



C.H.A.I.N. REPORT

Tri-County CHAIN

Report 2002-3

Stigma & Social Isolation

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Background

Unlike a physical attribute or characteristic, stigma is internalized. An individual may feel stigmatized by his or her HIV status whether or not he or she has suffered any discrimination or harm as a result of that condition. This “felt stigma” has consequences. An individual who perceives his or her HIV serostatus as a stigmatizing condition may go to some lengths to avoid experiencing an actual discriminatory event – by isolating him or herself, not disclosing his or her HIV status to others, or by avoiding the health and social service agencies which might further associate him or her with HIV.

This report seeks to understand the “epidemiology” of stigma in a representative group of HIV-positive adults in the Tri-County region of Westchester, Rockland, and Putnam counties, and its impact on help-seeking behavior. Among the key questions we have explored are the following:

- What are the proportions of individuals in the Tri-County CHAIN cohort who express feelings of being stigmatized, or who are socially isolated? Are certain groups more likely to express feelings of stigma and social isolation?
- What is the relationship between expressions of perceived stigma and perceived social isolation?
- What is the relationship among self-perceived stigma and social isolation and an individual’s interactions with the HIV health and human services system? Are individuals who express high levels of stigma and social isolation more likely to also express barriers to care? Are these individuals with higher levels of self-perceived stigma and social isolation more or less likely to use case managers, mental health professionals, and support groups?

The literature on stigma¹

Studies have shown that there is an important distinction to be made between “enacted stigma” and “felt stigma” (Scambler and Hopkins 1986; Green 1995). “Enacted stigma” refers to restrictions placed upon those with HIV/AIDS, whereas “felt stigma” relates to feelings of shame and fear of enacted stigma (Green 1995). “Felt stigma” has been shown to increase the stress associated with HIV/AIDS, to add to secondary psychological and social morbidity, and to affect the overall quality of life and physical well-being of those living with HIV/AIDS (Fife and Wright 2000). Moreover, not disclosing one’s serostatus because of fear of potential stigma

¹ This section is drawn from “An Exploration of Stigma, Disclosure, and Unmet Need for Medical Care Among an HIV-positive Population,” by Thurka Sangaramoorthy (Masters Thesis, August 2002, Columbia Mailman School of Public Health).

diminishes one's personal resources for health, mental, and social services, and limits treatment options for those living with HIV/AIDS (Chesney and Smith 1999; Herek 1999). This notion of hiding and concealment is a fundamental part of the feeling of shame, and to avoid shame, many individuals feel the need to evade the disclosure of their stigmatizing condition (Limandri 1989).

Many individuals choose not to disclose their HIV status because they are afraid of rejection and discrimination, or to avoid pity and to spare their loved ones the emotional pain of associative stigma (Limandri 1989; Siegel and Krauss 1991; Laryea and Gien 1993; Holt et al. 1998; Yoshioka and Schustack 2001). Others choose not to reveal their condition for fear of having to reveal their sexual orientation or illicit drug use (Limandri 1989; Seiel and Krauss 1991; Laryea and Gien 1993; Holt et al. 1998). As a result, non-disclosing individuals are associated with lower levels of perceived social support, very few partners, and uneasiness about their sexual orientation (Holt et al. 1998).

Furthermore, research has shown that many stigmatized HIV-positive individuals expect discrimination from health care professionals based on homophobia, race, and class. Demas et al. (1995) found that stigma resulted in one third of their HIV-positive respondents denying their HIV infection, which in turn led to delays in initiating and adhering to antiretroviral treatments. Thus, HIV-related stigma has a tremendous impact on the way individuals react to their illness— withdrawing from others, concealing their infections, impeding their desire to access and adhere to appropriate health care—all of which compromise their overall health and quality of life.

Major findings

- Overall, there are very high reports of felt stigma among respondents in the cohort – 77% (305 / 398) scored very high on the stigma scale and an additional 18% (71 / 398) reported moderate levels of felt stigma.
- Women are slightly more likely than men (80% compared to 73%) to express high levels of perceived stigma.
- For the most part, other than the gender difference noted above there were few group differences related to expressions of stigma, which suggests that such feelings are relatively universally experienced.
- Most people in the cohort have disclosed their status to more than their immediate friends and families (77%), whereas only 6% have not disclosed to anyone. Among respondents who report that they have never used drugs, 30% have disclosed to only a few close friends and family members or to no one at all, compared to 12% of individuals who report ever having used drugs.
- There were few characteristics of the HIV system associated with lower reported stigma

or greater numbers of people to whom the respondent has disclosed his or her status. The presence of a case manager, or recent visits to professional or supportive mental health were not statistically significantly associated with reducing rates of stigma or non-disclosure. Only recent attendance at support groups was suggestive of higher reported rates of HIV status disclosure.

Measuring Stigma and Social Isolation

In order to measure felt stigma specific to HIV we modified a scale that has been used for individuals suffering mental illness. The six item scale included the following questions, to which respondents were asked to report whether these things had happened “never, seldom, sometimes, often, or very often”:

1. I have worried that others will view me unfavorably because I am HIV+.
2. I have been in situations where I have heard others say unfavorable or offensive things about people with HIV.
3. I have avoided telling others outside my immediate family that I am HIV+.
4. I have been treated as less competent by others when they learn that I am HIV+.
5. I have been treated fairly by others who know I am HIV+.
6. Friends who learned I am HIV+ have been supportive and understanding.

We conducted a statistical test to measure the strength of the scale – in other words, how well a specific combination of the items listed above “hang together.” It happened that the first four items were moderately interrelated (based upon a test of scale validity, measured as a Cronbach’s alpha of .47), so we selected those four items as the stigma scale. If individuals reported that the first four items had happened “never or seldom” we scored that as “no self-reported stigma.” If individuals reported these events occurring “sometimes” we recorded it as “moderate” stigma, and if individuals indicated that these items occurred “often” or “very often” we considered it a score of “high” felt stigma.

To explore the issue of social isolation we considered two factors: the level of self-disclosure of a respondent’s HIV serostatus, and the strength of his or her informal social support network. Our assumption was that individuals who did not disclose their HIV status to many people tended to isolate themselves, particularly when it comes to requiring help related to the disease. Similarly, individuals who had few people to turn to for basic help or tasks, such as coming to their aid in their home, or watching their children for twenty minutes, were considered similarly to be relatively isolated.

A series of analyses were conducted to determine whether self-reported stigma or the measures of social isolation varied by population subgroups. We examined sociodemographic differences (gender, race/ethnicity, age, education, and annual household income), and risks and resources (HIV risk, geographical type, housing stability, insurance, and drug use). We also explored whether stigma and social isolation are correlated to one another, and whether there is any relationship between stigma or social isolation and elements of the HIV care system.

Table 1. Perceptions of Stigma: Sociodemographic Differences
(Tri-County CHAIN data, 2001-2002; row percentages)

Characteristic ¹	n	No Self-Reported Stigma	Moderate Self-Reported Stigma	High Self-Reported Stigma
FULL COHORT	398	6%	18%	77%
Gender				
<i>Male</i>	204	5%	22%	73%
<i>Female</i>	194	6%	14%	80%
Race				
<i>Black, non-Hispanic</i>	197	7%	17%	76%
<i>White, non-Hispanic</i>	82	6%	18%	76%
<i>Hispanic/Latino</i>	110	3%	18%	79%
<i>Other</i>	9	11%	22%	67%
Age categories*				
<i>20-34 years old</i>	48	4%	6%	90%
<i>35-50 years old</i>	275	4%	19%	77%
<i>51+ years old</i>	75	12%	20%	68%
Education (n=377)				
<i>Less than HS educ</i>	140	5%	17%	78%
<i>>=HS educ</i>	237	5%	19%	76%
Annual Household Income (n=369)				
<i>Less than \$10,000</i>	186	6%	16%	78%
<i>\$10,000 - \$24,999</i>	116	3%	24%	72%
<i>\$25,000 - \$44,999</i>	46	7%	20%	74%
<i>Greater than \$45,000</i>	21	0%	14%	86%

¹ Cells represent the percentage of CHAIN participants scoring LOW, MODERATE, or HIGH on a set of questions measuring self-perceived stigma. The cells represent row percentages.

* p < 0.05

**p < 0.01

*** p < 0.001

Table 2. Perceptions of Stigma: Resources & Risk Factor Differences
(Tri-County CHAIN data, 2001-2002; row percentages)

Characteristic ¹	n	No Self-Reported Stigma	Moderate Self-Reported Stigma	High Self-Reported Stigma
FULL COHORT	398	6%	18%	77%
HIV Risk				
<i>MSM</i>	62	5%	19%	76%
<i>Problem Drug Use</i>	164	5%	23%	72%
<i>MSM + Problem Drug Use</i>	19	0%	26%	74%
<i>Heterosexual & Other</i>	153	7%	11%	82%
Geography				
<i>Urban Westchester</i>	213	7%	18%	76%
<i>Suburban Westchester & Putnam</i>	112	4%	20%	76%
<i>Rockland</i>	73	4%	15%	81%
Housing Stability				
<i>Stably Housed</i>	328	6%	19%	74%
<i>Unstably Housed or Doubled-Up</i>	70	1%	11%	87%
Insurance				
<i>Medicaid</i>	266	6%	18%	76%
<i>ADAP+</i>	65	5%	15%	80%
<i>Private</i>	33	6%	24%	70%
<i>Other public</i>	28	0%	18%	82%
<i>None</i>	6	0%	17%	83%
Substance Abuse				
<i>Never used drugs</i>	137	5%	14%	81%
<i>Former drug user</i>	196	7%	19%	74%
<i>Current drug user</i>	65	3%	23%	74%

¹ Cells represent the percentage of CHAIN participants scoring LOW, MODERATE, or HIGH on a set of questions measuring self-perceived stigma. The cells represent row percentages.

* p < 0.05

**p < 0.01

*** p < 0.001

Table 3. The Relationship of Stigma and Social Isolation*(Tri-County CHAIN data, 2001-2002; row percentages)*

Characteristic ¹	n	No Self-Reported Stigma	Moderate Self-Reported Stigma	High Self-Reported Stigma
FULL COHORT	398	6%	18%	77%
By Disclosure of HIV Serostatus (n=371)				
<i>No one knows serostatus</i>	25	4%	20%	76%
<i>Some family & friends know status</i>	41	5%	7%	88%
<i>Many family & friends know status</i>	305	5%	20%	75%
By Social Support Network (aggregate)*				
<i>No functional network of family & friends</i>	43	12%	7%	81%
<i>Strong functional network of family & friends</i>	355	5%	19%	76%
By Social Support Network (detailed)				
<i>Can count on family or friends for everyday favors such as getting a ride, borrowing money, or errands</i> yes	256	5%	18%	76%
<i>Can count on family or friends for everyday favors such as getting a ride, borrowing money, or errands</i> no	142	6%	17%	77%
<i>Can count on family or friends to take care of R if confined to bed for several weeks</i> yes	282	5%	20%	75%
<i>Can count on family or friends to take care of R if confined to bed for several weeks</i> no	116	6%	14%	80%
<i>Can count on family or friends to talk about troubles with family relationships</i> yes	264	6%	21%	73%
<i>Can count on family or friends to talk about troubles with family relationships</i> no	134	5%	12%	83%
<i>Can count on family or friends to come to R's aid if s/he had an accident in the home</i> yes	318	5%	20%	75%
<i>Can count on family or friends to come to R's aid if s/he had an accident in the home</i> no	80	8%	8%	85%
<i>Can count on family or friends to "hang out with just for fun"</i> yes	277	5%	21%	74%
<i>Can count on family or friends to "hang out with just for fun"</i> no	121	7%	10%	83%
Access to a car				
<i>Has access to a car</i>	166	5%	13%	82%
<i>Does not have access to a car</i>	232	6%	21%	73%

¹ Cells represent the percentage of CHAIN participants scoring LOW, MODERATE, or HIGH on a set of questions measuring self-perceived stigma. The cells represent row percentages.

* p < 0.05

**p < 0.01

*** p < 0.001

Table 4. Perceptions of Social Isolation: Sociodemographic Differences
(Tri-County CHAIN data, 2001-2002; row percentages)

Characteristic ¹	n	HIV Status Disclosure			Social Networks	
		No one knows status	Few family or friends know status	Many family or friends know status	Strong functional network of family or friends	No functional network of family or friends
FULL COHORT	398	7%	11%	82%	89%	11%
Gender (n=371/398)						
Male	204	6%*	7%	87%	87%	13%
Female	194	7%	16%	77%	92%	8%
Race (n=371/398)						
Black, non-Hisp	197	9%	14%	77%	87%	13%
White, non-Hisp	82	3%	6%	91%	96%	4%
Hispanic/Latino	110	7%	11%	82%	88%	12%
Other	9	0%	0%	100%	89%	11%
Age categories (n=371/398)						
20-34 years old	48	7%*	23%	70%	90%	10%
35-50 years old	275	5%	9%	85%	91%	9%
51+ years old	75	12%	10%	78%	83%	17%
Education (n=366/377)						
Less than HS educ	140	10%**	17%	73%	93%	7%
>=HS educ	237	5%	8%	87%	93%	7%
Annual Household Income (n=358/369)						
Less than \$10,000	186	8%	14%	78%	90%	10%
\$10,000 - \$24,999	116	8%	6%	86%	95%	5%
\$25,000 - \$44,999	46	2%	11%	87%	96%	4%
> \$45,000	21	5%	5%	90%	100%	0%

¹ Cells represent the percentage of CHAIN participants scoring LOW, MODERATE, or HIGH on a set of questions measuring self-perceived stigma. The cells represent row percentages.

Note: Denominators noted in parentheses relate first to number of respondents answering questions about disclosing their HIV status, and the second number to those respondents answering questions about the strength of their personal networks.

* p < 0.05

**p < 0.01

*** p < 0.001

Table 5. Perceptions of Social Isolation: Resources & Risk Factor Differences
(Tri-County CHAIN data, 2001-2002; row percentages)

Characteristic ¹	n	HIV Status Disclosure			Social Networks	
		No one knows status	Few family or friends know status	Many family or friends know status	Strong functional network of family or friends	No functional network of family or friends
FULL COHORT	398	7%	11%	82%	89%	11%
HIV Risk						
<i>MSM</i>	62	2%*	7%	92%	94%	6%
<i>Problem Drug Use</i>	164	6%	9%	84%	89%	11%
<i>MSM + Problem Drug Use</i>	19	0%	0%	100%	89%	11%
<i>Heterosexual & Other</i>	153	10%	17%	73%	88%	12%
Geography						
<i>Urban Westchester</i>	213	8%*	8%	85%	91%**	9%
<i>Suburban Westchstr & Putnam</i>	112	8%	11%	81%	7%	93%
<i>Rockland</i>	73	3%	21%	76%	22%	78%
Housing Stability						
<i>Stably Housed</i>	328	6%	10%	84%	90%	10%
<i>Unstably Housed / Doubled-Up</i>	70	11%	17%	72%	86%	14%
Insurance						
<i>Medicaid</i>	266	8%*	10%	83%	88%*	12%
<i>ADAP+</i>	65	5%	24%	71%	88%	12%
<i>Private</i>	33	6%	6%	88%	100%	0%
<i>Other public</i>	28	0%	4%	96%	96%	4%
<i>None</i>	6	33%	0%	67%	67%	33%
Substance Abuse						
<i>Never used drugs</i>	137	10%***	20%	70%	89%	11%
<i>Former drug user</i>	196	5%	7%	88%	88%	12%
<i>Current drug user</i>	65	7%	5%	88%	94%	6%

¹ Cells represent the percentage of CHAIN participants scoring LOW, MODERATE, or HIGH on a set of questions measuring self-perceived stigma. The cells represent row percentages.

* p < 0.05

**p < 0.01

*** p < 0.001

Table 6. The Relationship of Stigma and the HIV Care System
(Tri-County CHAIN data, 2001-2002; row percentages)

Characteristic ¹	n	No Self-Reported Stigma	Moderate Self-Reported Stigma	High Self-Reported Stigma
FULL COHORT	398	6%	18%	77%
Barriers to care				
<i>Has experienced barriers to medical care or social services</i>	140	3%	20%	77%
<i>Has not experienced barriers to medical care or social services</i>	258	7%	17%	76%
Service utilization: Case Management/Counselor				
<i>Has a case manager/counselor</i>	80	3%	16%	81%
<i>Doesn't have case manager/counselor</i>	318	6%	18%	75%
Service utilization: Mental Health Provider				
<i>Has visited a psychologist, psychiatrist, social worker, or clergy for mental health issues in past 6 mos</i>	91	2%	15%	82%
<i>Has NOT visited a psychologist, psychiatrist, social worker, or clergy for mental health issues in past 6 mos</i>	307	7%	19%	75%
Service utilization: Support Group				
<i>Has attended a support group in past 6 months</i>	103	4%	18%	78%
<i>Has NOT attended a support group in past 6 months</i>	295	6%	18%	76%

¹ Cells represent the percentage of CHAIN participants scoring LOW, MODERATE, or HIGH on a set of questions measuring self-perceived stigma. The cells represent row percentages.

Note: The categories of service utilization referred to in the table above all refer to services reported by respondents to address psychological or mental health needs

* p < 0.05

**p < 0.01

*** p < 0.001

Table 7. The Relationship of Social Isolation and the HIV Care System
(Tri-County CHAIN data, 2001-2002; row percentages)

Characteristic ¹	n	HIV Status Disclosure			Social Networks	
		No one knows status	Few family or friends know status	Many family or friends know status	Strong network of family or friends	No network of family or friends
FULL COHORT	398	7%	11%	82%	89%	11%
Barriers to care						
<i>Has experienced barriers to medical care or social services</i>	140	6%	12%	83%	95%**	5%
<i>Has not experienced barriers to medical care or social services</i>	258	7%	11%	82%	86%	14%
Service utilization: Case Management						
<i>Has a case manager</i>	80	8%	5%	87%	90%	10%
<i>No case manager</i>	318	6%	13%	81%	89%	11%
Service utilization: Mental Health Provider						
<i>Has visited a psychologist, psychiatrist, social worker, or clergy for MH issues in past 6 mos</i>	91	7%	12%	81%	92%	8%
<i>Has NOT visited a psychologist, psychiatrist, social worker, or clergy for MH issues in past 6 mos</i>	307	7%	11%	82%	88%	12%
Service utilization: Support Group						
<i>Attended a support group in past 6 months</i>	103	3%**	5%	92%	91%	9%
<i>NOT attended a support group in past 6 mos</i>	295	8%	13%	79%	88%	12%

¹ Cells represent the percentage of CHAIN participants scoring LOW, MODERATE, or HIGH on a set of questions measuring self-perceived stigma. The cells represent row percentages.

* p < 0.05

**p < 0.01

*** p < 0.001

Note: The categories of service utilization referred to in the table above all refer to services reported by respondents to address psychological or mental health needs

DATA & METHODOLOGY

Background

The purpose of the Tri-County CHAIN Study is to assess the impact of the full continuum of services delivered to HIV positive persons living in Westchester, Rockland, and Putnam counties, and to identify unmet needs for services. The interviews for this study present quantitative profiles of respondents' needs for health and human services, their encounters with health care and social service organizations, their satisfaction with services, and their current health status. The people who participated in the baseline survey are being re-interviewed at approximately annual intervals.

In 2001, the Planning and Evaluation Subcommittee of the New York HIV Health and Human Services Planning Council authorized the Westchester Department of Health (WDOH) and Medical and Health Research Association of New York City, Inc. (MHRA), to develop a longitudinal study of Tri-County residents living with HIV similar to the existing New York City longitudinal project. The Mailman School of Public Health at Columbia University was contracted by MHRA to conduct the survey and carry out analyses of survey data.

Sample Design

One of the major goals of this study is to assemble a cohort that is broadly representative of all Tri-County residents living with HIV. The simplest strategy for achieving this goal, drawing a random household sample, is not feasible because persons with HIV are relatively rare in the population, and many are, for good reason, reluctant to disclose their HIV seropositive status. Therefore, to approximate the ideal sample, several sampling strategies were developed.

Agency-based random recruitment

The first strategy involved sampling clients and patients drawn from rosters of agencies providing medical and social services to persons living with HIV. To achieve a representative sample of clients, a two-step sampling procedure was followed. The first step involved identifying all health and social service agencies in the Tri-County region providing HIV services to at least ten clients. Since there were only 32 agencies or sites of service identified during this procedure it was determined to sample clients from the entire universe of agencies rather than sampling from this list.

The second step involved recruiting a random sample of clients from each participating agency. Random selection of clients was intended to minimize the tendency of agencies to refer their most satisfied and/or easier-to-reach clients. Each agency that agreed to help recruit participants assembled a list containing anonymous identifiers for all persons living with HIV who had contact with the agency within a year of constructing the list, and also designated one of their employees to act as a liaison/coordinator between the Columbia team and the sampled individuals. In order to be eligible for the study, individuals had to be residents of Westchester, Rockland, or Putnam counties, at least 20 years of age, and HIV-positive for at least 6 months. The Columbia team randomly drew between 15 and 25 identifiers from each agency list. The identifiers were returned to the agency coordinators who made initial contact with the sampled

clients to explain the purpose of the study and to determine if they were willing to participate. Only then did the agency coordinator send the names, addresses and telephone numbers of consenting clients to the Columbia field staff to schedule and conduct the interviews.

Agency-based sequential enrollment

In addition the agency-based random recruitment we employed a sequential enrollment strategy, in which all clients present at a given site during a specific time period were invited to participate in the study. Such a strategy could only be used at sites with sufficient numbers of clients (nominally 10-20 clients, at a minimum), who would be present for such a recruitment. The Tri--County CHAIN Field Director would coordinate recruitment with an agency coordinator from the participating agency. The agency would maintain a roster of all eligible clients present during the recruitment period so that a later analysis could be conducted to determine if CHAIN recruited most (or all) eligible clients present, and if those recruited were reasonably representative of all eligible clients present.

Interview Schedule

All interviews are conducted in person by trained interviewers. The major topics covered during the interviews include (1) initial encounter with the health care delivery system, (2) need for services, (3) access, utilization and satisfaction with health and social services, (4) sociodemographic characteristics of respondents, (5) informal caregiving from friends, family and volunteers, and (6) quality of life with respect to health status, psychological and social functioning. The interview schedule was developed based upon a listing of questions under each of these broader topics that was circulated to the Planning and Evaluation Subcommittee, WDOH and MHRA. Whenever possible, interview questions were taken from earlier surveys administered to persons living with HIV and were designed to match questions asked of participants in the New York City CHAIN study. In particular, information on use of health and social services was obtained using questions developed for a federally funded study of AIDS service utilization. Health status was assessed using survey questions that have well established psychometric properties (such as the Medical Outcomes Survey scale, and indices measuring health locus of control, and self-efficacy) and which have been widely administered to HIV positive populations. The interview takes between two and three hours to complete, dependent upon issues relevant to each client's unique service needs. Most interviews were conducted in English, although fifteen were conducted in Spanish and six in Creole. Sixteen of the three hundred and ninety-eight interviews were conducted on an abbreviated survey (a "short form") that captures most of the variables used in analyses. We have tried to note the appropriate denominator in the tables when the item being reported was not a part of the abbreviated form. These short forms were primarily used when respondents were physically or mentally unable to complete the entire survey.

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