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An intervention to assist men who have sex with men disclose their serostatus to family members: Results from a pilot study

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Abstract

The purpose of this study was to evaluate the efficacy of an intervention to assist HIV positive men who have sex with men (MSM) in forming and executing strategies for the disclosure of their serostatus to their families of origin. Results indicate that the intervention was successful in assisting men with the primary outcome of disclosure. Participants reported no regret with disclosures occurring during the intervention and follow-up period. Effects on secondary outcomes including family functioning, depression, loneliness, and perceived social support were inconclusive. Implications, refinements of this intervention, and suggestions for future disclosure research are provided.

Keywords

family; HIV; MSM; serostatus disclosure; regret

Introduction

The decision to disclose one's serostatus has been found to be one of the greatest challenges faced by HIV-positive men who have sex with men (MSM) [1]. Researchers have demonstrated that disclosure of serostatus to family members can create considerable emotional strain [2]. One study found that anxiety about disclosure to family was associated with increased depression [1]. This may be due to apprehension regarding whether or not to tell specific persons and uncertainty about how to tell them. Family dynamics that arise from shared and unshared values and belief systems may influence the anticipation of negative reactions such as rejection, isolation, or emotional abandonment. This, in turn, may heighten

disclosure-related anxiety or stress and may complicate the decision whether or not to disclose. In a qualitative study of serostatus disclosure in MSM, researchers found that participants often cited the importance of family when discussing their disclosure decisions and that family was important regardless of participant age and race and the physical proximity of the family member [3]. Evidence for the importance of family has also emerged in studies of nondisclosure. For example, one study found the most frequently cited reason for nondisclosure was emotionally protecting family [4]. Recent work in the area of HIV prevention has demonstrated the importance of serostatus disclosure to the improvement of mental and physical health outcomes of HIV-positive MSM [5]. Support from family of origin may play a role in this improvement, though the degree of this association varies across studies [1].

Scholars and service providers have suggested that interventions assisting persons in developing effective serostatus disclosure skills may decrease psychosocial distress [5,6]. Some researchers have called for, “interventions... to assist people living with HIV/AIDS in reducing disclosure-related stress, making effective disclosure decisions, and maximizing the potential positive outcomes that can occur with HIV-status disclosure” [1]. Despite evidence that interventions helping MSM develop skills and strategies to disclose to family members are needed, none currently exist.

Research in the area of serostatus disclosure suggests that disclosing to family of origin is important to MSM living with HIV, and that the potential for increased social support as a result of disclosure is one factor which could contribute to improved physical and mental well-being. However, disclosing a positive serostatus may also result in increased stress or anxiety. The purpose of this study was to evaluate the efficacy of an intervention designed to assist HIV-positive MSM regarding the disclosure of serostatus to their family members, and in forming and executing disclosure strategies. The intervention does not promote unilateral disclosure. Serostatus disclosure is not without its risks and can cause, at least temporarily, increased stress [6]. However, for those men who are in the process of making disclosure decisions, or those who need assistance in formulating disclosure strategies, the intervention provides guidelines that are relevant to HIV-positive men as they continue their disclosure work.

The intervention described in this study was developed using the Consequence Theory of Disclosure (CTD) [7]. The CTD suggests that disclosure of HIV serostatus occurs once the rewards for disclosing outweigh the associated costs. This theory employs core assumptions of social exchange theory, which posits that individuals avoid costly relationships and interactions and seek rewarding ones [8]. The intervention was designed to assist the disclosure of serostatus to family by helping MSM develop strategies for disclosure which minimized the potential costs of disclosing while maximizing the potential benefits.

Methods

Recruitment

The study was advertised to potential participants as a trial designed to help MSM improve their HIV disclosure skills and gain comfort and confidence disclosing to their family members. Participants for this study were recruited in two ways. The first was through advertising at local AIDS service organizations. Caseworkers were informed of the study and provided information about the project that they could distribute via flyers or newsletters. Second, recruitment materials were made available at HIV-related venues and forums (e.g., gay pride festivities). Participants were MSM, 18 years of age, able to speak and understand English, with an expressed interest in learning more about disclosure to

family. Recruitment resulted in 62 eligible HIV-positive MSM. Human subjects approval was granted by the Institutional Review Board of (to be inserted) University.

Design and Procedure

Participants completed an assessment at the beginning of the study and were interviewed about their family members by trained research associates in a private research office. From each structured interview a list of family network members was constructed. Demographic data (i.e., age, sex) for each family member, the length of the relationship, and the participant's satisfaction with each relationship was obtained by the interviewer. Then, participants were asked if each member knew of their serostatus and sexual orientation (yes/no). If a family member knew, the participant was asked the mode of disclosure in each case, and whether or not they regretted (yes/no) this person knowing. There are two modes of disclosure. *Firsthand disclosure* is defined as participants telling others themselves. *Secondhand disclosure* is defined as a third party disclosing the participant's HIV-positive serostatus and is further defined as to whether it was with or without the participant's consent.

Study Conditions

Intervention Condition—The pilot intervention was designed to assist HIV-positive MSM in the evaluation of disclosure to family members and to improve their HIV disclosure skills. A 4-session intervention with a 3-month follow-up was designed to assist HIV-positive MSM in forming and executing strategies for the disclosure of their serostatus to their families of origin. A description of the intervention can be found below. Those who were randomly assigned to receive the intervention immediately will be referred to as the *immediate intervention group*.

Waitlist-control Condition—Participants in the waitlist-control condition were provided with handouts on relevant local laws, FAQs about HIV, and resource and referral information. An attention control condition was not used for the waitlist-control. Participants returned three weeks later and three months post-baseline to complete research assessments. Persons randomly assigned to the waitlist-control condition will be referred to as the *control group*.

Participants in the control group who chose to cross over into the intervention, after the final observation of the 3-month waitlist period, also served as the baseline observation for the subsequent intervention period. These participants will be referred to as the *crossover group*. For purposes of analysis, another grouping which combined participants in the *immediate intervention* and *crossover* groups was used. The participants in this combined group will be referred to as the *full group*.

Training—A single facilitator, with over 15 years of experience working in the MSM community, was trained to deliver the intervention to all participants in the intervention and crossover groups. Training for the facilitator involved role-playing with project staff over a 2-month period. The facilitator also met with the principal investigator (PI) to review protocols and make corrections or improvements when needed.

Intervention Protocol

The intervention was developed and manualized through a collaborative effort by the research team and community stakeholders. The intervention development committee, led by the PI, was composed of a post-doctoral research fellow, an HIV prevention specialist, an HIV mental health caseworker, three HIV-positive MSM, and two graduate research associates. The three HIV-positive MSM were selected based on their differing levels of

disclosure to others. This assured adequate representation in terms of disclosure among the HIV-positive MSM community members on the committee. The intervention program was divided into five sessions. The first four sessions were conducted once per week over a 4-week period and the fifth session was conducted two months later. The fifth session was considered a 3-month follow-up and only functioned to measure the longer-term effects of the intervention program. During session 1, participants completed assessments and were introduced to the disclosure intervention. Session 2 involved reviewing the participant's best and worst disclosure experiences to family, an exploration of the participant's motivations related to disclosure or non-disclosure, and an examination of the potential costs and rewards associated with either action. The goal of session 3 was to develop a plan for disclosure. Participants were guided through the creation of a planned disclosure conversation with each family member. In the final session, the facilitator and participants reviewed a personalized *Family Disclosure Worksheet(s)* and all other intervention materials. Participants' feelings and decisions regarding disclosure to family members were discussed.

Primary Outcome Measures

Family information was collected using an adapted version of the Barrera's Arizona Social Support Interview Schedule [9]. For each family member disclosed to firsthand, participants were asked to discuss their comfort, nervousness, and confidence in disclosing using a 5-point Likert-type response set from *Very* to *Not Very*. For family members who were not yet disclosed to, the likelihood of disclosure as well as the importance and anxiety associated with the potential disclosure were assessed using the same Likert-type response set.

Secondary Outcome Measures

Family and friend social support were measured using adapted versions of the Perceived Social Support- Family (PSS-Fa) and Perceived Social Support- Friends (PSS-Fr) scales [10]. In the current study, observed internal consistency reliability ranged from .95 to .97 for the PSS-Fa and from .92 to .93 for the PSS-Fr. Mental health was assessed using the Center for Epidemiologic Studies- Depression Scale (CES-D) [11], the Openness Scale [12], and State versus Trait Loneliness Scale [13]. The CES-D is a 20-item self-report measure that assesses the existence and frequency of depressive symptoms that are not confounded with physical illness. Internal consistency reliability of the CES-D in this sample ranged from .91 to .94 across observations. The Openness Scale is a 30-item scale comprised of three 10-item subscales which evaluate openness with family, friends, and partners. Cronbach's alpha for this study was .94 for the family subscale, .96 for friends, and .95 for partners. Loneliness was measured with the State Versus Trait Loneliness Scale [13]. This scale consists of two 12-item, 5-point Likert-type scales designed to measure long-term, chronic, dispositional traits and short-term, situational or transient loneliness. Cronbach's alpha in this sample varied from .88 to .92 across observations. Family functioning was assessed using the Family Crisis-Oriented Personal Evaluation Scales (FCOPES) [14]. The measure exhibited strong reliability in this sample, with values of alpha ranging from .87 to .91 across observations.

Data Analysis

The primary outcome of the intervention was identified as disclosure. Disclosure was considered to have occurred if the participant reported having discussed his HIV serostatus with a family member who was reported as previously unaware. The frequency and nature of the disclosures that occurred between baseline and post-intervention and those that occurred between post-intervention and 3-month follow-up were explored using descriptive statistics. Disclosures occurring in the immediate intervention group were compared to those in the waitlist-control and crossover groups. Changes in secondary outcomes across the three

observations were evaluated with repeated-measures ANOVA. It was expected that, after disclosure, participants would report greater levels of perceived social support and lower levels of depression and loneliness. Finally, scores on the secondary outcomes were compared for persons who disclosed to at least one family member during the intervention period and those who did not.

Results

Participants ($N = 62$) were primarily white (63%), single (68%) men between the ages of 21 and 62 ($M = 43$ years, $SD = 8.9$). A majority (84%) identified their sexuality as gay, and 77% reported having sex only with men. At entry into the study, participants had been diagnosed with HIV for periods ranging from 13 months to 22 years ($M = 9.3$ years, $SD = 7.0$). Thirty-two percent reported earning from \$0 to \$500, 36% reported earning from \$501 to \$1000, 31% reported earning over \$1000 per month, and 1 participant did not respond. Random assignment resulted in the allocation of 34 participants to the intervention group and 28 participants to the control group.

A total of 447 family members were identified by the participants. Of these, 62% were members of the participants' nuclear families and the remaining 38% were members of their extended families. With respect to ethnicity, 32% of family members were identified as African American, 65% as Caucasian, 0.4% as Hispanic, and 3% as other. At the time of enrollment, 47% of family members were already aware of the participants' serostatus and 81% were aware of the participants' sexual orientation.

Preliminary Analyses

To assess the effectiveness of randomization, groups were compared on selected variables for participants and their family members. Among the participants, the groups were compared on both quantitative (e.g., participant age, openness to friends, family and partners) and qualitative characteristics (e.g., ethnicity, income). Among the participants' family members, baseline comparisons of immediate intervention and control groups included age of the family member, ethnicity, relationship to the participant, and awareness of the participants' HIV serostatus and sexual orientation. Two-tailed independent t tests were used to compare the groups on continuous variables. Pearson's chi-square or Fisher's exact tests were used to compare the groups on discrete variables. In all cases, no statistically significant differences between the immediate intervention and control groups were found.

Primary Outcome

The primary outcome for this study was disclosure. A total of 19 disclosures across groups occurred during the study period. Of these, 1 was reported by a participant in the control group during the waitlist period, 4 were reported by participants during the 4-week intervention period, and 14 occurred during the 3-month follow-up period. The disclosure that occurred during the waitlist period was made to a participant's father, who was identified as a 58 year-old Caucasian. At baseline the participant regarded disclosure to this family member as both "very likely" and "very important". Disclosure occurred in a relationship with which the participant reported being dissatisfied prior to disclosure. In this case, the participant disclosed his HIV serostatus to his father between the first and second waitlist sessions. This same participant also reported another disclosure (to his mother) after crossing over and receiving the intervention. Neither disclosure resulted in self-reported regret.

Among the four participants, each disclosed to 1 person during the immediate intervention period. Of these 4 disclosures, 2 were made to members of the participants' nuclear families (1 mother, 1 sister) and 2 were made to extended family members (1 cousin, 1 niece). Two of these family members were identified as African American and 2 were identified as Caucasian. Prior to the intervention, disclosure was regarded as "very important" in 3 of the relationships and "very likely" in 4. Participants reported that they were "very satisfied" with 3 of these relationships. Three of the 4 family members lived with or near the participant. After disclosure, none of the participants expressed regret that serostatus disclosure had occurred.

A total of 14 disclosures were reported during the follow-up period. These disclosures involved 12 different participants. Seven of the 12 participants began in the immediate intervention group, while the remaining 5 began in waitlist-control. However, it is important to note that only one of the 5 disclosing participants who started in the waitlist-control group disclosed during both the waitlist and follow-up periods. The remainder did not disclose until after they had crossed over and received the intervention. Seven of the 14 disclosures were made to members of the participants' nuclear families (2 fathers, 2 mothers, 2 sisters, 1 daughter) and 7 were made to extended family members (3 aunts, 3 cousins, 1 nephew). Of the 14 family members disclosed to during this period, 5 (36%) were identified as African American and 9 (64%) were identified as Caucasian. Among these relationships, disclosure was described as "important" or "very important" in 10 (72%) cases and "likely" or "very likely" in 9 (64%) cases. Participants reported being "satisfied" or "very satisfied" with 10 of these relationships prior to the intervention. Five (36%) family members lived in the same city as the participant, while the remaining 64% lived as far as several states away. As was the case with the disclosures reported during the intervention period, none of the participants expressed regret that they had disclosed.

Disclosure Trends

Trends in disclosure observed during the study were assessed graphically. In Figure 1, the percentage of family members disclosed to at each observation is plotted separately for the control, immediate intervention, crossover and full groups. Of the 212 family members identified by those in the control group, the number of those who were disclosed to increased from 97 at baseline to 98 at 3-month follow-up, representing an increase of less than 0.5%. The increase in percentage of family members disclosed to was much higher for those in the immediate intervention and crossover groups. Of the 235 family members identified by those in the immediate intervention group, the percentage of those who were disclosed to increased from 46% ($n = 109$) at baseline to 52% ($n = 120$) at 3-month follow-up. Of the 185 family members identified by those in the crossover group, the percentage of those who were aware of the participants' positive serostatus increased from 40% ($n = 73$) at baseline to 43% ($n = 79$) at 3-month follow-up. While disclosure increased in both the intervention and crossover group between baseline and 3-month follow-up, the difference in the proportion of family members disclosed to was not statistically significant in either case.

Secondary Outcomes

The effects of the intervention on secondary outcomes including family functioning, depression, loneliness, and perceived social support were mixed. One-way ANOVA and mixed-model repeated-measures ANOVA (i.e., session as a within-subjects factor, group as a between-subjects factor) were used to compare the immediate treatment and waitlist-control groups on each of the outcomes. No baseline differences were found on any of the outcomes. In the repeated measures analysis, no significant main effects of session or significant time by group interactions were found. The effect of treatment on secondary outcomes in the crossover group was then evaluated using one-way repeated measures

ANOVA. A significant effect of session on family functioning ($F_{(2, 28)} = 5.25, p = .012$) was found in this group. Contrasts revealed that the change between baseline ($M = 99.1, SD = 17.3$) and post-treatment ($M = 97.4, SD = 18.9$) was not significant ($F_{(1, 14)} = 3.91, p = .068$); however, family functioning scores increased significantly ($F_{(1, 14)} = 11.88, p = .004$) between post-treatment and 3-month follow-up ($M = 105.1, SD = 21.2$). In the final analysis, the immediate intervention and crossover groups were compared using one-way ANOVA at baseline and mixed-model repeated measures ANOVA. No significant differences at baseline were detected. However, a significant session by group interaction ($F_{(2, 33)} = 4.46, p = .019$) was found in family functioning. Contrasts indicated that, while no differences existed between the groups at post-treatment ($F_{(1, 34)} = 3.35, p = .076$), the crossover group functioning scores ($M = 105.1, SD = 21.2$) were significantly higher ($F_{(1, 34)} = 8.71, p = .006$) than the scores for the immediate treatment group ($M = 96.9, SD = 17.0$) at 3-month follow-up. Though no significant changes in perceived social support were found in the prior analyses, significant main effects of session on perceived social support from friends ($F_{(2, 51)} = 3.49, p = .038$) and family ($F_{(2, 52)} = 4.23, p = .019$) were identified. Contrasts revealed that perceived support from friends increased significantly ($F_{(1, 52)} = 3.99, p = .051$) from baseline ($M = 45.8, SD = 13.0$) to post-treatment ($M = 49.3, SD = 14.8$), and perceived support from family decreased significantly ($F_{(1, 53)} = 6.07, p = .017$) from baseline ($M = 59.6, SD = 18.7$) to 3-month follow-up ($M = 56.6, SD = 20.1$) and from post-treatment ($M = 58.8, SD = 20.0$) to 3-month follow-up ($F_{(1, 53)} = 5.66, p = .021$). The session by treatment interaction was not significant.

Discussion

This study examined the effectiveness of an intervention designed to assist HIV-positive MSM in disclosing their serostatus to family members. The intervention was successful in assisting some of the men with the primary endpoint of disclosure. For those who disclosed, none reported regret with their decision. Results demonstrated that most of the disclosures occurred among men who were in the immediate intervention and crossover groups during the follow-up period. There are a few possible explanations for the timing of the disclosures. Participants may have delayed disclosure until after the completion of the intervention. Participants may also need more time to execute the disclosure than allotted in the study design. In addition, waitlisted participants knew that crossing over into the intervention was permissible. As such, some men may have delayed disclosure until they completed the intervention resulting in lower disclosures in the waitlist period. Future trials of this intervention should incorporate a lengthened follow-up period to allow for longer disclosure processes and eliminate the crossover design to reduce possible confounded results.

The sample for this study was comprised of men who had expressed an interest in learning more about disclosing to family. This inclusion criterion may have limited the sample to MSM who already intended to disclose but may have desired assistance in doing so. This is supported by the fact that disclosures largely occurred in relationships where disclosure was rated as important and the relationship was rated as satisfying. Therefore, interventions such as this may be particularly effective with a motivated audience. However, participants initially indicated a wide range of comfort with disclosing to these particular family members. This suggests that the intervention may have enhanced efficacy to disclose. Interestingly, proximity or frequency of contact did not emerge as predictive of disclosure. Future researchers should incorporate more extensive measurement of contextual variables to improve our understanding of the role of the dyadic relationship in disclosure.

It was predicted that the intervention would have positive effects on the secondary outcomes of family functioning, depression, loneliness, and perceived social support; however, results on these outcomes were inconclusive. In most cases, no significant changes in secondary

outcomes were detected. Significant improvement in family functioning was observed in the crossover group, yet the same improvement was not observed among those who received the intervention immediately. Perceived social support from friends increased, but only in the analysis which combined both crossover and immediate intervention groups. Perceived social support from family declined, but the change was only statistically significant for the crossover group. Design and study limitations may have influenced these results. Given that disclosures were more likely during the 3-month follow-up, it is plausible that effects of the secondary outcomes would also not be immediately evident. Additionally, the relatively small sample size available for analysis may have increased the potential for spurious effects and reduced statistical power. Finally, the clinical significance of the few changes which were observed is unknown. A review of the literature suggests that more research regarding the specific nature and extent of the relationships between disclosure and family dynamics and the role played by family in HIV-positive MSM mental and physical health is needed. Future studies should include more extensive measures of family-level variables to assess the longer-term effects of disclosure on family functioning. Future trials should also incorporate a lengthened follow-up period and a booster session to strengthen intervention effects and statistical power.

The results of this study lead to additional important questions. First, if participants deliberately delayed disclosing, what were the key factors in deciding when they were ready? For those who did not disclose during the study period, was this the result of a deliberate decision not to disclose or a lack of readiness or opportunity? Did the costs outweigh the rewards or did they discover that disclosure was not important? Future researchers should explore correlates of non-disclosure to family from various perspectives.

Second, if the intervention did not lead to a significant number of disclosures, increased social support and coping skills or decreased depression and loneliness, then why is disclosing important to these men? One plausible reason might be that it is not the actual disclosure that is significant but rather the decision to disclose or not. In fact, the lack of a significant number of disclosures during the intervention may indicate that men were focused on the decision versus the behavior. Making the decision whether or not to disclose may be the more difficult and defining part of the disclosure process. Additionally, a positive resolution of nondisclosure may be equally satisfying as a positive disclosure experience. Therefore, studies which seek to assist disclosure to family may be missing an important part of the process. Assisting men with the decision to not disclose may be extremely important, yet overlooked. Interventions supporting disclosure should focus more closely on decision making and repercussions surrounding the nondisclosure decision regardless of whether the decision is to disclose or not to disclose. Intervention outcomes should be employed which address the actual decision to disclose and not just the outcome of the disclosure.

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Fig. 1. Percentage of family members who were aware of the participants' serostatus by observation and group (Control, Immediate Intervention, Crossover, and Full)