



C.H.A.I.N. REPORT

Tri-County CHAIN

Report 2002-5

Support Groups

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HIV Planning Council

Originally submitted Nov. 13, 2002
Final report submitted Apr. 1, 2003
HRSA Grant # H89 HA 0015-11

ACKNOWLEDGMENTS

A Technical Review Team (TRT) provides oversight for the CHAIN Project in New York City and in the Tri-County area of Putnam, Rockland, and Westchester counties. In addition to Peter Messeri, PhD, Angela Aidala, PhD, and David Abramson, MPH MPhil, of Columbia University’s Mailman School of Public Health, TRT members include Mary Ann Chiasson, DrPH, MHRA (chair); Kevin Garrett, Mayor’s Office of AIDS Policy; JoAnn Hilger, NYCDOH; Julie Lehane, PhD, Westchester County DOH; Jennifer Nelson, MHRA; and Tom Sentell, PWA Advisory Group. Additionally, the Tri-County CHAIN project regularly consults with Tom Petro, Jan Carl Park, Julie Lehane, and Renee O’Rourke of the Westchester Department of Health.

We are particularly grateful to all the participants in the Tri-County CHAIN Project who share their time and their experiences with us. We take their trust in us seriously, and hope that our project serves to amplify the voice of the HIV-positive community in Putnam, Rockland, and Westchester counties.

Tri-County CHAIN Project

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This research was made possible by grant number H89 HA 0015-11 from the US Health Resources and Services Administration (HRSA) HIV/AIDS Bureau. The CHAIN study is supported by the HIV Health and Human Services Planning Council of New York under a Title I grant of the Ryan White Comprehensive AIDS Resource Emergency Act of 1990 through the New York City Department of Health. It is conducted under the auspices of the Medical and Health Research Association of New York City, Inc, and in Tri-County under the Westchester Department of Health. Its contents are solely the responsibility of the researchers and do not necessarily represent the official views of the U.S. Health Resources and Services Administration; the City of New York; Putnam, Rockland, or Westchester counties; or the Medical and Health Research Association of New York.

Introduction

The academic literature on support groups suggest that they represent a safe haven for people who need support and guidance when coping with a difficulty, and they often succeed because of the homogeneity of the group (in that generally all attendees share a specific characteristic or disease) and the social environment created by the group leader. Support groups vary widely in their goals and the coping techniques they offer to group members, and they are often shaped by the leaders and the volunteer participants who compose the group. In an environment of solidarity, support groups often help people confront sensitive issues, and allow group members to share tools and resources for dealing with a specific condition.

The literature further suggests that support groups are particularly beneficial for people living with HIV/AIDS. Often, HIV+ individuals carry a double burden: they are physically challenged by the virus, and they experience a heavy emotional toll, as HIV is often a cause for social stigmatization. Previous studies note that many HIV+ patients value the encouragement, unique companionship, and sense of intimacy they find in HIV support groups. These gatherings have also proven to be profitable in disseminating information on new medications, programs, sources of funds, and activities aimed at helping the HIV/AIDS population.

Generally speaking, support groups may be characterized along a spectrum that extends from therapeutic groups, in which emotional and psychodynamic issues are often raised, to instrumental groups, in which a group leader or facilitator will assist group members to achieve certain instrumental objectives (such as sharing information on new medications and their effects).

This report explores some of the factors motivating attendance and cessation of support groups among a representative cohort of HIV+ adults living in Westchester, Rockland and Putnam counties. Among the research questions this report addresses are:

- Who attends support groups? Are certain groups more likely to attend support groups than others?
- Why do people attend support groups? What do they expect from support groups?
- Why do people stop attending support groups?

This analysis is based on the experiences of 358 individuals in the Tri-County CHAIN cohort.

Key Findings

- Approximately half (46%) of the respondents reported that they had ever attended a support group.
- The principal reasons cited by respondents for attending support groups included receiving emotional support and educating themselves about living with and managing HIV. Other minor reasons cited for attending included recreational purposes, incentives, to be with a specific group, and to support a spouse.
- Overall, there were no significant group differences between individuals who said they had ever attended support groups and those that said they had not.
- Women were slightly more likely to report that they attended support groups in order to share experiences with other women (13%), whereas men were more likely to say they attended support groups to obtain information (54%) or for an incentive (14%).
- Among the people who ever attended a support group, approximately half have stopped going. Among the reasons cited are: the group ended, there was no connection to the group, no interest, they did not like the group, there were barriers to attending, time constraints, the group was too depressing, the respondent or group moved location, or that respondents felt the issue was resolved. Unlike the reasons cited for attending support groups, no single reason for stopping attendance predominated.
- Finally, in an analysis examining the combined effects of these group differences, only one factor emerged that distinguished whether people had ever attended a support group – disclosure of HIV status. Individuals who had disclosed their HIV status to many friends and family members were 4.4 times more likely to have ever attended a support group than were individuals who had disclosed to only a few friends and family members.

Discussion

Approximately half (167 of 358) of the interviewed people said they had attended support groups. As illustrated in Table 1, many respondents who attended support groups shared the following characteristics: 72% are past or current drug users, 79% belong to minority groups (Blacks, Latinos and other non-White ethnic group), and 65% are exclusively heterosexual.

As illustrated in Table 2, the main reasons for attending support groups, cited by 69% of respondents, is emotional support: “[It] feels good going somewhere with people who are in the same boat”, “..I get hope, strength and stability”. The second popular reason why people have attended support groups is to obtain information about management of HIV, as stated by respondents: “To learn as much as possible about the disease,” “to learn about new treatment

therapies, access to other programs.” One respondent based his decision to stop taking his HIV medications on the discussions he had with fellow support group members, notwithstanding his doctor’s objections.

Other listed reasons for attending support groups vary according to gender or geographic area. As illustrated in Table 4, 73% of women attended support groups for emotional support, 13% of whom sought support from a specific (women’s) group: “To find out how other women deal with their life, especially how to deal with men”, or “what it’s like for a woman with children to take care of her children while sick.” Men, on the other hand, mainly attended support groups to get information (54%) or for an incentive (14%).

Table 5 illustrates a comparison of respondents living in urban areas, who tend to seek population-specific support groups, versus respondents living in suburban and rural areas, who are heavily drawn to attending support groups for general recreational and social purposes. “[I] like having somewhere to go when I’m lonely or bored.” No group differences were noted among individuals who were presently or formerly drug users when compared with respondents who have never used drugs.

Despite the many reasons for attending support groups, half of the people stopped going. There were a myriad of reasons reported for the drop in attendance, as illustrated in Table 3, although no particular reason predominated. Still, it is worth noting that virtually all of the reasons cited are related to emotional or psychodynamic issues, rather than specific barriers or issues related to instrumental objectives.

Finally, Table 6 illustrates the results of a multi-variate regression analysis in which a number of characteristics were considered together as explanations of what characterizes support group attendees versus those who never-attended. Such an analysis allowed us to control for competing explanations. In other words, if it turned out that men were more likely to attend support groups, one might offer as a possible explanation that men are more likely to be current or former drug users, and that is what is really driving the group differences. A regression analysis controls for these competing factors by analyzing men – regardless as to whether they were current or former drug users -- and their likelihood to attend support groups. Among the factors analyzed (all of which were relatively time-invariant, since the dependent variable of having ever attended a support group was not time-specific), only one variable emerged as statistically significant. Individuals who have disclosed their HIV status to many friends or family members are 4.4 times more likely to report that they have ever attended a support group. Gender, ethnicity, geographic type, substance abuse, and sexual orientation were not statistically significantly associated with attendance at support groups.

Furthermore, 81% of respondents who minimally disclosed their HIV status do not attend support groups. Clearly, it is possible that the psychological capacity and willingness to disclose one’s HIV status is closely related to one’s ability or interest in sharing emotionally charged issues with a group of people who are otherwise strangers to one another.

Table 1. Support Groups Attendance (Tri-County CHAIN data, 2001-2002) ¹

	Never attended a support group	Ever attended a support group
n	191	167
Gender		
<i>Male</i>	54%	49%
<i>Female</i>	46%	51%
Race/Ethnicity		
<i>White, non-Hispanic</i>	19%	22%
<i>Black, non-Hispanic</i>	56%	44%
<i>Hispanic/Latino</i>	22%	29%
<i>Other</i>	3%	5%
Residential characteristic		
<i>Urban</i>	55%	56%
<i>Suburban / Rural</i>	45%	44%
Substance abuse		
<i>Never a drug user</i>	37%	28%
<i>Ever a drug user</i>	63%	72%
Sexual orientation		
<i>Exclusively heterosexual</i>	69%	65%
<i>Ever MSM</i>	19%	23%
<i>Ever WSW</i>	13%	11%

¹ Note that analysis is based on a partial data set of n=358

Table 2. Reasons People Attend Support Groups (Tri-County CHAIN data, 2001-2002)

	n	%
Ever attended a support group (n)	167	
<i>Emotional / psychological support</i>	116	69%
<i>Educate themselves / get information</i>	78	47%
<i>Recreational purposes</i>	25	15%
<i>Incentives</i>	17	10%
<i>To be with specific population</i>	10	6%
<i>To support spouse</i>	3	2%

Table 3. Reasons People Stop Attending or Irregularly Attend Support Groups
(Tri-County CHAIN data, 2001-2002)

	n	%
Number of respondents who ever attended a support group	167	
<i>Group ended</i>	16	10%
<i>No connection with group</i>	14	8%
<i>No interest</i>	13	8%
<i>Did not like the group</i>	12	7%
<i>Barriers</i>	11	7%
<i>Time constraint</i>	8	5%
<i>Too depressing</i>	6	4%
<i>R or group moved</i>	6	4%
<i>Issue was resolved</i>	4	2%

Table 4. Reasons People Attend Support Groups, by Race/Ethnicity & Gender
(Tri-County CHAIN data, 2001-2002)

Characteristic ¹	Total	Race/Ethnicity			Gender	
		White	Black	Latino	Male	Female
Ever attended group (n)	167	36	73	49	90	167
<i>Emotional / psychological support</i>	69%	58%	67%	76%	67%	73%
<i>Educate themselves</i>	46%	44%	53%	43%	54%*	38%
<i>Other</i>	32%	44%	34%	18%	32%	31%

Note: "Other" includes recreational purposes, incentives, to be with a specific group, to support spouse, and professional pressures.

Table 5. Reasons People Attend Support Groups, by Geographical Type & History of Substance Abuse
(Tri-County CHAIN data, 2001-2002)

Characteristic ¹	Geographical Type		Substance Abuse	
	Urban	Suburban/ Rural	Never used drugs	Ever Used drugs
Ever attended group (n)	93	73	47	120
<i>Emotional / psychological support</i>	72%	66%	68%	71%
<i>Educate themselves</i>	49%	44%	49%	51%
<i>Other</i>	30%	34%	38%	29%

Note: Other includes recreational purposes, incentives, to be with a specific group, to support spouse, and professional pressures.

* p < .05

** p < .01

*** p < .001

Table 6. Factors Associated with Ever Attending a Support Group (n=344)

Respondent Characteristics	Odds of Attending	Confidence Interval
<i>Men (versus women)</i>	.91	.57, 1.42
<i>Black (versus non-Black)</i>	.78	.42, 1.44
<i>Latino (versus non-Latino)</i>	1.29	.66, 2.53
<i>Ever used drugs (versus never used)</i>	1.28	.78, 2.09
<i>Urban residence (versus suburban or rural)</i>	.98	.61, 1.59
<i>Disclosed HIV status to many friends/family (versus few/none)</i>	4.42***	2.15, 9.07

† p < .1 * p < .05 ** p < .01 *** p < .001

Appendix: 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 to 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.