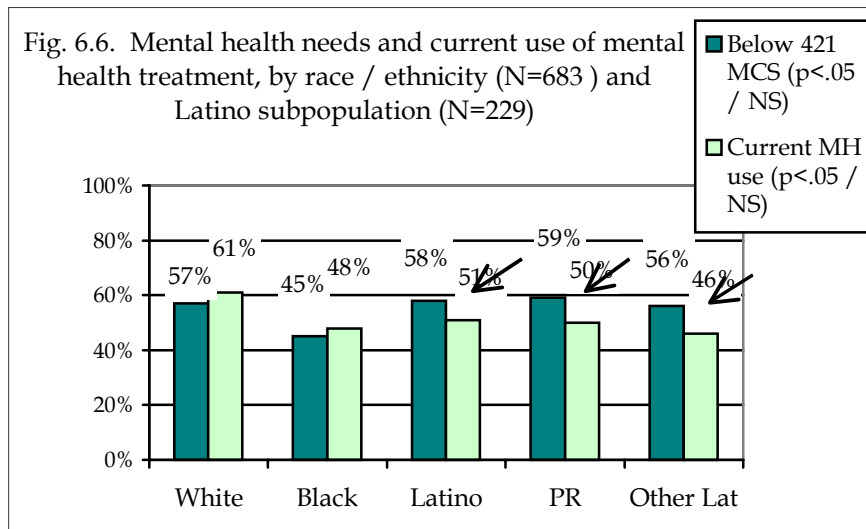
6.6. MENTAL HEALTH AND MENTAL HEALTH SERVICES

The major difference that cannot easily be attributed to population composition characteristics, and may in fact have its roots in cultural orientations, is in mental health scores and utilization.

CHAIN uses a standardized measure based on the MOS-SF36, Medical Outcomes Survey, to examine need for mental health services. A series of subscales are combined

into the “mental component summary score” (MCS), which is a measure of general mental health functioning. (See Aidala 1997, Aidala 2000, for more detailed discussion of this measure.) Research has shown that the MCS distinguishes groups differing in the presence and severity of psychiatric disorder. A score at or below a cut point of 42.0 (referred to as “low mental health”) on the summary score indicates current, clinically relevant psychiatric symptoms that may be the product of a diagnosable mental health condition.

We calculated the percentage of each group that scored below this cut point, indicating some potential *need* for mental health services. Then, we compared this percentage to the percentage who report actually *using* any mental health services. Not surprisingly, given that CHAIN is a sample of HIV-positive people with all the emotional challenges that poses for them, a large proportion (compared to the “general population”) of all the groups in the CHAIN cohort score below the “cut point,” suggesting some need for



mental health services. There are no statistically significant differences among groups in proportion showing symptomatology consistent with a clinical diagnosis (and possible need for services): Latinos and Whites are more likely to

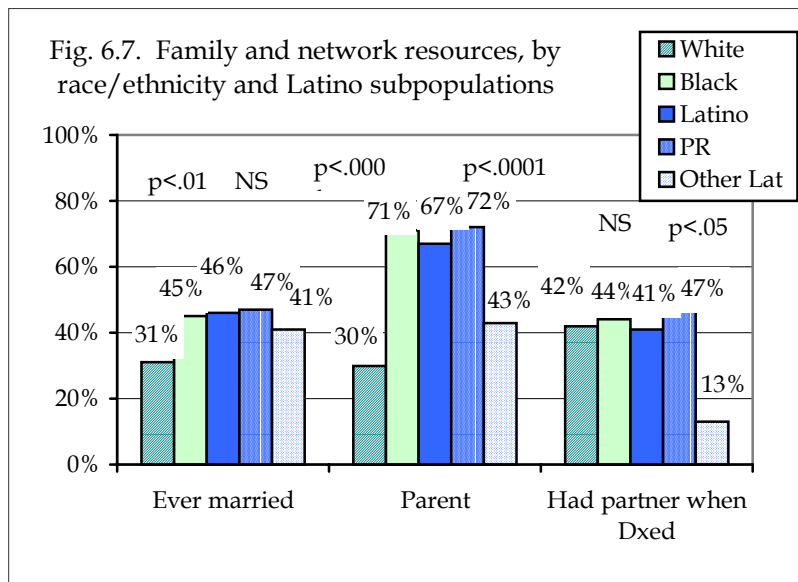
display symptoms than Whites, although Puerto Ricans are not more likely than Other Latinos to do so. There are no statistically significant differences among groups in proportions reporting that they are actually *using* mental health services.

There are, however, inter-group differences in the relationship of “need” to “use” in mental health indicators. The cohort’s Latinos are distinctive in that they are less likely to use than to need mental health services: Latinos as a group (and Puerto Ricans and Other Latinos within the group) are the only group for which there is a mental health “treatment gap” between “need” and “use” of services. In fact, both Whites and Blacks show *higher* proportions *using* services than “need” them. The appearance of this distinctive treatment “gap” in both Puerto Rican and Other Latino subgroups in almost exactly the same proportions, despite their many differences on other dimensions of service need and utilization, suggests that the reason for it may lie in some aspect of their shared cultural background, such as beliefs about mental health symptoms and care.

This pattern and interpretation are supported by other studies, both of the CHAIN sample and of other Latino populations elsewhere. Aidala (1996), examining those in the CHAIN sample with mental health “needs,” as defined by the standardized MCS instrument, found lower levels of mental health utilization among Latinos and Blacks. On the basis of both 1994 and 1998 cohorts, Aidala, Lee, and Abramson (2001) found that the most important predictor of use of mental health services was the individual’s perception and articulation of the *need* for such services, perceptions that may easily result from differing cultural orientations to what defines a mental health “problem” and what the appropriate “care” is for it.

A review of studies of Latino mental health service use (Vega and Alegría 2001) found similar patterns: higher rates of mental health symptomatology (or “need”) among Latinos living in the U.S. than among Latinos living in their native countries or among Whites in the U.S., combined with lower levels of use of mental health services than among U.S. Whites. The stress of migration and acculturation, exacerbated by poverty and discrimination, is thought to weaken naturally occurring social supports among immigrant populations and produce the higher rates of “need” among Latinos in the U.S. The lower utilization that creates the “gap” with “need” is attributed to a number of factors. There are nowhere enough bilingual and/or bicultural professionals to serve the Latino treatment population who might need services. Beyond that, there is some evidence that Latinos are more likely than other groups to rely on family and other informal supports more than formal mental health services.

6.7. FAMILY AND KIN RESOURCES - SOCIAL SUPPORT AND BURDEN



An individual’s family and household can provide important resources for both the emotional and practical aspects of a chronic disease, such as HIV, and discussions of Latino cultural patterns uniformly portray the value of and reliance on family, as a hallmark of the culture. However, being able to rely on family presupposes the existence of family. The sources of that potential

family-based support vary considerably across groups in the cohort, reflecting differences in sexual orientation, age, proportion female, and perhaps migration.

Both Blacks and Latinos are significantly more likely than Whites to have ever been married, and particularly to have had or parented a child, both indicators of at least the potential availability of family-based social support and burden. These data are hardly surprising in light of far lower proportions with same-sex sexual identities and experience among them

The more striking finding is that the proportion answering “Yes” to a question about “having a partner at the time of HIV diagnosis,” varies little across the major groups. (We did not ask about the nature of that partnership -- marital v. non-marital, same-sex v. opposite sex.) The exception to this generalization is the Other Latinos, who by virtue of their more advanced HIV infection perhaps have greater needs for family social support, but are the least likely to have had a partner at the time they were diagnosed. This is very likely because they are on the average the “youngest” of any of the groups in age, as well as the most recent to have arrived in New York. They have had less time, either socially (time on the Mainland) or chronologically (age), to enter into a partnership. As a result, they may have a distinctive set of needs from Puerto Ricans, and perhaps fewer close relationships on which to rely for social and other support. This possibility is supported by the higher expressed need of Other Latinos than Puerto Ricans for emotional support and other psychological services.

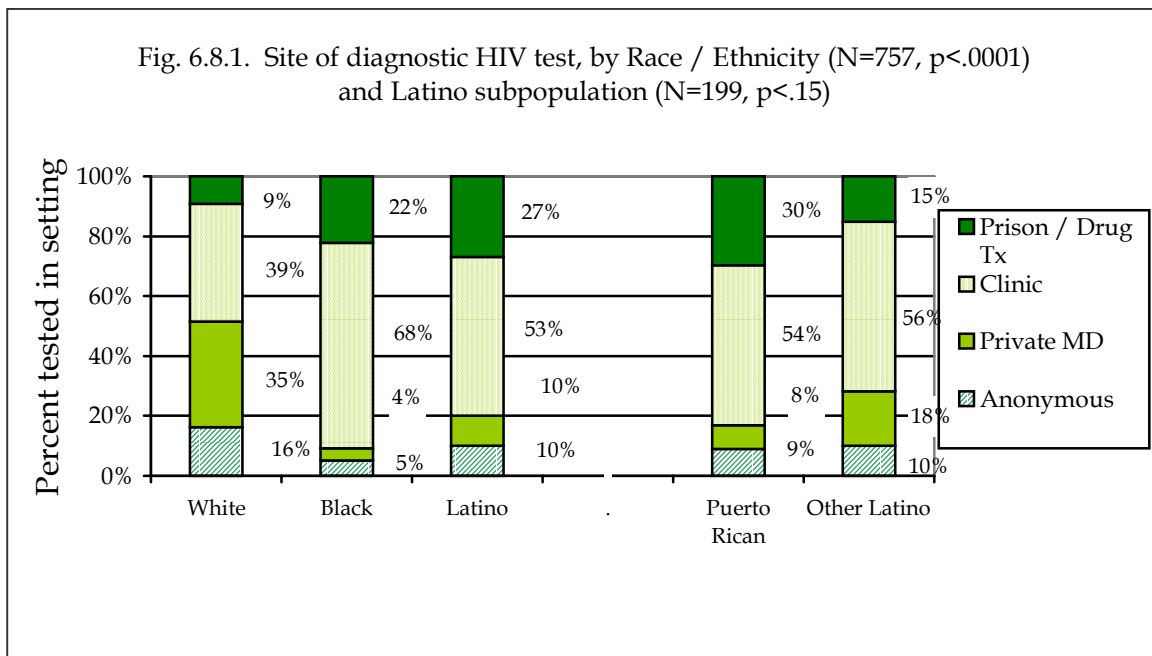
6.8. PATHWAYS TO HIV CARE

The path taken into care often exerts influences on later use of care, and on outcomes. At the same time, paths into care often vary by many social and economic characteristics, meaning that they are an important way in which inequalities in the larger social system can result in differences in utilization and outcome of health care.

Past CHAIN reports (Abramson and Sanger 2001) have indicated that there are different “pathways” at the beginning of HIV treatment, and those pathways are relatively stable over time. Whites are disproportionately represented in a “private M.D.” path, and Blacks and Latinos in a “clinic” (hospital or community-based) path as they start treatment. This pattern doubtless reflects health care accessibility and use prior to diagnosis, and the far higher proportions of White respondents with private insurance and employment, as opposed to the greater dominance of Medicaid among Black and Latino respondents.

However, another noteworthy finding is that the Other Latinos in the sample resemble their White counterparts more than they resemble Puerto Ricans in this respect: Other Latinos are significantly more likely to start out in the “private M.D.” pathway, and a high proportion report that they used the same provider before and after HIV diagnosis. There are few differences in delay between HIV diagnosis and initial presentation for treatment: approximately $\frac{3}{4}$ of each of the major groups had initially presented for treatment within 3 months after diagnosis.

Many of these group differences in first treatment are an outcome of where HIV was diagnosed, which we can think of as the initial stage of a treatment “pathway.” Although clinics are the most common test site among all groups, Whites are over 3 times more likely than Latinos as a whole to have used a private M.D. for testing. Similarly, Other Latinos are more than twice as likely as Puerto Ricans to have entered HIV care through the “private M.D.” HIV-diagnosis pathway. Another difference in test site is in proportion using a prison or drug-treatment program test site. Latinos are three times (and Blacks more than two times) as likely as Whites to have utilized this pathway, and Puerto Ricans twice as likely as Other Latinos. These differences are a direct reflection of higher rates of drug use, which over a lifetime produce higher proportions of these groups passing through correctional or drug-treatment settings, where testing is encouraged or required.



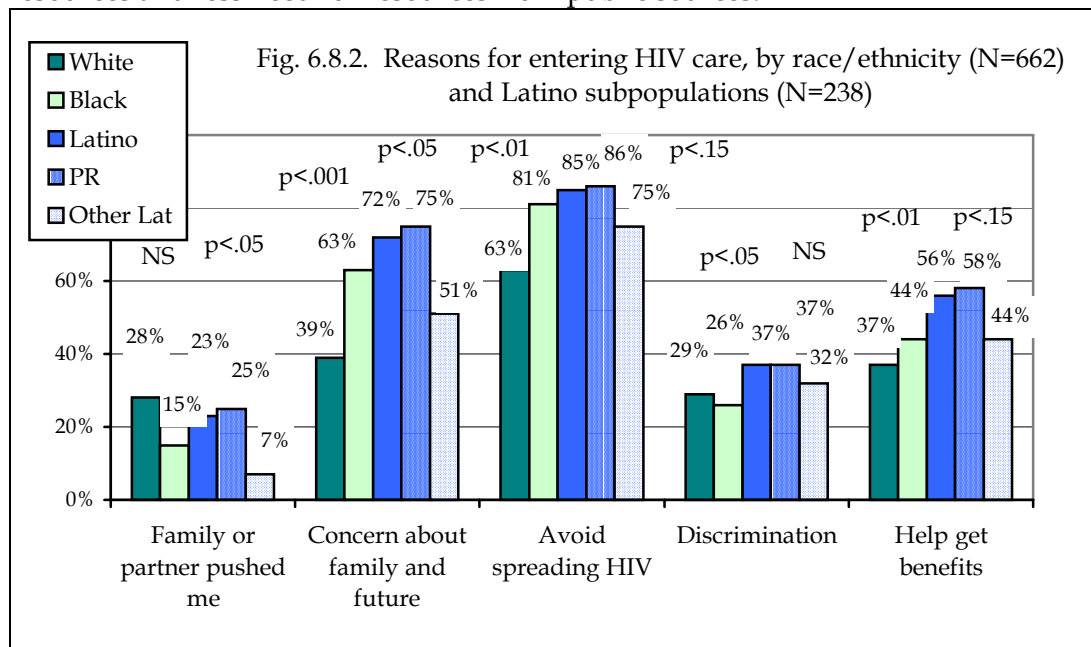
Why did the CHAIN participants enter HIV care when they did? Motivations are notoriously difficult to measure accurately in survey research, but a series of questions about whether particular motivations are important or not in decisions to seek treatment, provide some insights. We asked whether each “reason” was “very important,” “important,” “somewhat important,” or “not at all important,” and examined the proportions of each group saying that the reason was “very important” or “important.”

While the delay in seeking care differs little among the groups, the expressed reasons for seeking care are somewhat different, and reflect several inter-group differences. Latinos are more likely to have pursued care for what we might term “other-directed” or “interpersonal” reasons, rather than concerns about the self. These include “pressure from family or partner” as well as “concern about the future and family,” “concern about spreading HIV to significant others,” and “discrimination.”

One possible explanation of this difference is a “cultural orientation” one: almost any discussion of Latino cultural norms describes the importance of family to Latinos, both as a norm or ideal and an influence on actual behavior. If this were the explanation, we would expect to see similar rates of expression of these “other-directed” or “family-oriented” reasons across Latino groups.

Instead, this difference is explained by differences in composition. Other Latinos are consistently less likely to cite these reasons, especially those of family or partner pressure. In fact, as we have seen, the Puerto Rican Latinos who make up most of the Latino group in the cohort, are far more likely - by virtue of older age, greater likelihood of heterosexual orientation and behavior, and longer roots on the Mainland -- than the Other Latinos to have partners or children now, and to have had partners when diagnosed, so they are more likely to have to take account of family and partner relationships in their decisions.

Differences in composition also account for the other noteworthy group difference. Latinos, and Puerto Ricans more than Other Latinos, cite the opportunity to get financial and other benefits if they enter care, as a reason to do so. The reasons for this are straightforward: these groups have the fewest resources by virtue of lower employment and educational resources, higher rates of drug use, and the greatest need by virtue of poorer health status. The relatively modest benefits available to the AIDS-diagnosed in New York can make a greater difference in their lives and well-being than in the case of groups (such as Whites) with more of their own pre-existing financial and employment resources and less need for resources from public sources.

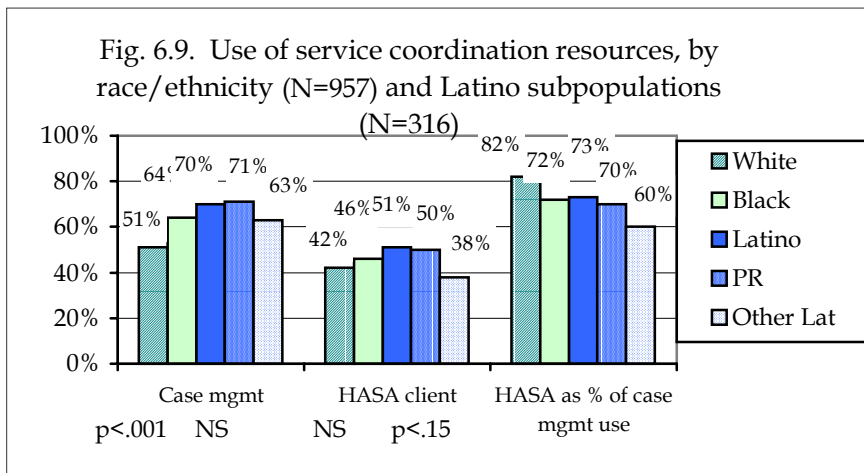


6.9. SERVICE COORDINATION

What differences are there in the services and resources that people had available to them? Prior CHAIN research (for example Messeri et al. 2000) has shown that ancillary services, such as case management, can play an important role in getting clients into needed medical and social services, and supporting them in the use of those services. Making ancillary services available can be an important route to equalizing disparities in health care.

Not surprisingly, there are significant though modest differences in use of any case management services, those with the greatest presumed service needs (the Latinos) being most likely to utilize case management. The percentage who are enrolled in NYC-administered income support and AIDS services through HASA varies relatively little across the groups, as we might expect within a cohort recruited from within HIV services other than private medical practices. All groups show similar rates of utilization of HASA services, presumably as those who started out with greater independent resources have turned to publicly-funded types of assistance as their disease has progressed and needs increased.

The use of case management services shows similar patterns. As case management is a major component of HASA services, it is difficult to assess how much of the case management use of the respondents is being met by HASA, and how much “unmet need” there is that is being picked up by non-HASA case management. We approached this question indirectly, by calculating the percentage of the group reporting (at study entry) being HASA clients, and dividing it into the percentage reporting *any* case management services, to produce a percentage of the group’s actual case management use that may be attributable to HASA case management specifically. Looked at from



this perspective, we see that there are significant inter-group discrepancies in the proportion of case management utilization that may be attributable to HASA.

The smallest HASA-overall “case management

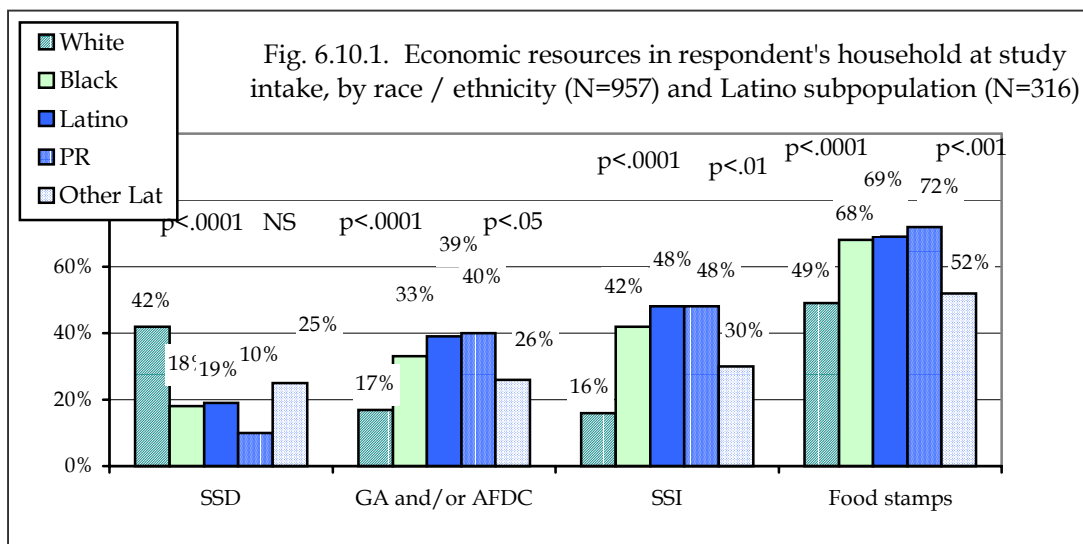
gap” is among the White respondents. Among the Whites, 82% appear to be using HASA as their only case management service, presumably because their needs for case management beyond the basic financial needs (for which HASA is the effective conduit) are smaller than those of other groups. The largest “case management gap” is among the Other Latinos: they are least likely to be HASA clients at all, and it is among them that HASA appears to represent the smallest proportion of case management utilization. This group may have unusually complex needs requiring use of multiple case management sources, which we might imagine from their rate of relatively “old” HIV

infections. In addition, some proportion of the group (chiefly the Other Latinos) may be unable to access HASA and other publicly-funded benefits because of the structural factors of citizenship or other legal barriers.

6.10. FINANCIAL AND ECONOMIC RESOURCES AND USE

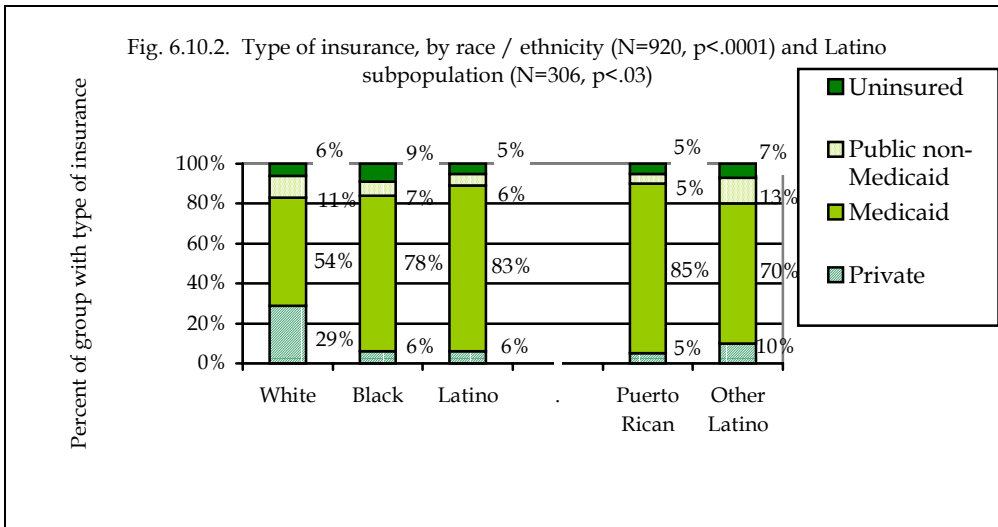
Economic resources are the source of many of the differences observed among racial and ethnic groups in the sample. A series of questions asked about whether any income in the respondent's household came from a variety of different sources. On any number of measures, the Latinos are as a group the least advantaged, even less advantaged than the slightly younger and healthier Black members of the cohort.

These disadvantages appear to pre-date the HIV diagnosis. Latinos and Blacks are the *least* likely to report income from Social Security Disability. While HIV may have been their qualifying disability, qualification for this income stream rests not only on a disability but also on a prior earnings history that includes a certain number of quarters of qualifying employment. Reflecting their generally lower level of pre-existing resources, Latinos and Blacks are, on the other hand, *more* likely to use Supplemental Social Security Income, a program that is designed for those who do not qualify for SSD



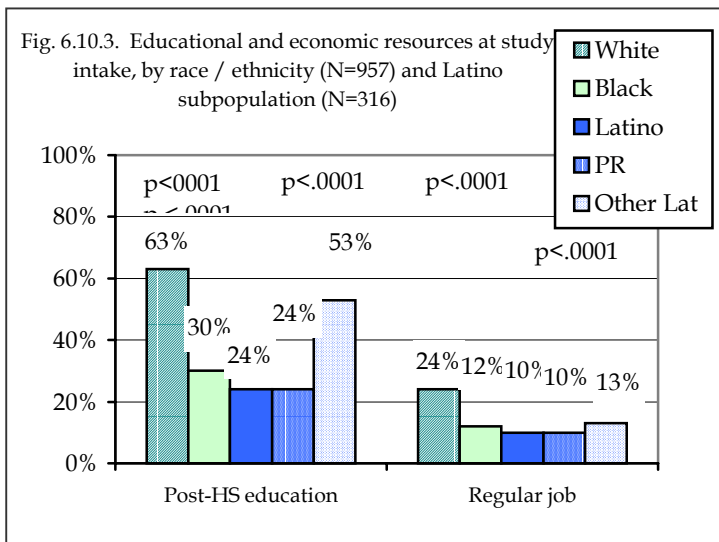
by virtue of lack of covered employment or other eligibility restrictions. They are also significantly more likely to report use of general types of means-tested income maintenance: Public Assistance or General Assistance (for single adults) and (for those with children) Aid to Families with Dependent Children (now TANF), as well as Food Stamps.

This general profile of substantial pre-existing economic differences gradually lessening somewhat after diagnosis is borne out by two other pieces of data.



1. *Insurance status* at time of study entry. The most common insurance type among all groups is Medicaid, a means-tested insurance that many working people qualify for only after they have spent down past assets. However, even with their longer time since diagnosis and more advanced infection, Whites are significantly more likely than Latinos and Blacks (and Other Latinos more likely than Puerto Ricans) to be using private insurance or a public non-Medicaid type (chiefly Medicare, which accompanies Social Security Disability) eligibility for

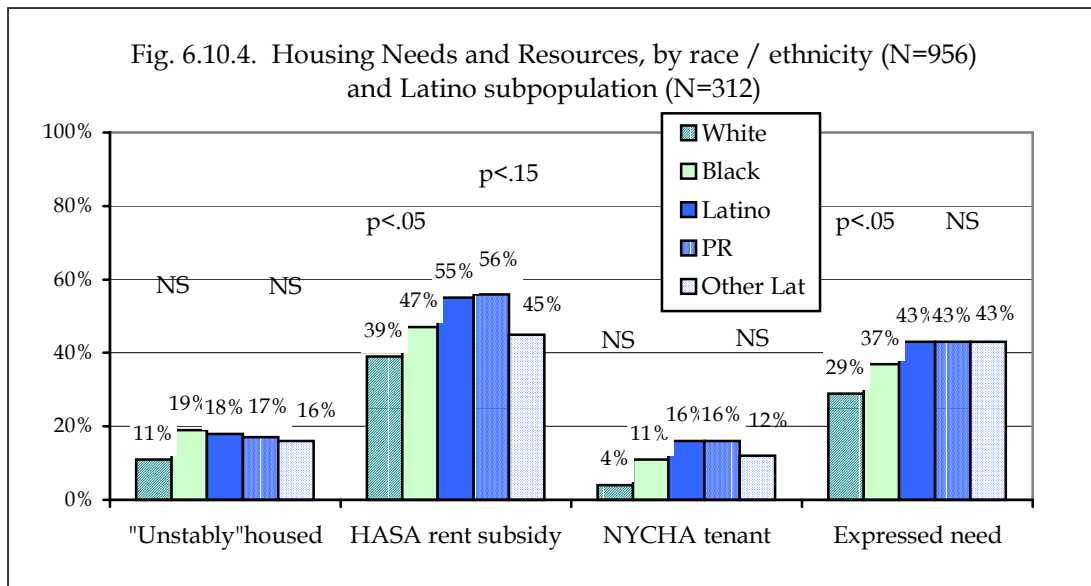
which rests on a substantial past history of documented employment.



2. *Employment.* Both Whites' and Other Latinos' higher levels of support through employment (someone in their households having a regular job) at study entry are probably a result of their

superior education and more advantaged position in the job market Whites are significantly more likely to have some post-high school education than are other groups, as are Other Latinos as opposed to Puerto Ricans within the Latino group.

Housing remains an area of great need in all groups, but needs at a basic level are often met. A relatively small percentage across all groups reported being “unstably” housed (defined as living in streets, shelters, SROs, or in an apartment but doubled-up). But this sets a low standard for “stable” housing, and many are using benefit programs to secure even a modest level of housing stability. Latinos are more likely than Blacks and even more likely than Whites to be needing and using a HASA rent subsidy. Some of this need probably pre-dates their HIV diagnosis, as a larger proportion of Latinos report living in NYC Housing Authority units, which by definition are income-based. Despite the existence and use of these programs, Latinos (both Puerto Rican and Other Latinos) are the most likely to cite housing as an area where they require further assistance.



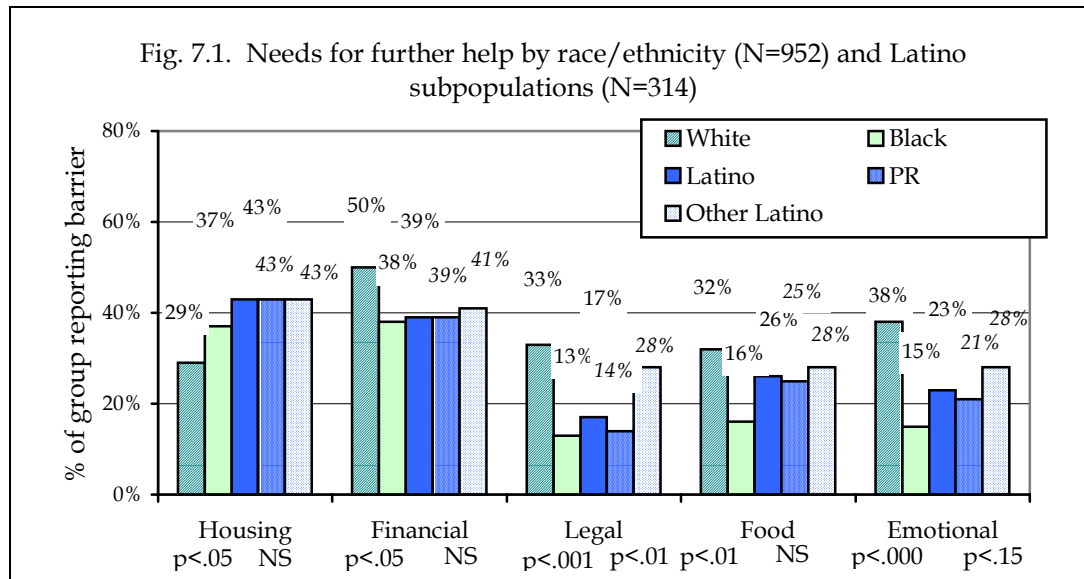
7. UNMET NEEDS AND THE FUTURE

We have seen that some inter-group differences gradually become reduced over the course of infection and care, but others remain, as they were a result of large pre-existing differences in resources and access to resources. What can we say about the future of the CHAIN cohort, and of the epidemic in New York?

7.1. EXPRESSED NEEDS

We asked a series of questions about areas where respondents still felt they had a “need” for services. The greatest unmet need among all groups is related to finances or housing. These are sides of the same coin, as housing forms the bulk of individuals’ living costs. Some may have an adequate place to live but require financial help to maintain it, others may need an adequate place and also need financial help to obtain it. The importance of expressed housing and financial needs is all the more striking when

we consider that large proportions of all groups (especially the Latinos and Blacks) are already receiving HASA rental subsidies.



One area of noticeable difference is the significantly greater expressed needs for legal help among the White and Other Latino respondents. This is probably a result of the greater prevalence of legal complexities in these groups. Both are largely composed of members of sexual minorities, who may require assistance regulating inheritance and similar legal matters outside the context of a legally-recognized partnership relationship. Many of the Other Latinos are born outside the Mainland, and it is possible that regulating immigration status contributes to this interest in legal assistance. Finally, it is striking that the highest levels of expressed need for emotional and psychological services are among Whites and Other Latinos. Although we cannot establish the reason on the basis of this data, we can speculate that it may relate to the lower levels of spousal and child support available to these groups because of their lower rates of partnership and parenthood.

Given the multiple needs for services, what are the barriers to getting services, and do they differ by group?

7.2. BARRIERS TO CARE

In general, a relatively small proportion of the cohort report having encountered any barrier to care, whether medical care, social services care, or both types. This low recognition of barriers may be due to one or both:

1. A sample (the CHAIN cohort) recruited in services being the “successful” seekers of services, so presumably they found the barriers surmountable;

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2. A general cultural bias toward self-sufficiency and away from admitting difficulties, which would make respondents likely to underreport barriers that they really did encounter.

The experience of Latinos in seeking care has been somewhat different than that of both their Black and White counterparts. On the surface it is surprising that the White cohort members (with their relatively advantaged position in society in general, and within the cohort in terms of income and education) should be significantly *more* likely to report almost any barrier than are the Blacks or Latinos, but this pattern is consistent across almost all the barriers we asked about. Although not a significant difference, Latinos are consistently more likely than Blacks to report barriers, whether we examine the barriers individually or as a whole. There are two possible explanations, neither of which excludes the other.

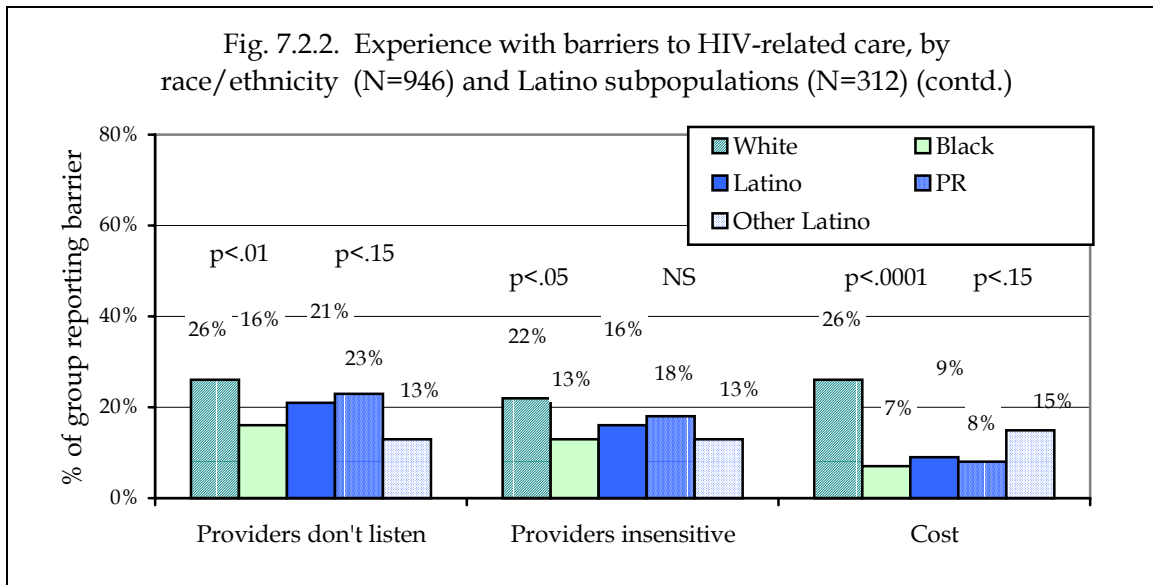
First, there may be differences in cultural orientations about seeking help, self-sufficiency, and being able to recognize a barrier or admit that one has been encountered. We cannot directly explore these with the available data. Second, there may be group differences in composition that may explain differences in seeking help, encountering and interpreting barriers. These group differences in composition may include:

1. Personal background characteristics that influence the experience of disease and care. Life experience as a drug user or member of a sexual or racial/ethnic minority brings with it a history of past experience in care and services that shapes expectations and perceptions of current and future experiences, affects the standard of comparison (past care) against which current care is judged, and in turn colors whether an experience is interpreted as good or bad. In fact, people who have had little care in the past may be the most likely to report satisfaction with their care now, simply because the experience of having care at all is relatively new to them.
2. Time in care and exposure to opportunities for barriers. Regardless of the nature of the encounter with the care system, individuals who have lived with their diagnosis longer will be exposed to the care system longer, and have more opportunities to encounter barriers that actually exist. Barriers may also differ according to type of entry (for example, site of the diagnostic HIV test) into the care system.

The most striking area of significant difference in barriers among the groups is that of the *cost* of services, which is far more likely to be reported by White respondents (and by Other Latinos relative to Puerto Ricans). These differences reflect differences in personal characteristics, specifically economic circumstances and resulting use of insurance. As we have shown, both of these groups are more likely to be working, using a private doctor, and have non-Medicaid insurance with its greater freedom of choice but also its burdensome deductibles, co-payments and gaps in coverage, which can become a substantial expenditure in the case of a chronic disease such as HIV. This is quite different from the situation of Medicaid patients, who are somewhat restricted in choice of provider, but enjoy comprehensive benefits with few additional costs. In addition,

some Other Latinos may also face a structural cost barrier as some, by virtue of documentation or citizenship status, may not be eligible for publicly-funded insurance at the same time that they lack adequate access to employment-based insurance.

Other areas of significant differences in barriers are in the belief that “providers don’t understand me or my problems,” that staff “don’t listen or are disrespectful,” or that “I didn’t know where to go.”



Contrary to initial expectations, very few respondents in any group (and only 48/957, or 5% of the total sample) reported a barrier because the “provider didn’t speak my language.” Curiously, White people were more likely to report this than Latinos, suggesting that this item may not relate literally to language barriers. Of the 48 reporting language barriers, 10 were Island-born Puerto Ricans (who may have migrated in older childhood or adulthood and never become fully at ease in English), 2 had been born in a Latin American country outside the U.S., and the remaining 36 had been born on the U.S. Mainland (including 25 born in NY). Of the 25, the largest group (of 17) had identified themselves as Black but non-Latino, suggesting that language barriers may occur among HIV-infected Haitian and/or West African immigrants as frequently as they do among Latinos.

7.3. LOOKING AT THE FUTURE IN NYC

We started by looking at the proportion of each racial/ethnic group that belonged to different age groups, as this age difference explains a great deal about inter-group differences in health and social histories and services use and needs. We close with a consideration of what the implications of the age structure are for planning, by looking at the question in a different way. We look to see the racial/ethnic breakdown of each age group. Understanding the makeup of age groups is important because trends

visible now in younger groups will have “ripple” effects on service needs as those groups age.

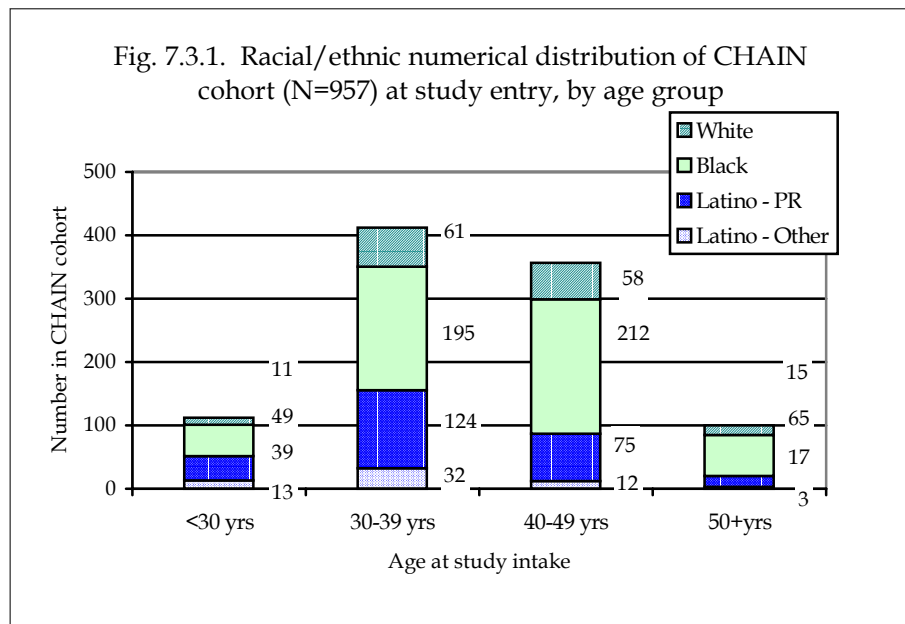
With the increases in survival times after HIV diagnosis, we can expect to see Latinos make up a larger proportion of NYC HIV-infected in the future, as their greater representation in what are currently the younger ages eventually translates into a larger representation at older ages in the future, and those now in the younger (more heavily Latino) age ranges enjoy better health and longer survival. We may, however, expect to see some changes in the profile of the HIV-infected *within* the Latino population, as newer immigrant groups (with their different behavioral patterns) come to represent a larger proportion of the Latino HIV-infected.

As we have seen earlier, the relatively younger age groups are disproportionately represented among the Latinos, and especially among the Other Latinos as compared to those of Puerto Rican origin. This suggests that the Latino population is on the whole younger than the others. In fact, almost half the under-30 members of the cohort are Latino, while less than 20% of those 50 and older are.

Currently, under-30s are a relatively modest absolute number and proportion (108/957 or 11%) of the cohort, but this is not surprising. We would expect a small proportion of this population-in-services represented by the CHAIN cohort to be below 30, for two reasons:

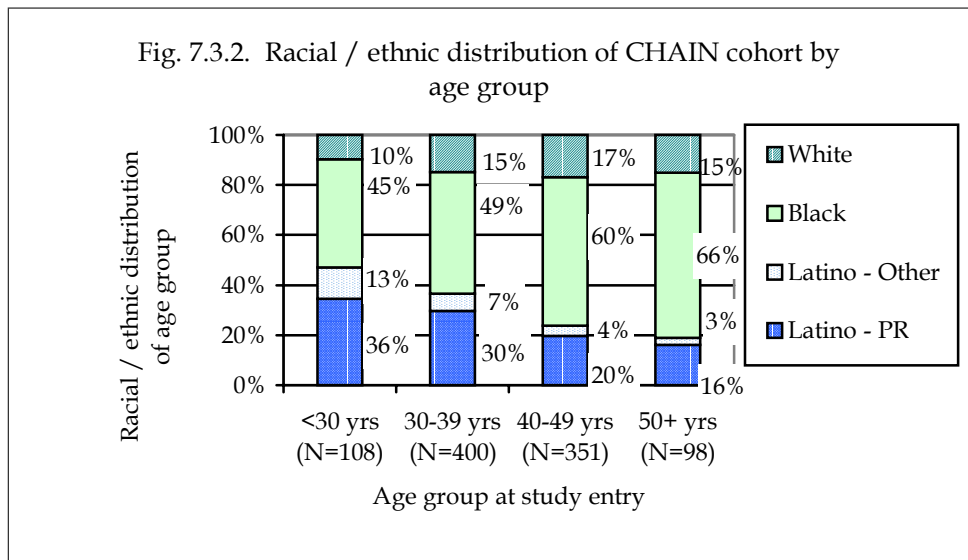
1. As age increases, so does the lifetime cumulative occurrence of behavior that can transmit risk and lead to infection, that would in turn create the “need” for services. Most importantly, both sexual behavior and drug injection tend to increase in the late teens and/or 20s, as people become adults.
2. The lag time after infection to diagnosis, and from diagnosis to service entry, means that

many of those infected in their 20s will not appear in agency services (the recruitment base for the CHAIN cohort) until their 30s or even later.



The current under-30 members of the cohort, though small in absolute numbers, probably represent a “tip of the iceberg” of the currently or potentially HIV-infected in their age range. The others may not appear at test sites or services until they reach higher ages. We would expect these younger segments to grow in both absolute and relative terms, as a part of the population-in-services. As young people, they potentially have many years of life expectancy ahead of them (and with the widespread use of antiretroviral medications in recent years, we would expect them to live far more of those years than their predecessors in the epidemic were able to), so their needs and service characteristics will shape the service system for years into the future.

The planning implications are seen more readily in Fig 7.3.2, which shows the distribution by race/ethnicity not as absolute numbers of the whole population-in-



services represented by the cohort, but as percentages represented by each racial/ethnic group within each age group. *The younger the age, the larger the proportion of Latinos in*

that age group. This suggests that the future face of the HIV-infected population in services will be more Latino than it is today. Also, within the Latino subgroup, the younger the age, the larger the proportion of Other Latinos as opposed to those of Puerto Rican background, meaning that the Latino population services will be even more diverse.

We have seen that the Other Latinos differ from the Puerto Rican Latinos in ways suggestive of an earlier period of the HIV epidemic in NYC. Specifically, the Other Latinos are more likely to be relatively young, male, more educated, migrants to the Mainland U.S. (and by implication New York) and have MSM risk profiles than are their Puerto Rican counterparts. Many of the findings on Puerto Ricans as well as Blacks are attributable at least partly to the greater representation of low-income drug users in the Puerto Rican and Black segments of the cohort. The non-Puerto Rican Latinos in the cohort resemble their White counterparts more than they do the Puerto Ricans, on many dimensions, which means that their service needs may be more similar to those of Whites. At the same time, they may face distinct service barriers related to their immigration and legal status.

8. CONCLUSIONS

A major finding is the degree to which the makeup of the CHAIN cohort's Latinos does not mirror that of New York City's overall Latino population, but is substantially more Puerto Rican in makeup than is the City's Latino population as a whole. This may be due to lower seroprevalence and "need" among non-Puerto Rican Latinos in New York, or lesser ability to access services, or both. The second major finding is the presence within the overall Latino group of a subgroup of non-Puerto Rican "Other Latinos," with a distinct demographic, need, and service profile from their Puerto Rican counterparts.

Despite differences in background and in other aspects of health, social and economic resources, and service utilization, at time of study entrance all groups reported approximately similar levels of use of basic HIV-related medical care, showing the influence of HIV-specific funding on minimizing disparities in access to HIV care. However, the pathways through which groups came to this care differ according to their prior and current resources and background, especially differences in socioeconomic background and history of drug use.

Latinos and Blacks in the general population are broadly more similar to each other than either are to Whites in many socioeconomic factors. In the CHAIN cohort, Latinos and Blacks both differ from Whites in:

1. Composition. Latinos and Blacks are likely to be younger, less likely to be male, and to have entered care with more pre-existing health problems. They also differ in risk background, having a higher proportion with both past and current drug use than Whites, as well as a lower proportion with same-sex identification and behavior.
2. Access to and use of resources. Latinos' and Blacks' use of resources reflects their different history than Whites, especially a history of drug use and fewer socioeconomic resources. Both Latinos and Blacks are *more* likely than Whites to:
 - Use pathways to treatment that run through prison, drug-treatment, or clinic-based testing and care (as opposed to the private M.D. pathway, which is more common among Whites).
 - Use drug-treatment services both currently and in the past.
 - Use, and presumably require, greater use of coordinative services such as case management.
 - Have the potential social supports that come with having been married, parented children, and had a partner at time of diagnosis.
 - Cite reasons related to significant others, or to accessing benefit programs, as reasons to enter HIV care.
 - Have lower levels of financial resources both before entering care (as shown by citing benefit programs as a reason to enter HIV care), as well as at study entrance (as shown by making use of income-tested benefits programs, and having Medicaid insurance).

At the same time, Blacks and Latinos are both *less* likely than Whites to:

- Use auxiliary medical services such as dental care or alternative health care.
- Identify as members of a sexual minority or have lifetime experience with same-sex sexual behavior.
- Report cost as a barrier to services (presumably because of their access to publicly-funded health insurance).

While Blacks and Latinos show many common characteristics when compared to Whites, Latinos are in turn different from both Blacks *and* Whites in other ways.

1. Composition. Latinos are more likely to:
 - Be relatively young. Latinos as a group are on the average the youngest major population in the U.S., and within the CHAIN cohort as well.
 - Have poorer health status (entering HIV treatment with pre-existing major health problems, report poor self-rated overall health at study intake, have a history of prior opportunistic infections)
 - Report a history of more intense drug use and specifically injection drug use.
 - Be born outside the Mainland U.S.
2. Show a distinctive pattern in relation to mental health symptomatology and care. Despite similar levels of mental health symptomatology across all groups, Latinos show distinctly lower *use* of mental health services than other groups. This treatment “gap” occurs in both Puerto Ricans and Other Latinos i, suggesting that the underutilization of treatment services may be a result of orientations to recognition and treatment of mental health or of lack of linguistically and culturally appropriate services, rather than to a difference in composition or personal resources.

There are also substantial differences *within* the Latino group. Some 19% of the cohort’s Latinos are of a background other than Puerto Rican. Within the Latino group, these Other Latinos differ from those of Puerto Rican origin in:

1. Composition. The Other Latinos are more likely to be young, male, well-educated, born outside the Mainland U.S., to report both behavior and identification as members of a sexual minority, and less likely to report a history of drug injection or consistent use. Despite poorer HIV health status, they enjoy better overall health, and had fewer pre-existing health problems when diagnosed.
2. Legal and structural differences. A large proportion of Other Latinos are born outside the Mainland, suggesting differences in citizenship status from Puerto Ricans, who are automatically American citizens.
3. Resources. Other Latinos are less likely to have been married, parented children, or had a partner at time of HIV diagnosis, probably due to their younger age and greater likelihood of being members of a sexual minority,. On the other hand, they are more likely to enjoy educational advantages, to be employed, to use private

insurance and medical care, to report cost as a service barrier, and less likely to use case management and similar services.

Finally, Latinos now represent approximately 1/3 of the population in HIV services. In the future, assuming that transmission patterns do not change radically, we can expect to see an increasing proportion of this service population made up of Latinos. This is attributable mainly to the disproportionate representation of Latinos in the younger ages of both the CHAIN cohort and the overall NYC population. Because of shifts in immigration and the concentration of Other Latinos in the younger age ranges, we can almost certainly expect to see a larger proportion of the Latinos in services made up of non-Puerto Rican background Latinos, with implications for both service needs and the existing resources for service provision.

If this is the case, we can expect to see an increased need for bilingual and bicultural services generally as the proportion of the population in services from Spanish-language cultural (and especially immigrant) backgrounds grows. At the same time, there may be a need to increase the accessibility of services and benefits for those who are not U.S. citizens, and to expand the reach of existing services aimed at Latinos to encompass the needs of younger, more educated, more MSM, and more immigrant populations.

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