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Research

Does harm reduction programming make a difference in the lives of highly marginalized, at-risk drug users?

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Abstract

Harm reduction is a controversial model for treating drug users, with little formal research available on its operation and effectiveness. In order to advance the field, we first conducted participatory research of harm reduction with 120 clients using nominal-group technique to develop culturally relevant outcomes to measure progress. Second, we conducted focus group interviews with a different group of clients to help validate the outcomes. Third, we used the outcomes in an evaluation of the largest harm reduction program in New York City, which involved a representative sample of 261 and entailed baseline, post, and six follow-up assessments. The participatory research resulted in outcomes of 10 life areas important to drug users. Evaluation results showed that program participants made positive improvements across most outcomes, with the most substantial progress made in how clients dealt with drug-use problems. Along with their participation in the program, progress in some outcomes was also associated with clients' type of drug use (i.e., stable vs. chaotic), where more stable drug use was associated with better ways of making an income and types of housing. Surprisingly, progress was not associated with the kinds or numbers of services received or the length of time in the program. This was attributed to the service delivery model of harm reduction, in which clients are less inclined to associate their success with a single staff person or with a single service or intervention received than with the program as a whole.

Introduction

Harm reduction programs operate with the assumption that some people who engage in high-risk behaviors are unwilling or unable to abstain. Using a "low-threshold approach," they do not require that clients abstain from drug use to gain access to services, nor expect adherence to one service to be eligible for another. Rather than having abstinence goals set for them, clients in such programs take part in a goal-setting process, an approach that has been shown to correlate consistently with retention and success [1,10]. Providers help clients make connections among their complex attitudes, behaviors, and the change they are trying to pursue through an interactive process, not a dogmatic format. Behavior change is regarded as incremental and based on the premise that people are more likely to initiate and maintain behavior changes if they have the power both to shape behavioral goals and enact them.

Research on harm reduction programs has been limited largely to demonstrating their success with reducing the transmission of HIV/AIDS among drug users as a result of

access to sterile syringes [2-6,11-13]. While this is an important accomplishment, little is known about the other low-threshold services that these programs provide and their overall impact in assisting drug users in making changes in life conditions, circumstances, and quality of life. This is partially due to a policy and funding environment that directs most support to traditional drug treatment and leaves harm reduction initiatives at a disadvantage. As a result, considerable research has been conducted to develop outcomes of drug treatment and assess its impact, while almost no research has tried to establish appropriate measures of harm reduction and evaluate its worth.

To advance the field of harm reduction, the investigators designed a two-phase participatory research project. First they conducted qualitative research with drug users in a large urban harm-reduction program to develop culturally appropriate outcome measures [8]. Second, they used these measures to evaluate the effectiveness of the program.

Program Description

The evaluation assessed the largest harm reduction program in New York City, which was founded in 1990 by former injection-drug users (IDUs) and activists as an underground syringe-exchange program. It has served over 51,000 marginalized drug users, predominantly in the South Bronx and East Harlem, who are HIV sero-positive or at risk of infection. Those served included individuals who were injection-drug users, crack smokers, problem drinkers, and sex trade workers, as well as individuals who were living at 100% or more of poverty level; who were foreign born, homeless, or in unstable living arrangements; and who lacked a regular source of medical care.

The major operating principles of the program include the following: (1) always be mobile and deliver services to users on the streets and in settings where they live and use drugs; (2) always provide services based on meeting users where they are; and (3) always remain participant-driven and centered on what users want and need. The major goal of the program is to connect marginalized drug users to needed services that will stabilize their lives and improve their well-being.

The services offered in the program include the following:

• Intensive street outreach to locate, engage, and retain IDUs and their significant others who are HIV infected and/or are at high risk of infection because of injection drug use/and or risky sexual behavior;

• Street-side services through two mobile vans, including a hospital medical unit conducting HIV primary care, HIV testing, STD screening, ob-gyn examinations, minor surgery, health screenings, and influenza vaccines;

• Health education, including safer injection education and orientation to HIV and drug treatment services;

• Harm-reduction counseling, including recovery readiness, relapse reduction, and long-term recovery;

• Assertiveness training for negotiating safer sex, reducing exploitation during commercial sex transactions, and reducing the harm of abusive relationships;

• One-for-one exchange of sterile syringes for used syringes;

• Support groups, including a users', men's, women's, and gay and lesbian groups;

• Acupuncture (ear and full-body) and Reiki;

• Transitional case management, including facilitation of access to HIV counseling and testing, primary care, intensive case management, drug treatment, housing, and mental health and nutritional services;

• Access to early intervention to locate, identify, engage, and then connect marginalized people who are HIV+ or at high risk of HIV to the AIDS service delivery system and to a range of HIV-related services (e.g., HIV testing, primary medical care, case management, drug treatment, legal services, and housing);

• Assistance in accessing entitlement benefits (Medicaid; SSI; welfare; birth certificates) and access to an attorney; and

• A 1–800 HOTLINE called GETTING CONNECTED to access hard-to-reach clients.

Methods

The methods used for the participatory research are described below, based on the two-phase approach of outcome development and program evaluation.

Phase I outcome development

Qualitative research was conducted with clients in the program to initially develop outcomes of harm reduction. The study was advertised in the six program sites, and a convenience sample of approximately 200 clients stratified by neighborhood, duration in the program, and types of services received was recruited. The demographics of the sample closely represented the larger program and

included 26% African American, 50% Latino, and 24% white; 72% male and 28% female; 17% ≤29 years of age; 26% between 30–39 years; and 45% ≥40 years of age.

First, clients participated in groups that allowed them to identify areas of life functioning that people like themselves (i.e., drug users) deemed important and meaningful to work on in the harm reduction program – income, housing, food (nutrition), family relations, self-improvement; connectedness to services/benefits/programs, dealing with negative feelings (mental health), health problems (physical health), and legal and drug-use problems. With these 10 life areas, 10 groups of approximately 10 clients were conducted using nominal-group technique (NGT).[1] This resulted in 10 scaled outcomes, which included measures of better to worse ways of making an income, being housed, etc. [8]

Next, 10 focus groups were conducted with clients to allow more of the target population to reflect on the validity of the measures. In most cases, a completely different group of clients who had participated in the NGT process for a certain outcome participated in the focus group related to that same outcome. This qualitative research resulted in hierarchical outcomes of harm reduction programming to measure incremental change in pertinent life areas from better to worse (Table 1 – see Additional File 1). These measures were considered culturally appropriate to the way drug users see the world and live their lives. It was also believed that these measures could show how clients improve over time.

Phase II evaluation

The main intent of the evaluation study was to assess whether drug users in harm reduction make significant progress in various life areas based on measures that were culturally appropriate and meaningful to them. Using the drug-user-generated outcomes from Phase I, instruments were developed to collect data at several points in time to measure client progress using a pre-, post-, and follow-up design. The first assessment with clients in the study, administered as face-to-face interviews, measured how clients' placed themselves on the scaled outcomes at baseline, when they entered the program (a retrospective measure), and "now" (i.e., post). Clients completing this assessment were then asked to call an 1–800 telephone number, one they used to regularly connect with the program, every three weeks, over a year, to take part in phone interviews with a trained interviewer who used an adapted version of the developed instrument to assess their progress with the outcomes.

Recruitment methods for Phase II were similar to those used in Phase I, which had resulted in a convenience sample of 261 program clients stratified by neighborhood, duration in the program, and types of services received. As might be expected with the unstable nature of the target population, study dropout took place across the follow-up assessments, which reduced the size of the matched sample that could be used for the evaluation. As the sample decreased over the follow-up assessments, the decision was made to use data from six of the seventeen follow-up assessments, resulting in a sample of 96 program participants for the evaluation with matched results across baseline, post, and follow-up assessments. While the follow-up sample was slightly older, more female and more of Black/African American descent than the baseline/post-sample, overall the demographics of the assessment samples represented the larger client base in the harm reduction program (Table 1).

Table 2: Demographic Characteristics of Clients in the Program and in the Baseline/Post and Follow-up Assessments

Characteristic	Baseline/Post (N = 261)	Follow-up (N = 96)	Program Client Base (N = 51,282)
Age			
≤29 years	11%	6%	13%
30–39 years	33%	27%	32%
≥40 years	56%	67%	55%
Sex			
Male	62%	58%	67%
Female	37%	40%	29%
Transgender	1%	1%	1%
Unknown			3%
Race/Ethnicity			
Latino	49%	41%	52%
Black or African American	33%	39%	28%
White	14%	17%	14%
Other	4%	3%	5%

Table 3: Change Across Mean Scores of Outcomes from Baseline to Post to Follow-up

Life Areas	Means Scores*			Level of Significance		
	Baseline	Post	Follow-up	Baseline vs. Follow-up	Baseline vs. Post	Post vs. Follow-up
Housing	4.10	3.28	3.17	≤.001	≤.001	NS
Income	5.61	4.05	3.36	≤.001	≤.001	NS
Family relations**	2.97	2.78	1.93	≤.001	NS	≤.001
Program services/benefits	5.97	5.08	5.94	NS	≤.001	NS
Food (nutrition)	4.04	3.82	3.57	≤.001	NS	NS
Health care	6.72	5.74	4.92	≤.001	≤.001	≤.01
Handling negative feelings	6.35	5.86	2.77	≤.001	NS	≤.001
Dealing with drug use problems	9.45	7.24	5.95	≤.001	≤.001	≤.01
Dealing with legal problems	5.11	4.50	3.71	≤.05	NS	NS

*Progress across outcomes are demonstrated in the *lowering* of mean scores because outcome scales were quantified from the "best" measures receiving the lowest scores and the "worst" receiving the highest. **While most outcome scales were constructed with scores from 1–10, the outcome scale for "family realtions" was constructed with scores from 1–6.

To explore the extent of client progress in the harm reduction program, data were analyzed using paired t-tests between baseline, post, and follow-up scores. To explore the influence of other factors on client progress, multiple regression was performed.

Evaluation results

The evaluation explored two related questions. First, it determined whether clients in harm-reduction programming made overall progress from the time they entered the program to their last follow-up assessment (i.e., from baseline to their sixth follow-up assessment). Second, because there tended to be more time between when participants entered the program to the post-assessment (i.e., approximately 60% had been in the program a year or longer) than from the post-assessment to the last follow-up assessment (approximately 6 months), the evaluation explored whether more client progress was made from baseline to post-assessment than from post to the last follow-up assessment.

Results based on these inquiries are shown in Table 2. Findings show that there was significant client progress across most outcomes from entrance in the harm reduction program to the last follow-up assessment (i.e., baseline to follow-up), which is demonstrated in mean scores on outcomes decreasing across the measurement points. The exception to this finding was with the outcome of "connectedness to valued programs/benefits." While there was significant progress from baseline to post-assessment, there was not significant progress from baseline to follow-up.

Findings also show that there was not always significantly more progress from entrance in the program to the post-assessment than from post-assessment to follow-up assessment across all outcomes. This expected result was shown for the outcomes of housing, income, connectedness to programs/benefits, and dealing with drug problems. For the outcomes of family relations and handling negative feelings, findings show that there was not significant change from baseline to post but there was from post to follow-up. For the outcomes food (nutrition) and dealing with legal problems, there was not significant change from baseline to post or from post to follow-up, although there was from baseline to follow-up. Finally, for the outcome of health care, there was significant change both from baseline to post and from post to follow-up.

To further explore the positive relationship between client progress in various life areas and participation in the harm reduction program, a number of relevant factors were explored to determine their impact on this relationship. Using multiple regression, the factors of "amount of time in the program," "program dosage received" (i.e., scope and frequency of the multiple services offered), "type of service received" and "type of drug use" (i.e., stable vs. chaotic) were entered into the model for analysis. Surprisingly, none of these factors had any consistent significant relationship with progress made in program outcomes. Stable drug use was marginally related to progress in the outcome of housing ($p \leq .07$) and significantly related to progress in the outcome of income ($p \leq .05$).

Discussion

While the findings from the evaluation were positive overall in showing a relationship in drug users' participation in harm reduction programming and improvement in various life areas, there were a number of limitations of the

study that should be discussed. First, the evaluation did not employ a comparison design to compare the progress of those who do and do not receive harm-reduction programming; this would have allowed results to be more confidently attributed to the program. Second, the reliability of the retrospective baseline measure has limitations. Participants were asked to provide information on the outcomes based on when they first entered the program. This meant that there was considerable variation in the recall required to obtain valid data across individuals who entered the program from as early as one month before to as long as six years before baseline.

Third, there were issues related to the reliability of the follow-up data for some outcomes. The instrument used to gather follow-up data was designed to allow for a shorter session with clients via a phone interview than the amount of time taken for the baseline face-to-face interview. Interviewers used open-ended questions and fit client responses into the available categories of the outcome scales. While this worked well for most outcomes, certain ones, such as "self-improvement" did not provide adequate data to allow appropriate measures at follow-up. For the outcome of "family relations," the data collected at follow-up resulted in a revision of the scaled outcome from one with a 10-item scale measuring better to worse types of family relations to a 6-item scale measuring close family relations to no relations.

The study, surprisingly, found that clients' progress in the harm reduction program was not associated with the kinds of services they received, their length of time in the program, or the number of services received over time. In order to understand and explain these results, it is important to understand the harm reduction approach, and specifically the way the program is structured, the way clients are integrated into the organization, and its service-delivery model.

To understand the harm reduction program's service-delivery model, it is helpful to look at the way in which most human service organizations that work with drug users are structured and the way in which clients are integrated into this more traditional model. Clients who meet eligibility requirements are usually assigned to one worker, usually a case manager. That worker provides most, if not all, services the client receives at the agency: intake and assessment, orientation to the agency, the development of a treatment plan, case management, behavioral contracting, referrals, follow-up, and support. Generally the relationship between the client and worker is an asymmetrical power relationship in which the worker has power and the client does not. While the client may have some input on the treatment plan, the worker generally assigns the client a number of tasks and responsibilities to perform; dictates and enforces the rules of the agency; and disciplines and terminates the client if he/she does not adhere to these rules. In the service relationship, the client has little or no choice in what services are received, how long the relationship lasts, and when the relationship begins and ends.

By contrast, there are no eligibility requirements in the harm reduction program studied in this research: anyone who wants services can receive them. Rather than having a single entry point, clients can join the program at any part of the organization, including the formal offices, the street-side service delivery sites, through any of the multiple programs offered, and even remotely through the 1–800, "get-connected," phone service. In addition, anyone of the 35 staff members can enroll clients into the program. Once enrolled, clients are not assigned to a single worker. They can receive services from any staff member, from as many staff members as they choose, and from any preferred program. Case managers are available if clients choose to have one, but it is clients who decide which services they receive and how often they access them. Relationships between clients and workers are symmetrical, with both empowered. The worker assists clients in completing those tasks the clients choose to complete, and the clients decide when the relationship begins and ends. While the program operates with the rule that violence is not tolerated and that clients cannot buy or sell drugs on agency property, if asked to leave the premises for breaking these rules, clients are still eligible to receive services at the street-side sites.

Both service-delivery models have consequences in the way workers and clients relate, in the way clients feel about themselves, and in the way clients relate to the overall program. In the more traditional service model, with an asymmetrical power relationship between client and staff, clients are more prone to viewing their success as a result of their relationship with a specific worker and his/her actions than their own actions. This is partly due to the nature of the client-worker relationship in the more traditional service model, which encourages subjective transference and counter-transference (i.e., client confuses the present with the past and transfers emotions and desires that are associated with important people from the past onto staff person). As a result, the relationship can be turned upside down, with the focus shifted from the client to the worker, whom the client regards as on the level of an important individual in his/her past. A client can often become overly personal in relating to the worker and can blame the worker if he/she cannot solve problems or attribute success to the worker if he/she can.

By contrast, in the harm reduction model, transference becomes diluted because of the nature of the relationship

between clients and workers, in which clients do not become tied to a single staff person and do not associate their progress with him/her. Rather, the client interacts with a number of staff, who assist the client in getting their needs met. Relationships between workers and clients tend to be short and transitory and, consequently, there is no time for the client-worker relationship to develop to the point where the client engages in transference. Without that transference, the client and staff focus on what the client needs instead of on an evolving relationship with a single staff person. When the client has success, he/she doesn't say "It's the worker who helped me." Instead, the client says "It's the program that helped me." Thus, the changes in life circumstances documented by the outcome study are less likely to be associated with a single worker, a single intervention, or a single program. Instead, the changes that clients make are more likely to be changes that result from the client's association with the organization as a whole.

It is not a surprising finding of the study that the clients' type of drug use (i.e., stable vs. chaotic) was more strongly related to their progress in the outcomes of housing and income than to other program outcomes. Making progress in these two outcomes, more than the others, generally requires either abstinence or controlled, low-level drug use to qualify for subsidized housing or to maintain an income-producing job. Clients' progress in the other program outcomes, despite that fact that their drug use may not always be stable, reflects on the potential impact of harm reduction programming. Having a supportive organization, whether they are out of control with their drug use or not, helps drug users to start believing in themselves and provides a much-needed social and psychological safety net to help them move forward in several areas of their lives.

Conclusion

Traditional drug treatment has not demonstrated high levels of client success, yet it has been able to garner considerable political support and resources. While drug treatment is an important option that should be made available for those drug users who choose it, less resources have been made available to support drug users who do not want to enter formal treatment programs. Harm-reduction programs, providing important life-sustaining services to active drug users, have historically been considered a more controversial approach to working with drug users, and little empirical research has been made available to judge its merits. The present study, though preliminary in nature, provides positive results that associate harm reduction programming with incremental and life-sustaining changes in drug users lives. These findings, along with those that have shown the positive effects of syringe-exchange interventions in reducing the transmission of HIV and other blood-borne viruses, demonstrate that harm reduction programs are a viable and promising approach to working with highly marginalized drug users.

Competing interests

None declared.

Additional material

Additional File 1

This table is "Outcomes of Harm Reduction Programming to Measure Incremental Change from Better to Worse."
Click here for file
[http://www.biomedcentral.com/content/supplementary/1477-7517-1-7-S1.doc]

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