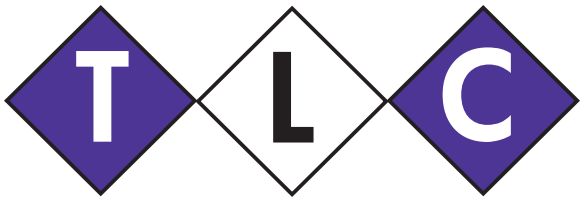

Together Learning Choices

A small-group intervention with young people living with HIV/AIDS

Implementation Manual, Part 1
Introduction and Overview

The University of California, Los Angeles
Center for Community Health
Semel Institute for Neuroscience and Human Behavior
Mary Jane Rotheram-Borus, Ph.D.
Lee E. Klosinski, Ph.D.

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Community Peers Reaching Out and Modeling Intervention Strategies (Community PROMISE) Center for Behavioral Research and Services California State University-Long Beach 1250 Bellflower Blvd. (PSY 440) Long Beach, CA 90840	***Project LIGHT*** Center for AIDS Intervention Research Medical College of Wisconsin 2071 North Summit Avenue Milwaukee, WI 53202
Healthy Relationships Community Prevention and Intervention Unit University of Texas Southwestern Medical Center at Dallas 400 South Zang Blvd., Suite 520 Dallas, TX 75208	***Real AIDS Prevention Project (RAPP)*** Family Health Council, Inc. 960 Penn Avenue, Suite 600 Pittsburgh, PA 15222
Mpowerment Center for AIDS Prevention Studies University of California-San Francisco 74 New Montgomery, Suite 600 San Francisco, CA 94105	***RESPECT*** RTI International 3040 Cornwallis Road, P.O. Box 12194 Research Triangle Park, NC 27709-2194
Partnership for Health IPR/Department of Preventive Medicine Keck School of Medicine University of Southern California 1441 Eastlake Ave., Suite 3409 Los Angeles, CA 90033	***Street Smart*** University of California Los Angeles Center for Community Health Semel Institute for Neuroscience and Human Behavior 10920 Wilshire Blvd., Suite 350 Los Angeles, CA 90024-6521
Popular Opinion Leader (POL) Center for AIDS Intervention Research Medical College of Wisconsin 2071 North Summit Avenue Milwaukee, WI 53202	***Video Opportunities for Innovative Condom Education and Safer Sex (VOICES/VOCES)*** Education Development Center, Inc. 55 Chapel Street Newton, MA 02158-1060

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Together Learning Choices

Implementation Manual, Part 1

Introduction and Overview

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How to Use This Manual

This Implementation Manual was developed as a guide for agencies implementing **TLC: Together Learning Choices** (formerly Teens Linked to Care), an intervention with young people with HIV.

Benefits of Prevention with People Living with HIV/AIDS

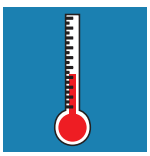
Prevention with people who are living with HIV/AIDS is necessary to reduce the transmission of HIV. This intervention provides additional benefits to participants such as:

- Enhancing their quality of life by providing them with the skills to prevent re-infection and to be pro-active about their health maintenance.
- Creating opportunities for them to connect with other people living with the virus.
- Teaching them the negotiation and practice of safer sex skills.
- Linking them to medical care and other services.
- Linking them to vital social and support services (such as support groups).
- Connecting them to prevention services that promote healthier living, leading to a longer life span.
- Helping them adhere to medical care including drug regimens and doctor visits.

Intended Audience for the TLC Implementation Manual

The staff of agencies implementing **TLC**, including the Program Manager and Facilitators, can use this manual to help them conduct the intervention.

Icons Used

This icon indicates that Trainers should say something or ask a question.	When this icon appears, refer to Implementation Manual.	When this icon appears, present slide to Facilitator Trainees.	This icon signals to the Trainers that the Feeling Thermometer should be used.	When this icon appears, Trainers should distribute Thanks Tokens.	When this icon appears, a role play occurs in the session.
					

Content

Organization of the Implementation Manual

The **TLC** Intervention Package contains the three-part ***TLC Implementation Manual*** essential for conducting the intervention with young people with HIV. Part 1 of the manual is the Introduction and Overview, which serves as an orientation to **TLC**. In it we briefly describe how the intervention was developed and how research determined its effectiveness. How **TLC** was modified during the translation and packaging process is explained. One module, ***Being Together***, was removed. We also discuss underlying principles of the intervention and explain its core elements and key characteristics. Additionally, Part 1 describes how to conduct the intervention sessions, including: advice on preparing for sessions, specific guidelines for Facilitators, an explanation of group processes and suggestions for handling problem behaviors during the sessions. A useful reference list and copies of several articles from professional journals that describe the research behind the intervention are included. Part 1 ends with a collection of optional energizer activities and CDC Information and Guidelines.

Parts 2 and 3 focus specifically on two modules, ***Staying Healthy*** and ***Acting Safe***, respectively. Each of these parts contains session guides for the eight sessions that make up each of the intervention modules. The session guides are prominently labeled with the module name and session number. Each session guide contains a statement of the aims for that session and a summary of the activities conducted in the session, along with the estimated duration of each activity. Session guides contain a full script and detailed instructions for the specific activities in that session. In each session script, **bold** text means to read or convey the information to the participants. Instructions to the Facilitator appear in regular text. The appendix of each script contains the handouts and wall charts used in that session.

The **TLC** Intervention Package contains other materials that will be used to implement the **TLC** intervention. Such materials include: pelvic and penis models for demonstrating correct condom use and reusable wall charts for Ground Rules, How to Use Thanks Tokens, Guidelines for Good Goals, SMART Problem-Solving Steps, Weekly Log, and other charts. Also included are laminated Thanks Tokens and other reusable activity materials.

Agencies will need to provide additional materials to implement **TLC**. These include refreshments and incentives for the sessions, raffle prizes and tickets, an easel with paper and markers, and male and female condoms for demonstrating their correct use. Session guides contain lists of required materials for each meeting.

TLC Intervention Package

1. Three-Part ***TLC Implementation Manual***
    - ***TLC Implementation Manual*** Part 1, *Introduction and Overview*
        - A brief overview of the intervention, the science behind it, its core elements, and its key characteristics.
        - A discussion of capacity issues related to implementing agencies, including a stakeholder's checklist and a budget with cost sheet.
        - Guidelines on implementing the intervention.
        - Information on evaluating the intervention including an evaluation plan, process and outcome monitoring methods, and sample instruments.
        - Several appendices with helpful implementation materials and CDC guidelines.
    - ***TLC Implementation Manual*** Part 2, *Staying Healthy Module*
        - An overview of the ***Staying Healthy*** module and the science behind it.
        - Session guides and Facilitators' notes.
    - ***TLC Implementation Manual*** Part 3, *Acting Safe* Module
        - An overview of the ***Acting Safe*** module and the science behind it.
        - Session guides and Facilitators' notes.
2. Implementation Materials
3. **TLC** Implementation Plan
4. **TLC** Marketing DVD

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Introduction to TLC

Introduction and Background

TLC: Together Learning Choices is an evidence-based HIV prevention and health promotion intervention with young people (ages 13 to 29) living with HIV. **TLC** is delivered in small, closed groups using cognitive-behavioral strategies to change behavior. It provides young people with the tools and skills necessary to live their best life and to be able to make healthy choices. The goal of the intervention is to help participants maintain health, reduce transmission of HIV and infectious diseases, and improve their quality of life. **TLC** is a product of extensive collaboration among researchers, youth living with HIV/AIDS from diverse backgrounds and perspectives, and staff from public and private agencies that serve young people living with HIV/AIDS.

Originally **TLC** consisted of the following three sequential modules and totaled 31 sessions.

- The ***Staying Healthy*** module encourages healthy living by focusing on health maintenance and forging effective partnerships with health care providers.
- The ***Acting Safe*** module is dedicated to primary and secondary HIV prevention by addressing sex- and substance use-related risk behaviors.
- The ***Being Together*** module emphasizes emotional well-being and improving quality of life.
- The **TLC** Intervention Package contains the ***Staying Healthy*** and ***Acting Safe*** modules. The ***Being Together*** module is not a part of the Intervention Package. The text box beginning on page 6 contains an explanation of why this change was made.

Research on the Intervention

TLC was evaluated with 310 HIV-positive youth ages 13 to 24 (27% African American; 37% Latino) who were assigned either to an intervention or a comparison condition. Of the youth in the intervention condition, 73% attended at least one session. The detailed results of the research study can be found in the published articles included in Appendix A.

Following the ***Staying Healthy*** module, the number of positive lifestyle changes increased 45% and use of positive coping styles increased 18% among females in the intervention compared to females in the comparison condition. Seeking and obtaining social support increased 11% among both genders in the intervention as compared to those in the comparison condition. All these changes were statistically significant.

Following the ***Acting Safe*** module, intervention participants reported 82% fewer unprotected sex acts, 45% fewer sex partners, 50% fewer HIV-negative sex partners, and 31% less substance use than those in the comparison condition. Again, all of these changes were statically significant.

TLC modules should be implemented in the order in which the intervention was developed: the ***Staying Healthy*** module first, followed by the ***Acting Safe*** module. The optional module, ***Being Together***, can be implemented last.

Modifications to the Intervention

During its preparation for use in the field, **TLC** was adjusted in the following ways to make implementation easier.

Materials for the ***Being Together*** module are not included as part of this intervention package. The module was not rigorously evaluated due to limited follow-up data and the outcomes were not linked to HIV risk reduction. However, the ***Being Together*** module significantly lowered overall emotional distress, expressions of emotional distress through physical symptoms and anxiety scores among youth in the intervention compared to youth in the comparison condition. In addition, youth in the intervention reported significantly less frequent use of nondisclosure as a coping mechanism than did youth in the comparison condition. The techniques used in this module may require extended training. For these reasons, ***Being Together*** is offered as an optional module. Materials, training and technical assistance for implementation may be obtained from the UCLA Center for Community Health, or the full module may be accessed at http://chipts.ucla.edu.

TLC was originally called Teens Linked to Care because it was designed to target teens and youth (ages 13 to 24) enrolled in HIV treatment programs. The intervention was renamed **TLC: Together Learning Choices** to better reflect the intervention's goals of linking HIV-positive young people to a broad range of care that includes emotional and social support as well as medical treatment.

TLC has been expanded to target HIV-positive young people from a wider age range (ages 13 to 29) who are receiving HIV-related services in a wider range of settings that include both medical clinics and social service agencies. The intervention addresses challenges faced by both HIV-positive adolescents and young adults and can be easily be adapted to a variety of settings, such as mental health centers.

It was also necessary to reduce the ***Staying Healthy*** and ***Acting Safe*** modules to eight sessions each, instead of the eight-to-twelve sessions that were originally offered. The Community Advisory Board that consulted with the **TLC** replication team strongly recommended a smaller number of sessions to make it feasible for agencies to implement the intervention and to successfully retain participants. This decision is consistent with the original research on **TLC** in which the mean number of sessions participants attended was 7.7 for ***Staying Healthy*** and 7.6 for ***Acting Safe***. Seventy percent of participants attended at least six sessions of ***Staying Healthy***, while 73% attended at least five sessions of ***Acting Safe***. This decrease in number of sessions did not result in reduction or change to the content of the intervention. Other changes that were made to the original protocol include:

- Elimination of redundant concepts and activities.
- Addition of updated information on prevention technology, medical management of HIV, and common "club drugs".
- Integration of a perspective that treats HIV as a chronic disease.
- Greater emphasis on non-scripted role plays.
- Incorporation of a Feel-Think-Do Framework that more explicitly highlights the intervention's underlying theory and the link between feelings, thoughts, and actions.

Note: All of the core elements shown to be responsible for **TLC's** effectiveness were maintained.

Underlying Theory and Principles

The **TLC** intervention is based on Social Action Theory. Social Action Theory asserts that a person's ability to change behaviors that endanger his or her health is influenced by the individual's cognitive capability (ability to think, reason, imagine, etc.) as well as environmental factors and social interactions that encourage or discourage the change process. Social Action Theory incorporates the principles that are expressed in traditional social-cognitive models of health-behavior change. These models include social-cognitive theory, the health belief model, and the transtheoretical model (stages of change), as well as theories related to social context, interpersonal relationships, and environmental influences.

With Social Action Theory as its foundation, **TLC** applies cognitive-behavioral strategies to maintaining health, reducing the risk for HIV and STI transmission or re-infection, and improving the quality of life of young people living with HIV. Strategies in the intervention include observing and imitating others as a means of learning new skills and improving old ones, building participants' belief that he or she can change a behavior (self-efficacy); and instilling the belief that changing behaviors will result in a desired outcome (response efficacy).

Feel-Think-Do (F-T-D) Framework

TLC applies the Social Action Theory by emphasizing awareness and identification of one's emotions, thoughts, and actions, which we refer to as the Feel-Think-Do Framework (F-T-D). F-T-D is a simple, low-literacy means of introducing more complex cognitive-behavioral concepts (e.g., emotional regulation, reframing, self-talk, problem-solving, assertive behavior and communication, triggers). It describes an interactive process. F-T-D is based on the idea that when we encounter a situation, we have a feeling about it (discomfort expressed through a reading on the Feeling Thermometer that is used throughout the intervention), a thought about it (what we say to ourselves), and what we do about it (the actions we take as a result of our feelings and thoughts). **TLC** participants are guided by F-T-D to recognize the connections between their thoughts and feelings and the behavioral choices they make, enabling them to more easily make behavioral changes.

> For example, George is a young man living with HIV. His health is excellent and he intends to keep it that way. He returns to the HIV clinic every three months for a check-up. The visits consistently cause George to have strong feelings of discomfort. His discomfort manifests itself as a rapid pulse and flushed face. It causes him to lose patience with the clinic staff and he often glares at them. He also forgets questions he has and has difficulty expressing himself with his healthcare provider. His thinking can become negative: "This clinic will make my viral load come back and I'll never be able to control it." By the end of the visit, George is usually tense, embarrassed by his behavior, and unsure of how to gain control of the situation.

If George were a participant in **TLC**, he would learn how F-T-D can help him gain control over this situation. George would first learn how to rate his feelings and emotions in terms of their likelihood to cause him discomfort. Then he would learn to distinguish different situations that lead to discomfort, and how his body reacts to different levels of discomfort (e.g., flushed face, sweaty palms, pounding head, etc.). Awareness that a certain event causes him discomfort can help George better prepare to deal with the situation.

Feel-Think-Do (F-T-D) Framework - *continued*

> For example, when he knows that a doctor's visit increases his feelings of discomfort, George can prepare by engaging in a relaxation exercise or positive self-talk prior to his visit to lower feelings of discomfort. He can also write down all the questions he has for his provider so he is able to remember them even if his discomfort levels increase.

A relaxation activity and/or positive self-talk can reduce the physical discomfort George's anxiety is causing. Self-talk and relaxation techniques, as well as reframing and stopping negative thoughts are some of the skills taught in **TLC** to control or stop thoughts. The problem-solving skills taught in **TLC** can help him identify a way to get his questions answered, such as writing down his questions as mentioned above. As a participant in **TLC**, George would also learn that his high discomfort levels lead him to act in an aggressive manner. In the intervention, he would not only learn to deal effectively with his discomfort, but also learn and practice more productive responses, such as assertive communication. Since George ***feels*** less discomfort, he is more likely to ***think*** rationally. **TLC** would teach George the skills he needs to be in control of this situation.

> For example, George is a young man living with HIV. His health is excellent and he intends to keep it that way. Prior to returning to the HIV clinic for his three-month check-up, he now does three things. First, he makes a list of all the questions he has for his provider. Second, he says to himself "This clinic visit is an investment in my health." Before leaving, he spends three minutes breathing deeply to relax himself. At the clinic, George smiles to the staff and states what he needs in a clear, polite manner. If he starts feeling uneasy and becomes anxious about his viral load, he says to himself, "Whatever my viral load, we're all one team working to keep me healthy." instead of "My viral load is back and can't be controlled." He calmly discusses his health with his provider and receives answers to all of his questions. George leaves the clinic feeling in control of his clinic visit.

After participating in **TLC**, George will be able to gain control of this situation and handle it more effectively, creating positive outcomes. By taking control of the situation, George will feel good about himself and others will feel better about their interactions with him.

Goals of TLC

The overall goal of **TLC** is increasing behaviors that promote:

- Healthy living.
- Effectively dealing with the challenges of daily living.
- Positive feelings, thoughts, and actions.
- Developing daily routines to stay healthy.

The ***Staying Healthy*** module supports the overall goal of **TLC** by:

- Increasing positive health related behaviors.
- Increasing positive coping skills for a healthy future and for managing challenges associated with stigma.

- Improving communication skills for positive relationships with health care providers.
- Decreasing barriers to successful medication adherence.

The ***Acting Safe*** module supports the overall goal of **TLC** by:

- Reducing the number of unprotected sex acts.
- Reducing the number of sex partners.
- Decreasing the number of uninfected sex partners or partners of unknown status.
- Reducing risky drug use behaviors.

These goals are achieved through **TLC's** core elements (see discussion of core elements in Section 4.2). During the sessions the participants see behaviors modeled, practice those skills, and as a result of skill acquisitions, are able to make the necessary behavioral changes.

Core Elements of TLC

Core elements are critical features of an intervention's intent and design and are responsible for its effectiveness. They must be maintained without alteration.

The following are core elements of **TLC**.

1. Development of emotional awareness through use of a Feeling Thermometer and identification of the link between feelings, thoughts, and actions (F-T-D Framework).
2. Teaching, modeling and practicing four **TLC** essential skills:
    a. Personal Problem-Solving.
    b. Short- and Long-Term Goal Setting.
    c. Emotional Awareness and Regulation.
    d. Assertive Behavior and Communication.
3. Consistent appreciation and reinforcement of positive participant behavior through the use of Thanks Tokens.
4. Identification of Ideal Self to help motivate and personalize behavior change.
5. Sessions delivered in small, highly participatory, interactive groups.

Through **TLC's** core elements, participants develop specific skills that give them a sense of control over their emotions and subsequent thoughts and actions. These skills are repeated and modeled in every session to provide participants with opportunities to practice the skills and ultimately apply them in everyday situations.

TLC Essential Skills

- **Personal problem-solving skills** are presented using a structured model called SMART, which involves five steps: 1. **S**tate the problem, 2. **M**ake a goal, 3. **A**chieve a list of all possible actions, 4. **R**each a decision, 5. **T**ry it and review it. Through this model, participants learn to analyze and identify different actions they might take toward solving a real-life problem. Participants are invited to bring up general problems to which they may be seeking solutions, or a difficult problem related to one of the sessions. The group applies the problem-solving format, selects a goal, identifies barriers, and plans the next steps. This newly learned life skill can be applied to a broad range of problems within and outside the context of HIV prevention.

- **Short- and long-term goal setting** occurs during the conclusion of sessions and usually focuses on a goal related to that sessions's activities or topic. Participants are taught the characteristics of good goals—realistic, clear, challenging but not impossible, and having an identifiable end-point. Once participants choose a goal, they identify the steps they will take before the next session to achieve that goal. A check-in period occurs in the first few minutes of the following weeks's session to discuss what happened. Not only is there the intrinsic reward of achieving one's goal (for those who do), but Facilitators reward (with praise and Thanks Tokens) the attempts that have been made. For those participants who did not achieve their goals, the check-in period allows them to analyze the reasons they were not successful.

- **Emotional awareness and regulation** is another central element of **TLC**. When young people are not able to identify their feelings accurately they are less able to deal with those feelings effectively. Many young people, for instance, describe feeling angry when they are, in fact, hurt and so their responses are likely to be more on the order of lashing out than acknowledging pain or hurt feelings and negotiating a solution to what has caused the hurt. **TLC** teaches participants how their thoughts, feelings, and actions influence each other. This awareness and techniques learned in **TLC** sessions help participants deal with their emotions and replace negative thoughts with positive thoughts, which leads to more positive and effective actions.

- **Assertive behavior and communication** are vital for effective and successful interactions with others. Verbal and non-verbal assertiveness facilitates the implementation of the skills taught in this intervention. For example, as a part of the choices we all have, we can choose to be passive, assertive, or aggressive. Participants are introduced to verbal and non-verbal assertiveness surrounding various life contexts (i.e., condom negotiation, interactions with health care providers, family members, etc.). Role plays are often utilized to provide participants with the opportunity to practice assertiveness. Facilitators repeatedly tie in verbal and non-verbal assertiveness skills with various session topics and model assertiveness skills whenever the opportunity arises.

TLC Learning Techniques

- **The Feeling Thermometer** is displayed on the wall during every session and helps participants assess and discuss their feelings of discomfort more effectively during the session. The Feeling Thermometer is a graphic design resembling a fever thermometer that has been enlarged and reproduced on a poster. The highest measurement on the Feeling Thermometer is 100 and it represents the most discomfort one can imagine feeling. That discomfort may be extreme anger, anxiety, excitement, nervousness, depression, or any other emotion that is experienced as discomfort. The bottom measurement is zero and this represents a total lack of discomfort, whether the associated feeling is happiness or calm or something else.

  Linking Feeling Thermometer levels with situations being discussed or with recent experiences helps participants identify when their emotions are or have been highly charged and what situations are likely to result in those high extremes of feelings. The person at or near 100 on the thermometer is likely to find that his or her discomfort interferes with good judgment and sound decision-making. The person at or near zero on the thermometer is better able to think and make decisions regardless of how he or she labels the particular feeling or emotion. The purpose of the Feeling Thermometer is to increase participants' emotional awareness and self-regulation.

- **Thanks Tokens** are two-inch-square pieces of laminated cardstock with a design on one side (a star is used in **TLC**, but another design may be substituted if you prefer). When praising a participant for a meaningful contribution to the session, such as for speaking out on an issue or coming up with an idea, the Facilitator will accompany the praise with a Thanks Token. The intent is to pair a compliment with a tangible symbol of appreciation to draw the participant's attention to the fact that he or she has been complimented. The Facilitator explains why the Thanks Token was given, e.g., "I liked your suggestion of how we might explain that better," or "I appreciate how you spoke up on that," at the time it is handed to the participant.

  Each participant is also handed a packet of 20 Thanks Tokens at the beginning of each session. Participants are asked to give a Thanks Token, along with a brief description of why, whenever another participant says or does anything he or she appreciates. In this manner, participants learn to deliver as well as receive compliments. When used consistently by both Facilitators and participants, Thanks Tokens leave most participants with positive feelings about themselves. It is important to note that Thanks Tokens are not a medium of exchange and are not "turned in" for anything of value. (Actually, participants will be asked to return the tokens at the end of the session so they can be reused in the next session.)

  The key to everyone using the Thanks Tokens rests on the Facilitators' comfort with them. If the Facilitators like using them and do so at every opportunity, the participants will also use them. **TLC** has been designed so that Thanks Tokens are designated to be used multiple times in every session. However, Facilitators are also encouraged to use Thanks Tokens whenever any other opportunities to use them arise in a session.

Both the Feeling Thermometer and Thanks Tokens are also used in **Street Smart**, another evidence-based intervention available from CDC's Capacity Building Branch-Diffusion of Effective Behavioral Interventions. The same techniques are used in both interventions; however, their explanations in this manual are more detailed and reflect insight gained from field-testing the **TLC** intervention.

TLC Learning Techniques - *continued*

- **Identification of Ideal Selves** helps **TLC** participants pinpoint their values as they relate to the way they would like to see themselves behave. Participants are asked to consider those values as they think about the ways they would like to act in specific situations. The Ideal Self is used as a decision-making guide to help motivate and personalize behavior change. Appeals to one's Ideal Self occur throughout the sessions.

- **Role plays** allow participants to watch and/or practice positive responses to potentially problematic

situations in an instructive and supportive environment. The **TLC** manual contains different types of role plays. A few are scripted and are used to introduce a particular session or topic. These scripted role plays should be practiced ahead of time and are to be acted by Facilitators, not participants. Other role plays are not scripted but a scenario is described and participants are asked to act it out without preparation. These role plays give participants an opportunity to explore new ways of dealing with high-risk situations. Instructions for each role play are found within the session guides. Facilitators should not let a role play go beyond 10 minutes and should monitor it to assure that participants understand and keeping to the point.

  It is important to make every effort to avoid role playing of stereotypes. Many of the role play situations describe interactions between persons with specific characteristics. These role plays are not intended to stereotype individuals by gender, age, or race–in fact, the Facilitators are encouraged to reverse stereotype roles whenever possible. For example, have a female play the role of the person who does not want to use a condom, or have young men role play young women and women role play men. This gives participants an opportunity to explore others' experiences and points of view.

Key Characteristics of TLC

The following key characteristics are crucial activities and delivery methods for conducting **TLC**, however they may be tailored to meet the needs of different agencies and at-risk populations. Key characteristics of **TLC** include:

- **Use of incentives.** We recommend using incentives to encourage participants to return to sessions, but it is up to each implementing agency to decide whether or not to use incentives, what kind to use, and the estimated value of an incentive. The most appropriate incentive strategies are those that your community advisory group and your participant pool think will work best to encourage attendance and participation.

- **Time.** With practice, all sessions can be finished in the two-hour time period indicated in the ***TLC Implementation Manual***. Although the agencies that tested the **TLC** Intervention Package ended up extending the length of their sessions as a result of discussions running longer, it is recommended that the sessions be kept to two hours as much as possible.

- **Intervals between sessions** can be tailored to the needs and capacity of your agency and population. A general rule of thumb is to conduct sessions once a week. Biweekly also may work for you, but we do not recommend monthly sessions except in very unusual situations. Facilitators want to allow participants enough time to practice the skills learned in the group and make progress on their goals, but not so much time that they forget lessons or lose interest. When planning for the session frequency, there are several things to be considered:

- Time for participants to think about what they have experienced.
- Ability to retain participants.
- Availability of both participants and Facilitators.

It is not recommended that an agency conduct all eight sessions in one day or a weekend.

- **Facilitators.** Two persons are needed to facilitate the groups. The same two Facilitators will be able to enhance group cohesiveness much better than having different Facilitators for different sessions. While it is preferable to have one Facilitator be male and one female (for purposes of modeling and providing a gender-specific point of view to the participants), that may not be possible in every circumstance. When necessary, same-gender Facilitators can conduct the sessions. If your group is all of one gender (all male, for instance), one of the Facilitators should be of this gender.

- **Group composition.** Implementing agencies may modify **TLC** with respect to the age, gender, and sexual orientation of participants. For example, if your agency's potential participant population is sufficiently large, you may wish to consider holding separate groups for younger (e.g., under 18) and older participants. You may not change **TLC** from a group to an individual delivery method (contact the UCLA Center for Community Health about similar interventions that are effective for individual use), but the composition of the group is flexible.

- **Group size.** We recommend that **TLC** groups be from four to eight participants in size, though slightly larger groups (up to 12) may be workable once your Facilitators have sufficient experience with the intervention to be comfortable with a larger group.

- **Building Group Cohesion:** Building cohesion is essential to **TLC** because participants may disclose personal experiences and they need to feel safe and supported as they do so. Building cohesion lays the foundation for building trust and trust creates the safe and supportive environment necessary for **TLC**. The agencies that tested the intervention used a variety of cohesion building activities. Some agencies used introductory sessions; others used meals served before or after the sessions. Other ways to build group cohesion are using "energizers" or "getting to know you" activities before, during and after the sessions.

- **Food/Snacks:** Implementing agencies are encouraged to provide refreshments for their participants. This is not a core element but strongly recommended.

- **Visual Aids:** The use of visual aids like the wall charts supplied in the **TLC** Intervention Package can help in the comprehension and retention of concepts. Visual aids can also help participants who have low literacy skills. It is recommended that visual aids be simple and universally understood.

- **Location: TLC** can be held anywhere there is a private room with enough space to accommodate the participants, the role plays and a refreshment table. The venue and room should be handicapped accessible. For some communities, venues that advertise services for people living with HIV/AIDS are not good places to hold **TLC** sessions. Some participants have not disclosed their status and therefore would not attend sessions at a place that would compromise their privacy.

Why We Use Groups

The use of sessions delivered in highly participatory, interactive small groups is a core element of **TLC** and cannot be changed. **TLC** uses groups as the framework in which health seeking and prevention behaviors are learned, practiced and reinforced because:

- Seeing other young people struggling with the same issues counteracts the belief that "I am alone" or "nobody feels this way but me" and increases young people's ability to learn new skills.
- Peer norms can be turned into an advantage in encouraging safer sex behaviors.
- Learning and practicing new skills in the supportive environment of **TLC** groups can enhance self-esteem.
- Practicing a skill in the presence of other young people tends to improve performance.
- Group interaction promotes a strong emotional experience, which facilitates learning.
- Learning in a participatory, non-judgmental, fun style with other young people can increase motivation.

Working with Adolescents in Group Settings

It is important to remember these points:

- Adolescence and young adulthood are times of experimentation. This frequently means engaging in unprotected sexual intercourse with multiple partners and using drugs or alcohol. For youth and young adults with HIV, these behaviors increase the risks both of infection with other sexually transmitted infections (STIs) and of re-infection with new strains of HIV. They also increase the probability of transmitting HIV and other STIs to their sexual partners.
- Developmental changes in behavior and ways of feeling, thinking and acting, as well as in the influence of peers, must be considered as essential elements in understanding and changing risky behaviors. Intervening with young people must include providing them with specific knowledge about HIV/AIDS and STIs and must build their awareness of their own feelings, thoughts and actions, so they can begin to apply this knowledge to their own lives. Building coping skills and providing access to resources are other essential elements of successful intervention programs.

Getting Started

This section describes what agencies must have in place to effectively implement **TLC: Together Learning Choices**. It is suggested that agencies wanting to implement **TLC** form a community advisory group recruited from community members, members of the target population, members of the agency's Board of Directors, and agency staff members. This group's role will be to inform and assist with all aspects of the pre-implementation and implementation process described below.

Organizational Assessment Activities

Conducting a needs assessment is the process of collecting information that describes the factors that put a population at risk and the resources they lack to address those factors. This type of assessment is conducted before implementing the **TLC** intervention and will provide important data on the need for **TLC** in a particular community or at a particular agency. A needs assessment can also provide insight into how TLC may need to be tailored to best serve your audience.

Agency capacity issues such as staffing, space, and budget, and developing an implementation budget are central getting-started activities. It is important to note that these activities do not need to happen strictly in the order they appear in this manual; they may happen simultaneously.

Agency Capacity Issues

The first thing to do before implementing this intervention is to address the agency capacity issues, starting with securing the "buy-in" of agency stakeholders.

Buy-In

Securing “buy-in” is crucial because it assures the support of agency administration and facilitates the allocation of agency resources for implementing the intervention. Obtaining "buy-in" is most effectively accomplished with an intervention champion. A champion is a mid- to upper-level administrator within the agency who serves as the intervention’s spokesperson, anticipates and answers questions about the need for the intervention, and is familiar with the resources needed to implement the intervention. The champion can be an individual or a group of people, but regardless of the number of champions, their central purpose is convincing agency staff and others that implementing **TLC** would enhance the quality of prevention services provided by the agency and that the agency is capable of implementing the intervention. The champion must have excellent knowledge of the intervention including its costs, core elements and key characteristics. The champion can use the **TLC** Marketing DVD and other information presented in the intervention package to gain the support of stakeholders, and to answer any questions or concerns they might have about **TLC**.

A stakeholder’s checklist is provided to guide agencies and the intervention champions in obtaining support and ensuring the successful implementation of **TLC**. Stakeholders may include volunteers on your Board of Directors/Executive Board, people in your community, other local agencies, your staff, and funders whose decisions and actions could impact the successful implementation of this intervention.

Stakeholder's Checklist

1. Assess the community to determine whether they will support the core elements of **TLC**.
2. Identify your stakeholders:
   a. Your agency's Board of Directors/Executive Board.
   b. Staff members from your agency who will have a role in the operation of the intervention:
      – Administrators who will obtain support.
      – Supervisors who will monitor the intervention.
      – Staff who will interact with participants at any level.
   c. Local agencies from which you could recruit participants, Facilitators or both:
      – Agencies offering support groups for young people living with HIV/AIDS.
      – Health care providers and mental health professionals serving people living with HIV/AIDS.
      – Social service agencies reaching people living with HIV/AIDS.
      – Organizations of people living with HIV/AIDS and organizations which may have members who are living with HIV/AIDS.
   d. Organizations which could provide assistance or other resources:
      – Vendors for incentives and refreshments.
      – Agencies, vendors, printers, publishers, broadcasters and others who can advertise the intervention.
      – Agencies that can provide a venue for the intervention.
      – Agencies that can provide child care.
      – Agencies that can provide transportation.
      – Agencies that can provide informed volunteers for your community advisory group to help tailor the intervention.
      – Other collaborating agencies to provide information for Resource Packets.
   e. Agencies with which your organization needs to maintain good community or professional relationships:
      – Local health department.
      – Local medical and mental health associations.
      – Your funding source(s).
      – Others.

3. Getting stakeholders informed, supportive and involved:

    a. Getting them informed about the intervention:

        – Decide in advance what specific roles you want each stakeholder to play. Who you will ask to:

            - Provide financial support.
            - Refer people living with HIV/AIDS to the intervention.
            - Serve as an intervention Facilitator.
            - Be a resource to whom you can refer participants.
            - Join your community advisory group.
            - Help tailor the intervention for your target population.
            - Assist in advertising the intervention.
            - Provide a room in which the sessions can be held.
            - Supply refreshments for participants.
            - Donate small incentives or prizes for participants.
            - Speak supportively about **TLC** in conversations with their associates.

        – Send letters that tell stakeholders about **TLC**, its importance, that your agency will be making the intervention available, the specific role(s) you think that they may play in the success of the intervention, and invite them to learn more.

        – Call in two weeks and assess their interest. If they are interested, schedule a time to meet (e.g., one-on-one, lunch-and-learn at your agency with a group of other stakeholders, presentation at their agency for several of their staff or association members).

        – Hold the meeting, show the **TLC** Marketing DVD if the setting and time allow, answer questions.

    b. Getting them supportive

        – Describe several specific roles they could play.

        – Emphasize the benefits of their involvement to themselves, their agency, the community and people living with HIV/AIDS, and answer questions.

        – Invite them to commit to supporting **TLC** by taking on one or more roles.

        – Keep track of commitments.

    c. Getting them involved

        – Soon after meeting, send a thank-you letter that specifies the role(s) to which they committed. If they did not commit, send a letter thanking them for their time and interest and ask them to keep the letter on file in case they reconsider later.

Stakeholder's Checklist - *continued*

- Provide immediate and specific work assignments to people who committed to a role that is important to pre-implementation.
- For people who committed to roles that begin later in the process, provide progress updates and a projected time frame for their involvement.
- Hold periodic celebratory meetings for supporters to acknowledge the value of their contributions, update them on the intervention's progress and keep them engaged.

Budget

Another getting-started activity is determining the cost of implementing the intervention. Implementing **TLC** requires the allocation of resources for: a 50 percent Full Time Equivalent (FTE) paid, experienced Program Manager, two 50-100 percent FTE Facilitators, and one optional 50 percent FTE Program Assistant. We estimate that each Facilitator will need to attend 40 hours or five days of training for each **TLC** module. Facilitators will also need time to prepare for sessions, conduct them and debrief after they are completed. The original intervention study also provided participants with a per session incentive, but this is not required to implement **TLC**. The intervention involves the use of an easel, easel paper, markers, forms and handouts and one small prize to be given away through a random drawing at the end of each session. **TLC** is not a high-maintenance intervention and can be made feasible for almost all agencies.

Cost Sheet

A cost sheet has been provided to highlight possible costs associated with implementing **TLC**. This is meant only as a guide. Depending on the number of times you implement the intervention or the specific needs of your agency, these figures will vary from organization to organization. The cost sheet assumes that your agency already has access to intervention participants. If this is not the case, you will need to add recruitment costs. It also assumes that there will be no donations, volunteers or in-kind contributions, and includes costs/values as if everything will need to be paid for by the agency.

Categories for Provider Costs to Implement the TLC Intervention

Categories	Pre-Implementation (start-up)			Implementation (intervention delivery)		
PERSONNEL	# Staff	% time or # hrs/wk		# Staff	% time or # hrs/wk	
SALARIED		(% FTE time spent on intervention)			(% FTE time spent on intervention)	
PROGRAM MANAGER	1	75%		1	50%	
FACILITATOR	2	50%		2	100%	
PROGRAM ASST.	1	50%		1	50%	
FRINGE BENEFITS		25%			25%	
FACILITY(IES)		(% time used for intervention)			(% time used for intervention)	
RENT						
OFFICE	$ x	% =		$ x	% =	
SMALL GROUP MEETING SPACE	0			$ x	# sessions = (inc. pre-sessions)	
UTILITIES	$ x	% =		$ x	% =	
TELEPHONE/FAX	$ x	% =		$ x	% =	
MAINTENANCE	$ x	% =		$ x	% =	
INSURANCE	$ x	% =		$ x	% =	
EQUIPMENT		(% time used for intervention)			(% time used for intervention)	
COMPUTER	$ x	% =		$ x	% =	
COPIER	$ x	% =		$ x	% =	
EASEL	$ x	% =		$ x	% =	
EQUIPMENT MAINTENANCE	$ x	% =		$ x	% =	
INTERNET SERVICE PROVIDER	$ x	% =		$ x	% =	
SUPPLIES						
POSTAGE & MAILING	$			$		
COPYING & PRINTING	$			$		
OFFICE SUPPLIES:						
PAPER (WHITE)	1 ream x		$ /ream =	5 reams x		$ /ream =
PAPER (COLORED)	0			3 reams x		$ /ream =
CERTIFICATE PAPER	0			1 pkg. x		$ /pkg. =
PENS	1 dozen x		$ /doz. =	3 dozen x		$ /doz. =
NAME BADGES	0			100 x		$ /each =
EASEL PAPER	0			2 pads x		$ /pad =
MARKERS	0			1 pkg. x		$ /pkg. =
PUSH PINS	0			1 box x		$ /box =
MASKING TAPE	0			1 roll x		$ /roll =
POCKET FOLDERS	0			10 x		$ /each =
TEACHING SUPPLIES						
ANATOMICAL MODELS						
MALE	10 x		$ /each =	0		
FEMALE	10 x		$ /each =	0		
LUBRICANT	0					
CONDOMS						
MALE	0			2 dozen x		$ /doz. =
FEMALE	0			2 dozen x		$ /doz. =
PRINTED MATERIALS						
FORMS	0			3		
INFORMATION SHEETS/FLIERS	5 gross x		$ /grs. =	0 x		$ /each =
OTHER MATERIALS						
PRIZES	0			8 x		$ /each =
CATERING/REFRESHMENTS				80 x		$ /person =
RECRUITMENT (OF STAFF/VOLUNTEERS)						
ADVERTISING	10 column inches x		$ /inch =	10 column inches x		$ /inch =
TRAVEL						
MILES TO/FROM INTERVENTION LOCATION (if other than regular work place)	# miles x		¢/mile =	# miles x		¢/mile =

Notes on Categories for Provider Costs

- Intervention delivery costs are based on an average of 10 participants times eight sessions per module. **TLC** should be implemented in the order in which it was developed: the ***Staying Healthy*** module first, followed by the ***Acting Safe*** module. The third module, ***Being Together***, which is optional, can be implemented last.
- Numbers of printed and other materials are calculated as follows: for each module implemented you will need approximately 10 sheets of paper (forms, handouts, evaluation) per person. For each session you also will need one name badge and one serving of refreshments per participant. One prize is awarded at each session.
- Both Facilitators will need to be compensated for their time spent recruiting, screening participants, training (four days per module) and practicing during pre-implementation. Intervention delivery time includes review before each session, travel to the sessions, session time and debriefing time. It also assumes weekly sessions for eight weeks, plus a week for preparation and wrap-up.
- Figures are based on one implementation of ***Staying Healthy*** and ***Acting Safe*** to one target population.

How To Conduct TLC Sessions

This section addresses the actual delivery of **TLC: Together Learning Choices** to youth.

Recruitment of Participants

It is important for your agency to have a recruitment plan in place that details how participants will be recruited, including recruitment venues, recruitment/marketing tools, and number to be recruited. The plan should also draw upon ideas and techniques used in the past to recruit and retain participants in programs. Your community advisory group should be able to provide your agency with the answers to some recruiting questions, such as:

- Where is the best place to recruit?
- What are the best recruiting strategies for your populations?
- What might motivate members of the target population(s) to attend **TLC**?

In Appendix B, there is a generic marketing information sheet that can be tailored, with the assistance of your community advisory group and used to recruit potential participants.

Participant Retention

Keeping participants engaged in the intervention can be a difficult task. The Facilitators have much of the responsibility for making sure that all participants:

- Have a chance to contribute to discussion.
- Have a chance to participate in activities.
- Have a chance to have their thoughts heard.
- Feel welcomed, safe and supported.

Facilitators also should work hard to maintain enthusiasm and sincerity when presenting **TLC** activities. The attitudes of the Facilitators are important motivation for participants to return to the group.

Incentives can also provide motivation for young people to keep attending **TLC** group sessions. Incentives will vary by agency, based on resources, agency policy and needs of the specific target group. Some agencies have been successful in soliciting incentives from local businesses. Seeking in-kind donations helps promote the mission of the agency in the community. It also gives local businesses an opportunity to participate in a larger HIV prevention effort.

Participant Retention - *continued*

Ways to increase retention and attendance at **TLC** group sessions can include reminders such as telephone calls, text messaging group members the day before a session, sending an "e-vite" invitation, etc. Facilitators may want to discuss reminders with the group to find out what form of contact is best.

Attendance Policy

TLC is a closed group. Once the sessions begin, participants cannot be added to the group. Participants should not miss two consecutive sessions. Each session builds on the previous session. Missing more than one session undermines the participant's ability to fully grasp the skills, making it difficult to participate in the other sessions.

Implementing agencies need to develop attendance policies that support the goals of **TLC** and clearly communicate these to participants and other stakeholders in the intervention.

Pre-Assessment Interviews

Pre-assessment interviews are an opportunity for your agency to interview potential **TLC** participants and assess their readiness to participate in the intervention. The interviews can be conducted by the Facilitators in a private room where the potential participant can freely answer questions in a welcoming and supportive environment. During the interviews, Facilitators ask potential participants about their previous group experience and their ability to handle conflict. The pre-assessment interviews provide Facilitators with an opportunity to assemble a group of participants whose personalities work well together. Additionally, during the pre-assessment interviews, participants can have their questions about **TLC** answered. Some sample interview questions are:

- What has been your experience with support groups or discussion groups?
- What do you like most/least about groups?
- How do you handle tension or conflict within a group of people?
- How long have you been diagnosed with HIV?
- How comfortable are you discussing HIV issues in a group setting?

Participants newly diagnosed with HIV may not be ready for the intervention. They may require referrals to medical care or individualized counseling.

A number of pre-assessment interview questions are provided in Appendix D. These questions can be tailored to fit your population.

Resource Packets

Participants in **TLC** may have questions and needs that cannot be addressed during the **TLC** sessions. Because of this, agencies may decide to create a Resource Packet to distribute to each participant. Packets should describe services and other resources available in their community. If used, the Facilitators should encourage participants to make use of these resources and remind them of the packet at the end of each session.

Following is a list of the types of materials that might be included.

- Business card or other contact information for the Facilitator and the sponsoring agency.
- Information on the limits of confidentiality and relevant notification laws.
- An introduction to the **TLC** intervention and why it is being implemented by this agency.
- A list of key agencies providing services to young people living with HIV/AIDS.
- A variety of resource brochures specific to the community. (e.g., information about where in the immediate area to find HIV/AIDS services assistance with housing, food, medical treatments, prescriptions, etc.).
- Up-to-date information on transmission of HIV, HIV medications, and HIV therapy/treatment.
- Printouts from websites of interest to participants.
- List of contributors of any donated food, gift certificates, or coupons.
- Any other materials that might serve as a resource to participants.

Some agencies have reported that its **TLC** participants do not like to receive take-home materials that mention HIV or AIDS. Implementing agencies should assess the merits and feasibility of posting the Resources Packet on a website with URL not associated with HIV/AIDS.

Pre-Delivery Checklist

This pre-delivery checklist is a quick reference of items that should be in place before **TLC** is delivered.

- Participants recruited.
- Participants assigned to groups.
- Location selected and room set-up.
- Table for food/snacks (prepared).
- Sessions scheduled.
- Pre-assessment interviews completed.
- Facilitation coordination and practice sessions held and completed.
- Resource Packets compiled and copied (if used).
- Supplies on-hand.
- Condoms, condom models and lubricant (lube) on-hand.
- Incentives obtained.
- Other intervention materials on-hand, prepared, copied, enlarged.
- Wall Charts posted.

Arranging for the Sessions

Number of Participants

- Four to 12 participants, of either or both sexes.

Number of Facilitators

- Two, preferably one male and one female.

Number of Sessions

- Eight group sessions in each module.

Frequency of Sessions

- It is recommended that sessions for each module be held once a week. However, how frequently the sessions are held will depend on the needs and specific circumstances of the participants and agencies.

Length of Sessions

- Each session should be at least two hours.
- It is recommended that there be a "social time" with refreshments after each session. This will make the sessions more fun and will encourage participants to engage further with one another and with the intervention. If held in advance with food removed when the session starts, it also encourages participants to be on time.

Physical Space and Atmosphere

- The atmosphere in a clinic or agency is a part of the intervention. Sessions should be conducted in a large, comfortable room protected from interruptions. In a safe atmosphere, peers support each other, learn from each other and build each other's self-esteem. Thus, group cohesion is supported in every session. The goal is for participants to build trust in each other and the Facilitators by asking questions and sharing their real-life experiences related to the issues being addressed in the sessions. They are more likely to do this if the sessions are held in a friendly, informal atmosphere where confidentiality is promised.

Participant Seating

- Participants should sit in a closed circle so that eye contact and interaction are encouraged and so it is easy to distribute Thanks Tokens.
- Avoid having all male or female participants sitting together to create balance.
- Split up cliques (groups of friends) or assign to another group, where possible.
- Place a disruptive participant next to a Facilitator.

Materials and Equipment

- Session-specific materials are described in the beginning of each session guide.
- Some materials are used in all sessions and some materials are specific to particular sessions.
- Items used across all sessions include:
  - Thanks Tokens.
  - Prizes.
  - Feeling Thermometer.
  - Easel Paper and markers.
  - Weekly Goal Cards.
  - Wall Charts: Ground Rules, Using Thanks Tokens, Guidelines for Good Goals, SMART Problem-Solving Steps, Weekly Log.

Facilitator Guidelines

Facilitators are encouraged to become very familiar with the content of the intervention. Until Facilitators feel confident with the intervention content, using the script as written is encouraged. Once Facilitators become comfortable with the intervention, they can summarize the material in their own words, making sure to use language consistent with the target population and including all the main points. Writing session notes on index cards is recommended. However, the use of index cards and summarizing should only be undertaken if Facilitators have practiced the sessions multiple times and feel very comfortable with the intervention content.

Facilitator Responsibilities

Facilitators have specific functions and tasks to perform before and during the sessions.

Responsibilities include:

1. **Use the session guides.**
   - The text that is **bold** is what facilitators should say or convey to the participants. The text that is not bold are cues for the facilitators to implement the activities.
   - Know the material well enough that you are familiar with the concepts and do not need to read the text directly.
   - Translate material into your own words once you become skilled at facilitating the activities.
   - Practice often.
2. **Manage the operation of the session.**
   - Provide the knowledge needed.
   - Apply your skills to the session contents and be familiar with the material beforehand.
   - Be on time and stay on time.

Facilitator Responsibilities - *continued*

- Manage communications in the session.
- Be prepared. Have all materials ready for that session and organized so that you can access them when you need them.
- Provide a safe emotional space.
- Be enthusiastic, optimistic and communicate your belief in the intervention.
- Be a good role model.
- Be empathic, but stay in your role.

3. **Recognize and reward positive behavior.**
   - Use supportive statements when you "catch someone doing something good."
   - Use Thanks Tokens to acknowledge participants' positive actions.
   - Support participants' efforts to move their behavior in the desired direction.
4. **Challenge disruptive or problematic behavior.**
   - Enforce Ground Rules to maintain order and a safe environment.
   - Use group processes to set and reinforce group norms.
   - Refer to Appendix E and the suggestions for handling problem behaviors.
5. **Elicit participants' assessment of their feelings.**
   - Use the Feeling Thermometer to help participants recognize how they feel—their level of discomfort.
   - Help participants label what feeling they are experiencing—anger, depression, guilt, pleasure, sexual arousal, etc.
6. **Encourage participation.**
   - Use Ground Rules (especially "confidentiality") to ensure the existence of a safe environment. This will help participants feel more comfortable addressing sensitive topics.
7. **Show participants how to act effectively.**
   - Model the skills **TLC** teaches.
   - Demonstrate coping and other skills.
   - Use role playing based on the participants' experiences to help peers learn from each other.
   - Practice problem-solving frequently.
   - Demonstrate effective communication and interactive behaviors, including assertiveness.
   - Help participants practice new ways of thinking, feeling and acting.

8. **Create concern in participants about:**
    - Unsafe sexual and substance-use behaviors.
    - Other forms of unhealthy behavior and lack of adherence to health-promoting behavior.
    - Involvement in risky situations and with risky partners.
9. **Build group cohesion through:**
    - Showing appreciation to participants for their contributions (e.g., Thanks Tokens).
    - Communicating clear expectations regarding how group members treat each other and how they participate—talking, sharing, role playing, checking feelings.
    - Encouraging self-disclosure through supportive statements, teaching communication skills, modeling, using the Feeling Thermometer, and demonstrating acceptance of group members regardless of the feelings and content expressed.
    - Having group members give each other praise, recognize what is positive about each other, provide constructive feedback, and share.

Facilitator Processes

Listed below are suggestions for dealing with specific aspects of group process and group functioning:

1. **Have one Facilitator direct the activities while the other monitors the process.**

    Functions of the Co-Facilitator include:
    - Giving feedback.
    - Keeping focus on tasks at hand.
    - Making sure everyone is participating in group.
2. **Co-Facilitators may switch roles regularly during the group, but both Facilitators should be equally prepared and equally responsible for all materials and activities.**
3. **Support each other and work as a team.**
4. **Equally share the content and process parts of the session.**
5. **Pay attention to each other's non-verbal as well as verbal communications.** Yield to your Co-Facilitator if it looks like he or she wants to say something or take the next part for some reason.
6. **You don't have to be an expert and have all the answers.** It's OK to say, "I don't know." You could also say that you will try to have an answer by the next session.

Facilitator Processes - *continued*

7. **Facilitators establish control from the beginning, indicating that they will:**
    - Direct the activities.
    - Set the pace.
    - Ensure group members' self-control.
    - Prevent self-harm by participants, harm to other group members, and destruction of property.
8. **Facilitators encourage behavior change by providing knowledge, support and reinforcement.**
9. **Facilitators are not therapists, counselors or pastors.** They cannot and must not try to reorganize personalities or heal dysfunctional families.
10. **When tempted to share personal information from your own life; ask yourself:**
    - Is this clearly helpful to the group?
    - Is it directly relevant to the topic or skill being learned?
    - Is there time?
    - Does the content involve material I am comfortable having most people know I am struggling with?

If the answer to any one of these questions is "no," don't share the information.

11. **Specific tips:**
    - Frequently reward desirable behaviors.
    - Be supportive.
    - Give compliments.
    - Be non-judgmental.
    - Encourage group cohesion.
    - Model appropriate assertive behavior.
    - Be firm.
    - Illustrate points through modeling.
    - Share personal experiences in a limited fashion.
    - Keep language simple.
    - Encourage participants to share their own experiences.
    - Build on participants' strengths.

- Listen.
- Let the participants do the reacting, responding, thinking and analyzing.
- Be flexible.
- Keep trying. If one approach doesn't work, find another one.

12. Things to note about participants:

- Are they paying attention? Watch for participants' non-verbal communications indicating interest or attention. Examples: eye contact, facial expressions, nodding head, body language open and toward speaker.
- Are they truly listening, not just looking as if they are? Listen for verbal cues indicating understanding, such as appropriate responses to questions and participation in discussion.
- Do they ask questions relevant to the content of the conversation?
- Do they make statements that reflect the content or emotion being expressed?
- Translating: Putting concepts into simpler, more precise, concise or common language, without changing the meaning of the experience.
- Reframing: Presenting an experience from a different perspective that promotes a change in the meaning of that experience. For example, a smoker who is trying to quit feels like a failure because one day she smoked two cigarettes. The smoker's previous typical number of daily cigarettes was 40, so the listener helped her reframe the situation as a 95% success on that day.
- Probe for barriers using active listening: What are the true barriers that participants had in coming to the group? What were their fears about participating? For example: "You sound like you've given this some thought. What do you think is the worst thing that can happen to you if you come to group?" Or, "You sound like you are not sure. What do you think is the worst thing that could happen to you?"
- Overcoming barriers: Participant says he or she has no time. Validate his or her feelings, then probe about what conflicts he or she has and problem-solve the situation with them (using the SMART Problem-Solving Steps) while emphasizing the value of the group. Identify what other participants said they wanted or got from the groups and use these as selling points.
  - Social support: Making new friends.
  - People like me: Meeting other HIV-positive people my age.
  - Information: Learning more about HIV, living with HIV, resources available.
  - Helping others (altruism): Desire to help others with HIV, provide support to others.

Debriefing

TLC deals with issues that may cause emotional responses for both the participants and the Facilitators. Debriefing allows the Facilitators a time to release those emotions in a supportive space. Your agency may have some specific methods for debriefing; the following is designed to add to your agency's existing procedures.

Two levels of debriefing can occur in an organization. One level is for the purposes of quality assurance of intervention delivery. For example, what you learn from the debriefing session may help you with future sessions. The Program Manager should lead the debriefing sessions and allow the Facilitators to talk through any issues that arose during the sessions. This debriefing session can be used to discuss what is and is not engaging participants and what alterations in delivery need to be made. Facilitators can seek advice or brainstorm solutions to issues or questions that come up during the session. They can also make plans on how to deal with situations that are likely to repeat, such as a participant who does not let others talk.

The second level of debriefing is regarding Facilitators' personal feelings about the session. This level of debriefing allows the Facilitator to examine any personal emotions that may have surfaced during the session. The Facilitator should take part in this debriefing process after each session with the Program Manager and may wish to keep a journal to express their feelings regarding the sessions. The Program Manager should refer the Facilitator to counseling services, if needed, and the Facilitator should be allowed to discontinue his or her role if the sessions become too emotionally overwhelming.

Here are some specific questions that might be asked in debriefing.

- **Participants:**
  - Who needs to be coaxed to participate?
  - Who needs to be kept from dominating the group?
  - Who might need referrals?
  - Who needs referral appointments made for them?
  - Who needs help with transportation? Child-care?
- **General session notes:**
  - What went well?
  - What did not go well?
  - How could delivery of the next session be improved?
  - What concepts did participants have trouble grasping?
  - What concepts need to be reinforced next time?
- **Environment:**
  - Was the room too hot/cold?
  - Were there enough chairs?
  - Could the participants be overheard?
  - Were there enough snacks?

Tips on Conducting a TLC Debriefing Session

- Remember that the purpose for the debriefing is to allow the Facilitators a time to release emotions from the sessions and to gain support from their colleagues.
- The role of the Program Manager is to guide the debriefing session. The Program Manager does not act as a counselor during the debriefing.
- Create an environment where the Facilitators can relax and voice their opinion without fear of scrutiny.
- Each individual should be given between five and seven minutes to express both negative and positive feelings about the session. This period allows time for each Facilitator to relax from the emotion felt during the session.
- The person who leads the debriefing needs a working knowledge of the Stages of Grief: Denial, Anger, Bargaining, Depression, and Acceptance.
- Guilt may be another emotion expressed by the Facilitators. The Facilitators may experience guilt when recognizing similar behavior patterns or risky behaviors in themselves while listening to the group testimonials. The Facilitators may experience guilt for not being infected with HIV. The feeling of guilt could be a result of surviving and not understanding why or how. Facilitators living with HIV/AIDS may still be dealing with the same issues presented in the intervention. It is important for them to identify those personal issues and not allow them to impact how they facilitate the group.
- Questionnaires can be used that help elicit feelings, opinions, and behaviors so that the Facilitators can express their emotions, thoughts, and actions. Topics that might be covered include:
  - How did you identify with the group members today?
  - What made you uncomfortable during the session?
  - What was the highlight of today's session?
  - What was the low point of today's session?
  - What would you like to see different about group activities?
  - What behavior do you feel indicated how uncomfortable you were with the group topic or an individual's statement?
- The debriefing topics should focus on the events of the job and not veer into personal issues (if possible). If personal issues are a problem and impede the group setting, it might be suggested that the Facilitators utilize their Employee Assistance Program, if available.
- Keeping a journal may be suggested to allow for the expression of personal issues and thoughts. Journaling can also be used to brainstorm ideas and to express issues about the group sessions.
- The Program Manager can have a session based on the need to confront certain blind spots that may be hindering the group's progress.
- A goal of debriefing is that the Facilitators leave stress behind.

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Evaluating TLC

There are two key reasons to evaluate a program or intervention such as **TLC: Together Learning Choices**: accountability and improvement. Accountability could be to the community, staff, clients or a funding source. Implementing agencies must also consider their ethical obligation to properly implement any program or intervention. Evaluation also helps improve the quality of the delivery of the intervention. Evaluation informs the agency on what worked and what did not work, information valuable in helping agencies fine-tune their programs. Agencies should consult funder requirements for evaluation as needed.

There are several different types of evaluation that an implementing agency may want to conduct depending on agency priorities and funder requirements: 1) process monitoring, 2) process evaluation, 3) outcome monitoring.

Process Monitoring

Process monitoring is a method of collecting data that describes the services provided and the resources used to deliver those services. Process monitoring answers questions such as:

- How many sessions were delivered?
- What resources were used?
- What additional resources are needed?

Process monitoring serves as a supplement to the normal data collection of how many people attended, their gender, race/ethnicity, risk behavior, age, etc. It can also address recruitment and retention.

Process Evaluation

Process evaluation aids an agency in determining how closely the core elements were implemented and documents the tailoring and adapting that was done for the population and agency. Process evaluation ensures that an agency is delivering **TLC** and not some variation of the intervention. Some sample questions include:

- Was each core element maintained?
- Were the sessions delivered as described in the Implementation Manual?
- Was the intended target population enrolled?

Outcome Monitoring

Outcome monitoring, when required and appropriate, is the process of collecting data about knowledge, attitude, skills or behaviors before and after the intervention. Outcome monitoring answers the question:

- Were there any changes in the participants' behaviors following the intervention?

Sample Outcome Monitoring and Evaluation Forms have been included in Appendix F to guide agencies.

Appendix A

Articles on Original Research

Rotheram-Borus, M. J., Lee, M. B., Murphy, D. A., Futterman, D., Duan, N., Birnbaum, J. M., Lightfoot, M., and the Teens Linked to Care Consortium. (2001). Efficacy of a preventive intervention for youths living with HIV. American Journal of Public Health, 91:400-405.

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Rotheram-Borus, M. J., Murphy, D. A., Wight, R. G., Lee, M. B., Lightfoot, M., Swendeman, D., Birnbaum, J. M., and Wright, W. (2001). Improving the quality of life among young people living with HIV. Evaluation & Program Planning, 24:227-237.

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Efficacy of a Preventive Intervention for Youths Living With HIV

Mary Jane Rotheram-Borus, PhD, Martha B. Lee, PhD, Debra A. Murphy, PhD, Donna Futterman, MD, Naihua Duan, PhD, Jeffrey M. Birnbaum, MD, MPH, Marguerita Lightfoot, PhD, and the Teens Linked to Care Consortium

A B S T R A C T

Objectives. HIV transmission behaviors and health practices of HIV-infected youths were examined over a period of 15 months after they received a preventive intervention.

Methods. HIV-infected youths aged 13 to 24 years (n=310; 27% African American, 37% Latino) were assigned by small cohort to (1) a 2-module ("Stay Healthy" and "Act Safe") intervention totaling 23 sessions or (2) a control condition. Among those in the intervention condition, 73% attended at least 1 session.

Results. Subsequent to the "Stay Healthy" module, number of positive lifestyle changes and active coping styles increased more often among females who attended the intervention condition than among those in the control condition. Social support coping also increased significantly among males and females attending the intervention condition compared with those attending the control condition. Following the "Act Safe" module, youths who attended the intervention condition reported 82% fewer unprotected sexual acts, 45% fewer sexual partners, 50% fewer HIV-negative sexual partners, and 31% less substance use, on a weighted index, than those in the control condition.

Conclusions. Prevention programs can effectively reduce risk acts among HIV-infected youths. Alternative formats need to be identified for delivering interventions (e.g., telephone groups, individual sessions). (*Am J Public Health.* 2001;91:400–405)

Youths represent about 50% of all HIV infections worldwide[1] and 18% of reported HIV cases in the United States.[2] Nationally, there are about 110000 youths living with HIV.[3] On the basis of data from seropositive adults,[4,5] we anticipate that at least one third of these youths may continue their transmission behaviors after learning their serostatus.[6] HIV-infected youths who do not change their sexual risk acts or injection drug use may both infect others and become reinfected with new viral strains.[7] Therefore, it is important to change the health behavior and transmission acts of youths with HIV, both for their self-preservation and for the prevention of transmission to others.

With those considerations in mind, we designed and evaluated an intervention for HIV-infected youths consisting of 2 modules delivered in sequence. Based on the results of an extensive qualitative study of such youths,[8,9] the intervention began with "Stay Healthy," a 12-session module that aims to increase the positive health behaviors of youths with HIV.[10] The intervention was conducted from 1994 to 1996, before the introduction of highly active antiretroviral therapy.[11] Even then, the long-term survival of HIV-infected persons was associated with healthy lifestyles[12] and assertively managing health regimens and relationships with health care providers.[13] Since the introduction of highly active antiretroviral therapy, changes in health behavior are even more important because of the negative consequences of sporadic adherence to these medications,[14] as well as the potential reductions in transmission because of decreased viral loads.

The second module of the intervention, "Act Safe" (11 sessions), aims to enhance altruistic motivations to reduce transmission acts. This module was based on previous successful interventions to reduce sexual and substance-use risk acts with seronegative persons.[15]

The Social Action Model,[16] which was used as the theoretical basis of the intervention, was based on an extensive qualitative study of HIV-infected youths[8] and studies with seropositive adults.[15,17,18] This model takes into account contextual factors as it focuses on improving affective states that influence self-regulation (e.g., coping) and building skills to improve self-regulation (negotiation skills, self-efficacy).[15]

As shown in Figure 1, assessments were conducted before the first module ("Stay Healthy"), between the 2 modules, and after the second module ("Act Safe"). This design allowed us to assess HIV-infected youths' response to the "Stay Healthy" module alone, as well as to assess their response to both modules.

Methods

Participants and Assignment

The study was conducted at 9 adolescent clinical care sites in 4 AIDS epicenters: Los Angeles, New York, San Francisco, and Miami. Over a 21-month period (1994 to 1996), 351 of the 393 HIV-infected youths who received care at the sites were recruited after giving informed consent (25 [6.4%] refused participation; 17 [4.3%] were too ill). Parental consent was obtained for nonemancipated youths younger than 18 years.

Mary Jane Rotheram-Borus, Martha B. Lee, Debra A. Murphy, Naihua Duan, and Marguerita Lightfoot are with the Department of Psychiatry, University of California, Los Angeles. Donna Futterman is with the Montefiore Medical Center, Bronx, NY. Jeffrey M. Birnbaum is with the King County Hospital Center, Brooklyn, NY. The Teens Linked to Care Consortium is at the University of California, Los Angeles.

Requests for reprints should be sent to Mary Jane Rotheram-Borus, PhD, 10920 Wilshire Blvd, Suite 350, Los Angeles, CA, 90024 (e-mail: rotheram@ucla.edu).

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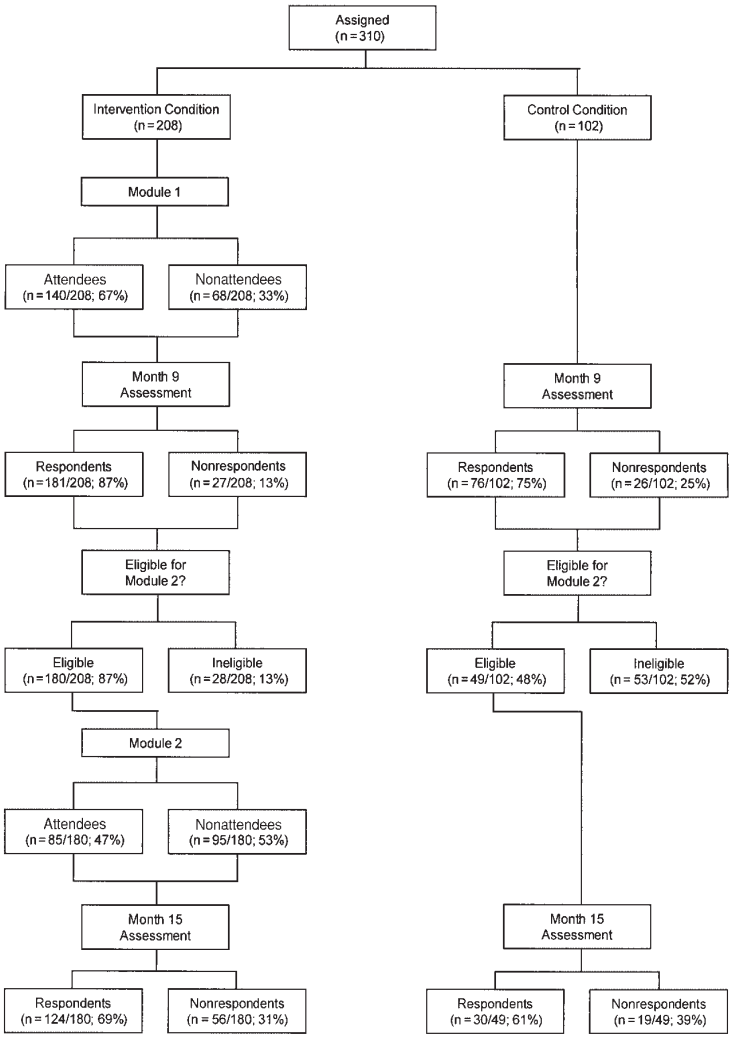

FIGURE 1—Design of the trial, indicating the number of HIV-infected youths eligible at each stage of the study and the number followed up after each intervention module.

Two baseline assessments were conducted at a 3-month interval to establish the stability of risk behaviors, with an incentive of $20 to $25 per assessment. Five HIV-infected youths were too sick to participate, and 36 were lost to follow-up before the second baseline. The remaining 310 youths participated in the study: 126 from Los Angeles, 91 from New York, 49 from San Francisco, and 44 from Miami.

Successful HIV interventions with youths have generally been delivered in a small-group format[15,19]; following this design, we delivered our intervention in small groups (cohorts). Cohorts of about 15 HIV-infected youths each were assigned sequentially to the intervention and control conditions. It took several months to assemble a sufficient number of youths to form a cohort; in 7 of 9 sites, the last cohort was assigned to the intervention condition. Therefore, across the 9 sites, there were 16 cohorts in the intervention condition (n = 208) and 9 cohorts in the control condition (n = 102).

Given the sequential nature of the assignment, there is a concern about imbalance between the intervention and control conditions. We conducted regressions to assess the potential bias that might emerge over time during participant recruitment, regressing each risk behavior reported at the baseline interview on the order of entry into the study. No significant time trends were found.

The second baseline interview was conducted before assignment to the intervention condition. As shown in Figure 1, the first module of the intervention, "Stay Healthy," was then delivered to the youths assigned to the intervention condition over a period of 3 months. Youths in both conditions were reassessed at month 9. Among the 310 youths initially assigned, 257 (83%) were reassessed successfully at this time, 181 in the intervention condition and 76 in the control condition (Figure 1).

Module 2 ("Act Safe") of the intervention was then delivered over a period of 3 months, and youths were reassessed at month 15. Because the duration of the study was limited, 77 youths were recruited too late to participate in module 2, and 4 were ineligible owing to illness or death. The remaining 229 youths (180 in 14 intervention cohorts and 49 in 5 control cohorts) were eligible to participate in module 2. Among these, 154 (67%; 124 in the intervention and 30 in the control condition) completed the month 15 assessment after module 2.

Intervention

Module 1 focused on coping with learning one's serostatus, implementing new daily routines to stay healthy, issues of disclosure, and participating in health care decisions. Module 2 aimed to reduce substance use and unprotected sexual acts by having youths identify their risk behavior triggers and modify their patterns of substance use as well as increase self-efficacy of condom use and negotiation skills.

A detailed manual (available online at http://chipts.ucla.edu) guided the 2 intervention modules, which comprised 23 sessions of 2 hours each.[10] Each participant received $10 for the first session attended in each module and $2 increases in incentives for subsequent sessions.

The intervention was usually delivered by 2 facilitators, 1 male and 1 female. The cohorts were mixed according to sex. The facilitators received intensive training of 3 days for each module from teams of experienced cognitive-behavioral intervention researchers. They also received ongoing supervision. The training included review of the study's theoretical orientation, the intervention manual, and videotapes of model sessions, as well as practice in conducting the intervention.

Quality assurance ratings were conducted from randomly selected videotapes of sessions; ratings for more than 80% of the sessions exceeded criteria for content and process measures of fidelity. On assessments conducted at sessions 5 and 11 of each module, youths in the intervention reported liking their sessions (mean = 4.2 on a scale of 1–5); they also rated their facilitators as highly trustworthy (mean = 4.2 on a scale of 1–5).

Across both modules, 151 of 208 youths (73%) assigned to the intervention condition

attended at least 1 session (71 attended module 1 only, 22 attended module 2 only, and 58 attended both). Intervention attendees were those assigned to the intervention condition who attended at least 1 session; intervention nonattendees were those assigned to the intervention condition but who never attended a session. Among those who attended at least 1 session in module 1, the mean number of module 1 sessions attended was 7.7 (SD=3.55); 70% attended 6 or more sessions (median=9) out of a total of 12. Among those who attended at least 1 session in module 1 (n=80), the mean number of module 2 sessions attended was 7.6 (SD=3.2); 73% attended 5 or more sessions (median=8) out of a total of 11. Youths in the control condition received standard care at the adolescent clinical care sites and received the intervention at the study's conclusion.

Assessments

Data were collected by an ethnically diverse team of trained interviewers who used computer-assisted interviewing. Quality assurance ratings were conducted from randomly selected audiotapes; 91% met criteria on ratings of completeness, positive tone, and crisis referrals. For all assessment domains, activities reported for the previous 3 months are defined as "recent" behaviors.

We derived 3 indices of health behavior: (a) a weighted index of medical care contacts (the weighted sum of the number of nights [n] for a hospital stay [weight of 5], the number of clinic, office, or emergency room visits [n] [weight of 4], the number of home health care visits [n] [weight of 3], the number of personal support for everyday tasks [n] [weight of 2], and the number of phone consultations [n] [weight of 1] [α=.62]); (b) the number of medical appointments missed; and (c) the number of positive lifestyle changes (α=.71) (n=12 potential behaviors; e.g., balanced diet, exercise, vitamins, adequate sleep).

We also examined 3 health status measures: (a) T-cell count; (b) physical health symptoms, a summary count of 23 physical symptoms (α=.88, r=0.70 with chart review of 31 HIV-infected youths)[20]; and (c) physical health distress score, calculated as a mean of the intensity (range=0–5) of each symptom (α=.90).

We assessed coping style with a modified version of the Dealing with Illness Inventory,[21] with 37 items rated on a 1-to-5 Likert scale and factor analyzed into 7 factors: positive action (10 items; α=.88), social support (5 items; α=.77), spiritual hope (4 items; α=.74), passive problem solving (5 items; α=.75), self-destructive escape (5 items; α=.81), depression/withdrawal (4 items; α=.66), and nondisclosure/problem avoidance (4 items; α=.66).

On the basis of extensive sexual history data, we derived the following 4 indices: (a) no recent sexual risk (abstinence [no vaginal or anal intercourse] or 100% condom use over the last 3 months), (b) the number of sexual partners—total count and separate counts by serostatus, (c) the percentage of vaginal and anal sex acts unprotected by condoms with HIV-negative partners, and (d) the percentage of partners to whom disclosure of serostatus was made before intercourse.

On the basis of extensive substance-use data, we derived the following 6 indices: (a) use of alcohol and marijuana only, (b) use of hard drugs, (c) a weighted index of drug use (derived as the sum of the frequency of the use of each drug category, weighted as follows: marijuana=1, amphetamine/stimulants=2, steroids=3, crack/cocaine=4, heroin=5),[22,23] (d) symptoms of abuse and dependency, (e) entry into and completion of substance-use treatment, and (f) a sum of the number of different drugs used.

Emotional distress was assessed with the Brief Symptom Inventory,[24] a 53-item, reliable index of mental health symptoms (α=.97).

Data Analysis

We conducted as-treated analyses[25,26] comparing intervention attendees vs control subjects and intervention attendees vs intervention nonattendees. (Results of intent-to-treat analyses are similar on all outcomes, except for the weighted substance use index for module 2, and are available from the authors.) We used mixed-effects analyses of covariance models to compare continuous postintervention scores across the cohorts, controlling for baseline scores (the second baseline), city, sex, and ethnicity as covariates and treating the cohort as a random effect. We report the adjusted mean outcomes for each condition (intervention attendees, control subjects, intervention nonattendees), adjusted for baseline scores, city, sex, and ethnicity. Similarly, we used mixed-effects logistic regression models to compare categorical postintervention outcomes, controlling for baseline status, city, sex, and ethnicity and treating the cohort as a random effect. We interpreted the intervention effect by using the relative effect size, defined as the intervention effect (the difference between the score of youths in the intervention condition and in the control condition) divided by the score of youths in the control condition, converted into a percentage.

We examined the association between each outcome and the number of intervention sessions attended among intervention attendees to assess the dose–response relationship. No significant associations were found, most likely because of the relatively high attendance among intervention attendees.

Results

Table 1 describes the HIV-infected youths at the baseline assessment (n=310); the subgroup of youths available for the module 1 analysis is very similar to the group of those assigned at baseline (n=257). At baseline, most participants (72%) were male; 88% of these males were gay or bisexual. The youths ranged in age from 13 to 24 years (mean=20.7; SD=2.1); females were younger than males by about 1.5 years (P<.001). Most youths (64%) belonged to ethnic minority groups, 55% had graduated from high school, 31% were currently enrolled in school (mean=11th grade; SD=2.31), and 84% had been employed. On average, youths had tested seropositive for HIV more than 2 years before recruitment (mean=2.1; SD=2.0; median=1.4 years).

We conducted extensive analyses to assess the presence of selection bias, comparing subgroups by assignment, attrition, and participation at each module (results available from the authors). Although the intervention assignment procedure was not randomized, it was successful in producing subgroups that were comparable throughout the study. Only 3 differences were found: (1) the intervention and control conditions were not balanced by site (χ^2_6=29.1; P<.001), because 7 of 9 sites ended with an intervention cohort; (2) because Miami had more female HIV-infected youths, and youths from Miami were not eligible for module 2, more males attended only module 1 (χ^2_2=11.3; P<.05) compared with other groups; and (3) intervention attendees were more likely to use social support as a coping strategy (an outcome measure) at baseline. City, sex, ethnicity, and baseline status were controlled for in all analyses; therefore, those differences do not confound our findings.

Table 2 summarizes the as-treated analyses comparing intervention attendees, intervention nonattendees, and control subjects.

Module 1: "Stay Healthy"

On average, youths had missed 1 medical appointment (SD=1.2) in the previous 3 months. The most commonly cited reason for missing appointments was ease of rescheduling. When physical health status was controlled for, there were no differences in missed appointments across conditions. T-cell counts, the number of physical health symptoms, and distress associated with physical health symptoms were similar across conditions.

TABLE 1—Baseline Characteristics and Risk Behaviors of Study Participants in a Preventive Intervention for Youth Living With HIV

	Intervention Attendees (n=140)	Controls (n=102)	Intervention Nonattendees (n=68)	Overall (n=310)
Mean age, y (SD)	20.7 (2.1)	20.6 (2.2)	21.0 (1.9)	20.7 (2.1)
12–17, % (n)	7 (10)	10 (10)	4 (3)	7 (23)
18–20, % (n)	34 (47)	31 (32)	31 (21)	32 (100)
21–24,[a] % (n)	59 (83)	59 (60)	65 (44)	60 (187)
Male, % (n)	71 (100)	75 (77)	69 (47)	72 (224)
Gay/bisexual (male only), % (n)	88 (87)	95 (72)	78 (36)	88 (195)
Ethnicity,** % (n)				
African American	33 (46)	22 (22)	22 (15)	27 (83)
Latino	32 (45)	46 (47)	34 (23)	37 (115)
White	18 (25)	12 (12)	32 (22)	19 (59)
Other	17 (24)	21 (21)	12 (8)	17 (53)
City,** % (n)				
Los Angeles	36 (50)	49 (50)	38 (26)	41 (126)
New York	37 (52)	13 (13)	38 (26)	29 (91)
San Francisco	12 (17)	21 (21)	16 (11)	16 (49)
Miami	15 (21)	18 (18)	7 (5)	14 (44)
Diagnostic status, % (n)				
Asymptomatic	57 (77)	61 (60)	62 (41)	59 (178)
Symptomatic	35 (47)	29 (28)	29 (19)	31 (94)
AIDS	9 (12)	10 (10)	9 (6)	9 (28)
T-cell count	499.0	468.1	474.9	483.4
Health-related issues				
No. of medical care contacts	21.1	19.0	21.8	20.5
No. of appointments missed	1.1	0.8	1.4	1.1
No. of positive lifestyle changes	4.8	5.0	4.9	4.9
No. of physical health symptoms	9.8	10.0	8.8	9.6
Mean physical health distress score	1.0	1.0	0.9	1.0
Coping				
Social support*	2.7	2.4	2.3	2.6
Positive action	3.4	3.4	3.3	3.3
Sexual behavior				
No sexual-risk pattern, % (n)	73 (102)	67 (68)	74 (50)	71 (220)
No. of sexual partners	3.1	2.6	2.6	2.8
No. of HIV-negative partners	4.9	2.2	2.2	3.4
No. of HIV-positive partners	0.4	0.5	0.4	0.4
Disclosed serostatus to sexual partners, %	53.5	54.0	54.3	53.8
Unprotected sex acts, %	11.3	12.6	7.2	10.8
Brief Symptom Inventory score	0.9	0.9	0.9	0.9
Substance use				
Abstains from alcohol and drugs, % (n)	24 (34)	22 (22)	19 (13)	22 (69)
Alcohol abstinent, % (n)	37 (52)	30 (31)	29 (20)	33 (103)
Drug abstinent, % (n)	44 (61)	48 (49)	41 (28)	45 (138)
Alcohol/marijuana use, % (n)	72 (101)	75 (77)	79 (54)	75 (232)
Marijuana use only, % (n)	46 (65)	43 (44)	50 (34)	46 (143)
Hard drug use, % (n)	35 (49)	30 (31)	32 (22)	33 (102)
Weighted index	69.6	36.8	33.5	50.9
No. of drugs used	1.1	0.9	1.1	1.0
Injection drug use,* % (n)	12 (17)	4 (4)	4 (3)	8 (24)

[a]There was 1 24-year-old youth living with HIV.
*$P<.05$; **$P<.01$.

Among females, the number of positive lifestyle changes was significantly higher among intervention attendees than among control subjects (relative effect size [RES]=45.9%; $P=.003$) and intervention nonattendees (RES=35.4%; $P=.016$).

The positive action coping subscale score was significantly higher for females who were intervention attendees than for females in the control condition (RES=17.6%; $P=.029$). For both sexes, the social support coping score was significantly higher among intervention attendees than among control subjects (RES=10.8%; $P=.04$) and intervention nonattendees (RES=16.8%; $P=.006$).

Module 2: "Act Safe"

Overall, only about 30% of HIV-infected youths reported having any sexual partners at the 15-month assessment. Compared with nonattendees, intervention attendees reported significantly fewer sexual partners (RES=51.5%; $P=.033$) and fewer HIV-negative sexual partners (RES=54.3%; $P=.035$). Intervention attendees had a lower percentage of unprotected sexual risk acts than control subjects (RES=82.1%; $P=.013$) and intervention nonattendees (RES=74.0%; $P=.075$). There was no significant difference in disclosure of serostatus to sexual partners.

Comparing intervention attendees and nonattendees, there were significant reductions in the weighted substance use index (RES=49.7%; $P=.024$), the prevalence of alcohol or marijuana use (RES=25.7%; $P=.045$), and the

TABLE 2—Intervention Effects Based on Comparisons Among Intervention Attendees, Controls, and Intervention Nonattendees

	Intervention Attendees	Controls	Intervention Nonattendees	RES, Attendees vs Controls
	Module 1 ("Stay Healthy")			
	(n = 129)	(n = 76)	(n = 52)	
Index of no. of medical care contacts	22.1	24.1	23.9	−8.2
No. of appointments missed	1.1	0.5	1.4	101.9
T-cell count	416.5	408.1	509.1[b**]	2.1
Positive lifestyle changes (females)	6.0	4.1[a***]	4.5[b**]	45.9
No. of physical health symptoms	8.4	8.7	9.1	−3.1
Mean physical health distress score	0.8	0.9	0.9	−7.7
Brief Symptom Inventory score	0.7	0.7	0.8	2.8
Positive action (females)	3.4	2.9[a**]	3.5	17.6
Social support (males and females)	2.6	2.3[a**]	2.2[b***]	10.8
	Module 2 ("Act Safe")			
	(n = 80)	(n = 30)	(n = 44)	
Sexual behavior				
No sexual-risk pattern, %	80	67[a**]	75	19.4
No. of sexual partners	1.7	3.0	3.4[b**]	−45.0
No. of HIV-negative partners	1.4	2.9	3.1[b**]	−50.0
No. of HIV-positive partners	0.2	0.2	0.2	15.0
Disclosed serostatus to sexual partners, %	64.2	55.6	54.8	15.4
Unprotected sex acts, %	2.8	15.5 [a**]	10.6[b*]	82.1
Substance use				
Alcohol/marijuana, %	63	67	84[b**]	−6.0
Hard drugs, %	21	27	39[b*]	−22.2
Weighted index	20.2	29.2	40.2[b**]	−30.8
No. of drugs	1.3	1.4	1.6	−6.3
Brief Symptom Inventory score	0.8	0.8	0.9	−1.2

Note. RES = relative effect size, defined as 100% × [(attendee's outcome − control outcome) / control outcome]. Adjusted means are different owing to different analytic modules.
[a]Intervention vs control.
[b]Intervention attendees vs intervention nonattendees.
*$P < .10$; **$P < .05$; ***$P < .01$.

use of hard drugs (RES = 45.0%; $P = .097$). There were no significant differences between conditions in the number of drugs used or in emotional distress. Fewer than 5% of YLH reported contact with substance abuse treatment facilities across intervention conditions at any assessment; no changes were expected or observed on these measures because of the low base rates.

Discussion

Continued risk among HIV-positive persons has been well documented[5,27,28]; this is one of the first studies of a prevention program with HIV-infected youths. The efficacy of this program appears to be similar to that of preventive interventions for seronegative persons.[29] At a cost of $513 per youth, the "Act Safe" module resulted in a 50% reduction in the number of HIV-negative partners, an 82% decrease in the number of unprotected sex acts, and a 31% reduction in a weighted index of drug use. The "Stay Healthy" module (delivery cost of $467 per youth) focused on changing health behavior; however, fewer benefits were demonstrated. At baseline, 58% of HIV-infected youths were highly satisfied with their physician's competence and 68% reported high levels of assertiveness, providing little opportunity for improvement.[30] Females in the "Stay Healthy" module changed health habits and increased their active coping styles. Both males and females increased their social support coping styles. Improvements in health behaviors have become increasingly important since the introduction of highly active antiretroviral therapy.[11,14] Therefore, any future health promotion interventions must also focus on issues of medication adherence, as well as enhancing healthy lifestyles and assertiveness with care providers.

It is important to note that the behavioral changes were specific to the content of the intervention sessions in each module; for example, the "Stay Healthy" module did not affect sexual risk, even though health behaviors did change. The "Act Safe" module changed substance use and sexual risk, but no further changes occurred in health acts. We also did not find a dose effect, which is not surprising, given the high attendance rate among intervention attendees.

The sample recruited for the study was relatively large, was recruited from 9 sites in 4 AIDS epicenters, matched the sociodemographic profile of HIV-infected youths in the Centers for Disease Control and Prevention's national AIDS and HIV case data,[2] and demonstrated expected developmental patterns (e.g., risk acts increased with age; test–retest correlations on each measure increased with age). Although biological markers would have been desirable to confirm youths' self-reports, these measures were not available at the time this study was initiated. Substantial evidence confirms the reliability and validity of self-reports of HIV-related risk acts.[31]

Over time, most HIV-infected youths engaged in exemplary health behaviors and low rates of transmission behavior. While their lifetime patterns were very risky (51% had had more than 20 sexual partners, 27% had bartered sex, 87% had used hard drugs, and 16% had injected drugs), only 22% of youths reported

engaging in unprotected sex in the 3 months before the baseline assessment, most disclosed their serostatus to all sexual partners, and only about half used drugs (mainly marijuana).[30] Receiving ongoing health care may account for relatively low levels of risk. Yet, a recent meta-analysis of the effect of HIV testing[32] suggests that early detection alone may be a substantial preventive intervention. Not all HIV-infected youths need preventive interventions; HIV providers may need to screen for ongoing risk before delivering preventive interventions.

However, the mode of delivering preventive interventions to HIV-infected youths must be reexamined, as 27% did not attend even 1 intervention session. The youths reported liking and trusting the small-group format. Yet, scheduling difficulties, fears of stigmatization in a group setting, and slow accrual of HIV-infected youths led to fewer attending the intervention. Small groups also are not feasible in rural communities or for youths selected according to sex or language use; recruitment would be too slow. Alternative intervention strategies need to be evaluated (e.g., individual sessions, Internet-based or telephone groups). □

Contributors

M. J. Rotheram-Borus was the principal investigator on the project; she designed the study and wrote the first draft of the manuscript. M. B. Lee provided data analysis and wrote the Methods section of the manuscript. D. A. Murphy designed the assessment tools and edited subsequent drafts of the manuscript. D. Futterman worked on study design and implementation. N. Duan provided data support, methodologic review, and help with the writing and structure of the manuscript. J. M. Birnbaum and M. Lightfoot worked on the project and were involved in implementation of the intervention, data collection, and manuscript development. The Teens Linked to Care Consortium was involved in data collection and project implementation.

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Improving the quality of life among young people living with HIV

Mary Jane Rotheram-Borus[a,*], Debra A. Murphy[a], Richard G. Wight[a], Martha B. Lee[a], Marguerita Lightfoot[a], Dallas Swendeman[a], Jeffrey M. Birnbaum[b], Whitney Wright[a]

[a]*AIDS Institute, Center for HIV Identification, Prevention, and Treatment Services, Department of Psychiatry, University of California, Los Angeles, USA*
[b]*Kings County Hospital/SUNY Health Science Center, New York, USA*

Abstract

A three-module intervention was designed to address the multiple needs of young persons living with HIV (YPLH): (1) Staying Healthy, (2) Acting Safe, and (3) Being Together. YPLH from three cities were assigned by small cohort to either an Immediate Intervention Condition or a Control Condition. Building on the positive effects of the Staying Healthy and Acting Safe Modules, this paper reports the effects of the Being Together Module, an eight-session cognitive-behavioral intervention aimed at improving YPLHs quality of life. The YPLH ($n = 104$) were aged 14–23 ($M = 21.03$); 73% were male; most were Latino (43%) or African American (24%). YPLH in the Immediate Intervention Condition were significantly less emotionally distressed on multiple indices than those in the Control Condition, and those who attended the intervention showed decreasing emotional distress even when controlling for HIV symptomatology. HIV preventive interventions must promote emotional well-being, as well as reduce risk acts and promote health behaviors.

Keywords: HIV; Quality of life; Young people

1. Introduction

The World Health Organization and The Center for Disease Control estimate that 50% of all HIV infections occur among young people aged 15–24 years old (UNAIDS, 1998; CDC, 1999). It is estimated that nationally there are over 110,000 young people living with HIV (YPLH) (Rotheram-Borus, O'Keefe, Kracker & Foo, 2000). As a result of highly active antiretroviral therapy (HAART), the survival trajectory for YPLH has been extended (CDC, 1998), resulting in the transition of HIV from a debilitating terminal illness to a more manageable chronic illness. Given the transition in the course of disease, quality-of-life (QOL) issues become more salient. Quality of life may play a crucial role in influencing positive health behaviors and reducing or eliminating risk behaviors. Yet, little is known about the QOL of YPLH. The goal of this article is to examine the results from an intervention module, Being Together, aimed at improving QOL among YPLH.

Having a satisfying QOL is only one of the challenges facing YPLH. Initial challenges for YPLH are to acquire health care, follow medical regimens (now including HAART medications), and reduce transmission behaviors. To address these issues, a three-module intervention was designed (Rotheram-Borus & Miller, 1998) and delivered to YPLH, as outlined in Fig. 1. The goal for each module was to attempt to change a different behavioral outcome: (1) Staying Healthy (targeted health care utilization and health behaviors); (2) Acting Safe (addressed transmission acts); and (3) Being Together (aimed at improving QOL). Similar to almost all successful interventions identified in the NIH Consensus Development Conference (1997), this intervention was delivered in small groups and used cognitive-behavioral strategies to change behaviors. Each module of the intervention was based on the social action model (Ewart, 1991), which emphasizes how contextual factors influence the individual's ability to emotionally respond, solve problems, and act effectively in stressful situations. For example, YPLHs social relationships (e.g. with their doctors for health outcomes and with their sexual partners for transmission acts) are critical contextual features that must be addressed to change health and transmission behaviors. Setting mood is additional contextual features of behavior change addressed in each module.

The evaluation of the first two modules was summarized in a previous report (Rotheram-Borus et al., 2000, in press). The first module, Staying Healthy, addressed YPLHs motivation for self-preservation by encouraging positive health behaviors. Compared to the Control Condition, YPLH who

* Corresponding author. Tel.: +1-310-794-8280; fax: +1-310-794-8297.
E-mail address: rotheram@ucla.edu (M.J. Rotheram-Borus).

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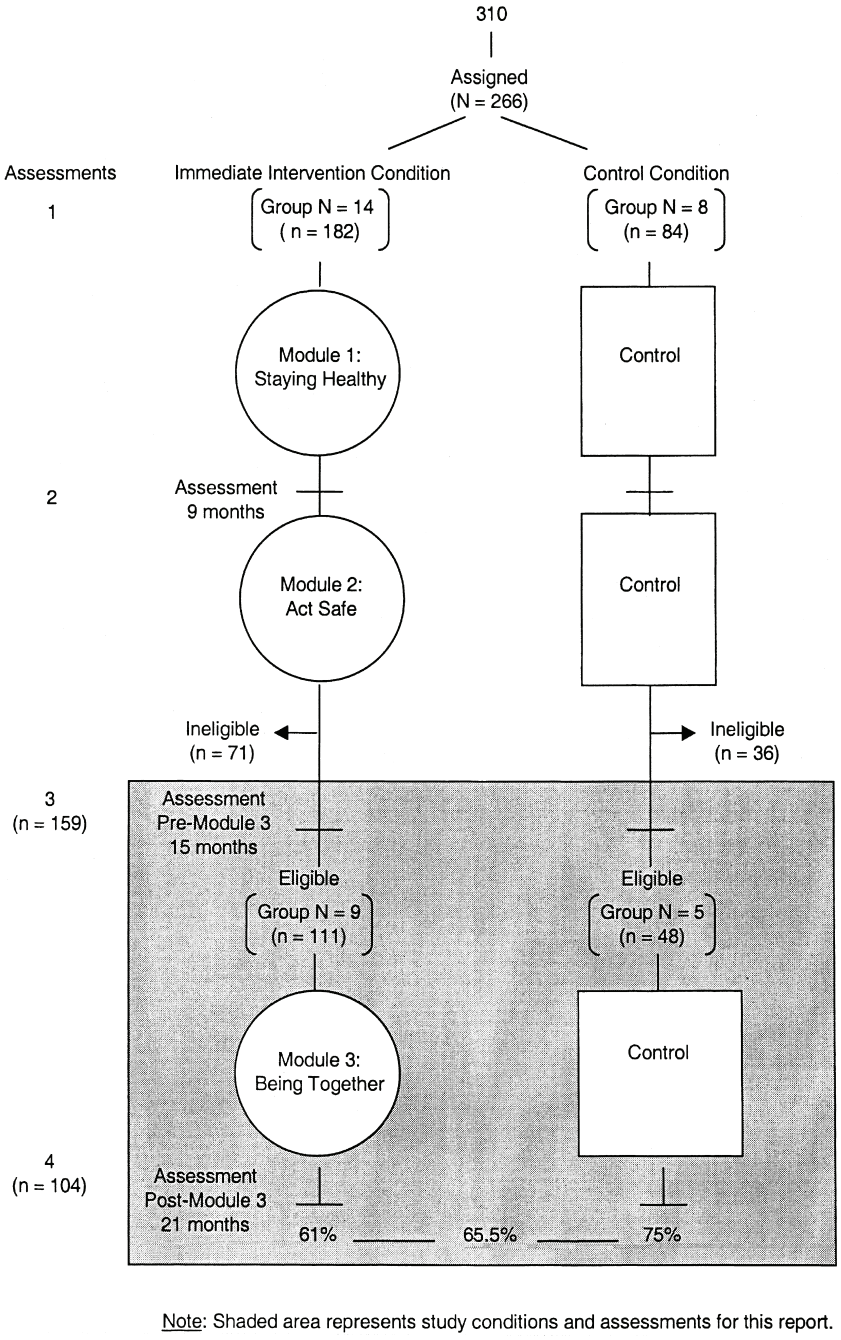

Fig. 1. Design of the trial indicating the number of YPLH assessed at baseline, prior to, and subsequent to delivery on Module 3.

attended the Staying Healthy Module increased positive coping styles, and the females improved health habits and health outcomes 3 months following the module. Once health behaviors had been improved, the public health agenda was addressed by trying to reduce YPLHs substance-use and risky sexual behaviors in Module 2 (Acting Safe). YPLH who attended the intervention had 52% fewer sexual partners, 54% fewer seronegative sexual partners, 82% fewer unprotected sexual risk acts, and 31% less substance use on a weighted index 3 months later, compared with YPLH in the Control Condition. Thus, the first two modules of this intervention were successful in addressing health care, illicit drug use, and sexual transmission behavior issues (Rotheram-Borus et al., 2000, in press).

The third and final module of the intervention, Being Together, focused on improving the overall QOL among YPLH, and this paper summarizes these outcomes. Studies of HIV-infected adults have demonstrated the efficacy of small-group interventions in improving individuals' emotional and social functioning, as well as sense of

well-being (Kelly et al., 1993). A good QOL is of primary importance to those with a chronic or terminal illness because it makes positive behaviors salient and maintains motivation (Lawton, 1999). The benefits of maintaining a healthy lifestyle must be experienced daily or else there is reduced motivation for self-preservation. A positive QOL motivates individuals to sustain healthy behaviors over time.

The importance of QOL was recognized over four decades ago when Karnofsky, Abelmann, Craver and Burchenal (1948) developed a measure to assess quality of functioning. Almost concurrently, the World Health Organization (WHO) expanded its definition of health to include mental and social well-being (1947). Quality of life is a rich construct that can be operationalized in a variety of ways. Among persons living with HIV, QOL is typically measured, and was assessed in this study, with scales that ascertain four core areas: (1) physical health or physical health-related distress; (2) physical functioning; (3) energy/vitality; and (4) mental health or emotional well-being (Cohen, Hassan, Lapointe & Mount, 1996; Cunningham, Bozzette, Hays, Kanouse & Shapiro, 1995; Holmes & Shea, 1997; Lenderking, Testa, Katzenstein & Hammer, 1997; Lubeck & Fries, 1997; Piette, Wachtel, Mor, & Mayer, 1995).

Undoubtedly, illness severity is the strongest indicator of QOL among adult persons living with HIV (e.g. Lenderking et al., 1997; Smith et al., 1996; Sowell et al., 1997). Aside from illness severity, the QOL among persons living with HIV has been found to be a function of several sociodemographic factors and risky lifestyle histories. Women living with HIV appear to experience a lower level of QOL than men living with HIV (Lenderking et al., 1997). Among adult persons living with HIV, poor QOL has been associated with low income, older age, unemployment, stigma, fatalism, injection drug-use history, and low satisfaction with social support (Smith et al., 1996; Sowell et al., 1997; Swindells et al., 1999). We could not identify published studies that specifically address factors related to QOL among YPLH. Building on previous literature, Module 3 of the intervention was designed to improve QOL.

A frequently cited correlate of QOL among persons living with HIV is coping style (Friedland, Renwick & McColl, 1996; Hays et al., 1995; Leiberich et al., 1997; Lutgendorf, Antoni, Schneiderman & Fletcher, 1994; Renwick & Friedland, 1996; Swindells et al., 1999). For example, emotion-oriented coping has been shown to be negatively associated with QOL among persons living with HIV (Friedland et al., 1996). Lutgendorf et al. (1994) reported that QOL among persons living with HIV is positively associated with active coping, use of more functional appraisals, and decreased use of denial/avoidance coping. Leiberich et al. (1997) found evasive-regressive coping among persons living with HIV to be associated with low QOL and high emotional distress. Therefore, as a secondary outcome, we hypothesized that participation in Module 3 would influence coping style because this module addressed coping strategies for reducing negative feelings.

2. Methods

2.1. Participants and assignment

2.1.1. Initial sample

The study was conducted in eight adolescent clinical care sites in Los Angeles, New York, and San Francisco. The clinical sites were hospital-based adolescent medical clinics or community-based agencies that draw clients from multiple sources, including advocacy groups and advertisements. From these sites, 302 YPLH were recruited with informed consent. Parental consent was obtained if the YPLH was under age 18 and if the parents were available (e.g. the YPLH was not homeless) and knew the youth's HIV status. Each YPLH was paid $20–25 to participate in a 2.5-h interview at the time of recruitment.

We reassessed the recruited YPLH approximately 3 months later. At this time, 36 YPLH were too sick to participate or were lost to follow-up. Thus, 266 YPLH were available to be assigned to the Immediate Intervention and the Control conditions, 126 from Los Angeles (two sites), 91 from New York (five sites), and 49 from San Francisco (one site).

YPLH were assigned to the Immediate Intervention or Control conditions in small cohorts of about 15 YPLH each. The number of YPLH in each cohort ranged from 4 to 20; all cohorts started at a minimum of 10 YPLH, but some YPLH were lost before assignment took place. The YPLH recruited were held in a waiting state until a sufficient number were recruited from the same site to form a cohort, a process usually taking several months. We assigned alternating cohorts within each site to the Immediate Intervention and Control conditions. To gain support for the program from the clinical staff, each site started with a cohort in the Immediate Intervention Condition; the next cohort was assigned to the Control Condition, etc. In six of our eight sites, we had an odd number of cohorts. Thus, the last cohort was assigned to the Immediate Intervention Condition. Therefore, as shown in Fig. 1, across the eight sites there were 14 cohorts in the Immediate Intervention Condition ($n = 182$; 13 per cohort, on average) and eight cohorts in the Control Condition ($n = 84$; 11 per cohort, on average).

Since sequential cohorts of YPLH were assigned to the intervention conditions, this design could result in a bias in the estimated intervention effect. If there was a systematic trend in the participants recruited, for example, the participants who were recruited early, and thus assigned to the Immediate Intervention Condition, may have engaged in more risk behaviors than those recruited later. Therefore, we used logistic regression to assess the presence of such time trends, regressing order of entry into the study on each index of risk behaviors collected at the baseline interview. No significant time trend was found in this analysis.

Among YPLH assigned to the Immediate Intervention and Control conditions ($n = 266$), most were male (79%); gay or bisexual males accounted for 69% of participating

Table 1
Sociodemographic characteristics at baseline of those who were evaluated prior to and following the module 3 intervention, those lost to follow-up, and those ineligible for participation (*P < 0.05)

	Evaluated ($n = 104$) %	Lost ($n = 55$) %	Ineligible ($n = 107$) %
Male*	73	93	77
Gay/Bisexual (Male only)	93	80	91
Lesbian (Female only)	18	0	13
Ethnicity			
African American	26	11	30
Latino	42	42	36
White	18	31	19
Other	13	16	16
Mean Baseline Age (in years) (SD)	21.03 (2.05)	21.44 (1.70)	20.67 (1.95)
High School Graduate/GED	63	72	61
City*			
Los Angeles	49	58	40
New York	36	18	41
San Francisco	15	24	19
HIV Symptomatic	30	47	42
Recent Unprotected Intercourse	20	20	17
Drugs/Alcohol Abstinence	20	15	20
No. Outpatient Visits (visits per subject)	5.20 (4.59)	5.46 (4.53)	6.13 (5.04)

YPLH. Participant age ranged from 13 to 24 years ($M = 20.96$, SD = 2.1); females were younger than males by about 1.2 years ($P < 0.0005$). Most YPLH belonged to ethnic minority groups (79%), and 64% had graduated from high school or had their GED. On average, YPLH had tested seropositive for HIV 2.1 years before they were recruited (SD = 2.1; median = 1.4 years).

2.1.2. Module 3 sub-sample

It took longer to recruit the YPLH than anticipated and, as a result, the funding ended before all YPLH completed all modules. It was not possible to extend funding because ethical considerations required that all YPLH had to be provided with the intervention, including those in the Control Condition. There were 159 YPLH who were recruited with sufficient time for evaluation of Module 3 (shaded area of Fig. 1); 55 were lost to follow-up (almost all during the delivery of Module 1). Thus, pre- and post-assessments were conducted with 104 YPLH for Module 3. As shown, 66% (104/159) of the original cohort were assessed for Module 3: 61% of those eligible from the Immediate Intervention Condition and 75% of those eligible from the Control Condition.

Table 1 presents baseline comparisons for the 104 YPLH for whom pre- and post-assessments were conducted, the ineligible YPLH ($n = 107$) who were recruited too late to be included in the assessment of Module 3, and the YPLH who were lost during the first 6 months of the study (i.e. during the delivery of Module 1; $n = 55$). As shown, the three groups differed in only two ways: more heterosexual males were lost to follow-up, and Los Angeles lost more YPLH compared to other sites. The analyses of the intervention effects controlled for these two factors.

As also shown in Table 1, most YPLH eligible for Module 3 were gay or bisexual males who self-identified as African–American or Latino. More than half were high school graduates (or GED equivalent), most lived in Los Angeles or New York, and their mean age was 21 years (SD = 2.05). Nearly one third reported symptoms of HIV in their lifetime, but almost none had physical symptoms concurrent with the intervention. One out of five YPLH had recently (within the past 3 months) engaged in unprotected anal or vaginal intercourse, and a similar proportion had abstained from drugs and alcohol. In addition, YPLH had recently made five outpatient medical visits on average.

2.2. Intervention

Table 2 summarizes the content of each intervention module. Prior to the delivery of Module 3, all participants in the Intervention Condition received Modules 1 and 2 of the intervention. Therefore, the evaluation of Module 3 reflects the impact of Module 3, given the delivery of the previous two modules. The eight sessions of the Being Together Module emphasized how YPLH could increase their life satisfaction and emotional strength by: (1) identifying a basic set of values that define a personal identity as a person living with HIV, in particular distancing themselves from a self-destructive sense of self; (2) reducing negative emotional reactions (pain, loss, and discontent) in response to living with their serostatus; (3) increasing perceptions of personal control; (4) reducing self-destructive motivations, particularly for substance use; and (5) living fully and joyously in the present moment. In these eight sessions, YPLH learned how to develop an awareness of every moment in life through meditation. Each session of the intervention had a basic structure as follows: (1) review successes and goals from the previous session; (2) present new content; (3) set goals for the coming week; and (4)

Table 2
Content of intervention sessionst

Session	Content
	Module 1: Staying Healthy
1	Attitudes toward living with HIV
2	Exploring future goals
3	Disclosure of status
4	Coping with stigma
5	Staying healthy
6	Drug and alcohol use
7	Changing substance abuse
8	Preventing re-infection
9	Staying calm
10	Attending health care appointments
11	Taking prescribed medications
12	Participating in medical care decisions
	Module 2: Act Safe
1	Protecting yourself and your partner
2	Selecting protection methods and sex acts
3	Disclosing your serostatus to your partner
4	Getting a partner to accept using condoms
5	Refusing unprotected sex
6	Establishing the commitment to be drug-free
7	Stopping drug and alcohol thoughts
8	Avoiding external triggers
9	Avoiding internal triggers
10	Handling anxiety and anger to reduce drug use
11	Handling drugs, alcohol, and sex
	Module 3: Being Together
1	How can I have a better quality of life?
2	How can I reduce negative feelings?
3	Who am I?
4	Is what I see the real thing?
5	What direction should I follow?
6	How can I be a good person?
7	How can I get wise?
8	How can I care about others?

identify positive experiences during the session. While YPLH varied in age from 14 to 23 years, the content and structure of the module were similar for all YPLH. Because the YPLH had initiated high risk acts at early ages, the intervention issues were very similar across age, and most participants were older adolescents (i.e. over age 16).

The intervention was delivered in small-group settings by facilitators trained specifically for this project. Facilitators were ethnically diverse male and female co-leader pairs. They received intensive training from teams of experienced cognitive-behavioral intervention researchers. The training included reviewing the study's theoretical orientation, the intervention manual, and a videotape of model sessions, as well conducting practice sessions. Actual group sessions were videotaped and rated for content delivery. Participants received $10 for the first intervention session they attended. For each subsequent session attended, the incentive increased cumulatively by $2 ($12 for the second session, $14 for the third session, etc.). SeeRotheram-Borus et al. (2000, in press), for full methodological details of the intervention.

Table 3 summarizes the comparisons of background factors at baseline among three subgroups of YPLH based on their Module 3 intervention status: Intervention Attended (those assigned to the Immediate Intervention Condition who attended at least one session; $n = 42$), Control ($n = 36$), and Intervention Non-Attended (those assigned to the Immediate Intervention Condition who did not attend any sessions; $n = 26$). There were no statistically significant background differences between YPLH in the three conditions. Among YPLH assigned to the intervention, 62% ($n = 42$) attended at least one session. Among those who attended intervention sessions, mean attendance at Module 3 was 5.33 sessions (SD = 2.58, range = 1–8), indicating that 67% of the sessions were attended.

2.3. Assessments

Assessments were conducted at four points for YPLH in both conditions: (1) prior to any intervention; (2) 3 months following the delivery of Module 1; (3) 3 months following the delivery of Module 2 and prior to Module 3; and (4) 3 months following the delivery of Module 3. This report focuses on differences in YPLH from the third and fourth assessment points, as shown in Fig. 1.

Data were collected by trained, ethnically diverse interviewers using assessments programmed on laptop computers. Training for the interviewers included: reviewing all questions and role playing each question in the interview schedule, discussing hypothetical situations in-depth, reviewing intensively the written interviewer's guide created for this study, adhering to the crisis protocol, reporting physical or sexual abuse, using laptop computers, and making referrals. Different staff were used for the interviews than for the intervention delivery. Each interviewer received weekly individual supervision, including feedback from the QA review of their audiotaped interviews. All interviews were audiotaped, and about 10% were randomly monitored for QA. Assessments of appropriate referrals for crisis-related behaviors (suicide, health problems), clarification of ambiguous responses, and correct reading of transition statements indicated that interviewers had met interviewer criteria on 91% of the occasions, with a range of 82–100% for individual interviewer's accuracy.

2.3.1. Primary outcome: quality of life

The first three QOL measures were items from the Medical Outcome Study SF-36 instrument (Ware & Sherbourne, 1992). First, a subjective assessment of poor health was obtained by asking, 'In general, would you say your health is: excellent (1), very good (2), good (3), fair (4), or poor (5)?' Second, YPLH were asked how much they were physically limited by performing 10 activities of daily living, such as lifting objects, climbing stairs, or bathing and dressing (Ware & Sherbourne, 1992). Responses ranged from 'limited a lot (1)' to 'not limited at all (3)' ($\alpha = 0.94$). Third, YPLH were asked to rate their energy/vitality level

Table 3
Baseline characteristics for module 3

	Intervention attended ($n = 42$) %	Control ($n = 36$) %	Intervention non-attended ($n = 26$) %
Male	81	61	77
Gay/Bisexual (Male only)	91	95	95
Lesbian (Female only)	13	21	17
Ethnicity			
African American	33	25	15
Latino	38	44	46
White	21	11	23
Other	7	19	15
Mean Baseline Age (in years) (SD)	21.26 (1.68)	20.67 (2.51)	21.15 (1.89)
High School Graduate/GED	73	53	60
City			
Los Angeles	50	44	54
New York	38	36	31
San Francisco	12	19	15
HIV Symptomatic	34	26	28

on a nine-item scale (Ware & Sherbourne, 1992) ($\alpha = 0.86$), which assessed the amount of time they felt full of energy, nervous, worn out, etc. Responses ranged from 'all of the time (1)' to 'none of the time (6)'.

The fourth aspect of QOL (mental health) was assessed by measuring symptoms of emotional distress with the Brief Symptom Inventory (BSI; Derogatis, 1993), which assesses the degree to which persons are bothered by mental health symptoms [scored 0 ('not at all') to 4 ('extremely'). A global estimate of emotional distress was obtained with the total 53-item scale ($\alpha = 0.96$), and the nine primary symptom dimensions of the BSI were disaggregated to measure specific symptomatologies: somatization (seven items, $\alpha = 0.81$), obsessive-compulsive disorder (six items, $\alpha = 0.88$), interpersonal sensitivity (four items, $\alpha = 0.68$), depression (six items, $\alpha = 0.83$), anxiety (six items, $\alpha = 0.83$), hostility (five items, $\alpha = 0.70$), phobic anxiety (five items, $\alpha = 0.82$), paranoid ideation (five items, $\alpha = 0.65$), and psychoticism (five items, $\alpha = 0.73$). Emotional distress was also measured with the 37-item Manifest Anxiety Scale (Reynolds & Richmond, 1985) ($\alpha = 0.91$). Symptoms of anxiety were measured as 'present' (2) or 'absent' (1). We examined sub-scales of the Manifest Anxiety Scale (physiological anxiety, worry/oversensitivity, and social concerns/concentration), but found no significant differences among the Intervention Attended, Intervention Non-Attended, and Control conditions. Therefore, these sub-scales are not presented. HIV symptomatology was assessed by asking YPLH at the post-Module 3 assessment, 'Have you had HIV symptoms in the past 3 months?'

2.3.2. Secondary outcome: coping style

A modified version of the Dealing with Illness Inventory was used to assess coping style (Namir, Wolcott, Fawzy & Alumbaugh, 1987; Murphy, Rotheram-Borus & Marelich, 2000). YPLH were asked how often they used select coping styles in the previous 3 months to help them deal with their HIV disease. Responses ranged from 'never' (1) to 'always' (5). Five of the factor-analyzed sub-scales are included in these analyses: positive action (11 items, $\alpha = 0.84$), self-destructive escape (six items, $\alpha = 0.72$), social support (five items, $\alpha = 0.76$), passive problem-solving (eight items, $\alpha = 0.81$), and non-disclosure (four items, $\alpha = 0.62$).

2.4. Data analysis

For this analysis, an intent-to-treat analysis was conducted by evaluating participants who were assessed at points 3 and 4 (see Fig. 1). Using pre-intervention scores, gender, and city as covariates, analysis of covariance (ANCOVA) was conducted to examine post-intervention scores between the Immediate Intervention and Control conditions. For intent-to-treat analyses, relative effect sizes were calculated with the following formula using data from ANCOVA results: 100% × [(Intervention Outcome–Control Outcome)/Control Outcome]. After completing the intent-to-treat analysis, three-condition comparisons were made among the Intervention Attended, Control, and Intervention Non-Attended conditions to explore intervention effects that differentiated YPLH who were assigned to the intervention but did not attend from those who were assigned and did attend. Relative effect sizes for the three-condition comparisons were calculated with the following formula using data from ANCOVA results: 100% × [(Intervention Attended Outcome–Control Outcome)/Control Outcome]. Means were adjusted to make them comparable with respect to baseline scores. Dose effects were assessed with Spearman correlation analyses: correlations between number of intervention sessions attended and each study variable were examined. There were no significant Spearman correlations between the number of intervention sessions attended and outcome variables. Therefore, no dose effects are reported.

Longitudinal Ordinary Least Squares (OLS) multivariate

Table 4
Intervention effects based on intent-to-treat analyses and three-condition analyses (means adjusted for pre-intervention scores, gender and city). *$P < 0.05$, **$P < 0.01$

	Immediate intervention ($n = 68$)	Control ($n = 36$)	Relative Effect Size[a] ($n = 42$)	Intervention Attended ($n = 36$)	Control ($n = 26$)	Intervention non-attended	Relative effect size (%)[b]
Poor Health Rating (1–5)	2.30	2.51	8.4%	2.47	2.51	2.00	1.6
Low Physical Limitation (1–3)	2.82	2.73	3.3%	2.82	2.73	2.81	3.3
Energy/Vitality (1–6)	4.08	4.02	1.5%	4.06	4.02	4.11	1.0
Brief Symptom Inventory (0–4)							
Global	0.48	0.80[c]**	40.0%	0.43	0.80[d]**	0.55[e]*	46.3
Somatization	0.45	0.73[c]*	38.4%	0.38	0.72[d]**	0.54	47.2
Anxiety	0.33	0.79[c]**	58.2%	0.29	0.79[d]**	0.39[e]**	63.3
Phobic Anxiety	0.34	0.71[c]**	52.1%	0.25	0.71[d]**	0.45	64.8
Manifest Anxiety (1–2)	1.33	1.38	3.6%	1.33	1.38	1.34	3.6
Coping (1–5)							
Non-Disclosure	2.16	2.48[c]*	12.9%	2.03	2.47[d]**	2.35	17.8

[a] 100% × [(Intervention Outcome–Control Outcome)/ Control Outcome].
[b] 100% × [(Intervention Attended Outcome–Control Outcome)/ Control Outcome].
[c] Immediate Intervention vs. Control.
[d] Intervention Attended vs. Control.
[e] Control vs. Intervention Non-Attended.

regression analyses were used to elaborate relationships between intervention condition membership and change in QOL, to highlight the directions of associations and to assess the independent effects of coping. Change was computed by subtracting the value of a variable from its subsequent value. For OLS analyses, previous values of the dependent variable are controlled, so that coefficients for independent variables are effects on change in the dependent variable between two time points. In addition, previous values and change scores for coping are included as independent variables in the regression models. When a change score is included as a predictor of a subsequent outcome, previous scores represent the amount of the score that is stable between two time points, and the change score represents variation between the two time points. In all regression analyses, the comparison group for intervention attendance was Control Condition membership. For multivariate analyses, recent HIV symptomatology was controlled. By including HIV symptomatology as a covariate, it was possible to delineate effects of the intervention on QOL, independent of the effect of HIV symptoms on QOL. This type of control is important because presentation of somatic symptoms could be confounded by symptoms of HIV infection (Castellon, Hinkin, Wood & Yarema, 1998; Kalichman, Sikkema & Somlai, 1995).

3. Results

3.1. Intervention Effects

Table 4 presents post-intervention adjusted mean scores and relative effect sizes in the intent-to-treat analysis for the five domains of QOL for YPLH in the two intervention conditions. Table 4 also summarizes the three-condition analysis comparing Intervention Attended, Intervention Non-Attended, and the Control conditions. As shown, results are similar between the intent-to-treat analysis and the three-condition analysis.

The pre-post differences on BSI global and subscale scores for the Intervention Condition decreased from 0.19 to 0.22; in contrast, the scale scores for the Control Condition increased from 0.04 to 0.19. After Module 3 implementation, YPLH assigned to the Immediate Intervention Condition had significantly lower global BSI scores than the Control Condition (relative effect size = 40.0%). On specific symptom scales, YPLH in the Intervention Attended Condition had significantly lower scores on somatization (relative effect size = 38.4%), anxiety (relative effect size = 58.2%), and phobic anxiety (relative effect size = 52.1%). There were no significant differences by intervention condition on the other six BSI subscales, and these scores are not shown in Table 4. Scores on the Manifest Anxiety scale did not differ significantly between the Immediate Intervention and Control conditions, or among the three conditions (Intervention Attended, Intervention Non-Attended, Control). Coping style was significantly different only for non-disclosure style of coping. Pre-post difference scores decreased 0.06 for the Intervention Condition (0.17 decrease for the Intervention Attended Condition) and increased 0.15 for the Control Condition. YPLH in the Intervention Attended Condition reported significantly lower levels of non-disclosure coping (i.e. refused to think about serostatus, hiding serostatus, etc.) than the Control Condition (relative effect size = 17.8%), as shown in Table 4. YPLH in the different conditions did not differ significantly on any of the other coping styles, and these scores are not shown in Table 4.

Table 5
Regression of post-module 3 global BSI, BSI-somatization, and BSI-phobic anxiety on intervention group status, HIV symptomatology, and change in non-disclosure coping ($n = 93$), $^{*}P < 0.05$, $^{**}P < 0.01$

Independent variables	Global BSI			BSI Somatization			BSI-Phobic Anxiety		
	B	(SE)	β	B	(SE)	β	B	(SE)	β
Pre-Module 3 BSI	0.49	(0.07)	0.57**	0.38	(0.07)	0.44**	0.48	(0.07)	0.56**
Intervention Attended[a]	− 0.20	(0.09)	− 0.19*	− 0.31	(0.11)	− 0.27**	− 0.30	(0.12)	− 0.23*
Intervention Non-Attended[a]	− 0.09	(0.11)	− 0.08	− 0.09	(0.12)	− 0.07	− 0.13	(0.14)	− 0.10
HIV Symptoms in Past 3 Months (/no)	0.36	(0.13)	0.23**	0.61	(0.14)	0.36**	0.18	(0.16)	0.10
Pre-Module 3 Non-Disclosure Coping	0.10	(0.05)	0.19*	0.09	(0.05)	0.15	0.11	(0.06)	0.18*
Change in Non-Disclosure Coping	0.08	(0.06)	0.12	− 0.03	(0.07)	− 0.03	0.13	(0.08)	0.15
	$R^2 = 0.53$			$R^2 = 0.48$			$R^2 = 0.45$		
	$F(6,86) = 16.16$**			$F(6,86) = 13.09$**			$F(6,86) = 11.73$**		

[a] Reference group = Control condition.

There were no significant pre- and post-intervention mean differences among YPLH in either of the intervention conditions for subjective poor health, physical limitations, or energy/vitality level, which may be indicative of the relative healthiness of this cohort. That is, the absence of a significant intervention effect may have resulted from initially high levels of energy/vitality and low levels of physical limitation. For example, prior to implementation of Module 3, the mean level of physical limitation for all YPLH was 2.77 (SD = 0.42). Responses to this scale range from 1 to 3 (where 3 = *not at all physically limited*), clearly demonstrating that most YPLH were experiencing no limitations in their physical activity and that changes in physical limitation were constrained by ceiling effects. Similarly, ceiling effects on pre-intervention scores were found for energy/vitality ($M = 4.26$ (SD = 1.30), range = 1–6). These constrained pre-intervention scores, combined with the small sample size, may have made it difficult to detect a significant intervention effect.

3.1.1. Elaboration of intervention effects

Elaboration of the intervention effects was accomplished by introducing other select variables into OLS regression models for change in emotional distress. In the Elaboration Model, a focal relationship is expanded upon in an attempt to further explain or specify the relationship (Aneshensel, 1999; Rosenberg, 1968). The focal relationship may be weakened or bolstered by other factors or may remain unaffected. In either case, it has been made more meaningful.

Focal relationships between intervention group attendance and the QOL were elaborated by including covariates in longitudinal analyses of three of the emotional distress outcomes that differed significantly by intervention condition (global BSI, BSI-somatization, and BSI-phobic anxiety). HIV symptomatology was controlled to account for confounding effects of HIV-related health on emotional distress. Non-disclosure coping and change in non-disclosure coping were included as correlates because bivariate analyses revealed a significant positive association between this style of coping and the global BSI measure (Pearson $R = 0.21$, $P < 0.05$) and because the Intervention Attended Condition differed significantly from the Control Condition on this measure, as discussed above. Demographic variables (age, gender, city, sexual orientation, ethnicity, and education) were controlled for in initial analyses, but none of these variables were independently associated with emotional distress and, therefore, are not included in the OLS models. In these analyses, the intervention effect is a measure of its independent effect on change in emotional distress over time, holding constant non-disclosure coping, change in non-disclosure coping, HIV symptomatology, and initial levels of emotional distress. The regression model for BSI-anxiety is not presented because change in BSI-anxiety was not independently associated with non-disclosure coping, change in non-disclosure coping, or HIV symptomatology.

Correlates of the global BSI measure of emotional distress, BSI-somatization, and BSI-phobic anxiety are shown in Table 5. Decrease in global emotional distress between the pre- and post-Module 3 assessments was a function of being in the Intervention Attended group. Increase in global emotional distress was a function of persisting high levels of emotional distress, Control Condition membership (as opposed to Intervention Attended membership), HIV symptomatology, and elevated levels of non-disclosure coping prior to Module 3. That is, YPLH in the Intervention Attended Condition were less likely to experience increasing emotional distress than YPLH in the Control Condition, who initially scored high on non-disclosure coping and emotional distress, and who experienced symptoms of HIV in the past 3 months. Independent variables in this model accounted for a large amount of variance in changing emotional distress, largely attributable to persisting levels of emotional distress.

Decreasing somatization was a function of being in the Intervention Attended group. Increasing somatization was a function of persisting levels of somatic symptoms, Control Condition membership (as opposed to Intervention Attended membership), and HIV symptomatology. The effect of HIV symptomatology was larger in magnitude than the Intervention Attended effect but established the independent influence

of the intervention on decreasing somatization, holding constant the effect of HIV-related health. Similar to the model for global emotional distress, independent variables in this model accounted for a large proportion of the variance in changing somatization, largely attributable to persisting somatization.

Decreasing phobic anxiety was associated with being in the Intervention Attended group. Increasing phobic anxiety was associated with persisting phobic anxiety, Control Condition membership (as opposed to Intervention Attended membership), and pre-Module 3 non-disclosure coping. HIV symptomatology was not independently associated with increasing phobic anxiety, and this model accounts for 45% of the variance in increasing phobic anxiety.

4. Discussion

The Being Together intervention module, which aimed to improve the QOL among YPLH, had a statistically significant influence on emotional distress, a key aspect of QOL. Compared to YPLH in the Control Condition, YPLH who attended the Being Together intervention reported significantly lower levels of global emotional distress, somatization, anxiety, and phobic anxiety, as measured by the BSI, with relative effect sizes ranging from 46.3 to 64.8%. BSI scores found among these YPLH were also lower than scores found in an adolescent nonpatient normative sample (Derogatis, 1993). In addition, intervention attendance was associated with decreasing emotional distress over time. These results demonstrate that the intervention was successful in providing YPLH with skills and affective response repertoires that improved their psychological health.

For this study, we examined how the intervention effect on emotional distress would be weakened or bolstered by controlling for HIV symptomatology. We found that the intervention influences YPLHs emotional distress, even when controlling for HIV symptoms in the past 3 months. This is an important finding in light of the fact that change in emotional distress, especially somatization, may have reflected HIV symptom experience. Standardized regression coefficients indicated that effect sizes for intervention attendance and HIV symptomatology were somewhat similar. In fact, the unstandardized effect size for intervention attendance fell within the 95% confidence interval of HIV symptomatology for both the global BSI measure and somatization. The focal relationship between intervention attendance and decreasing somatization was enhanced by controlling for HIV symptomatology, which did not independently influence change in phobic anxiety.

Non-disclosure coping independently affected global emotional distress and phobic anxiety. The relationships were positive, indicating that high and increasing levels of this style of coping were related to increasing emotional distress. These findings are consistent with previous research (Murphy et al., 2000), in which non-adaptive coping was associated directly with increased anxiety and depression. Thus, in comparison to Control Condition membership, intervention attendance is related to decreasing emotional distress, taking into account unit change in non-disclosure coping. The magnitude of the intervention effect in all regression models was larger than that for non-disclosure coping, demonstrating the pervasive influence of the intervention in affecting YPLHs mental health.

The Being Together intervention module was associated with differences in only one coping style: non-disclosure coping. There was no significant interaction effect between intervention attendance and non-disclosure coping on any of the mental health outcomes. Further investigation is needed to identify how non-disclosure influences QOL.

The intervention may have been associated with somatic symptomatology because of the intervention's focus on developing meditation skills. Meditation is a widely used technique for stress management, as well as pain management and control (Gordon, Sobel & Tarazona, 1998; McCain et al., 1996; Vigne, 1997). Meditation may enable YPLH to learn to appraise their experience of HIV symptoms or other health problems in relation to the meanings they attach to bodily sensations, rather than to their awareness of underlying disease. By utilizing meditation techniques for exploring the self, and by learning how not to separate the self from pain and physical symptomatology, YPLH may be instilled with skills that allow them to endure discomfort or perceive lower levels of discomfort. Experiences of discomfort may, in turn, be manifested in terms of somatic symptoms.

Limitations of the study and the data analyzed and presented merit mention. Because of slow recruitment rates and clinician' concerns, we did not randomly assign individual YPLH to intervention conditions, which may pose a threat to internal validity. Examination of the sociodemographic, health, and transmission behaviors among the YPLH did not indicate a selection bias. We assessed a relatively large number of primary and secondary outcomes which increases the possibility that the significant intervention effects were due to chance. The small sample size may also have limited our ability to detect significant and important differences between groups of YPLH based on their intervention status (i.e. attended, non-attended, and control). For example, the three groups did not differ by gender, even though 81% of YPLH who attended the Being Together module were male and only 61% of YPLH in the control group were male. In addition, it was not possible to control for multiple other possible predictors of emotional distress in the longitudinal regression models because the sample size limited the number of independent variables that could be examined. In the longitudinal regression models, endogeneity of the change in coping score could have resulted in biased parameter estimates. However, there was no indication that a serious selection bias was operating and those factors that were associated with retention in the study (being male and in San Francisco or New York) were

controlled in all analysis. Although we treated change in coping as an independent variable, it is possible that it may have been influenced by other variables in the system and such endogeneity may have affected the results.

The changes found in association with attending this intervention module are going to become increasingly important as YPLH live longer with the success of highly active anti-retroviral therapies. A positive QOL provides motivation for survival and healthy behaviors among those with a chronic or terminal illness. By promoting positive states of emotional well-being, interventions that aim to improve QOL may also support the public health agenda by encouraging and supporting the maintenance of behaviors that reduce HIV transmission and drug-resistant viral mutation.

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Appendix B

Recruitment of Participants

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Recruitment of Participants

Develop a recruitment plan. The plan should identify the following:

Goal

- Determine the number of potential participants desired.

Recruitment Venues

- Your own agency.
- Other agencies serving young people living with HIV.
- Clinics serving young people living with HIV.
- Faith-based groups attended by young people living with HIV.
- Popular online destinations and community bulletin boards (e.g., craigslist.org).
- Other Venues where young people living with HIV gather.

The TLC Pitch

- Develop talking points to describe **TLC** and what it offers participants.

Recruitment/Marketing Tools

- Assess agency resources available to produce flyers, brochures, posters, etc.
- Determine strategic placement of marketing materials.

Use Your Community Advisory Group to Test Ideas

- Use the community advisory group your agency assembled to test the ideas contained in your recruitment plan.
- Discuss with the groups questions such as:
  - What is the best place to recruit?
  - What are the best recruiting strategies for your population?
  - What might motivate members of the target population to attend **TLC**?

WHAT DO YOU WANT?

To **MEET OTHER YOUNG PEOPLE** like yourself?

To stay **HEALTHY**?

To **PROTECT YOURSELF** and other people?

To **UNDERSTAND** your feelings?

To set and meet **GOALS**?

To **SOLVE PROBLEMS**?

To be **MORE ASSERTIVE**?

TLC: Together Learning Choices

A group for young people living with HIV.
It can change your life.

For information, contact 555-5555

Appendix C

Energizer Activities

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Energizer Activities

The exercises that follow provide Facilitators with optional activities to include in the sessions to provide laughter or just a change of pace, as needed. Feel free to use them when you find them appropriate, throughout the sessions. Please, however, try them out with other agency staff members before you use them with participants. You may find some of them more or less appropriate for your population. Each is appropriate for small to medium or large-sized groups. If any equipment or supplies are required, they are mentioned.

Ha Ha

Participants lay down side by side on floor. The first person lays the back of his or her hand on next persons stomach and that person lays the back of his or her hand on the stomach of the person next to him and so on. The first person in line is told to laugh by saying HA once. The next person in line is to laugh by saying HA HA (two times). The third person is HA HA HA, and and so on. Any person who breaks into a giggle is out of the game and must get up, and and the line moves over to fill in that space. The winner is the last one left.

Scavenger Hunt

Required: Just a pencil and paper

Instead of a regular scavenger hunt, give individuals a list of characteristics, like "likes Hip Hop music" or "is from another state." Each person will have to walk around the group talking to other people to find out who matches up with each statement and write that person's name next to it. The first person who finishes the list wins and reads off who matched up with what.

Memory Test

Required: Items for memory test, such as various small office supplies or toys, or types of condoms or other materials related to safer sex, tray to display these on, and paper and a pencil for each person.

Hand out paper and a pencil to each person (or group). Announce you will have a memory test. Put the items you have selected on the tray and carry it past the participants, giving them a brief (but reasonable) view of it. Then remove the tray from sight and ask them to list what was on the tray. The person (or group) who lists the most objects is the winner. You can give extra points or break ties by asking specific questions like what brand a given item was, what color, etc.

Rumor

Required: Blackboard and chalk, paper and pencil, or Easel Paper and marker

This activity is just like "telephone," but is done by teams. Tell the people who are selected to make a rumor up related to the session's topic or related to a myth about HIV.

Participants line up in teams, across from each other. Each team selects one person to meet with people selected from the other teams to make up a rumor. It must not be mean. Once they have come up with a rumor, they write it on a piece of paper (so that it is not visible to others) and give it to the Facilitator.

At the signal to start, they return to their teams and each whispers the rumor to the next person in line on that team. That person whispers the rumor to the next, and and so on. The last person to receive the rumor will run to the board and write the message. The first team that is the closest to the correct rumor wins.

Getting to Know You

Have participants pair up and ask the following questions of each other, then introduce each other to the group, using the information gained in the interviewing only.

- What is your name?
- Tell me something that you are good at or something you recently accomplished?
- Tell me something you like to do in your free time?
- What attracted you to your job?
- What is the name of your first pet?
- What is the name of the street you grew up on?
- What is one thing you are willing to share that not too many people would know about you?
- What do you hope to get out of **TLC**?

More Fun Variation of Musical Chairs

Required: One chair per player

Have the person who is "it" stand in the center of a circle of chairs. There should be no extra chairs, so "it" has to stand. Whoever is "it" may select whatever criterion he or she wishes for the chair exchangers, for example: "Everyone wearing black shoes change seats." Then "it" tries to take a chair in the general confusion. The one left standing is the new "it," who may say, "Everyone wearing a belt change seats." The game continues for a few minutes, until the Facilitator calls a halt.

Who Does This Belong To?

This is a children's activity for reinforcing personal ownership over one's body; adults seem to like it as well. In any rhythmic melody, with everyone standing and swaying in unison, the leader says (and the participants imitate): "Who does this belong to? To me, to me!" repeatedly, all pointing first to lips, chest, bottom, and crotch. It generally ends in laughter.

Spell Your Name

As a group, participants (standing) spell their own names with their hips or whole bodies, swiveling them however needed to spell them in whatever language they speak.

Simon Says

This imitative activity has a leader giving (and modeling) instructions to raise one's hand(s), take a step, jump, etc., with some of the instructions preceded by the words, "Simon says (raise your right hand)" and others without the instructions, for example, "Raise your left hand." Participants are to perform only those actions preceded by the words, "Simon says," even though the leader performs all of the actions. Many people get caught up in following the actions modeled before the words register. Those who miss are "out." The last one standing wins.

Lu-ka ka

Required: One chair per person

"Lu-ka" is Swahili for stand; "ka" is Swahili for sit. Everyone (including the leader) stands in front of a chair. The leader calls out slowly, "Lu-ka ka, lu-ka ka, lu-ka, lu-ka, lu-ka ka," and he or she and all participants follow the instructions by sitting or standing as indicated. Gradually the leader increases the speed and varies the words so that it's not predictable what' coming next. You're "out" when you make a mistake. Last one standing wins. You may, of course, substitute "stand up" and "sit down" in any language you wish.

Change Your Seats

Midway in the session, have people change seats so they are not sitting next to either person they sat next to in the previous half.

Mingle

The participants are to stand up and pretend they're at a party, talking to each other in a friendly way. When the Facilitator calls out a number (from 2 to half the size of the group), they have to quickly form groups the size of that number (usually 2, 3, 4, 5 . . .). Those not in a group of the correct size must sit out. This continues until only one small group is left.

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Appendix D

Sample TLC Pre-Assessment Interview Questions

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Sample TLC Pre-Assessment Interview Questions

Pre-assessment interviews are an opportunity for **TLC** Facilitators to interview potential **TLC** participants and assess their readiness to participate in the intervention.

Conduct the interviews in a private room where the potential participant can freely answer the questions in a welcoming and supportive environment.

Remember that this is an opportunity to leave a striking first impression. Project a warm, welcoming and inviting attitude. Maintain eye contact with potential participants, practice active listening and share any appropriate **TLC** marketing material your agency has created.

Promote **TLC** as an opportunity to meet other young people living with HIV in a fun, interactive environment.

The interview should not last longer than 30 minutes. It is not recommended that this interview time be used to ask sensitive questions about sexual or drug-use behavioral risks for HIV. These behaviors can be assessed later on after greater rapport with the participant has been established.

Sample interview questions include:

- When were you diagnosed with HIV?
- Do you go to school or work?
- What has been your experience with support groups or discussion groups?
- What do you like most/least about groups?
- How do you handle tension or conflict within a group of people?
- Are you willing to share your HIV diagnosis with a group of other young people living with HIV?
- Do you have questions about **TLC** that I can answer for you?

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Appendix E

Suggestions for Handling Problem Behaviors

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Suggestions for Handling Problem Behavior

BEHAVIOR	POSSIBLE CAUSES	FACILITATOR RESPONSES
One participant argues frequently	• Likes to be the center of attention. • Wants to keep people from getting close. • Angry about something. • Upset about personal problems. • Needs to dominate. • Thinks arguing demonstrates intelligence. • Doesn't know another way to interact socially.	• Keep the group calm. • Obtain Feeling Thermometer reading. • Use relaxation exercises to bring the tension level down if needed. • Find points in what the person is saying that have merit. • Engage the person in an assertiveness role play. • Have the person practice self-talk in a provocative situation. • Have the group brainstorm pros and cons regarding the points being made. • In a private moment ask what is bothering the person.
Several participants argue frequently	• Don't like each other. • May be members of opposing cliques. • Lack skills in social problem solving or assertiveness.	• Emphasize points of agreement. • Point out objectives that cut across both positions. • Create role plays for others to perform on resolving the conflict. • Have members find positive qualities in the opponents. • Give out praise for positive behavior. • Emphasize that group members can be good and still present troublesome behaviors.
Participant won't talk	• Is frightened. • Feels insecure. • Is bored. • Is indifferent. • Feels superior. • Knows all the answers, or thinks he or she does. • Wants to be drawn out. • Is depressed.	• Give praise for any small response. • Obtain Feeling Thermometer reading and discuss. • Ask for help in reading a script or role playing. • Assign work in pairs. • Encourage the group to give the person Thanks Tokens for participation. • If the person is depressed, provide a referral for individual counseling. • Say, "Let's hear from someone we haven't heard from today".
Participant is overly talkative	• Participant is eager to share and earn praise. • Participant needs to show off and receive attention. • Participant may know a great deal and want to show it. • Participant typically talks a great deal. • Participant may feel nervous or insecure.	• Don't put participant down. • Ask thoughtful questions to make the person pause. • Interrupt with, "That's an interesting point. What do other people in the group think about it?" • Take the person aside and say that you need help in letting other group members have the experience of coming up with answers.
Participant is disruptive	• Causing trouble gets attention of Facilitator. • Angry about something and doesn't know how else to express it. • Trying to hide feelings of insecurity. • Looking for peer respect. • In emotional pain.	• Ignore, redirect, and reward. • Give praise when the person is calm. • Invite to role play a part. • Divide participants into small groups; put the disruptive person with strong peers. • Stay physically close in order to reinforce appropriate behavior through Thanks Tokens. • Ask the client to take a five minute break. • Ask the client to leave and come back next time.

Suggestions for Handling Problem Behavior - *continued*

BEHAVIOR	POSSIBLE CAUSES	FACILITATOR RESPONSES
Participant complains frequently	• May have legitimate reason to complain. • Has a pet peeve. • Griping is participant's personal style. • Has a great many dysfunctional thoughts.	• See if appropriate changes can be made. • Point out what can be changed and what can't. • Use Feeling Thermometer and explore feelings behind the thoughts. • Involve the group in addressing the issues. • Create a role play where someone is unhappy and wants to bring about change, using "I" statements. • Discuss the complaints privately.
Participant rambles	• Is anxious. • Isn't clear about topic. • Wants to contribute but doesn't know how. • Has trouble concentrating. • Bothered by dysfunctional thoughts. • Is trying to impress but is unsure.	• Orient to the topic. • Refocus the group. • Interrupt with a question about the topic at hand. • Ask the group to respond to the person's comments. • Give praise and Thanks Tokens for any comments that lead back to topic. • Say, "That's interesting, but I don't think I'm clear about how that relates to this". • Give the person a task to respond to and ask the person to think aloud, helping him or her stay focused. • Model staying on target.
Participant takes a stand and refuses to change	• Believes strongly in a particular point of view. • Connects position with self-esteem. • Is opinionated. • Hasn't understood other points of view. • Feels threatened.	• Ask the person to argue against own viewpoint. • Have the group respond to the point of view. • Ask the person to repeat back the other positions that have been stated. • Get Feeling Thermometer readings and explore source of any discomfort. • Give Thanks Tokens for believing strongly and for expressing other positions.
Participant focuses on wrong topic	• Doesn't understand the direction of the session and the group. • Has a personal agenda. • Needs to feel assertive. • Doesn't want to deal with the topic at hand.	• Take the blame. Say, "Something I said must have gotten you off the topic. We're talking about _____". • Try to find out if the topic the person is on has a personal significance. • Ask the group if the person's topic is one that needs to get dealt with. • Ask the person to think about the correct topic and then give a Feeling Thermometer reading; explore where any discomfort is coming from.
Participant constantly seeks the Facilitator's point of view	• Wants attention, praise. • Looking for advice. • Trying to copy the leader's behavior. • Doesn't understand what position is the best one to take. • Wants to challenge the Facilitator.	• Give Thanks Tokens for participating and paying attention. • Throw questions back to the group. • Give direct answers if appropriate. • Don't take away the person's opportunity to solve his or her own problem. • Ask for situations that demonstrate the question and role play them.
Participant cannot read well	• Never had opportunity to learn. • Is dyslexic. • Needs glasses. • Has eye problem.	• Have another group member assist with prompting. • Have another group member be the person's shadow and take over only the reading part of the exercises. • Give Thanks Tokens for trying. • Arrange for outside assistance on the basic problem.

BEHAVIOR	POSSIBLE CAUSES	FACILITATOR RESPONSES
Participant makes incorrect statements	• Doesn't know the facts. • Believes myths about the topic. • Goes along with peer group distortions.	• Ask the person what the consequences of the statement would be. • Ask the group to react to the statement. • Accept that the person does believe it with, "I can see how you feel," or, "That's one way of looking at it". • Say, "I see your point, but how does it fit with _____?" • Have the group try to figure out how such a belief got started. • Make sure the person doesn't end up feeling stupid or embarrassed.
Participant speaks in an inarticulate way	• Feels awkward speaking in a group. • Has ideas but is unsure how to express them appropriately.	• Don't say, "What you mean is this". • Ask, "Do you mean," and then rephrase in more appropriate language what you think the participant may have been trying to say. • Have the person write out what he or she wants to say and then coach him or her. • Pair the person with someone else who will model the desired language when they work together on a task. • Praise participant language that comes close to expressing the ideas appropriately. • Have the person make very small presentations at first.
Participant is consistently late	• Has outside responsibilities that interfere (child care, job, school). • Is hostile to group. • Angry at HIV status.	• Speak to participant and discover why; problem-solve a solution; set boundaries. • Serve food ½ hour before start time, then remove it. • Ask group for recommendations.
Participant comes to session drunk or high	• One-time slip up. • Dependency problem.	• Refer to ground rules and ask participant to leave until sober. • Process with group. • Speak to participant outside of group.

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Appendix F

Sample Outcome Monitoring Form and TLC Pre- and Post-Intervention Survey

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Sample Outcome Monitoring Form and TLC Pre- and Post-Intervention Survey

Each agency's funding source will have different requirements for process monitoring, process evaluation, and outcome monitoring. This Appendix includes forms that are supplied as suggestions. Each can be modified to fit your agency's requirements, target population, resources, and needs. Included are a Sample Outcome Monitoring Form, and a Pre- and Post-Intervention Survey. Agencies should consult their funder for evaluation requirements and standards.

Sample Outcome Monitoring Form

Condom Use and Sexual Risk Behaviors	
Initial Outcome Monitoring Interview	**Follow-up Outcome Monitoring Interview**
GENERAL SEXUAL ACTIVITY	
1. During the past 12 months, have you had sex with anyone? [1] Yes [2] No (Skip to Q 10) [9] Refused	1. Since your last interview, have you had sex with anyone? [1] Yes [2] No (Skip to Q 15) [9] Refused
2. During the past 12 months, have you had sex with only males, only females, or both? [1] Only males [2] Only females [3] Both males and females [9] Refused	2. Since your last interview, have you had sex with only males, only females, or both? [1] Only males [2] Only females [3] Both males and females [9] Refused
SEX AND CONDOM USE WITH MAIN PARTNERS	
3. During the past 12 months, have you had a main sex partner? [1] Yes [2] No (Skip to Q 7) [9] Refused	3. Since your last interview, have you had a main sex partner? [1] Yes [2] No (Skip to Q 7) [9] Refused
4. Is your main sex partner male or female? [1] Male [2] Female [9] Refused	4. Is your main sex partner male or female? [1] Male [2] Female [9] Refused
5. The last time you had sex with your main partner, what type of sex did you have? (Check all that apply) [1] Oral [2] Vaginal [3] Anal [4] Other (Specify_____) [9] Refused	5. The last time you had sex with your main partner, what type of sex did you have? (Check all that apply) [1] Oral [2] Vaginal [3] Anal [4] Other (Specify_____) [9] Refused
6. The last time you had sex with your main partner, did you or your partner use a condom? [1] Yes [2] No [8] Cannot Remember/Don't Know [9] Refused	6. The last time you had sex with your main partner, did you or your partner use a condom? [1] Yes [2] No [8] Cannot Remember/Don't Know [9] Refused

Condom Use and Sexual Risk Behaviors	
Initial Outcome Monitoring Interview	**Follow-up Outcome Monitoring Interview**
SEX AND CONDOM USE WITH NON-MAIN PARTNERS	
7. During the past 12 months, have you had sex with someone who is not your main partner or whom you did not consider your main partner at that time? [1] Yes [2] No (Skip to Q 10) [9] Refused	7. Since your last interview, have you had sex with someone who is not your main partner or whom you did not consider your main partner at that time? [1] Yes [2] No (Skip to Q 10) [9] Refused
8. The last time you had sex with someone who is not your main partner, what type of sex did you have? (Check all that apply) [1] Oral [2] Vaginal [3] Anal [4] Other (Specify_____) [9] Refused	8. The last time you had sex with someone who is not your main partner, what type of sex did you have? (Check all that apply) [1] Oral [2] Vaginal [3] Anal [4] Other (Specify_____) [9] Refused
9. The last time you had sex with someone who is not your main partner, did you or your partner use a condom? [1] Yes [2] No [8] Cannot Remember/Don't Know [9] Refused	9. The last time you had sex with someone who is not your main partner, did you or your partner use a condom? [1] Yes [2] No [8] Cannot Remember/Don't Know [9] Refused
SEX PARTNER RISKS	
10. Have you ever had sex in exchange for money, drugs, or shelter? [1] Yes [2] No [8] Cannot Remember/Don't Know [9] Refused	10. Since your last interview, have you had sex in exchange for money, drugs, or shelter? [1] Yes [2] No [8] Cannot Remember/Don't Know [9] Refused
11. Have you ever had sex with someone whom you knew or suspected of having HIV/AIDS? [1] Yes [2] No [8] Don't Know [9] Refused	11. Since your last interview, have you had sex with someone whom you knew or suspected of having HIV/AIDS? [1] Yes [2] No [8] Don't Know [9] Refused
12. Have you ever had sex with someone whom you knew or suspected of being an injecting drug user? [1] Yes [2] No [8] Don't Know [9] Refused	12. Since your last interview, have you ever had sex with someone whom you knew or suspected of being an injecting drug user? [1] Yes [2] No [8] Don't Know [9] Refused

Sample Outcome Monitoring Form - *continued*

Condom Use and Sexual Risk Behaviors	
Initial Outcome Monitoring Interview	**Follow-up Outcome Monitoring Interview**
SEX PARTNER RISKS	
13. The last time you had sex, did you use injected drugs or alcohol? [1] Yes [2] No [8] Cannot Remember [9] Refused	13. The last time you had sex, did you use injected drugs or alcohol? [1] Yes [2] No [8] Cannot Remember [9] Refused
14. The last time you had sex, did you use any non-injected drugs or alcohol? [1] Yes [2] No [8] Cannot Remember [9] Refused	14. The last time you had sex, did you use any non-injected drugs or alcohol? [1] Yes [2] No [8] Cannot Remember [9] Refused
STD/HIV STATUS	
15. During the past 12 months, has anyone told you that you had a sexually transmitted disease, or STD, for example, herpes, gonorrhea, chlamydia, genital warts? [1] Yes [2] No [8] Cannot Remember/Don't Know [9] Refused	15. Since your last interview, has anyone told you that you had a sexually transmitted disease, or STD, for example, herpes, gonorrhea, chlamydia, genital warts? [1] Yes [2] No [8] Cannot Remember/Don't Know [9] Refused
16. Have you ever been told by a doctor or other health professional that you were infected with HIV or that you have AIDS? [1] Yes [2] No [8] Cannot Remember/Don't Know [9] Refused	16. Since your last interview, have you ever been told by a doctor or other health professional that you were infected with HIV or that you have AIDS? [1] Yes [2] No [8] Cannot Remember/Don't Know [9] Refused

Injection Drug Use and Other Drug-Related Risks	
Initial outcome monitoring interview	**Follow-up outcome monitoring interview**
1. Have you ever, even once, used a needle to inject a drug that was not prescribed for you? [1] Yes [2] No (Skip to Q 11) [8] Cannot remember/ Don't Know [9] Refused (Skip to Q 11)	1/2. Since your last interview, have you used a needle to inject a drug that was not prescribed for you? [1] Yes [2] No (Skip to Q 11) [8] Cannot remember/ Don't Know [9] Refused (Skip to Q 11)
2. In the past 12 months, have you ever used a needle to inject a drug that was not prescribed for you? [1] Yes [2] No (Skip to Q 11) [8] Cannot remember/ Don't Know [9] Refused (Skip to Q 11)	
3. The last time you used a needle for injecting drugs, where did you get the needle from? [1] Pharmacy [2] Needle exchange [3] Street [4] Shooting gallery [5] Friend [6] Dealer [7] Other (Specify _____)	3. The last time you used a needle for injecting drugs, where did you get the needle from? [1] Pharmacy [2] Needle exchange [3] Street [4] Shooting gallery [5] Friend [6] Dealer [7] Other (Specify _____)
4. The last time you used a needle for injecting drugs, was it a new and unused needle? (A needle in an unopened package or with an intact seal) [1] Yes [2] No [8] Cannot remember/ Don't Know [9] Refused	4. The last time you used a needle for injecting drugs, was it a new and unused needle? (A needle in an unopened package or with an intact seal) [1] Yes [2] No [8] Cannot remember/ Don't Know [9] Refused
5. The last time you used a needle to inject drugs, what drug did you inject? [1] Heroin [2] Cocaine [8] Speedball (heroin and cocaine together) [9] Methamphetamine	5. The last time you used a needle to inject drugs, what drug did you inject? [1] Heroin [2] Cocaine [8] Speedball (heroin and cocaine together) [9] Methamphetamine
6. The last time you used a needle to inject drugs, did you know or suspect someone else had used it before you? [1] Yes [2] No [8] Cannot remember/ Don't Know [9] Refused	6. The last time you used a needle to inject drugs, did you know or suspect someone else had used it before you? [1] Yes [2] No [8] Cannot remember/ Don't Know [9] Refused

Sample Outcome Monitoring Form - *continued*

Injection Drug Use and Other Drug-Related Risks	
Initial outcome monitoring interview	**Follow-up outcome monitoring interview**
7. Have you ever used a needle that you knew or suspected someone else had used before you? [1] Yes [2] No [8] Cannot Remember/Don't Know [9] Refused	7. Since your last interview, have you ever used a needle that you knew or suspected someone else had used before you? [1] Yes [2] No [8] Cannot Remember/Don't Know [9] Refused
8. Did you use bleach (or other solutions) to clean the needle before you used it? [1] Yes [2] No [8] Cannot remember/ Don't Know [9] Refused	8. Did you use bleach (or other solutions) to clean the needle before you used it? [1] Yes [2] No [8] Cannot remember/ Don't Know [9] Refused
9. The last time you used a needle for injecting drugs, did someone else use the needle after you? [1] Yes [2] No [8] Cannot remember/ Don't Know [9] Refused	9. The last time you used a needle for injecting drugs, did someone else use the needle after you? [1] Yes [2] No [8] Cannot remember/ Don't Know [9] Refused
10. The last time you used a needle for injecting drugs, did you have sex with someone while you were high? [1] Yes [2] No [8] Cannot remember/ Don't Know [9] Refused	10. The last time you used a needle for injecting drugs, did you have sex with someone while you were high? [1] Yes [2] No [8] Cannot remember/ Don't Know [9] Refused
11. In the past 12 months, have you smoked, sniffed, or taken drugs that you did not inject? [1] Yes [2] No (Stop) [8] Cannot remember/ Don't Know (Stop) [9] Refused (Stop)	11. Since your last interview, have you smoked, sniffed, or taken drugs that you did not inject? [1] Yes [2] No (Stop) [8] Cannot remember/ Don't Know (Stop) [9] Refused (Stop)

Injection Drug Use and Other Drug-Related Risks	
Initial outcome monitoring interview	**Follow-up outcome monitoring interview**
12. The last time you used drugs that you did not inject, what did you use? (Check all that apply) [1] Crack [2] Cocaine [3] Heroin [4] Methamphetamine/Speed/Crystal [5] Downers/Tranquilizers (Valium, etc.) [6] Ecstasy [7] Barbiturates [8] PCP (angel dust) [9] Nitrites [10] LSD [11] Inhalants [12] Alcohol [13] Other (Specify _____) [99] Cannot remember/Don't Know	12. The last time you used drugs that you did not inject, what did you use? (Check all that apply) [1] Crack [2] Cocaine [3] Heroin [4] Methamphetamine/Speed/Crystal [5] Downers/Tranquilizers (Valium, etc.) [6] Ecstasy [7] Barbiturates [8] PCP (angel dust) [9] Nitrites [10] LSD [11] Inhalants [12] Alcohol [13] Other (Specify _____) [99] Cannot remember/Don't Know
13. How did you use the drug? (Check all that apply) [1] Snort [2] Sniff [3] Inhale [4] Smoke	13. How did you use the drug? (Check all that apply) [1] Snort [2] Sniff [3] Inhale [4] Smoke
14. The last time you used non-injected drugs, did you have sex with someone while you were high? [1] Yes [2] No [8] Cannot remember/ Don't Know [9] Refused	14. The last time you used non-injected drugs, did you have sex with someone while you were high? [1] Yes [2] No [8] Cannot remember/ Don't Know [9] Refused

TLC Pre- and Post-Intervention Survey

Please answer the following questions to help <Name of Implementing Agency> and its HIV prevention programs gather information to help with their HIV prevention efforts. Your answers are anonymous. Thanks for your help.

1. How old are you? _____

Please circle the number next to the response which best reflects your answer.

2. What is your sex? Female ..... 1 Male ..... 2 Transgender 3

3. What is your ethnicity?

Asian/Pacific Islander 1	Native American 4
African American 2	Caucasian 5
Latino/a 3	Other_____6 (Please Specify)

4. How do you identify yourself? (Circle one)

Homosexual/Gay ..... 1 Bisexual ..... 2 Heterosexual 3

5. What is the zip code where you live?_____

6. Do you live in <local city>? Yes. . . . 1 No. . . . 2

7. Do you work in <local city>? Yes. . . . 1 No. . . . 2

To help prevent the spread of HIV, the <Name of Implementing Agency> needs to know about risk behaviors of young people. Some of these questions are personal. You may choose not to answer any questions. We appreciate your cooperation in answering the following questions. Please check the box next to the response which best reflects your answer.

8. In the last 3 months, have you had sex?
   - ☐ Yes
   - ☐ No (Skip to Question #12)
   - ☐ Refused to Answer (Ref)

9. If yes, how many sex partners did you have?

   Number of men _____

   Number of women _____

   Don't Know (DK) _____

   Refused to Answer (Ref) _____

10. In the last 3 months, how often did you or your partner(s) use condoms for anal sex?
    - ☐ Always
    - ☐ Most of the time
    - ☐ Sometimes
    - ☐ Never
    - ☐ Don't Know (DK)
    - ☐ Refused to Answer (Ref)
    - ☐ Not Applicable (NA)

11. In the past 3 months, have you had unprotected sex with someone whom you knew had HIV/AIDS?
    - ☐ Yes
    - ☐ No
    - ☐ Don't Know (DK)
    - ☐ Refused to Answer (Ref)

12. In the past 3 months, did you use? (Check all that apply)
    - ☐ Crystal
    - ☐ Ecstasy
    - ☐ Cocaine
    - ☐ Crack
    - ☐ Heroin
    - ☐ Amphetamine/Speed (pills)
    - ☐ Downers/Tranquilizers (Valium, etc.)
    - ☐ Nitrites
    - ☐ LSD
    - ☐ Inhalants
    - ☐ Alcohol
    - ☐ Other: (Specify): _____

13. In the last 3 months, did you have sex with someone while you were high on drugs and/or alcohol?
    - ☐ Yes
    - ☐ No
    - ☐ Don't Know (Dk)
    - ☐ Refused to Answer (Ref)

Please answer the following true or false statements regarding HIV safer sex behaviors and HIV testing. Circle T is you think the statement is True and F if you think the statement if False.

17. It takes a minimum of three weeks after exposure before the HIV antibody will show up on an HIV test.
    T
    F
18. Using heavy drugs or alcohol before sex can impair your judgment about condom use.
    T
    F
19. You can prevent the transmission of HIV during anal sex by withdrawing before ejaculation.
    T
    F
20. You can prevent the transmission of HIV during anal sex by using a latex condom and water-based lubricant.
    T
    F

Thank you for completing this survey.

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Appendix G

CDC Information and Guidelines

- The ABC's of Smart Behavior
- CDC Content and Review Guidelines for HIV Programs
- Male Latex Condoms and Sexually Transmitted Diseases
- CDC Statement on Nonoxynol-9 Spermicide Contraception Use-US (1999)
- CDC Statement for Study Results of Product Containing Nonoxynol-9 (2000)

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The ABCs of Smart Behavior

To Avoid or Reduce the Risk for HIV

A Stands for abstinence.

B Stands for being faithful to a single sexual partner.

C Stands for using condoms consistently and correctly.

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CDC Content and Review Guidelines

for HIV Programs

Centers for Disease Control and Prevention

Revised Interim HIV Content Guidelines for AIDS-Related Written Materials, Pictorials, Audiovisuals, Questionnaires, Survey Instruments and Educational Sessions for CDC Assistance Programs

I. Basic Principles

Controlling the spread of HIV infection and the occurrence of AIDS requires the promotion of individual behaviors that eliminate or reduce the risk of acquiring and spreading the virus. Messages must be provided to the public that emphasize the ways by which individuals can protect themselves from acquiring the virus. These methods include abstinence from illegal use of IV drugs as well as from sexual intercourse except in a mutually monogamous relationship with an uninfected partner.

For those individuals who do not or cannot cease risky behavior, methods of reducing their risk of acquiring or spreading the virus must also be communicated. Such messages are often controversial. The principles contained in this document are intended to provide guidance for the development and use of HIV/AIDS-related educational materials developed or acquired in whole or in part using CDC HIV prevention funds and to require the establishment of at least one Program Review Panel by state and local health departments, to consider the appropriateness of messages designed to communicate with various groups. State and local health departments may, if they deem it appropriate, establish multiple Program Review Panels to consider the appropriateness of messages designed to communicate with various groups.

A. Written materials (e.g., pamphlets, brochures, curricula, fliers), audiovisual materials (e.g., motion pictures and videotapes), pictorials (e.g., posters and similar educational materials using photographs, slides, drawings or paintings) and marketing, advertising, Web site-based HIV/AIDS educational materials, questionnaires or survey instruments should use terms, descriptors or displays necessary for the intended audience to understand dangerous behaviors and explain practices that eliminate or reduce the risk of HIV transmission.

B. Written materials, audiovisual materials, pictorials and marketing, advertising, Web site-based HIV/AIDS educational materials, questionnaires or survey instruments should be reviewed by a Program Review Panel established by a state or local health department, consistent with the provisions of section 2500(b), (c) and (d) of the Public Health Service Act, 42 U.S.C. Section 300ee(b), (c) and (d), as follows:

SEC. 2500. USE OF FUNDS.

(b) Contents of Programs.--All programs of education and

information receiving funds under this title shall include information about the harmful effects of promiscuous sexual activity and intravenous substance abuse and the benefits of abstaining from such activities.

(c) Limitation.--None of the funds appropriated to carry out this title may be used to provide education or information designed to promote or encourage, directly, homosexual or heterosexual sexual activity or intravenous substance abuse.

(d) Construction.--Subsection (c) may not be construed to restrict the ability of an educational program that includes the information required in subsection (b) to provide accurate information about various means to reduce an individual's risk of exposure to or to transmission of, the etiologic agent for acquired immune deficiency syndrome, provided that any informational materials used are not obscene.

C. Educational sessions should not include activities in which attendees participate in sexually suggestive physical contact or actual sexual practices.

D. Program Review Panels must ensure that the title of materials developed and submitted for review reflects the content of the activity or program.

E. When HIV materials include a discussion of condoms, the materials must comply with Section 317P of the Public Health Service Act, 42 U.S.C. Section 247b-17, which states in pertinent part:

“educational materials . . . that are specifically designed to address STDs . . . shall contain medically accurate information regarding the effectiveness or lack of effectiveness of condoms in preventing the STD the materials are designed to address.”

II. Program Review Panel

Each recipient will be required to identify at least one Program Review Panel, established by a state or local health department from the jurisdiction of the recipient. These Program Review Panels will review and approve all written materials, pictorials, audiovisuals, marketing, advertising and Web site materials, questionnaires or survey instruments (except questionnaires or survey instruments previously reviewed by an Institutional Review Board--these questionnaires or survey instruments are limited to use in the designated research project). The requirement applies regardless of whether the applicant plans to conduct the total program activities or plans to have part of them conducted through other organization(s) and whether program activities involve creating unique materials or using/ distributing modified or intact materials already developed by others. Materials developed by the U.S. Department of Health and Human Services do not need to be reviewed by a panel. Members of a Program Review Panel should understand how HIV is and is not transmitted and understand the epidemiology and extent of the HIV/AIDS problem in the local population and the specific audiences for which materials are intended.

A. The Program Review Panel will be guided by the CDC Basic Principles (see Section I above) in conducting such reviews. The panel is authorized to review materials only and is not empowered either to evaluate the proposal as a whole or to replace any internal review panel or procedure of the recipient organization or local governmental jurisdiction.

B. Applicants for CDC assistance will be required to include in their applications the following:

1. Identification of at least one panel, established by a state or local health department, of no less than five persons who represent a reasonable cross-section of the jurisdiction in which the program is based. Since Program Review Panels review materials for many intended audiences, no single intended audience shall dominate the composition of the Program Review Panel, except as provided in subsection d below.

In addition:

a. Panels that review materials intended for a specific audience should draw upon the expertise of individuals who can represent cultural sensitivities and language of the intended audience, either through representation on the panel or as consultants to the panels.

b. Panels must ensure that the title of materials developed and submitted for review reflect the content of the activity or program.

c. The composition of Program Review Panels must include an employee of a state or local health department with appropriate expertise in the area under consideration, who is designated by the health department to represent the department on the panel.

d. Panels reviewing materials intended for racial and ethnic minority populations must comply with the terms of a-c above. However, membership of the Program Review Panel may be drawn predominantly from such racial and ethnic populations.

2. A letter or memorandum to the applicant from the state or local health department, which includes:

a. Concurrence with this guidance and assurance that its provisions will be observed.

b. The identity of members of the Program Review Panel, including their names, occupations and any organizational affiliations that were considered in their selection for the panel.

C. When a cooperative agreement/grant is awarded and periodically thereafter, the recipient will:

1. Present for the assessment of the appropriately identified Program Review Panel(s) established by a state or local health department, copies of written materials, pictorials, audiovisuals and marketing, advertising, Web site HIV/AIDS educational materials, questionnaires and surveys proposed to be used. The Program Review Panel shall pay particular attention to ensure that none of the above materials violate the provisions of Sections 2500 and 317P of the Public Health Service Act.

2. Provide for assessment by the appropriately identified Program Review Panel(s) established by a state or local health department, the text, scripts or detailed descriptions for written materials, pictorials, audiovisuals and marketing, advertising and Web site materials that are under development.

3. Prior to expenditure of funds related to the ultimate program use of these materials, assure that its project files contain a statement(s) signed by the chairperson of the appropriately identified

Program Review Panel(s) established by a state or local health department, specifying the vote for approval or disapproval for each
proposed item submitted to the panel.

4. Include a certification that accountable state or local health officials have independently reviewed written materials, pictorials, audiovisuals and marketing, advertising and Web site materials for compliance with Section 2500 and 317P of the Public Health Service Act and approved the use of such materials in their jurisdiction for directly and indirectly funded community-based organizations.

5. As required in the notice of grant award, provide to CDC in regular progress reports, signed statement(s) of the chairperson of the Program Review Panel(s) specifying the vote for approval or disapproval for each proposed item that is subject to this guidance.

D. CDC-funded organizations, which are national or regional (multi-state) in scope or that plan to distribute materials as described
above to other organizations on a national or regional basis, must identify a single Program Review Panel to fulfill this requirement. Those guidelines identified in Sections I.A. through I.D. and II.A. through II.C. outlined above also apply. In addition, such national/ regional panels must include, as a member, an employee of a state or local health department.

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CENTERS FOR DISEASE CONTROL AND PREVENTION

For more information
CDC's National Prevention Information Network
800) 458-5231 or www.cdcnpin.org

CDC National STD/HIV Hotline
(800) 227-8922 or (800) 342-2437
En Español (800) 344-7432
www.cdc.gov/std

Fact Sheet for Public Health Personnel:

Male Latex Condoms and Sexually Transmitted Diseases

In June 2000, the National Institutes of Health (NIH), in collaboration with the Centers for Disease Control and Prevention (CDC), the Food and Drug Administration (FDA), and the United States Agency for International Development (USAID), convened a workshop to evaluate the published evidence establishing the effectiveness of latex male condoms in preventing STDs, including HIV. A summary report from that workshop was completed in July 2001 (http://www.niaid.nih.gov/dmid/stds/condomreport.pdf). This fact sheet is based on the NIH workshop report and additional studies that were not reviewed in that report or were published subsequent to the workshop (see "Condom Effectiveness" for additional references). Most epidemiologic studies comparing rates of STD transmission between condom users and non-users focus on penile-vaginal intercourse.

Recommendations concerning the male latex condom and the prevention of sexually transmitted diseases (STDs), including human immunodeficiency virus (HIV), are based on information about how different STDs are transmitted, the physical properties of condoms, the anatomic coverage or protection that condoms provide, and epidemiologic studies of condom use and STD risk.

The surest way to avoid transmission of sexually transmitted diseases is to abstain from sexual intercourse, or to be in a long-term mutually monogamous relationship with a partner who has been tested and you known is uninfected.

For persons whose sexual behaviors place them at risk for STDs, correct and consistent use of the male latex condom can reduce the risk of STD transmission. However, no protective method is 100 percent effective, and condom use cannot guarantee absolute protection against any STD. Furthermore, condoms lubricated with spermicides are no more effective than other lubricated condoms in protecting against the transmission of HIV and other STDs. In order to achieve the protective effect of condoms, they must be used correctly and consistently. Incorrect use can lead to condom slippage or breakage, thus diminishing their protective effect. Inconsistent use, e.g., failure to use condoms with every act of intercourse, can lead to STD transmission because transmission can occur with a single act of intercourse.

While condom use has been associated with a lower risk of cervical cancer, the use of condoms should not be a substitute for routine screening with Pap smears to detect and prevent cervical cancer.

Sexually Transmitted Diseases, Including HIV

Sexually transmitted diseases, including HIV
Latex condoms, when used consistently and correctly, are highly effective in preventing transmission of HIV, the virus that causes AIDS. In addition, correct and consistent use of latex condoms can reduce the risk of other sexually transmitted diseases (STDs), including discharge and genital ulcer diseases. While the effect of condoms in preventing human papillomavirus (HPV) infection is unknown, condom use has been associated with a lower rate of cervical cancer, an HPV-associated disease.

There are two primary ways that STDs can be transmitted. Human immunodeficiency virus (HIV), as well as gonorrhea, chlamydia, and trichomoniasis – the discharge diseases – are transmitted when infected semen or vaginal fluids contact mucosal surfaces (e.g., the male urethra, the vagina or cervix). In contrast, genital ulcer diseases
– genital herpes, syphilis, and chancroid – and human papillomavirus are primarily transmitted through contact with infected skin or mucosal surfaces.

Laboratory studies have demonstrated that latex condoms provide an essentially impermeable barrier to particles the size of STD pathogens.

Theoretical basis for protection. Condoms can be expected to provide different levels of protection for various sexually transmitted diseases, depending on differences in how the diseases are transmitted. Because condoms block the discharge of semen or protect the male urethra against exposure to vaginal secretions, a greater level of protection is provided for the discharge diseases. A lesser degree of protection is provided for the genital ulcer diseases or HPV because these infections may be transmitted by exposure to areas, e.g., infected skin or mucosal surfaces, that are not covered or protected by the condom.

Epidemiologic studies seek to measure the protective effect of condoms by comparing rates of STDs between condom users and nonusers in real-life settings. Developing such measures of condom effectiveness is challenging. Because these studies involve private behaviors that investigators cannot observe directly, it is difficult to determine accurately whether an individual is a condom user or whether condoms are used consistently and correctly. Likewise, it can be difficult to determine the level of exposure to STDs among study participants. These problems are often compounded in studies that employ a “retrospective” design, e.g., studies that measure behaviors and risks in the past.

As a result, observed measures of condom effectiveness may be inaccurate. Most epidemiologic studies of STDs, other than HIV, are characterized by these methodological limitations, and thus, the results across them vary widely--ranging from demonstrating no protection to demonstrating substantial protection associated with condom use. This inconclusiveness of epidemiologic data about condom effectiveness indicates that more research is needed--not that latex condoms do not work. For HIV infection, unlike other STDs, a number of carefully conducted studies, employing more rigorous methods and measures, have demonstrated that consistent condom use is a highly effective means of preventing HIV transmission.

Another type of epidemiologic study involves examination of STD rates in populations rather than individuals. Such studies have demonstrated that when condom use increases within population groups, rates of STDs decline in these groups. Other studies have examined the relationship between condom use and the complications of sexually transmitted infections. For example, condom use has been associated with a decreased risk of cervical cancer – an HPV associated disease.

The following includes specific information for HIV, discharge diseases, genital ulcer diseases and human papillomavirus, including information on laboratory studies, the theoretical basis for protection and epidemiologic studies.

HIV / AIDS

HIV, the virus that causes AIDS
Latex condoms, when used consistently and correctly, are highly effective in preventing the sexual transmission of HIV, the virus that causes AIDS.

AIDS is, by far, the most deadly sexually transmitted disease, and considerably more scientific evidence exists regarding condom effectiveness for prevention of HIV infection than for other STDs. The body of research on the effectiveness of latex condoms in preventing sexual transmission of HIV is both comprehensive and conclusive. In fact, the ability of latex condoms to prevent transmission of HIV has been scientifically established in “real-life” studies of sexually active couples as well as in laboratory studies.

Laboratory studies have demonstrated that latex condoms provide an essentially impermeable barrier to particles the size of STD pathogens.

Theoretical basis for protection. Latex condoms cover the penis and provide an effective barrier to exposure to secretions such as semen and vaginal fluids, blocking the pathway of sexual transmission of HIV infection.

Epidemiologic studies that are conducted in real-life settings, where one partner is infected with HIV and the other partner is not, demonstrate conclusively that the consistent use of latex condoms provides a high degree of protection.

Discharge Diseases, Including Gonorrhea, Chlamydia, and Trichomoniasis.

Discharge diseases, other than HIV
Latex condoms, when used consistently and correctly, can reduce the risk of transmission of gonorrhea, chlamydia, and trichomoniasis.

Gonorrhea, chlamydia, and trichomoniasis are termed discharge diseases because they are sexually transmitted by genital secretions, such as semen or vaginal fluids. HIV is also transmitted by genital secretions.

Laboratory studies have demonstrated that latex condoms provide an essentially impermeable barrier to particles the size of STD pathogens.

Theoretical basis for protection. The physical properties of latex condoms protect against discharge diseases such as gonorrhea, chlamydia, and trichomoniasis, by providing a barrier to the genital secretions that transmit STD-causing organisms.

Epidemiologic studies that compare infection rates among condom users and nonusers provide evidence that latex condoms can protect against the transmission of chlamydia, gonorrhea and trichomoniasis. However, some other epidemiologic studies show little or no protection against these infections. Many of the available epidemiologic studies were not designed or conducted in ways that allow for accurate measurement of condom effectiveness against the discharge diseases. More research is needed to assess the degree of protection latex condoms provide for discharge diseases, other than HIV.

Genital Ulcer Diseases and Human Papillomavirus

Genital ulcer diseases and HPV infections
Genital ulcer diseases and HPV infections can occur in both male and female genital areas that are covered or protected by a latex condom, as well as in areas that are not covered. Correct and consistent use of latex condoms can reduce the risk of genital herpes, syphilis, and chancroid only when the infected area or site of potential exposure is protected. While the effect of condoms in preventing human papillomavirus infection is unknown, condom use has been associated with a lower rate of cervical cancer, an HPV-associated disease.

Genital ulcer diseases include genital herpes, syphilis, and chancroid. These diseases are transmitted primarily through “skin-to-skin” contact from sores/ulcers or infected skin that looks normal. HPV infections are transmitted through contact with infected genital skin or mucosal surfaces/fluids. Genital ulcer diseases and HPV infection can occur in male or female genital areas that are, or are not, covered (protected by the condom).

Laboratory studies have demonstrated that latex condoms provide an essentially impermeable barrier to particles the size of STD pathogens.

Theoretical basis for protection. Protection against genital ulcer diseases and HPV depends on the site of the sore/ulcer or infection. Latex condoms can only protect against transmission when the ulcers or infections are in genital areas that are covered or protected by the condom. Thus, consistent and correct use of latex condoms would be expected to protect against transmission of genital ulcer diseases and HPV in some, but not all, instances.

Epidemiologic studies that compare infection rates among condom users and nonusers provide evidence that latex condoms can protect against the transmission of syphilis and genital herpes. However, some other epidemiologic studies show little or no protection. Many of the available epidemiologic studies were not designed or conducted in ways that allow for accurate measurement of condom effectiveness against the genital ulcer diseases. No conclusive studies have specifically addressed the transmission of chancroid and condom use, although several studies have documented a reduced risk of genital ulcers in settings where chancroid is a leading cause of genital ulcers. More research is needed to assess the degree of protection latex condoms provide for the genital ulcer disease.

While some epidemiologic studies have demonstrated lower rates of HPV infection among condom users, most have not. It is particularly difficult to study the relationship between condom use and HPV infection because HPV infection is often intermittently detectable and because it is difficult to assess the frequency of either existing or new infections. Many of the available epidemiologic studies were not designed or conducted in ways that allow for accurate measurement of condom effectiveness against HPV infection.

A number of studies, however, do show an association between condom use and a reduced risk of HPV-associated diseases, including genital warts, cervical dysplasia and cervical cancer. The reason for lower rates of cervical cancer among condom users observed in some studies is unknown. HPV infection is believed to be required, but not by itself sufficient, for cervical cancer to occur. Co-infections with other STDs may be a factor in increasing the likelihood that HPV infection will lead to cervical cancer. More research is needed to assess the degree of protection latex condoms provide for both HPV infection and HPV-associated disease, such as cervical cancer.

Department of Health and Human Services

For additional information on condom effectiveness, contact
CDC's National Prevention Information Network
(800) 458-5231 or www.cdcnpin.org

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MMWR

Weekly

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Nonoxynol-9 Spermicide Contraception Use --- United States, 1999

Most women in the United States with human immunodeficiency virus (HIV) become infected through sexual transmission, and a woman's choice of contraception can affect her risk for HIV transmission during sexual contact with an infected partner. Most contraceptives do not protect against transmission of HIV and other sexually transmitted diseases (STDs) (*1*), and the use of some contraceptives containing nonoxynol-9 (N-9) might increase the risk for HIV sexual transmission. Three randomized, controlled trials of the use of N-9 contraceptives by commercial sex workers (CSWs) in Africa failed to demonstrate any protection against HIV infection (*2*--*4*); one trial showed an increased risk (*3*). N-9 contraceptives also failed to protect against infection with *Neisseria gonorrhoeae* and *Chlamydia trachomatis* in two randomized trials (*5*,*6*), one among African CSWs and one among U.S. women recruited from an STD clinic. Because most women in the African studies had frequent sexual activity, had high-level exposure to N-9, and probably were exposed to a population of men with a high prevalence of HIV/STDs, the implications of these studies for U.S. women are uncertain. To determine the extent of N-9 contraceptive use among U.S. women, CDC assessed data provided by U.S. family planning clinics for 1999. This report summarizes the results of that assessment, which indicate that some U.S. women are using N-9 contraceptives. Sexually active women should consider their individual HIV/STD infection risk when choosing a method of contraception. Providers of family planning services should inform women at risk for HIV/STDs that N-9 contraceptives do not protect against these infections.

CDC collected information on types of N-9 contraceptives purchased and family planning program (FPP) guidelines for N-9 contraceptive use. The national FPP, authorized by Title X of the Public Health Service Act, serves approximately 4.5 million predominantly low-income women each year. Program data for 1999 were obtained from all 10 U.S. Department of Health and Human Services (HHS) regions on the number of female clients and the number of female clients who reported use of N-9 contraceptives or condoms as their primary method of contraception. CDC obtained limited purchase data for 1999 for specific N-9 contraceptives and program guidelines from eight state/territorial FPPs within six HHS regions. State health departments, family planning grantees, and family planning councils were contacted to request assistance in collecting data on purchasing patterns of the 91 Title X grantees; of the 12 FPPs that responded, eight provided sufficient data for analysis.

In 1999, a total of 7%--18% of women attending Title X clinics reported using condoms as their primary method of contraception. Data on the percentage of condoms lubricated with N-9 were not available. A total of 1%--5% of all women attending Title X clinics reported using N-9 contraceptives (other than condoms) as their primary method of contraception (Table 1). Among the eight FPPs that provided purchase data, most (87%) condoms were N-9--lubricated (Table 2). All eight FPPs purchased N-9 contraceptives (i.e., vaginal films and suppositories, jellies, creams, and foams) to be used either alone or in combination with diaphragms

or other contraceptive products. Four of the eight clinics had protocols or program guidance stating that N-9--containing foam should be dispensed routinely with condoms; two additional programs reported that despite the absence of a clinic protocol, the practice was common. Data for the other two programs were not available.

Reported by: *The Alan Guttmacher Institute, New York, New York. Office of Population Affairs, U.S. Dept of Health and Human Services, Bethesda, Maryland. A Duerr, MD, C Beck-Sague, MD, Div Reproductive Health, National Center Chronic Disease and Public Health Promotion; Div of HIV and AIDS Prevention, National Center HIV/AIDS, STDs, and TB Prevention; B Carlton-Tohill, EIS Officer, CDC.*

Editorial Note:

The findings in this report indicate that in 1999, before the release of recent publications on N-9 and HIV/STDs (*4,6,*7), Title X family planning clinics in the U.S. purchased and distributed N-9 contraceptives. Among at least eight family planning clinics, most of the condoms purchased were N-9--lubricated; this is consistent with trends in condom purchases among the general public (*8*). The 2002 STD treatment guidelines state that condoms lubricated with spermicides are no more effective than other lubricated condoms in protecting against the transmission of HIV infection and other STDs (7). CDC recommends that previously purchased condoms lubricated with N-9 spermicide continue to be distributed provided the condoms have not passed their expiration date. The amount of N-9 on a spermicide-lubricated condom is small relative to the doses tested in the studies in Africa and the use of N-9--lubricated condoms is preferable to using no condom at all. In the future, purchase of condoms lubricated with N-9 is not recommended because of their increased cost, shorter shelf life, association with urinary tract infections in young women, and lack of apparent benefit compared with other lubricated condoms (7).

Spermicidal gel is used in conjunction with diaphragms (*1*); only diaphragms combined with the use of spermicide are approved as contraceptives. The respective contributions of the physical barrier (diaphragm) and chemical barrier (spermicide) are unknown, but the combined use prevents approximately 460,000 pregnancies in the United States each year (*1*).

The findings in this report are subject to at least two limitations. First, data on specific products and patterns of contraceptive use were limited; CDC used a nonrepresentative sample of regions and states that voluntarily provided data, and specific use patterns of the contraceptives could not be extrapolated from these data. Second, data correlating use of N-9 contraceptives with individual HIV risk were not available.

Prevention of both unintended pregnancy and HIV/STD infection among U.S. women is needed. In 1994, a total of 49% of all pregnancies were unintended (*9*). Furthermore, 26% of women experience an unintended pregnancy during the first year of typical use of spermicide products (*1*). In 1999, a total of 10,780 AIDS cases, 537,003 chlamydia cases, and 179,534 gonorrhea cases were reported among U.S. women. Contraceptive options should provide both effective fertility control and protection from HIV/STDs; however, the optimal choice is probably not the same for every woman.

N-9 alone is not an effective means to prevent infection with HIV or cervical gonorrhea and chlamydia (*2*,7). Sexually active women and their health-care providers should consider risk for infection with HIV and other STDs and risk for unintended pregnancy when considering contraceptive options. Providers of family planning services should inform women at risk for HIV/STDs that N-9 contraceptives do not protect against these infections. In addition, women seeking a family planning method should be informed that latex condoms, when used consistently and correctly, are effective in preventing transmission of HIV and can reduce the risk for other STDs.

Introduction and Overview

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Table 1

TABLE 1. Number of women using male condoms or nonoxynol-9 (N-9) products as their primary method of contraception, by Title X Family Planning Region — United States, 1999

Region*	No. of women served	Male condoms No.	Male condoms (%)	N-9 products† No.	N-9 products† (%)
I	179,705	27,726	(15)	1,251	(1)
II	404,325	73,069	(18)	21,515	(5)
III	487,502	73,088	(15)	4,807	(1)
IV	1,011,126	93,011	(9)	29,630	(3)
V	522,312	61,756	(12)	2,489	(1)
VI	478,533	40,520	(8)	11,212	(2)
VII	238,971	15,949	(7)	1,386	(1)
VIII	133,735	15,131	(11)	4,885	(4)
IX	672,362	109,678	(17)	14,547	(2)
X	186,469	17,320	(9)	1,275	(2)
Total	**4,315,040**	**527,248**	**(12)**	**92,997**	**(2)**

* Region I=Connecticut, Maine, Massachusetts, New Hampshire, Rhode Island, Vermont; Region II=New Jersey, New York, Puerto Rico, Virgin Islands; Region III=Delaware, District of Columbia, Maryland, Pennsylvania, Virginia, West Virginia; Region IV=Alabama, Florida, Georgia, Kentucky, Mississippi, North Carolina, South Carolina, Tennessee; Region V=Illinois, Indiana, Michigan, Minnesota, Ohio, Wisconsin; Region VI=Arkansas, Louisiana, New Mexico, Oklahoma, Texas; Region VII=Iowa, Kansas, Missouri, Nebraska; Region VIII=Colorado, Montana, North Dakota, South Dakota, Utah, Wyoming; Region IX=Arizona, California, Hawaii, Nevada, American Samoa, Guam, Mariana Islands, Marshall Islands, Micronesia, Palau; Region X=Alaska, Idaho, Oregon, Washington.

† Primary method of contraception reported by these women was one of the following: spermicidal foam, cream, jelly (with and without diaphragm), film, or suppositories.

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Table 2

TABLE 2. Number of nonoxynol-9 (N-9) contraceptives purchased by Title X Family Planning Programs in selected states/territories, 1999

State/territory	No. of clients served	Physical barrier method: Condoms with N-9	Physical barrier method: Condoms without N-9	N-9 chemical barrier methods: Gel	Vaginal: Film	Vaginal: Insert	Jelly	Foam
Puerto Rico	15,103	148,072	5,000	12,900	0	NA*	12,841	2,400
New York†	283,200	1,936,084	NA	0	73,788	NA	3,112	23,830
West Virginia	60,899	1,300,000	9,360	0	0	NA	1,200	9,900
Florida	193,784	3,920,000	560,000	0	468,720	NA	5,760	25,920
Tennessee	111,223	2,865,160§	717,088	0	94,500	12,528	756	2,758

Tennessee	111,223	2,865,160*	717,088	0	94,500	12,528	756	2,756
Michigan	166,893	631,000	254,000	0	0	NA	1,000	1,200
Oklahoma	58,392	708,480	0	0	394,560	NA	1,200	0
Oregon	57,099	151,900	276,000	345	25,764	2,074	272	3,007

* Not available.
† 41 of 61 grantees responded.
§ Purchasing by family planning and sexually transmitted disease programs are combined and cannot be separated.

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Introduction and Overview

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Notice to Readers: CDC Statement on Study Results of Product Containing Nonoxynol-9

During the XIII International AIDS Conference held in Durban, South Africa, July 9--14, 2000, researchers from the Joint United Nations Program on AIDS (UNAIDS) presented results of a study of a product, COL-1492,* which contains nonoxynol-9 (N-9) (*1*). N-9 products are licensed for use in the United States as spermicides and are effective in preventing pregnancy, particularly when used with a diaphragm. The study examined the use of COL-1492 as a potential candidate microbicide, or topical compound to prevent the transmission of human immunodeficiency virus (HIV) and sexually transmitted diseases (STDs). The study found that N-9 did not protect against HIV infection and may have caused more transmission. The women who used N-9 gel became infected with HIV at approximately a 50% higher rate than women who used the placebo gel.

CDC has released a "Dear Colleague" letter that summarizes the findings and implications of the UNAIDS study. The letter is available on the World-Wide Web, http://www.cdc.gov/hiv; a hard copy is available from the National Prevention Information Network, telephone (800) 458-5231. Future consultations will be held to re-evaluate guidelines for HIV, STDs, and pregnancy prevention in populations at high risk for HIV infection. A detailed scientific report will be released on the Web when additional findings are available.

Reference

1. van Damme L. Advances in topical microbicides. Presented at the XIII International AIDS Conference, July 9--14, 2000, Durban, South Africa.

* Use of trade names and commercial sources is for identification only and does not constitute endorsement by CDC or the U.S. Department of Health and Human Services.