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Formal and informal organizational activities of people who inject drugs in New York City: Description and correlates

Samuel R. Friedman, Enrique R. Pouget, Milagros Sandoval, Yolanda Jones, and Pedro Mateu-Gelabert

National Development and Research Institutes, New York

Abstract

Background—Little is known about group memberships of people who inject drugs.

Methods—We interviewed 300 injectors about formal and informal group participation and risk behaviors.

Results—Many took part in groups related to problems and resources associated with injecting drugs, religion, sports or gender. Harm reduction group and support group participation was associated with less risk behavior; sports groups participation with more risk behavior.

Discussion—Group involvement by people who inject drugs may be important to their lives and/or affect prevention or infectious disease transmission. More research is needed about determinants and consequences of their and other drug users' group memberships.

Keywords

drug users; people who inject drugs; PWID; IDUs; risk behaviors; group membership; Big Events; structural interventions; HIV

Background

Group membership is one of the fundamental concepts of sociology. Theories of social capital¹² and social movements³⁴ point to the importance of formal and informal memberships and involvement in group activities both for shaping people's interpretations of events and for providing social resources and contacts to pursue personal goals. A great deal of activity is spent trying to reach, recruit and retain people to take part in both formal and informal groups.

Furthermore, large-scale social changes often are caused by the activities of social groups—and, in addition, lead people to quit or to join groups based on their changing relevance to those people.⁵⁶ We have analyzed how "Big Events" and structural interventions are processes that can change the contexts of people's lives, and their group affiliations and thus sometimes precipitate HIV epidemics and/or increases in high-risk sexual and drug use activity.⁷⁸⁹¹⁰¹¹¹²¹³

Given this, and the great amount of both qualitative and quantitative research about HIV and people who inject drugs, it is remarkable how little is known about the formal and informal group memberships of people who inject drugs. As one illustration of this, neither the Risk Behavior Assessment questionnaire that was used in the early 1990s for a large-scale NIDA-funded study of HIV among people who inject drugs (and crack smokers) nor the current CDC National HIV Behavioral Survey (NHBS) contains any questions about group memberships of drug users.

This exploratory paper aims to describe the formal and informal memberships of men and women who inject drugs and to describe how such memberships are statistically related to HIV risk behaviors.

Methods

300 PWID were recruited by referral from an allied large New York City respondent driven sampling study (RDS) of people who inject between November 29, 2012 and June 12, 2013. This allied study used RDS to recruit a diverse and somewhat representative group of PWID. Although we cannot claim that those who took part in our study were a representative sample, our sample was quite diverse (See Table 1).

After providing informed consent, each participant was interviewed. Respondents were asked to list up to 5 types of formal and 5 types of informal groups they were involved with in the last year. (We used a list of 45 kinds of groups; see Table 2). The introduction and format of the questions about formal groups were as follows:

I am going to ask you several questions about groups and activities you may be a member of OR take part in, also groups or activities you may have once been part of and have dropped out of them. Often times taking part in or belonging to Formal and Informal groups/affiliations /activities require a commitment on your time, you may belong to one or to many: It can also be things that you enjoy doing like volunteering your time at a nursing home or community organization, taking part in political or community demonstrations or other activities

Formal groups are institutions or formal associations such as churches or sport teams.

1. Of the formal groups listed below that you may have been involved with during the last 12 months, which are the top 5 that you have been most committed to, if any?

This was later followed by the question:

3. *How much time do you spend with such formal group(s) ?*
 1. 1 to 5 hours a month
 2. 6 to 10 hours month
 3. 11 to 20 hours a month
 4. 21 or more hours a month

Questions about informal groups were introduced as follows:

Informal groups are groups of people who come together for a similar goal, for example, to watch each others' kids, to watch out for other's on their block, block parties and other informal groups like group sex events, or Swinger groups. Informal groups would also include small groups of people who engage in activities together on a regular basis such as sports, tenants helping tenants, block parties groups, playing music together, chatting groups or video gaming, going to local bars.

The questions about participation in informal groups were similar to but not identical to those about formal groups:

1. From this list below of informal groups listed below that you may have been involved with during the last 12 months, which are the top 5 that you have been most committed to, if any?
3. *How much time do you spend with such group(s)?*
 1. None
 2. 1 to 5 hours a month
 3. 6 to 10 hours month
 4. 11 to 20 hours a month
 5. 21 or more hours a month

The lists of 32 kinds of formal groups and 13 kinds of informal groups were developed in the course of many in-depth interviews with PWID. Each of these lists included, in addition, space for several "other" kinds of groups (followed by a space to write in what this "other" kind of group was). Table 2 lists the kinds of groups involved and the proportion of those responding who indicated that they took part in groups of the given type. During data collection and analysis, it became clear that the distinction between formal and informal sports groups might not be valid and reliable, so we combined them into "sports groups" for analysis; and in Table 2 we include this as well as the data for informal and formal sports groups. In order to describe which groups of people who inject drugs were more likely to take part in which kinds of groups, we used logistic regression to study statistical associations of group membership with drug and sex risk behaviors, sex, race (Black/non-Black), Hispanic ethnicity, age (<40 versus 40+), education (< high school graduation; high school graduation or GED; any post-high-school education); and drug injection frequency (injected weekly or less versus daily injection or more). Our definition of unprotected sex was different from that used in many studies and focused on consistent and correct use: We asked participants how many partners did they have vaginal sex with in the last 30 days; then asked how many partners they had anal sex with in the last 30 days; and then asked the number of times they used a condom, "*using a condom the entire time the penis was in the vagina or anus.*" We defined an answer as "unprotected sex" if they did not report *always* doing this. Most ordinal variables were dichotomized at reasonable approximations to median splits. We conducted logistic regressions only for those group participation variables

that 5% or more of the respondents took part in. (With the exception of “Other” since that contained a mix of kinds of groups.)

Results

Sample characteristics for the 169 men and 131 women PWID participants are presented in Table 1. There was a strong association between age and race: 37.7% of non-Blacks and 64.3% of Blacks were aged forty or above. This reflects the extent to which recent decades have seen few Blacks in New York City taking up drug injection.¹⁴

From Table 2, we can see that most people who inject drugs in our sample took part in formal groups (61.7%) and about a fifth (22.7%) in informal groups, with 71.7% reporting engagement in at least one group. Although there was at least one sample member who reported engaging in most of the *kinds* of formal and informal groups, there were only a few categories that 5% or more took part in. These were religious groups (5.7%), women’s groups (11.5% of women) and men’s groups (6.5% of men), support groups (13.7%), groups at harm reduction centers (27.7%), groups that people had to take part in connected with probation or parole programs (12.7%), and informal groups of people who hang out together (9.7%). If we combine the informal and formal group data for sports groups, 5.7% (17) people reported involvement in one or the other (no one reported both).

Relatively few PWID participants spent large amounts of time in any of these categories of groups. There were five exceptions to this. Of 40 participants who took part in formal support groups (such as Narcotics Anonymous, Alcoholics Anonymous or mental health support groups), 20 took part 6 – 10 hours per month and 4 took part 11 – 20 hours per month. Of 37 who took part in probation- or parole-related groups, 3 took part 6 – 10 hours per month and 2 took part 11 – 20 hours per month. Of 29 who took part in informal hang-out groups, 3 spent 6 – 10 hours per month, 11 spent 11 – 20 hours per month with them and 15 spent 21 hours per month or more. Of 15 who took part in sports groups, 5 did this 6 – 10 hours per month, 2 did it 11 – 20 hours per month and one did it more than 20 hours per month. Of 81 with data on this who took part in harm reduction groups, 36 took part 6 – 10 hours per month, 12 spent 11 – 20 hours and one spent more than 20 hours a month in these activities.

Blacks were significantly less likely than non-Blacks to take part in informal groups (15.1% vs. 28.7%) but more likely to take part in groups associated with harm reduction centers (32.2% vs. 14.8%) and those associated with probation or parole (18.5% vs. 0.8%). Drug injectors who were over 40 years old (who also tended to be Black) were significantly more likely to take part in formal groups (70.4% vs. 50.7%), harm-reduction associated groups (40.9% vs. 11.8%), and probation/parole-associated groups (18.9% vs. 3.7%), but less likely to take part in sports groups (3.1% vs. 8.8%). People who inject drugs at least daily, as compared with less frequent injectors, were more likely to take part in informal groups (27.8% vs. 14.5%) but less likely to take part in support groups (9.7% vs. 19.7%). Men were more likely to take part in probation or parole associated groups (16.6% vs. 7.6%).

Table 3 presents associations between involvement with formal and informal groups with which at least 5% of respondents said they were involved and selected injection and sexual self-reported risk behaviors.

Membership in support groups was associated with reduced odds of injecting drugs at least daily and with lower odds for several forms of sexual risk. PWID who participated in probation or parole-associated groups were less likely to report sexual risk behaviors. Those in harm reduction groups were significantly less likely to use injection preparation equipment like cookers, filters or rinse water that other people had used (or to backload [OR = 0.29, CI 0.12, 0.71]), and also less likely to engage in a range of sexual risk behaviors.

From our formative qualitative research, we know that the informal hang-out groups that PWID in New York take part in often include both PWID and non-injectors. Membership in informal hang-out groups was associated with less likelihood of engaging in unprotected sex. PWID who participated in informal hang-out groups also tended to be more likely to let others inject with syringes they had used (OR = 2.18; CI 0.99, 4.81) whereas participants in harm reduction groups tended to be less likely to engage in such distributive syringe sharing (OR = 0.53; CI 0.28, 1.01).

Taking part in sports group was not associated with gender, but was associated with higher odds of both injection and sexual behaviors.

Discussion

People who inject drugs in New York seem to take part in considerable group activity. Most of this activity is related to problems and resources that are associated with injecting drugs in New York, including harm reduction, being on parole or probation, or spending lots of time “hanging out” with others. Others, however, are probably fairly common in non-users as well, such as taking part in religious groups, women’s groups, men’s groups and sports. Other forms of activities, such as taking part in Occupy Wall Street while it was taking place, or working with tenants’ or block groups, are less widespread but do occur. We were a little surprised, based on our data in the qualitative phase of the study, that more people did not take part in such “civic engagement” activities. This may reflect our subjective biases, but might possibly result from people who inject drugs being more likely to report such activities in informal qualitative interviews than in formal questionnaires.

This study is limited by a non-representative (though diverse) sample and by the fact that it relies on self-report data. Social desirability bias may well be inflating reports of safer behavior, and if such biases are affected by, or otherwise correlated with, group membership, the accuracy of some of our findings may be reduced. In addition, analyses of group membership are limited by the numbers of people who took part in some groups. This limitation is particularly strong for women’s groups and men’s group, since there were only 15 and 11 women and men, respectively, who took part in these groups. The limitations of doing such research in any one city are shown by the absence of significant mention of involvement in drug users’ advocacy and action organizations. (In addition, since it did not come up during the ethnography, we did not ask explicitly about membership in such users’

groups.) Had we conducted this study in places where there were large users' groups, such as Rotterdam in the 1980s or some East African cities at the current moment, a substantial proportion of our sample might well have been members of such groups.

To the extent that our data are accurate, they have important implications. First, they show that many people who inject drugs take part in a range of group activities. Such activities can reduce the isolation that many drug users feel. They also can potentially provide venues for mobilization and organizing around health issues or around drug policy issues.

Second, membership in some kinds of groups is associated with greater or lesser participation in risk behaviors for HIV, hepatitis C and/or other sexually transmitted infections. As might be expected, participation in informal hang-out groups is associated with risky behavior. Perhaps surprisingly, in light of the extent to which social work programs sometimes encourage it, participation in sports groups is highly associated with a range of high-risk behaviors—although this could be a spurious relationship with age, since younger participants were more likely both to take part in sports groups and to take part in risk behaviors. (Unfortunately, only 17 participants took part in sports groups, so we could not test whether this relationship was spurious.) Those who take part in groups due to probation or parole reported less sexual risk behavior.

Harm reduction groups appear to be well-developed in New York, as shown by the fact that 28% of participants take part in groups associated with harm reduction. Membership in them is associated with lower self-reported injection equipment sharing and less backloading, as well as with less sexual risk behavior. This suggests that harm reduction group activities may have formed a focal point or subculture of lower risk in a risky environment.

This paper suggests that the involvement of people who inject drugs in group activities may be an important part of their lives. Group membership has implications for many kinds of interventions by and for drug users, and for the spread (and prevention) of infectious diseases. Membership in some groups may indicate the potential to be effective peer leaders for peer-led interventions. It may also be beneficial to consider some groups (such as harm reduction groups) as focal points for community-based (or “group-based”) participatory research. In addition, it is likely that large-scale structural changes in cities or other social environments, as well as social interventions around HIV prevention or other issues, may affect the group involvements of people who inject drugs. We therefore suggest that much more research be done of the determinants and consequences of group memberships of people who inject drugs.

Conclusions

This article's primary contribution is probably that it both shows the importance of taking organizational involvements of people who inject drugs seriously and provides methodological tools with which to measure them. We have described how organizational ties are associated with selected HIV risk behaviors. Groups provide structure for individuals' social lives, and can help to mediate environmental influences and to develop and communicate HIV-related behavioral norms.⁸ We urge others to use these tools to study

if the organizational involvements of people who inject drugs (or those who use drugs by other routes of administration) are associated with involvement with medical and social service agencies, with helping other people in their community,¹⁵ and with health and medical outcomes.

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TABLE 1

Selected participant characteristics and HIV risk-related behaviors in the last 30 days. N = 300 people who inject drugs.

Characteristic	% (N) for total sample
Gender	
Male	56.3 (169)
Female	43.7 (131)
Age	
19–29	17.6 (52)
30–39	28.5 (84)
40–49	33.6 (99)
50–62	20.3 (60)
Race	
White	43.7 (117)
Black	54.5 (146)
Other ²	1.8 (4)
Hispanic ethnicity	42.7 (128)
Marital status	
Never married	43.7 (131)
Married or living together	31.3 (94)
Divorced, separated or widowed	25.0% (75)
Educational achievement	
Less than high school graduation	37.7 (112)
High school graduate or GED	43.7 (131)
More than high school graduate	18.7 (56)
Employment status	
Employed full-time or part-time	20.0 (60)
Student	3.3 (10)
Unable to work due to disability or retired	16.6 (50)
Homemaker	4.7 (14)
Unemployed	53.3 (160)
Other, including illegal activities	2.0 (6)
Income category (per year)	
Less than \$10,000	62.1 (185)
\$10,000-\$19,999	35.9 (107)
\$20,000 or more	2.0 (6)
Veteran of U.S. armed forces	19.1 (51)

Characteristic	% (N) for total sample
Discharge status (among veterans)	
Honorable	38.8 (19)
General	28.6 (14)
Other than honorable/punitive	32.7 (16)
Homeless	19.4 (56)
Self-reported IV infection status (% positive)	20.8 (60)
<i>HIV risk behavior during the last 30 days</i>	
Frequency of illicit drug injecting	
One per week or less	5.7 (15)
Once per week	39.0 (103)
Once per day	25.0 (66)
Twice per day or more	30.3 (80)
Shared syringes	27.9 (83)
Receptively shared syringes	16.4 (49)
Distributively shared syringes	26.2 (78)
“Backloaded/piggybacked ³ ”	17.4 (52)
Shared drug preparation equipment	35.6 (106)
Injected daily or more frequently	55.2 (144)
Had > 1 vaginal or anal sex partner	44.3 (133)
Had any unprotected vaginal or anal sex ⁴	49.0 (147)
Exchanged sex for money, drugs or other goods	14.0 (42)

¹ Effective sample sizes (n) for category percentages vary due to non-response for some items, and percentages may not add up to 100 due to rounding.

² Other = American Indian/Alaskan Native, Asian, Native Hawaiian/Other Pacific islander, and multiple racial groups.

³ Used an individual syringe to withdraw or receive drugs from a common syringe containing drugs prepared for more than one person.

⁴ We asked participants how many times they had vaginal or anal sex with and without “using a condom the entire time the penis was in the vagina or anus,” and defined an answer as “unprotected sex” if they did not report *always* doing this.

TABLE 2

Kinds of formal and informal groups that participant people who inject drugs belonged to or participated in during the prior 12 months. N = 300 people who inject drugs.

Kind of group	% (N) for total sample
Any formal group	61.7 % (185)
Any informal group	22.7 (68)
Any formal or informal group	71.7 (215)
Formal groups	
Harm Reduction or similar group (Methadone maintenance, Outpatient, Drug Treatment)	27.7 (83)
Support Group (NA, AA, mental health)	13.7% (41)
Probation/Parole	12.7 (38)
A women's group	11.5 (15)
A men's group	6.5% (11)
Religious or Church group	5.7(17)
Service group (helping / volunteering at homeless shelters, food banks, hospitals, GMHC)	3.7 (11)
A group for members of your race, ethnicity, nationality or similar group	3.7 (11)
Occupy Wall Street or other demonstration group	3.0 (9)
Neighborhood group (e.g. block watch, take back our streets,)	2.7% (8)
Sports club or team (bike riding club, dance, auto club, motorcycle club)	2.3 (7)
Job Center- Workfare (Employment for benefits)	2.3 (7)
Employment	2.0 (6)
Gay, lesbian, bi, or transgender group (all six who said yes were men)	2% (6)
School	1 (3)
Groups that mentor kids (for example, an after school or weekend program)	1 (3)
Tenant Association	1.0 (3)
Band or other musical group	0.7 (2)
School Fraternity	0.7 (2)
Labor union	0.3 (1)
Youth group	0.3 (1)
Video Gamers	0.3 (1)
Dance Groups	0.3 (1)
Chatting Groups (on line)	0.3 (1)
Community Service	0.3 (1)
Summer group programs	0 (0)
Political club (Including voting registration)	0 (0)
Gang (street)	0 (0)
Jail/Prison	0 (0)
Urban gardening or a group concerned about healthy food	0 (0)
Literary or Art	0 (0)
Professional society	0 (0)

Kind of group	% (N) for total sample
Other Hobby club (What hobby clubs _____?)	
Other (please list)	6.3 (19)
<i>Informal groups</i>	
Hanging out group	9.7 (29)
Informal Sport group (e.g. meeting to play soccer every Sunday)	3.3 (10)
Bar group (group of people you meet at bar regularly)	3.0 (9)
Tenant helping tenants	2.7 (8)
Play music together group	2.3 (7)
Local block group (not block association)	1.3 (4)
Video gaming	1.3 (4)
Group sex parties group	1.3 (4)
Watching movies group	1.0 (3)
Informal Internet group	0.3 (1)
Club/Parties group	0.3 (1)
Block gang	0.3 (1)
Graffiti group	0 (0)
Other (Please describe) _____	
Formal or informal sports group (see text)	5.7 (17)

Associations of group involvement with injection and sexual risk behaviors in prior 30 days among approximately 300 people who inject drugs*

Table 3

Group	Odds ratio and 95% C.I. of risk behavior					
	Receptive syringe sharing	Shared a cooker, filter or rinse water that someone else had previously used to inject	Inject drugs at least daily	Had sex with more than one partner	Had any unprotected vaginal or anal sex ^L	Gave or received money, drugs or other gifts in exchange for sex
Religious group	1.09 (.371, 3.189)	.539 (.171, 1.70)	1.32 (.419, 4.14)	1.124 (.421, 3.00)	2.63 (.903, 7.66)	2.26 (.841, 6.05)
Women's group (among women)	.329 (.071, 1.54)	.100 (.013, .789)	.676 (.207, 2.21)	.505 (.169, 1.51)	.339 (.102, 1.13)	.637 (.205, 1.98)
Men's group (among men)	Undefined	Undefined also	.765 (.196, 2.98)	.163 (.020, 1.31)	.093 (.012, .741)	.285 (.035, 2.30)
Support group	.697 (.317, 1.53)	.716 (.349, 1.47)	.440 (.215, .900)	.357 (.168, .758)	.332 (.159, .690)	.380 (.162, .892)
Harm reduction group	.583 (.317, 1.07)	.299 (.161, .557)	.642 (.374, 1.10)	.505 (.297, .858)	.390 (.229, .663)	.432 (.237, .788)
Probation or parole associated group	.782 (.353, 1.73)	.520 (.236, 1.15)	.606 (.299, 1.23)	.199 (.081, .493)	.279 (.127, .612)	.275 (.104, .729)
Informal hang out group	1.98 (.899, 4.34)	1.54 (.709, 3.33)	1.39 (.587, 3.31)	1.02 (.473, 2.21)	.362 (.155, .845)	1.29 (.585, 2.85)
Formal or informal sports group	2.77 (1.004, 7.65)	4.33 (1.46, 12.8)	4.76 (1.03, 21.9)	6.43 (1.81, 22.9)	5.26 (1.48, 13.9)	4.13 (1.48, 11.5)

* 95% confidence intervals estimated by logistic regression. N's vary due to missing data.

^L We asked participants how many times they had vaginal or anal sex with and without "using a condom the entire time the penis was in the vagina or anus," and defined an answer as "unprotected sex" if they did not report *always* doing this.