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Retaining clients in an outcome monitoring evaluation study: HIV prevention efforts in community settings☆

Bryce D. Smith [a,*], Elizabeth J. Kalayil [a,b], Alpa Patel-Larson [a], Brenda Chen [a,b], Marla Vaughan [a,1]

[a] Program Evaluation Branch, Division of HIV/AIDS Prevention, National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention, Centers for Disease Control and Prevention, Mail Stop E-59, 1600 Clifton Road, NE, Atlanta, GA 30333, USA
[b] MANILA Consulting Group, Inc., McLean, VA, USA

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ABSTRACT

The Centers for Disease Control and Prevention (CDC), Division of HIV/AIDS Prevention (DHAP) conducted outcome monitoring studies on evidence-based interventions (EBIs) provided by CDC-funded community-based organizations (CBOs). Critical to the success of outcome monitoring was the ability of CBOs to recruit and retain clients in evaluation studies. Two EBIs, Video Opportunities for Innovative Condom Education and Safer Sex (VOICES/VOCES) and Healthy Relationships, were evaluated using repeated measure studies, which require robust follow-up retention rates to increase the validity and usefulness of the findings. The retention rates were high for both VOICES/VOCES CBOs (95.8% at 30 days and 91.1% at 120 days), and Healthy Relationships CBOs (89.5% at 90 days and 83.5% at 180 days). This paper presents an overview of the retention of clients, challenges to follow-up, and strategies developed by CBOs to achieve high retention rates. These strategies and rates are discussed within the context of the CBOs' target populations and communities.

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1. Introduction

Measuring outcomes provides an indication of ongoing program effectiveness by determining if intended outcomes are produced and objectives are achieved. A critical element in cohort studies is the ability to follow-up with participants over time (Hunt & White, 1998). Poor retention of participants in a longitudinal study can skew study outcomes, threaten internal and external validity, and lessen statistical power (Shadish, Cook, & Campbell, 2002). When working with HIV-affected and hard-to-reach populations in prevention intervention studies, high retention rates can be very hard to achieve (Leonard et al., 2003). Lack of stable housing (Mausbach, Semple, Strathdee, Zians, & Patterson, 2007), unreliable transportation (Skeer, Amaro, & Raj, 2002), drug use (Brown-Peterside et al., 2001), incarceration (Brown-Peterside et al., 2001), domestic abuse (McFarlane, 2007), severe depression (Johnson et al., 2008) and caregiving for children and others (Skeer et al., 2002) are common barriers to conducting follow-up interviews. Furthermore, a multi-site evaluation of a HIV prevention intervention in the Houston area found that service providers could be reluctant or unable to conduct follow-up interviews (Begley, Fourney, Elreda, & Teleki, 2002). For service providers, some barriers to collecting follow-up data include a belief that data collection impedes service provision, a low level of commitment to the evaluation due to lack of understanding of its purpose or importance, and high rates of staff turnover at community-based organizations (CBOs) (Begley et al., 2002). In an evaluation of an HIV prevention intervention delivered to HIV-positive prisoners prior to their release, Grinstead, Zack, and Faigeles (2001) reported that tracking this particular group involved a considerable staff commitment and time investment.

Researchers, evaluators, and social service CBOs have developed many strategies to increase retention rates. These include provision of cash and non-cash incentives for participants and staff (Dilley et al., 2007; Jones et al., 2008; Kamb et al., 1998; Leonard et al., 2003; Purcell et al., 2004), acquiring multiple contact phone numbers and addresses (Leonard et al., 2003), using appointment cards or pocket calendars (McNall, Welch, Ruh, Mildner, & Soto, 2004), being flexible in terms of timing when conducting follow-up interviews (Brown-Peterside et al., 2001; Mausbach et al., 2007), providing childcare and food (Skeer et al., 2002), having staff solely

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☆ The findings and conclusions in this report are those of the authors and do not necessarily represent the views of the Centers for Disease Control and Prevention.

[*] Corresponding author. Present address: Prevention Branch, Division of Viral Hepatitis, National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention, Centers for Disease Control and Prevention, Mail Stop E-37, 1600 Clifton Road, NE, Atlanta, GA 30333, USA. Tel.: +1 404 639 6277; Fax: +1 404 718 8595.
E-mail address: bsmith6@cdc.gov (B.D. Smith).

[1] Present address: Applied Research and Evaluation Branch, Division for Heart Disease and Stroke Prevention, National Center for Chronic Disease Prevention and Health Promotion, Centers for Disease Control and Prevention, USA.

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dedicated to data collection and not service provision (Begley et al., 2002; Brown-Peterside et al., 2001), and collaborating with all staff who are responsible for the study (e.g., prevention services personnel and field staff (Begley et al., 2002; Leonard et al., 2003).

This paper describes follow-up retention strategies and rates from the Centers for Disease Control and Prevention's (CDC) Division of HIV/AIDS Prevention's (DHAP) efforts to evaluate the outcomes of evidenced-based interventions delivered by CBOs through the Community-based Organization Behavioral Outcomes Project (CBOP). The experiences of diverse CBOs as they implemented an evaluation study and retained clients over time are explored. A variety of strategies were utilized, and these efforts are described here so that they may be drawn on by other practitioners who are attempting to achieve challenging retention goals.

2. Methods

2.1. The Community-based Organization Behavioral Outcomes Project

CBOP is a family of evaluation studies that assesses the outcomes reported by clients after participation in evidence-based interventions (EBIs) provided by DHAP-funded CBOs. This paper focuses on the post-intervention retention strategies and rates from evaluations of two interventions—one for persons at very high risk for HIV infection (Video Opportunities for Innovative Condom Education [VOICES/VOCES] (O'Donnell, C.R., O'Donnell, L., Doval, Duran, & Labes, 1998; O'Donnell, L.N., Doval, Duran, & O'Donnell, C., 1995; Sweat, O'Donnell, C., & O'Donnell, L., 2001) and another for persons living with HIV (Healthy Relationships; Kalichman et al., 2001).

2.2. CBOP grantees and study participants

CBOP conducted a 2-year evaluation of the two EBIs in 11 CBOs; four were implementing VOICES/VOCES and seven were implementing Healthy Relationships. Geographically varied within the United States, the CBOs were located in urban and rural settings on the East and West Coasts, and in the Southeast and Southwest. CBOP CBOs were determined through a competitive process in which eligible CBOs applied for funding. These CBOs were concurrently funded by DHAP to provide prevention services and collect standardized monitoring and evaluation data.

CBOP had several eligibility criteria for clients, and enrollment was a two-stage process. First, a client must have been enrolled in the intervention, then he or she could be recruited by the CBO to participate in CBOP. (Persons were allowed to participate in the intervention regardless of their participation in CBOP.) To enroll in CBOP, the client had to agree to baseline and follow-up data collection. During baseline data collection, the client provided demographic and behavioral risk data, as well as detailed contact information for the collection of follow-up data. Clients had to be at least 16 years old. No data were collected from clients who declined to participate in CBOP. CDC determined that the study was program evaluation (not human subjects research) and did not require IRB approval at the federal level. Each CBO followed their own policies and procedures regarding human subjects research and program evaluation.

The demographic characteristics of CBOP clients varied among CBOs, depending on each CBO's target population and the intervention provided. Clients' backgrounds were diverse (e.g., incarcerated and homeless populations, substance abusers, economically disadvantaged persons, middle class individuals). Clients were also mixed in terms of race/ethnicity and sexual orientation, including African American heterosexual men, women, and men who have sex with men (MSM); Spanish-speaking heterosexual Hispanics/Latinos and Hispanic/Latino MSM; and white MSM. Of the 11 grantees, 2 provided services exclusively to Spanish-speaking Hispanics/Latinos, and 8 primarily served African Americans. For additional demographic details on VOICES/VOCES and Healthy Relationships participants in CBOP, please see Fisher et al. (2011) and Heitgerd et al. (2011), respectively.

2.3. Evaluation design

CBOP employed a repeated-measures design (data were collected at baseline and at two post-intervention follow-up data collection points), with no control or comparison groups. The repeated measures provide data to determine whether any change in risk behavior has occurred after participation in the interventions and whether a change was maintained over time. Baseline data were collected within 30 days before the intervention. For VOICES/VOCES, the two follow-up data collection points were at 30 and 120 days after the one-session intervention. For Healthy Relationships, the two follow-up data collection points were at 90 and 180 days after the final intervention session. The data collection periods for the VOICES/VOCES and Healthy Relationships evaluation studies were December 1, 2006–January 31, 2008, and December 1, 2006–July 31, 2008, respectively.

All persons who met the eligibility criteria and agreed to participate were enrolled in the study, and their follow-up data were collected regardless of whether they completed the intervention (Little & Yau, 1996). Sample size was limited to the number of clients that CBOs could enroll during the period specified for the collection of baseline data for each study and ranged from 200 to 257 for VOICES/VOCES and 105 to 154 for Healthy Relationships.

2.4. Retention strategies and rates

All clients who enrolled during the designated baseline periods in CBOP were included in the analysis of retention rates. Rates were computed for each of the two follow-up time points for each CBO. The rates were calculated as the number of enrollees who completed the follow-up data collection divided by the total number of CBOP enrollees at that CBO. This total included persons who became incarcerated during the intervention period. A client was eligible for the second follow-up even if the first follow-up was missed. For VOICES/VOCES, the follow-up time period was one week before and two weeks after the 30-day time point. The follow-up time period for the 120-day follow-up was two weeks before and after the 120-day follow-up time point. For Healthy Relationships, the follow-up time period was two weeks before and after both the 90-day and 180-day time points.

Since the primary goal of the CBOs was to provide services to their communities, clients were allowed to re-enroll in the intervention if they had previously dropped out of it during the course of the study. Once a client completed his or her second follow-up interview, they could re-enroll in the intervention (if they had not completed it previously) but could not participate in CBOP data collection a second time. Clients who re-enrolled were only counted once in the analysis of retention rates.

Chi-square comparison of mean tests were conducted to assess for differences in clients retained versus those lost to follow-up by gender, age, race, primary language, relationship status, and education. In addition, the HIV status of VOICES/VOCES clients and length of time since first positive HIV test for Healthy Relationships clients were explored for variations between clients retained compared with clients lost to follow-up. All analyses were conducted using SAS v9.2 (SAS Institute).