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Social Networks 17 (1995) 189–217

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**SOCIAL  
NETWORKS**

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## Who knows your HIV status? What HIV + patients and their network members know about each other <sup>☆</sup>

Gene A. Shelley <sup>a,\*</sup>, H. Russell Bernard <sup>b</sup>, Peter Killworth <sup>c</sup>,  
Eugene Johnsen <sup>d</sup>, Christopher McCarty <sup>b</sup>

<sup>a</sup> *Georgia State University, Atlanta, GA 30341, USA*

<sup>b</sup> *University of Florida, Gainesville, FL 32611, USA*

<sup>c</sup> *NERC Oceanography Unit, Oxford, OXI 3PU, UK*

<sup>d</sup> *University of California, Santa Barbara, CA 93106, USA*

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### Abstract

This research reports on an analysis of personal network data collected from 70 HIV-positive HIV/AIDS patients (48 men, 22 women; 45 black, 25 white). Issues examined were the conditions surrounding the difficulty of knowing information about social network members, including knowledge of HIV status. The stigmatizing nature of AIDS resulted in selective knowledge regarding a person's HIV status (and other information) among their social network members. Informants' networks appeared smaller than those for other groups we have investigated, and this may be due to informant self-limiting, or alter rejection of HIV informant. These results will be useful in determining the amount of HIV + in the general population, and these methods could be applied to other hard-to-count populations.

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### 1. Introduction

Previous research has attempted to use social network methods to estimate hard-to-count populations, specifically the incidence of HIV-positive individuals (Bernard et al., 1989, 1991; Laumann et al., 1989, 1993; Killworth et al., 1990, 1995;

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<sup>☆</sup> This work was conducted under NSF grant No. SBR-9213615. Much of the analysis took place with the welcome hospitality of the Bureau of Economic and Business Research at the University of Florida, which also provided computing support. We are also indebted to Georgia State University for providing office space for some of the interviews. In addition, we would like to thank Howard Kress and Craig Lindsey for assisting with some of the data collection. Most of all, we are extremely grateful for the time, energy and openness of all the HIV-positive individuals who participated in these interviews.

\* Corresponding author, at 2517 Roseberry Lane, Grayson, GA 30221, USA.

Johnsen et al., 1995). Our previous methods have proposed an average social network size of around 1700 (cf. Freeman and Thompson, 1989; Killworth et al., 1990; Johnsen et al., 1995). As discussed in Johnsen et al., this estimate is corroborated by the results of a survey of a representative sample of 1451 surgeons in the US (Shelley and Howard, 1992). The methods are based on asking people if they know someone in a specific hard-to-count population (i.e. the HIV-positive population) and also if they know people in various known populations and countable subpopulations. Then these known population sizes are used to predict personal social network size and the size of specific 'unknown' populations.

These methods have predicted an average network size of about 466 for random samples of US households in the General Social Surveys of 1988, 1989, 1990, 1991 and 1993, based on respondent knowledge of AIDS victims. One interpretation of these results could be that the personal social network (for brevity, henceforth 'network') size for AIDS victims is only about one-third of that of the general population (Johnsen et al., 1995). On the other hand, these results could be due to lack of respondent knowledge of the existence of persons with AIDS in their network.

A person's HIV status may not be information that is widely disseminated throughout that person's network. As there is some social stigma associated with being HIV-positive (Hardy, 1990; McCaig et al., 1991; Barr et al., 1992), this information is likely to be more constricted than other types of information. If information is constrained in some way, then it is important to our method to discover the circumstances of transmission of that information to the members of that person's network.

We assume, as a working hypothesis, that the networks of people who are HIV-positive and those who have never even been exposed to HIV are approximately the same size. Then, if information about being HIV-positive were restricted to only one-third of the total network, the anomalies in the derived network sizes found by our previous methods would disappear.

This study was designed to look in more depth at information transmission in the HIV-positive population, including specifically who receives information on HIV status. Some questions asked were: (1) Is the network of HIV-positive individuals really smaller than that of those who are not HIV-positive? (2) Is knowledge of HIV status limited? (3) What are the socio-demographic characteristics (i.e. gender, race) and other factors governing who gets personal information such as HIV status? (4) Does knowing HIV status mean that one limits other information about their network members? (5) What are the hardest things to know about someone and will they help us predict who knows someone's HIV status?

## 2. Methods

The data in this study come from in-depth, semi-structured interviews conducted with 70 HIV-positive individuals. Informants responded to a research

advertisement posted at several locations (meeting places, hospitals and clinics) that served HIV-positive clientele. Informants were paid a nominal fee for participation and were assured of individual confidentiality. Interviews lasted an average of 3 hours. The length of the interview varied as a result of scheduling problems, the health of the informant and the number of social network members mentioned in the interviews.

### *2.1. Personal data and the ethnographic interview*

We began the interviews by asking informants about their gender, race, age, sexual preference, education, etc. We then asked them about whom they had told of their HIV status and what factors determined their divulging this information. We were interested in who knew particular information, but since this can come by circuitous routes, and much informant inaccuracy can occur in reports of these routes, we chose to use only the simpler question. Finally, we asked informants to tell us some of their personal experiences with being HIV-positive and their family's and friends' reactions to their HIV status.

### *2.2. Rating task*

Each person was asked to evaluate a list of 30 items that people could know about one another (Table 1). Informants rated each item on a 1–5 scale according to how easy they thought it was, in general, to know each item about their network members.

### *2.3. Network generators*

Next, we began building the informant's network, using several network generators in order to get a cross-section of the entire social network, including both intimates and acquaintances. For all network generators, the definition of 'knowing' someone was that the informant and the alter could recognize one another and that there had been some contact with the alter in the last 3 years. 'Contact' could have been by phone, mail or in person. The network generators were:

*First names.* We asked informants which of 40 first names represented people whom they knew and had contact with in the past 3 years.

*Occupations.* For each of 50 occupations (auto mechanic, surgeon, etc.) we asked informants "Do you know anyone who is a(n) X?"

*GSS.* The 1986 General Social Survey contained a single question network generator: Whom have you talked to about important, confidential matters in the last 6 months?

Table 1  
The 30 items of knowledge about others that were evaluated by informants about their alters

1	Type of usual work or occupation
2	Work status (working or not)
3	Marital status
4	Approximate income
5	Educational level attained
6	Number of siblings
7	Birthplace
8	Current address
9	Number of children
10	Age
11	Real first name
12	Political party
13	Religious preference
14	Whether or not one is a member of a labor union
15	Whether one has ever been on active duty for military training or service for at least 2 consecutive months
16	Whether or not one has ever been punched or beaten by another person
17	Whether one has ever been threatened by a gun or shot at
18	Whether during the last year someone broke into or somehow illegally got into one's apartment or home
19	Whether during the last year someone took something directly from one by using force
20	Membership of groups or organizations
21	Amount of time lived in current community and address
22	HIV status
23	General health status
24	Blood type
25	Whether or not one has a criminal record
26	Whether or not one has ever been on drugs
27	Sexual preference
28	Most important problems that one or members of one's household has had during the last 12 months
29	Major events that happened to one during the last 12 months
30	Travel during the past 12 months

*Myers.* Who is important to you? This question comes from the Myers Resources and Social Support Instrument (Myers, 1981).

*Fischer and McCallister.* The questions forming this generator were a modified version of an instrument used by Fischer and McCallister (1983). We have also used this modified version in our previous research (Bernard et al., 1990, 1991; Killworth et al., 1990; Shelley, 1992). This generator poses questions concerning who would give advice or provide support with common problems.

1. Who would take care of your house if you went out of town?
2. If you work outside of your home, who would you talk to about work decisions?

3. Who, if anyone, has helped with household tasks in the last 3 months?
4. With whom have you engaged in social activities in the last 3 months (such as going to movies, had over for dinner, etc.)?
5. Who do you talk to about hobbies?
6. Who is your 'best friend'?
7. Who do you talk to about personal worries?
8. Who do you get advice from when making important decisions?
9. If you needed a large sum of money, who could you borrow it from?
10. Who are the adult members of your household, excluding you?
11. Who do you feel especially 'close to'?

*Phone book method.* This generator consisted of 305 last names randomly selected from a phone book in a major city. the method was first used by Poole in the 1950s (Poole, 1978) and was further developed by Freeman and Thomson (1989). In this study we used a list we had used in our earlier research and the Freeman and Thompson list. Informants were randomly given alternate lists.

#### 2.4. *Alter information*

We asked informants a few basic questions about each of their listed alters (i.e. race, gender, marital status, sexual preference), and then asked about the type of relationship (relative, lover, co-worker, friend, enemy, etc.), the length of the relationship and frequency of contact. Informants then evaluated each of the following questions on a 1–5 scale:

1. How close do you feel to this person?
2. How well do you know this person?
3. How influential would this person be in your decision making?
4. Is this person generally a positive, negative or neutral support to you?

#### 2.5. *Reported item knowledge*

Finally, informants went through the list of 30 items (Table 1) and told us (a) whether they knew those things about each of their alters, and (b) whether each alter knew those SAME things about them. Informants were asked not to guess during this exercise but only to report things they DEFINITELY knew about the alter and vice versa.

### 3. Knowledge of HIV Status

#### 3.1. *Description of the sample*

We tried to achieve equal numbers of males, females, blacks and whites as informants for this study, but white female HIV-positives were very hard to locate.

White females are only 3% of known AIDS cases (Centers for Disease Control and Prevention, 1993). However, part of the difficulty in locating white females was the reluctance of women in general to let anyone know their HIV status. At one clinic, there was a separate HIV clinic (on a different floor) for women. This clinic did not have any signs or evidence indicating that it was in fact an HIV clinic. A caregiver at the clinic said that “the women don’t want anything on the walls that says this is an HIV clinic” and no flyers about the research were permitted at this clinic.

The final sample was 70 informants, with 25 whites (5 women, 20 men) and 45 blacks (17 women, 28 men) (Table 2). Since informants were recruited partially through public clinics, this probably eliminated access to some more affluent informants who received medical services from private physicians. However, some informants came to us through city organizations that spanned social and financial statuses.

Table 2 shows the range of informants on several characteristics. Educational background varied from 8 to 18 years of education, with an average of 13 years (s.d. = 2.65). Most informants (72%) identified themselves as being from an urban background. The average age of informants was 36 (s.d. = 6.98; range 22–52) and the average income was just \$8674 (s.d. = 9950.73; range 0–66000), with many informants having no income at all. Some had been homeless or were currently living in halfway houses or with relatives. Some informants had lived in the same place for a long time, but others had moved around a lot. Informants had lived at their current residence 2 years (s.d. = 2.99; range a few days to 15 years). The average time they had lived in Atlanta was 15 years (s.d. = 13.90; with a range of a few days up to 44 years). Most informants (59%) attended support group sessions, but most (63%) did not attend church. Of those claiming a religious preference, most (70%) were Protestants.

Most informants (70%) were not working but some did have full-time (15%) or part-time jobs (9%). According to our informants, most (if not all) co-workers of these informants were unaware that they were working with someone who was HIV-positive. In general, people who worked full time were fearful of losing their jobs if their co-workers became aware of informants’ HIV status.<sup>1</sup>

Most (60%) informants were single, but 20% of informants were cohabiting with someone. Only 2% of informants were married and living with a spouse, but others had been married (11% divorced, 4% separated, 3% widowed).

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<sup>1</sup> This fear is not unfounded. A survey ( $N = 3460$ ) of corporate and public service employees, covering a wide geographic area of the US and involving a variety of organizations (Barr et al., 1992) showed that a substantial minority (about 30%) believed HIV infection could be transmitted through casual contact and were fearful of working with someone who was HIV-positive. In addition, a National Health Interview Survey in the United States found that about one-third of the survey respondents had similar misconceptions about transmission of HIV through casual contact such as shaking hands or sharing public toilets (Hardy, 1990). Misconceptions are more prevalent among African-Americans, Hispanics, persons aged 50 or older and those with less than a high school education (McCaig et al., 1991).

Table 2  
 Characteristics of the 70 informants and the 2534 alters (for questions asked about alters)

Informant			
Race	Women	Men	Total
Black	17	28	45
White	5	20	25
Total	22	48	70
		Informant %	Alter %
Black		64	57
White		36	41
Other race		0	2
Men		69	60
Women		31	40
Years of education (mean 13.01; s.d. = 2.65)		Informant %	
8–11		24	
12		29	
13–16		37	
17–18		10	
Background		Informant %	
Urban		72	
Rural		17	
Mixed		11	
Religion		Informant %	
Protestant		70	
No religion		20	
Catholic		7	
Jewish		1	
Gay church		2	
Work status		Informant %	
Not working		70	
Part-time		9	
Full-time		15	
Marital status		Informant %	Alter %
Cohabiting		20	7
Divorced		11	9
Married		2	23
Separated		4	2
Single		60	45
Widowed		3	2
Don't know		NA	12

Table 2 (continued)

Informant		
Sexual preference	Informant %	Alter %
Bisexual	12	5
Gay	37	22
Straight	51	65
Don't know	NA	8
Cause of HIV + status	Informant %	
Sexual relations	49	
Intravenous drug use	22	
Transfusion	1	
Sex AND IV drugs	17	
Through partner	11	
Health status	Informant %	
Very good	22	
Good	30	
Average	33	
Poor	12	
Very poor	3	

Informants were asked to state their sexual preference. Half (51%) responded that they were heterosexual (straight), while some (37%) replied that they were homosexual (gay) or bisexual (12%). Almost half (49%) thought they had become HIV-positive through sexual contact alone because they had no history of intravenous drug use, while 22% said that they had used IV drugs and thought they could only have been infected through that use. Another 17% had used IV drugs and had had unprotected intercourse, so they could not distinguish between the two as a probable source of their HIV infection.

Only one person became HIV-positive through a blood transfusion. However, 11% became infected through a sexual partner who either had a transfusion, was an IV drug user, or had had unprotected sexual intercourse with another partner. Some informants felt that they had been purposely infected by their partner because the partner was aware of his/her HIV status and did not tell the informant.

Several women said that they got the virus from former husbands or sexual partners who were IV drug users and/or bisexual (which they did not find out until later). One woman was very upset because her partner knew he was HIV-positive and never even suggested using a condom. "He said he wasn't HIV + and we discussed it too. I really hate him for it. He was with another woman right after me. He's going around killing people. I saw him at an AIDS support group and he still denied having HIV."

Informants reported having the HIV virus an average of 5 years (s.d. = 2.86; range 'only just found out' to 14 years). Of those who had been diagnosed as having AIDS, some had been living with AIDS for as much as 6 years and others

had just been diagnosed a few weeks before the interview (mean = 0.43 years, s.d. = 1.08).

Most informants felt fairly healthy, with about 85% reporting that their health status was at least average or better. Their reported average T-cell count was 344 (s.d. = 225.6; range 15–1200). T-cells are a form of white blood cell which normally help the body protect itself against infection. A count of less than 200 cells per microliter of blood indicates severe immunosuppression. Theoretically, the lower one's T-cell count, the 'sicker' one is. However, T-cell count was not always related to how these informants reported they felt. This was confirmed by ANOVAs which showed no statistical significance between T-cell count and reported health status. In fact, some persons with very low counts reported that they felt their health was good, while some who reported a high count said they felt in poor health. Most informants felt the T-cell count was not an accurate method of determining health status, although it is used to determine disability levels. (When the T-cell count drops below 200, then one is said to have AIDS and can collect United States Government disability payments). One informant said, "I'm tempted to go off my meds so my T-cells will drop below 200 and I can get disability benefits. I am too tired to work."

### 3.2. *Social network (alter) characteristics*

The 70 informants in this study generated 2534 alters, or an average of 36 alters each (s.d. = 16.57; range 9–87). As in most social network data, many alters had similar characteristics to informants. Sixty-seven percent of alters were reported to live in the same city as the informant. The average alter age was 34 (s.d. = 12.12), close to the informant average age of 36. Informants were also racially similar to alters (who show a slightly higher percentage of blacks and a slightly lower percentage of whites than found in informant data). Alter data also include other races (Asian, Hispanic, Native American and mixed race).

The alter and informant data were also very similar in the percent of men and women represented, although the alter data showed slightly more women. The marital status of alters represented more married and fewer single people. Some informants did not know the marital status of their alters. The distribution of alter sexual preferences was on average slightly more 'straight' than the equivalent for informants. Again, some informants did not know their alters' sexual preference.

### 3.3. *Relationship characteristics*

Table 3 shows some characteristics of the network relations. Most alters had been known by informants for a year or more. Almost half (46%) of the alters had been known by informants for more than 5 years.

By definition in this study, informants had been in contact with all their alters during the past 3 years, but 15% of alters were not in contact with the informant anymore at the time of the interview. In essence, these alters had 'dropped out' of the informant's network. Other alters (10%) were seen rarely, maybe every year or

Table 3  
 Characteristics of the 2534 informant/alter relations

	Percent of Data
<b>Relationship length</b>	
1 month or less	2
2 – 6 months	9
7 months to a year	14
1.5–2 years	12
2.5–5 years	17
More than 5 years	46
<b>Frequency of contact</b>	
No contact any more	15
Every day	12
Several times a week	12
Once a week	13
Every 2 weeks	8
Once a month	12
Every 2 or 3 months	10
Every 6 months	8
Once a year	6
More than once a year	4
<b>Closeness of alter</b>	
Unfriendly	3
Neutral	17
Not close, but friendly	33
Close	27
Very close	20
<b>How well informant knows alter</b>	
Not known well	10
Known a little	21
Moderately known	28
Well known	21
Known extremely well	20
<b>How influential alter is in informant's decision making</b>	
Not influential	27
Neutral	25
Moderately influential	18
Influential	15
Very influential	15
<b>Support for informant</b>	
Positive support	58
Neutral support	36
Negative support	6

so. About 12% of alters were in daily contact with informants. Approximately one-third each of alters were seen on a more-or-less weekly or monthly basis.

Informants said that they were close or very close with almost half (47%) of the alters. They thought they knew many alters a small or moderate amount (49%), or even well or extremely well (41%).

Informants deemed 52% of alters noninfluential, 18% as moderately influential, and 30% as having a great deal of influence on their decisions. Influence was determined in two ways. One was whether or not the informant would listen to and follow the advice of certain alters (who turned out generally to be parents or people the informant admired). The other was whether the informant's decision impacted the alter. For example, even a child or infant would be deemed as influencing the decision-making of the informant because the informant would consider the child's welfare in making decisions.

Fifty-eight percent of alters were said to be a positive support for informants, 36% were reported to be neutral in terms of support, and 6% were judged to be a negative support. Some of these alters were relatives or lovers who had reacted badly to the HIV status of the informant.

### *3.4. Social network size*

One important question in this research was "Do HIV + individuals have smaller networks?" Killworth et al. (1995) addresses this question using the mathematical methods we have used in the past. Table 4 examines the network generators directly for differences in network size among the populations we have studied. However, these network members were retrieved in response to these specific generators, and the members are 'active' in the sense that informants and alters have been in contact during the last 3 years. Thus they might be called 'active, generated networks' and would be a portion of an individual's 'total personal social network.' Since this is true for all the populations in Table 4, it is possible to make comparisons in these active, generated networks. Two of the populations comprised 'healthy' informants from Jacksonville, Florida, and Mexico City, Mexico. The other two populations (HIV + and dialysis patients) were under medical care for their respective illnesses. We surmised that being ill would restrict network size.

Indeed, the networks of the 'healthy' Jacksonville informants were larger than the networks of either the dialysis informants or the HIV + informants. Table 4 shows that the HIV + total generated network size is 18.22, which was computed by adding the average network size retrieved from each of the GSS, Fischer and Phone Book network generators. This number is less than half the size of Jacksonville informants' total network size (40.21). Although the Mexico City informant network sizes were smaller than those of the Jacksonville informants (possibly due to cultural differences in understanding the generators), they are comparable to the dialysis patients and the HIV + group. However, note that HIV + informants reported a larger GSS network than Mexico City informants.

Table 4

Average number of alters (s.d. in parentheses) retrieved by the network generators indicated for several populations of study, including HIV-positive individuals, dialysis patients, 'healthy' people in Jacksonville, Florida, and 'healthy' people in Mexico City

Network generator	HIV + ( <i>N</i> = 70)	Populations of study		
		Dialysis ( <i>N</i> = 53)	Jacksonville ( <i>N</i> = 98)	Mexico City ( <i>N</i> = 99)
GSS	4.33 (2.74)	1.68 (2.29)	6.88 (4.89)	2.95 (2.66)
Fischer	9.99 (6.99)	10.53 (5.66)	21.82 (16.7)	10.05 (6.45)
Phone Book	3.90 (5.10)	3.70 (4.18)	11.51 (11.32)	4.20 (7.66)
Total	18.22	15.91	40.21	17.20
Average Network (size using above three generators)	6.07	5.30	13.40	5.73
Myers	7.39 (5.75)	12.26 (7.29)	NA	NA

This is understandable, since the GSS question concerns talking to others about confidential matters.

It appears from these data that the 70 HIV + informants in this study do, in fact, have smaller networks. The Phone Book instrument retrieved a network which was 34% of the size of the Phone Book portion of the Jacksonville network, i.e. very close to the 33% hypothesized. In two cases of life-threatening illness (HIV + and dialysis patients) we see similar attenuation of networks.

Some HIV + individuals told us explicitly in the interviews that they reduced their interaction with unsupportive people and perhaps individuals who were going to die soon. One said, "it makes you not want to meet people, not invest the time in them because time is short." Another was trying to protect his family and friends by 'distancing' himself "in case something bad happens," to spare them the pain of his death.

Many informants discussed the heartache of seeing the people they cared about die. One man said, "I have a couple of friends but you have to love people from a distance and not get too close to them. You won't have to discuss your HIV status or feel bad when they die." Another who has been HIV + for many years said:

In 5 years, I've seen more die than they (his parents) have in 75 years. Three-fourths of my friends are dead. It's quite a psychological thing to deal with. I have a lot of trouble peer wise, watching all my friends die. Sometimes my whole body shuts down inside. I don't want to know people who are going to die. There are 3 or 4 people a week in the obits. We all watch the obits.

This is visible in Table 4, showing the much lower average of 'important' people (retrieved by the Myers generator) among the HIV + informants' (7.39) networks than among the dialysis patients (12.26).

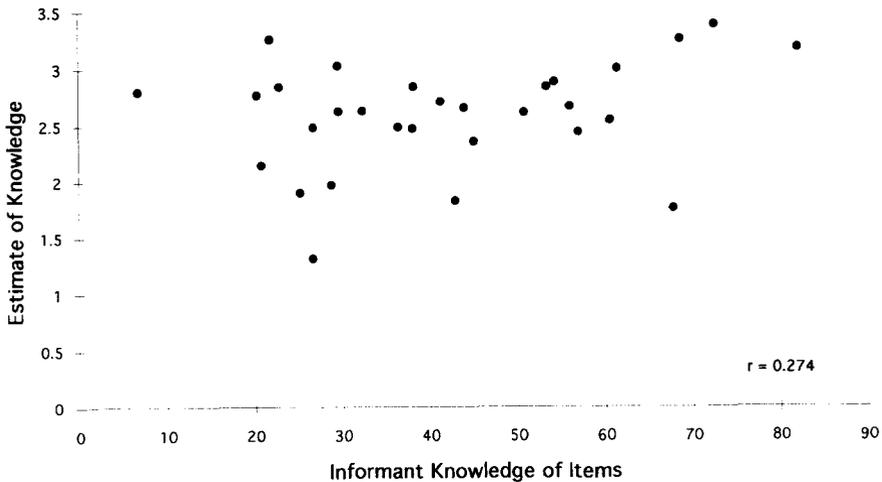


Fig. 1. Correlation between informants' estimation of difficulty of knowing versus actual difficulty of knowing items.

### 3.5. Estimating difficulty of knowing

Recall that we asked informants to rate how easy it was to know the 30 items about their alters. Fig. 1 shows the correlation between the informants' estimation of difficulty compared to the actual difficulty (as measured by the percentage of items known about alters). As is evidenced by the random scatter of points on this figure ( $r = 0.274$ ), these informants are not able accurately to estimate difficulty of knowing.

Some informants commented that they could 'recognize' certain traits in an alter (sexual preference, criminal record or drug use) because of having had similar experiences. Other things, like type of work, marital status, number of children, etc., were said by some informants to be obvious from appearances. One informant evaluated what he might know about others as low because "people lie so much". Another person said he would be well aware of practically all the items in Table 1 about his alters because "I demand honesty from my friends."

### 3.6. Differences between alter and informant knowledge

Informants were asked to indicate whether or not they knew any of the 30 items about each alter on their alter list, and also if those alters knew that same information about the informant. Fig. 2 shows the high correlation between informant and alter knowledge ( $r = 0.968$ ). Thus the points are very close to a straight line which could be drawn through these data.

A little more than half the time informants know more about the alter than vice versa. (Fig. 3 shows which specific items are higher for informants.) Thus, informants claim that they know slightly more about their alters than their alters know

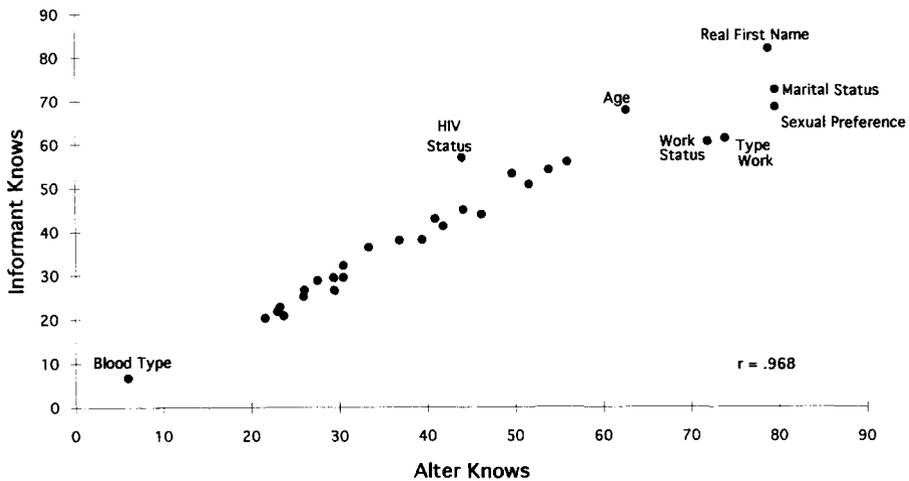


Fig. 2. Correlation between informant and alter knowledge of 30-item list.

about them. Most of the differences between alter and informant knowledge lie in the highest percentages. The largest differences between alter and informant knowledge occurred in item HIV status, wherein informants claimed to know more about the HIV status of their alters than their alters knew about informants.

This is due in part to the fact that most informants do limit who knows their HIV status. In addition, some informants told us they 'know' particular alters are HIV-positive because of the symptoms exhibited by those alters. In some of these cases the alters themselves had not actually been tested. Informants often said they or their alters were afraid of finding out they were HIV-positive and so avoided being tested.

Other items with larger percentage differences (all in favor of the alter knowledge) were marital status, sexual preference, age, type of work, and work status, all of which were higher for alters. Informant and alters had equal percentages for current address.

We wanted to see which items are LESS known than HIV status, and surmised that there would be many more items better known than HIV status. We thought that if one knows the items harder to know than HIV status, then one will surely know the HIV status. However, as seen in Fig. 3, there are 23 HARDER items to know than HIV status. Clearly the hardest item to know about someone was (predictably) blood type. Next hardest was political party and membership of a labor union. Intuitively, these items will be known almost exclusively by well-known alters.

The average number of items known by alters about the informant was 13 (s.d. = 9.01; range 0–30). Informants said only 27 alters (out of  $N = 2534$ ) knew nothing at all about them, and said that 108 alters knew just one thing. The highest percentage of items known by alters about informants was 152 people (6%) who knew six things about the informant.

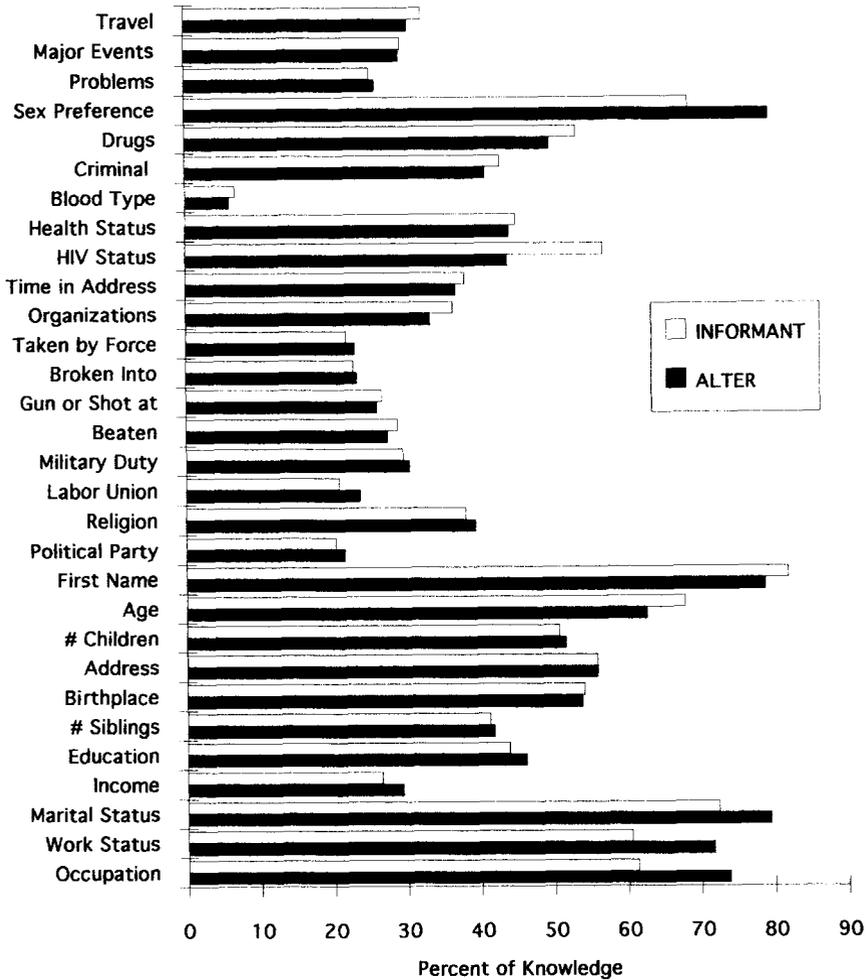


Fig. 3. Percent of alter and informant knowledge.

The average number of items known by an informant about alters was also 13 (s.d. = 8.95; range 0–30). Informants said that they knew nothing at all about only 14 alters, and for 76 of them informants only knew one thing. The highest percentage known by informants about alters was 7.9% (201 alters) who knew 29 things about the alters.

### 3.7. Differences in knowledge by relation type

The informants reported the type of relation of each alter. These responses, grouped into categories, are shown in Table 5. Most (47%) alters were relatives or friends (31%). Some alters (9.7%) were in the same organization, which most of

Table 5

Types of relations reported by informants and percentage of these types represented in the data. Also shown are the percentages of the types of relations who know the alters' and informants' HIV status.  $N = 2534$  in all cases

Type of relation	Alter % in data	Alter % knowing HIV status	Informant % knowing HIV status
Relative	47.0	49.0	39.4
Friend	31.3	61.5	47.9
Same organization	9.7	73.9	60.0
Medical personnel	3.6	94.4	23.3
Work-related	3.5	47.7	42.0
Former <sup>a</sup>	2.4	61.3	51.6
Other <sup>b</sup>	2.0	42.0	42.0
Missing data	0.6	33.3	33.3

<sup>a</sup> Former lover, co-worker, school mate, teacher, boss, etc.

<sup>b</sup> Neighbor, acquaintance, enemy.

the time meant the same support group. We examined whether or not a particular type of relation was likely to know the informants' HIV status. As expected, medical personnel (95%) and those in the same organization (74%) had a high percentage of knowledge of informants' HIV status. One HIV-positive man said, "I would tell my support group. Everyone there is HIV-positive and I'm comfortable there."

Friends and 'formers' (former lover, neighbor, co-worker, etc.) were almost equally likely to have this information about informants (about 60% knew). Less than half (49%) of the relatives were privy to informant HIV status, which was barely above the percentage (42%) of 'others' (including acquaintances, current neighbors, enemies) who possessed this information. Thus relatives did not possess as much knowledge about informant HIV status as we expected. The informants themselves explain this.

A white female said,

I didn't tell Mom, because she has made a couple of comments, things like the government infecting people and (her mother said) 'being around them is gonna make it happen'. I have not told ANY family (Mom or my sister). Friends in the (support) group are the only ones who know. The only two people, aside from members of my support group and doctors, who know are my former lover (who gave her the HIV) and my son's father.

A gay, white male said,

I told my brother and he said he was (HIV +). She (my mother) had just found out about my brother in 1986–87 but had never talked about it. I don't think she wants to know. We had the first discussion last week. My father is alcoholic and

she is afraid if he finds out he may go back (to being an alcoholic). Probably my mother doesn't want to accept it although she does ask about my health.

A black woman said,

The only people who know are my Mom and sisters. I have not even told my twin brother.

A black man said,

I wouldn't tell my father. He wouldn't understand. He knows that I go to support groups but he thinks it is for my addiction.

These statements also illustrate the importance of support groups and show why the percent of knowledge of HIV status among support groups is so high (Table 5).

### 3.8. *Gender and race differences in knowledge*

Since we interviewed informants but not their alters, data about what informants know about their alters should be more reliable than data about what they think alters know about them. In discussing differences between genders and races, we consider only informant percentages of knowledge.

#### 3.8.1. *Differences by gender*

Fig. 4 shows the differences in the amount of knowledge that informants have about their alters, separated by gender of informant. In most cases, male informants knew a larger percentage of information, although the differences between men and women were not great. The exceptions to higher knowledge by females were number of children, real first name, criminal record, drug record and major events in the last 12 months. These items may seem to be likely to be known by women, especially perhaps female relatives of informants. However, blood type was known by 6.8% of male informants vs. 4.8% of female informants. A greater percentage of men (47.3) than women (35.8) knew their alter's HIV status.

#### 3.8.2. *Differences by race*

Several items were virtually identical for both black and white informants: educational level, number of children, punched or beaten, problems, and major events. However, white informants had a tendency to know more about their alters than did the black informants (Fig. 5).

Blacks knew a greater percentage of information for 10 of the 30 items. Some items may reflect the traditional values of family and religion – number of siblings, birthplace, age, real first name, religious preference, group membership, and blood type. Black informants were more than twice as likely to know their alters' blood type (7.8% vs. 3%) than were white informants.

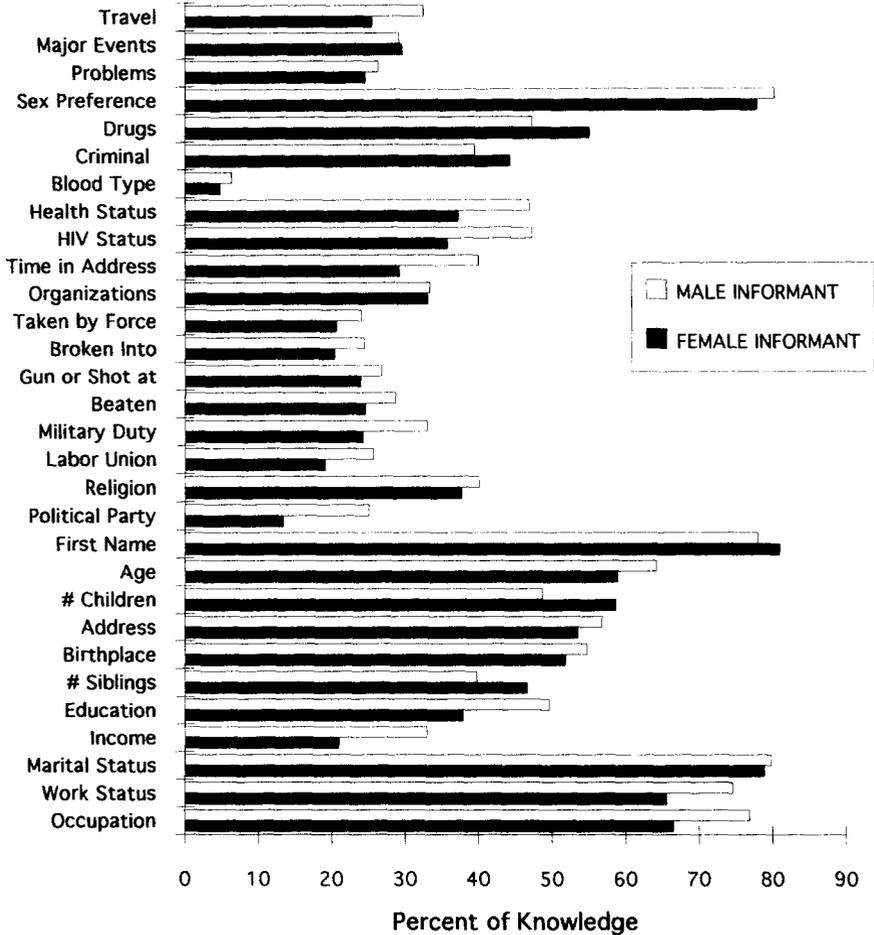


Fig. 4. Differences in amount of knowledge informants have about their alters, shown by gender of informant.

Blacks also knew more about alters' criminal record and drug record, and whether the alter has been threatened by a gun or shot at. This may reflect their disproportionate experiences with crime and drugs. Many black HIV + informants in this study reported acquiring the virus through IV drugs, while whites were more likely to state that they acquired the virus through homosexual relations.

The items known more by whites concerned job, marital status, sexual preference, income, political party, union membership, amount of time in current community and address, and general health status.

White informants had greater knowledge about their alters' HIV status (54% vs. 38%) than did black informants. Reardon et al. (1993) reported that although black IV drug users had a higher HIV infection rate, they were three times less

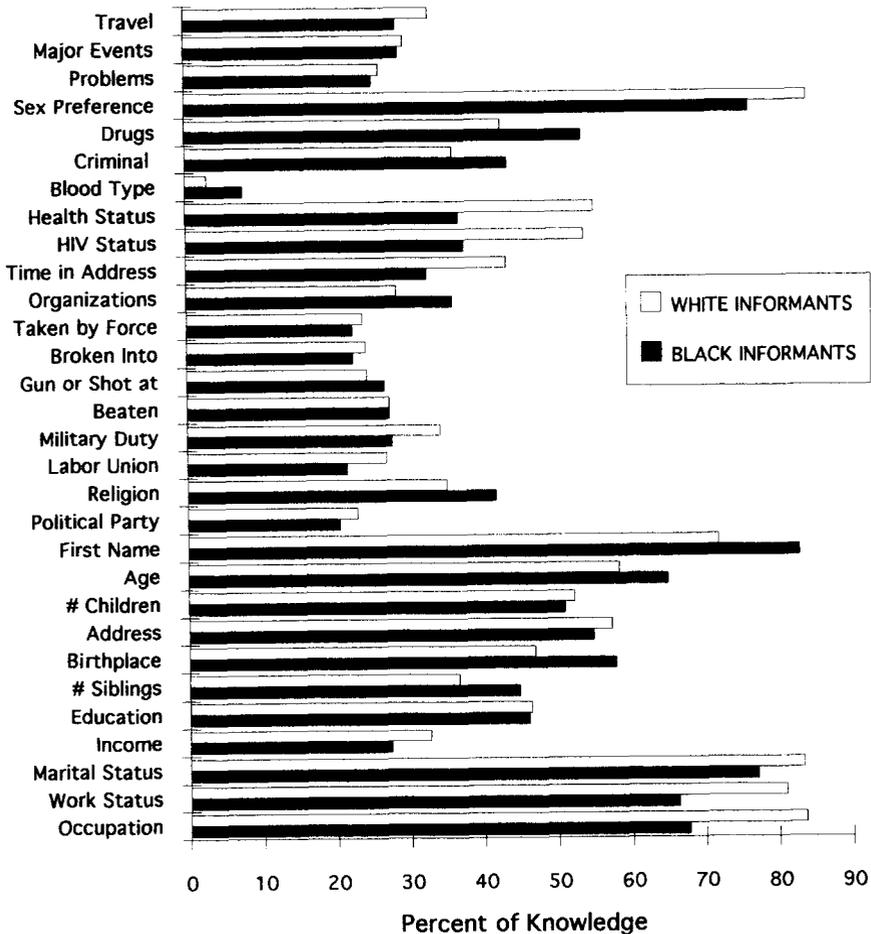


Fig. 5. Differences in amount of knowledge informants have about their alters, shown by race of informant.

likely than other racial groups to know of their infection. However, gay or bisexual IV drug users were more likely to know.

Thus, there may be an underestimation bias in HIV prevalence estimation for blacks in voluntary testing surveys. If one has engaged in risky behaviors and not taken an HIV test, then one is not certain of having the virus. The information that one is HIV-positive cannot be transmitted to others.

Many informants said that they had been afraid to get tested. Some potential informants could not be interviewed because they had not been 'officially' told they were HIV-positive, although the individuals were sure they had the virus. A gay black man said, "Many of my friends haven't been tested but assume they are positive and accept that they are because of behavior. They don't want to lose their

jobs.” One HIV + black woman stated that her boyfriend in another State was afraid of getting a positive test result. “He promised he went to get tested but I don’t believe him. He’s chicken shit to be tested and have to deal with it alone. He’s sick and in denial but he won’t be tested.”

One thing that causes people to avoid testing is that they fear loss of relationships (Schnell et al., 1992). One black man said, “At first I avoided making love. They just thought I had ‘sugar’ [which can make men tired and uninterested in sex]. I know that if I tell a girl I will lose her. People don’t know the difference between the virus and AIDS.” One woman said,

My last boyfriend, I didn’t tell. I went to the clinic but I told him I was volunteering at the program. I went through the isolation of not telling. If you get intimate you should tell. I was just about to tell him but my neighbor told him first. He was very upset because we had sex a few times without protection. He got tested and was angry and ended our relationship. He threatened me with the police but I gave him every chance to protect himself. I offered him condoms but he didn’t want to use them.’

Blacks sometimes also fear being labeled as a homosexual because there is less social tolerance of homosexuality in the black community (Ernst et al., 1991). Consequently, black men are less likely to be open about their sexuality to their primary support network (Ostrow et al., 1991). Several black men directly addressed this subject:

Gayness is a little more accepted in the white community. In the black community it is very bad to be gay.

Being HIV is connected by blacks with being gay. I’m not gay and I don’t want to be thought of as gay.

The reason I didn’t tell before was because of discrimination. I would be labeled as a homosexual.

I didn’t tell my ‘using buddies’ for a year after I found out. As a black person, they make assumptions ... they label you. People assume I’m the risk when they are more dangerous to me.

Another black male had been the victim of a ‘hate crime’. He and some friends were on a sidewalk in a black neighborhood. They were all in dresses. A car went by and the occupants (all black also) fired on the gay group and he was shot in the back and is now paralyzed for life. He said that people say “we can beat it (homosexuality) out (of) you”. He said his cousin used to try to beat it out of him until he got him to stop.

Black informants also feared being stigmatized as having AIDS and treated as a pariah. Fear of contracting AIDS makes some people afraid of being in the same

room with someone who is HIV-positive. In fact, “a lower level of knowledge of unproved transmission mechanisms among black respondents may increase their likelihood of adopting useless safeguards against HIV infection” (Peruga et al., 1992). Some of these useless safeguards include making the HIV + person use items separate from others in the household. One black man said,

At the end of '84 I told my family. They didn't understand and blocked me out of their lives for a good year. They gave me special dishes, knives, forks, and glasses. I had separate bed linens which I had to wash separately from the rest of the family. I even had to wash my clothes separately. I had a special chair that was the only one I could sit in. My family wouldn't even hug me. I wasn't allowed to hug my nieces and nephews. I wasn't even allowed to hold my sons. But I've been telling my family and giving them pamphlets. I've educated them and changed their mind.

One black woman said,

One time at dinner (in the halfway house) I sneezed and a woman in the dining room got up and threw her tray in the garbage. She said, 'It's bad enough to be with drug addicts. I don't want to be with any diseases.' She used to snicker and call me an AIDS bitch. But she shied off that after I told the whole community (about being HIV + ). I know of a neighbor who had HIV and had to use separate bed linens. She had to sleep on a plastic couch and had to wash her linens every day.

### 3.9. *Limits on alter knowledge*

There are obviously some differences in who knows certain information about others. A majority of informants (74%) said they limited who knows their HIV status for some of the reasons mentioned above. One black male reported,

No one in my family knows (my HIV status). I will probably tell my little brother. I think they will disown me. They don't know I'm gay either. I am worried to death. I have told very few people. I haven't lost any friends because I haven't told many. My true friends though I don't think I would lose them if I told them. I don't want people to treat me any differently, or worry. I also fear discrimination.

Another black male said,

My family and close friends don't feel comfortable. A lot of people aren't open minded. Some people say 'people like that (with AIDS) need to die'. Just 'kill 'em up so they won't be spreading it to normal folks'. They say, 'you have The Package'. They think only gay people have this. Well, 90% of my friends are gay. I'm the only straight male in my support group.

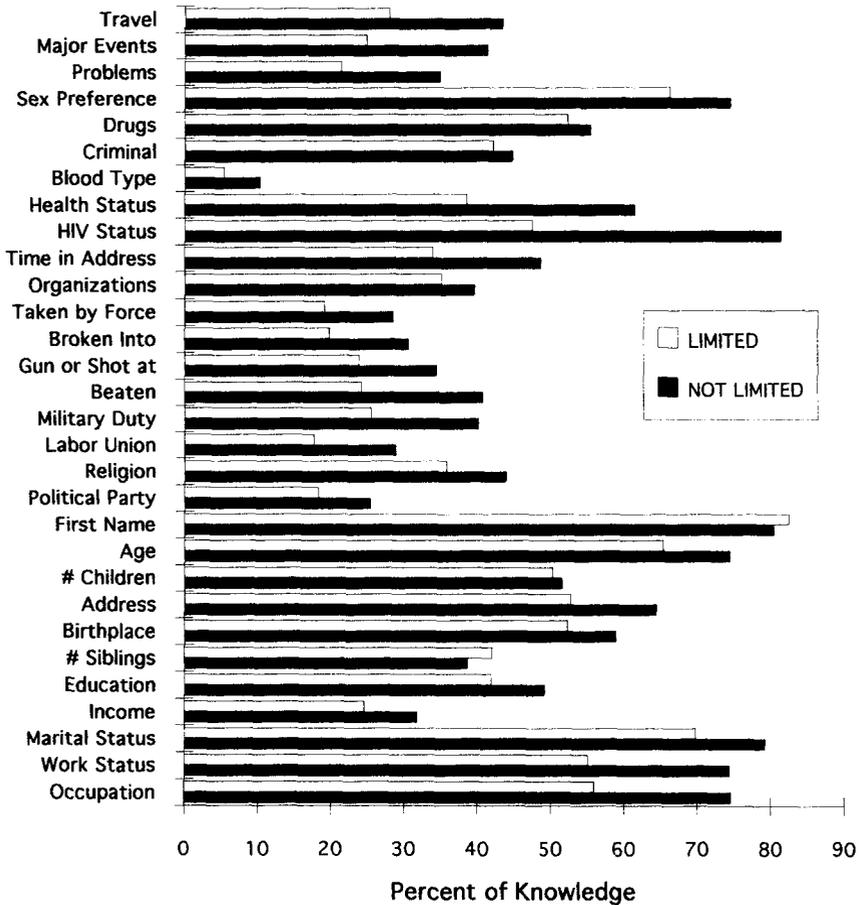


Fig. 6. Comparison of item knowledge between those who limit knowledge of their HIV status and those who say they do not limit it.

A white male said,

I have not told my friends really. One guy was real close and I told him but he had it himself and never told me.

Do people who limit knowledge of their HIV status also limit other information known by alters? Fig. 6 shows a comparison of item knowledge between those who limit their HIV status and those who say they do not limit it. With the exception of two items, those who say they limit knowledge of their HIV status also limit other information about themselves.

The two exceptions are number of siblings and real first name. Unless one uses an alternate name or nickname, it is difficult to suppress the knowledge of real first name among alters who know each other even casually.

There were significant differences (at the 5% level) between limiters and non-limiters on most items. However, 13 items, although higher for non-limiters, were not significantly different (items 5–7, 9–13, 20, 24–27). The largest percentage difference between limiters and non-limiters is HIV status. Limiters say that 47% of alters know their HIV status, as opposed to non-limiters, 81% of whose alters know their HIV status. Another item, blood type, is reported by informants as only known by a small percentage of alters. However, 5% of limiters vs. 10% of non-limiters report alters knowing their blood type.

Blood type and HIV status are related bits of information. Individuals are likely to learn their blood type when they find out their HIV status. Consequently, both pieces of information may be passed to alters concurrently. Many informants said that their mothers knew their blood types and that the announcement of informant's HIV status brought on a discussion of the family's blood types.

Ninety-two percent said there are some people they would not tell about their HIV status. Even some who said they would NOT limit who knew their HIV status admitted that there were some people they would not tell. People who would not be told included employers, co-workers, strangers, and people they just met. Also included in this group were family members, depending on the individual situation. One black informant said he simply would not tell 'black people' because of the stigma in the black community. Finally, some people (both males and females) would not tell a date their HIV status until/unless it looked like they were going to become intimate. In a few cases, even in this circumstance, HIV status would not be divulged.

On the other hand, all but one informant said there were people they would definitely tell about their HIV status. Most of the time this group included medical personnel, sexual partners and some family members. The one informant who would not tell said that she had not and would not tell anyone. She said,

I don't want my kids to know. They are too young, they would not understand. I'm afraid to tell my boyfriend. He might hurt me or my children. And also my family don't know. I hear people say, 'I don't want to be around people with it', so I don't think people would want to be around me. My boyfriend is scared of people with HIV. I have told no one. I guess I'll have to when I get sick. I'll tell my Mom or sister. I'm very scared to tell anybody I know.

No members of her network knew about her HIV status and she did not know anyone else's either. This woman plans to keep this information to herself until she becomes too sick and cannot keep the secret any more.

We asked informants whether they believed that people may treat them differently because of their HIV status. We thought virtually all informants would answer affirmatively owing to adverse discrimination. Ninety-four percent of informants indeed answered affirmatively, but some said they were treated BETTER than before they found out their HIV status. In fact, one gay, white male said, "The difference is very positive most of the time. It brings you closer to the people

around you. They stopped arguing. They didn't want to waste the time they had with me."

A black woman said, "It brought me and my momma closer. I really don't have that many friends but the ones I have they are more concerned about me than I do myself." Another black woman said, "It's something that I'm not ashamed of. I'm hoping I can leave something, leave a message that it can happen to anybody. I would emphasize protected sex. Besides people I constantly come in contact with might comfort or strengthen me." Four informants said they had not been treated differently and that people treated them exactly as before.

Some informants had told their families and some had not. At times only certain family members would be told. Sometimes it would take a long time for the family to be told. One man said, "I waited 8 years to tell them. They were shocked." There were some informants who had not seen their families in several years because they did not want to tell them about being HIV-positive. These informants wanted to tell their families someday but agonized over how and when to do it. One black man said:

I would tell my family eventually. I'm feeling more and more at ease with myself. I need to tell my family because they have to accept me or reject me because eventually they are going to have to bury me. I don't know how I'm gonna tell 'em. They really don't know who I am. I went home the last time and my mother didn't even recognize me. Even from a kid I never hardly stayed at home that much. I was always in and out of jail. I just want them to know something about me so they can say something good about me at my funeral. A friend of mine told me that he heard I had AIDS. I said, 'no, whoever told you that is lying'.

This informant has good reason to fear the reaction from his family. This is a shocking piece of information which can hurt everyone. One gay, black male talked about when he first told his mother.

Yes, my first encounter hurt. My mother is very affectionate but when I told her (about the HIV) I put my face up to her to get a kiss. I asked for a kiss and she kissed the back of her [own] hand. It was extremely painful, the most painful thing I've ever endured in my life. She literally said, 'I'm afraid of you. I'm afraid if you touch me, I'm going to get it.' I had to use separate silverware and dishes. In prison they washed my clothes separately. All of my friends have it (HIV). One person, once I told him about it, it pushed him back and he really changed. That experience slowed me down from talking about it.

A white male also talked of the pain he felt when he told his daughter.

My daughter at first was horrified. She said, 'I don't care what the surgeon general says, you could kill me!' My daughter is the only family I have. We lived in a small town. My daughter and I left because everyone knew I had it. I left

first but my daughter couldn't stay either because everybody knew. But my friends are sensitive about it. One said, 'so and so's coming over. Don't say anything about the AIDS'. Another time I went to a party and the person with me said, 'If you want something to eat, let me hand it to you.' Yes, I have lost a lot of friends. They say this or that but when it comes down to it they don't come around or call anymore.

One black man was rejected by his family because (against his wishes) someone told them about his HIV.

They reacted negatively. It's a total rejection by my family. I don't communicate with them. I was tested in jail and found out I was HIV + . I wasn't going to tell my family but the parole board told my mother. She rejected my parole because the way it was explained to her she would have to take care of me. They made it sound like I wouldn't be able to take care of myself. So my mother wouldn't let me come home. I was really upset with them. I couldn't even go to the town where I had my home. My house and car are still back there.

Interestingly, this man had a lot of alters generated from the name generators but he knew very little about them (and vice versa) because they were people he had met in jail or were (drug) shooting buddies.

A few informants said they were very open about their HIV status and did not limit this knowledge among their alters. The reason given for not limiting would typically be "why not, the disease needs to be normalized." However, for the most part the people who had this philosophy were gay, white males who had a good support system among the gay community. Others did not have the open support and felt very stigmatized. Guilt feelings were common among these informants. A black male said, "I feel guilty for being around people who are clean. I wonder if I breathe on this kid nearby and he has a cut finger if I could hurt him. You never know how much of a killer you are. Sometimes you think you're a walking time-bomb. You get tired of the prejudice, you get tired of fighting prejudice."

#### **4. Summary and conclusions**

These data from men and women, blacks and whites, represent a variety of social classes, sexual preferences, and methods of becoming HIV-infected. This was a convenience sample, and we discovered as we had in previous research (Shelley et al., 1990) with healthy people that information flow is dependent on many processes, and that we probably need more data on each subgroup to get a clearer picture.

However, we were able to answer the questions we posed:

- (1) *Is the network of HIV-positive individuals really smaller than of those who are not HIV-positive?*

Yes, especially in ‘important people’ because those with HIV cannot afford to waste time with people who do not support them either physically or emotionally. The network sizes for these 70 informants seem to be about one-third the size of general population networks we have investigated. The network could be smaller because the HIV community is closely knit, so people tend to see the same people regularly. Many of the informants and alters are in the same support groups and attend the same organizational meetings.

In addition, these network members die off in alarming numbers, and people are fearful of replacing them in the network only to have to suffer the pain of the replacements’ deaths. One informant said that the death of friends does make it hard to try to make new friends. He said his New Year’s resolution was to try and make friends with people who do not have the virus so he can look forward to seeing them live awhile.

Network size depends on many things. Some HIV-positive individuals limit their networks, but some actually said they started building up their networks. A gay white man said, “My network is larger because I’m HIV + . I started building it. A network of friends for support is a necessity for emotional support. Some people have withdrawn when they found out about it. I have been working part-time to involve myself in the HIV and AIDS networks. I’m a volunteer at one of the organizations.”

However, most people either self-limited their networks or their alters did it themselves. “Yes, some friends stopped coming around, stopped calling, most out of ignorance and fear. So I dropped them. They just didn’t know what to say. People don’t have the time to deal with this (HIV/AIDS). Yes my family was very positive, but my friends didn’t react positive so I dropped them. I don’t need negative people.”

*(2) Is knowledge of HIV status limited?*

Yes, for various reasons having to do with the stigma of AIDS, most informants limit who has knowledge of their HIV status. People that informants would not tell include employers, co-workers, strangers, people they just met and some family members. Sometimes this group also included sexual partners. People who would be given the HIV information include medical personnel, sexual partners, very close friends and family members.

*(3) What are the socio-demographic characteristics (i.e. gender, race) and other factors governing who gets personal information such as HIV status?*

Medical personnel and people in the same organizations (notably the support groups) have the most knowledge about informants. Friends and ‘formers’ (lovers, neighbors, school mates, etc.) had the next best knowledge, followed by relatives and others (including acquaintances). Relatives’ knowledge was not as high as might have been expected owing to the fact that some informants were severely

limiting their relatives' knowledge of information such as HIV status or sexual preference.

Overall, male informants knew slightly more information about their alters (including knowledge of HIV status) than did female informants. White informants knew much more information (including sexual preference and HIV status) about their alters than did black informants. However, black informants were more than twice as likely to know their alters' blood type, the hardest thing to know in these data. Knowledge of HIV status is related to being tested for HIV, which blacks do at a lower rate than whites, even though the black infection rate is higher than that for whites.

Informants fear that a positive HIV test will label them as homosexual, which is a very ostracized group in the black community. In addition, owing to misconceptions about HIV transmission, blacks may suffer more social stigma in their families and communities.

The percentages of information alters and informants know about each other are similar, so in general if knowledge of an item is high for the informant then it is similarly high for the alter. However, in these data overall informants seemed to know a bit more about their alters than they perceived the alters knew about them. There are some exceptions, however. Alters knew more about informants' work status, type of work, marital status, and sexual preference. Informants knew more about alters' HIV status. This was probably owing to the informants' limiting of individuals who have knowledge of that information.

*(4) Does knowing HIV status mean that one limits other information about network members?*

Yes. For all but two items (real first name and number of siblings), those who limit their alters' knowledge of HIV also limited other knowledge. However, 13 of the 30 items were not significantly different.

*(5) What are the hardest things to know about someone and will that help us predict who knows someone's HIV status?*

As reflected by these data, there are 23 information items harder to know about people than HIV status. Some of the hardest items were blood type, political party and labor union membership. Perhaps if a person knows these three 'hard' things to know about some alter, then they would also be likely to know that alter's HIV status, provided that the alter knew it. The knowledge of HIV status can be learned from an HIV test, or at later stages it can be ascertained fairly reliably through acquisition of risk factors and symptoms of HIV disease.

We discovered many other things from these data. Fifteen percent of network alters retrieved by generators who had been in contact with the informant in the last 3 years had now dropped out of the network.

Using a rating scale, people cannot accurately estimate how difficult it is to know information about their social network members. However, there are various

subgroups represented in these data, which may be contributing to the differences in perception of item knowledge.

There is still significant stigma relating to AIDS that keeps people from telling their HIV status. This keeps them from taking precautions with partners, which helps infection to spread.

Although having HIV can be a devastating experience, several informants said that it actually changed their life for the better. One gay black male said, “My HIV status made me want to stop using drugs. It turned my life around. It changed for the better. I know what I want now. I don’t have a lot of patience with people who don’t know what they want. I have no time for people who are not winners or not about something. Life is too short and precious to be useless.”

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