



Project Talk

1

Project Talk: Teens and Adults Learning to Communicate

January 2003



About Project Talk

Project TALK is an eight-year study of families living with HIV in New York City. Funded by the National Institute of Mental Health, the goal of this project is to examine how having a parent with AIDS influences the developmental tasks of adolescence and early adulthood and to examine the impact of a family intervention. The project examines the impact of a coping skills intervention among parents and AIDS-affected youth compared to families receiving standard care.

Three areas are examined:

- 1) The social, behavioral, and emotional adjustment of youth, in areas that are likely to be impacted by having a parent living with HIV;
- 2) The ways in which adolescents' development proceeds in terms of pregnancy, parenting choices, employment patterns, and intimacy and quality of romantic relationships; and
- 3) Parents' bonds with their children, their own transmission behaviors, health, and mental health.

Acknowledgments

Families were recruited from the New York City Human Resources Administration, Division of AIDS Services.

Dr. Mary Jane Rotheram-Borus is the founder and director of the Center for Community Health at the UCLA Neuropsychiatric Institute.

A large team of professionals made this project possible. Most important was the willingness of families to share their lives with us for many years.

For more information, please contact: Patricia Jones, MPH at 310-794-3612.

Funded by the National Institute of Mental Health
Grant # MH 449958

WHY DO WE NEED INTERVENTIONS FOR FAMILIES?

The number of families influenced by a parent living with HIV continues to rise. Internationally, most adults become infected with HIV from their sexual partners, resulting in 38-40 million infected persons living with HIV. As the numbers of HIV-infected persons increase, their families are

affected by HIV. Parents' HIV illness affects not only themselves, but also their children. By the year 2000, from 72,000-125,000 children in the United States have had a parent die from AIDS; nearly half of these children were between the ages of 11 and 17. In the world, there are 13 million AIDS

orphans. Because of the increased benefits of medical treatments for HIV and the ability to reduce transmission between parent and child, the number of parents with HIV and their HIV-affected children will increase.

HIV and Family Stress

Parental Stress



Emotional distress is high among families coping with HIV. Some parents living with HIV may exhibit helplessness as they cope with their diagnosis. Some parents with HIV become argumentative under stress, leading to disruptions in their relationships with their children. Parents have to decide if, when, and how to disclose their HIV status to their children. Parents also have to make decisions about potential guardianship for their children. Given these challenges, our intervention helps parents plan for their children's long term adjustment, maintain their parental roles while ill, prepare their children for their potential death, and have positive relationships with their children.

Stress on Adolescents

The stress generated by medical illness frequently radiates throughout the family, straining both parents' and children's established coping patterns. Family structure, cohesiveness, parenting skills, social supports, and stressful events significantly influence family members' responses to the stress of HIV, even following death. A parent's chronic illness may lead to mental health and problem behaviors among children. Adolescents often take on the role of parent and are increasingly expected to care for younger siblings. Adolescents must contend with their parents' ongoing physical symptoms, frequent hospitalizations, and uncertain prognoses. Prior to HIV infection, substance



abuse in their neighborhoods exposed many of these children to chaotic family lives. With longer life spans, parents with HIV are reinitiating substance use after many years of abstinence. When they do use drugs, their children's conduct problems and mental health symptoms increase. Children of parents living with HIV may also have to cope with ridicule and stigmatization from peers, further increasing their sense of alienation. In our study, 46% of the youth living with an HIV positive parent reported psychiatric problems, 39% reported anxiety problems, and 20% reported experiencing depression. Rates were higher among daughters as compared to sons. In the intervention, adolescents are taught to cope with their parents' illness, reduce problem behaviors, and plan for their adult roles.

Bereaved Adolescents

Early parental death is believed to be one of life's most stressful events for children. Bereaved adolescents are more emotionally distressed, experience behavior problems, and have impaired social relationships. Younger bereaved children are known to be at increased risk for depression, agoraphobia, conduct problems and suicide attempts. In addition to emotional distress, younger bereaved children are also more likely than their peers to have academic difficulties, decreased self-esteem and somatic complaints. Unfortunately, the impact of parental death increases over time. Since the start of Project TALK, almost half of the parents have died, making this the first prospective study of adolescent bereavement mounted since the 1970s and the only study of bereaved African American and Latino adolescents. For bereaved adolescents and their new caregivers, the intervention has a special module to help begin new goals and to cope with new living situations.



Research Methods

From 1993–1994, 307 eligible families (412 youth & 307 parents) were recruited, reflecting 84% of all traceable referrals to the Division Of AIDS Services in New York City during that time period. Of these, 134 parents with HIV died at about 28 months after recruitment, leaving 169 HIV-infected parents as participants in this cohort. Over 6 years, we retained more than 85% of the parents and youth with at least one annual assessment. Assessments were conducted every three months for 2 years and then at six-month intervals (n=17 assessments).

Parents were primarily Latino (47%), African-American (33%), and some were White (12%). Most parents were female and were an average age of about 38 years old. Parents in the control condition were similar.

Among the adolescents in the study, the ethnic distribution was similar to the parents. The majority were Latino (51%) and African-American (35%). The youth were an average age of about 15 years old. Almost all of the youth were in school and were female.

Project Talk Intervention

Focus groups, pilot work, and previous research informed the intervention design. The intervention was based on social learning theory and cognitive-behavioral principles. An extensive detailed manual contained the specific goals, activities, and scripts for each session (**available at <http://chipts.ucla.edu>**). Each session began with a review of goals set in the previous session, followed by an introduction of new material; new skills were then practiced and new goals set for the next week. A Feeling Thermometer was used in each session to help participants recognize and practice controlling negative emotional states. Group members were encouraged to compliment each other; tokens (small squares of construction paper) accompanied these compliments as a tangible cue of a social reward. Group members received a companion workbook where they kept records of their individual goals and accomplishments toward reaching those goals.

In Module 1, parents met together for 8 sessions and focused on adapting to their HIV status, maintaining healthy lifestyles, coping with negative feelings related to their diagnosis, and making decisions about disclosing their status to others. In Module 2, both parents and their

adolescent children were invited to attend; some sessions were joint and others separate for parents and adolescents. Module 2 aimed to reduce the parents' emotional distress, support positive family routines, help their children to avoid high-risk behaviors, and make custody plans for their children. Module 2 also aimed to improve the adolescents'



copied with the parents' HIV diagnosis and possible death, learn skills to reduce high-risk behaviors (e.g., sexual, substance use acts, teenage pregnancy), and to reduce emotional distress. If parents died, Module 3 was delivered to new caregivers and adolescents, and focused on grief and bereavement as well as setting new life goals over 8 sessions.

The groups were usually held on alternating Saturdays in a community center or school with one 2-hour session held in the morning and another 2-hour session held in the afternoon. Transportation, child-care, and meals were provided. Participants were allowed to take part in make-up sessions other than regularly scheduled sessions. Because AIDS was discussed in the intervention, only adolescents who knew that their parent was HIV-positive were invited to attend the intervention.

Results

IMPROVEMENTS ARE FOUND FOR PARENTS AND YOUTH

By two years after recruitment, adolescents and parents in the intervention reported significantly fewer problem behaviors and less emotional distress than those in the control condition (Figure 1 and 2). The time-trend analysis showed that both intervention adolescents and parents began to relapse into old behaviors after two years. Relapse occurred through 48 months, so that there was no significant difference at the 48-month assessment point in problem behaviors and emotional distress among participants in the intervention and standard care conditions. Yet overall, adolescent conduct problems and parental problem behaviors tended to be lower in the intervention condition over four years compared to the standard care condition.

Coping skills were also significantly higher among intervention youth and parents had significantly more positive social support in the intervention condition, compared to standard care condition.

These results suggest that interventions that have been time-limited (expecting that interventions work in a manner similar to immunizations) are associated with relapse. As parents live longer with HIV, it will be even more important to incorporate prevention into ongoing treatment settings and to maintain programs over time. Further, mechanisms for providing ongoing support and skills are needed to maintain intervention effects over longer periods, particularly as survival of parents living with HIV increases substantially.

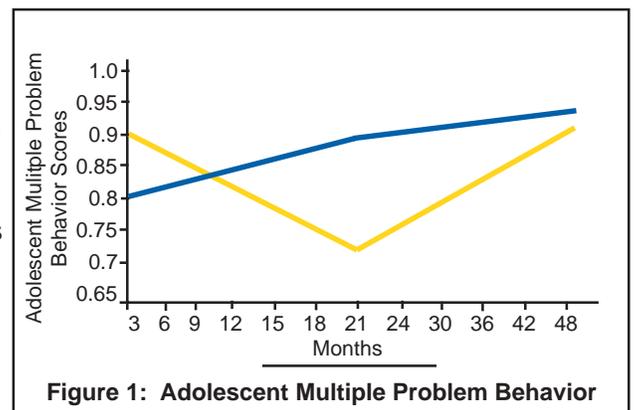
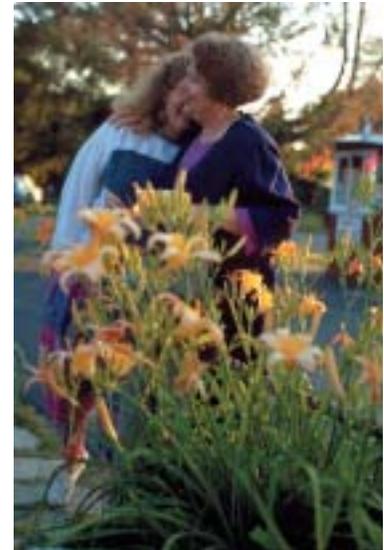


Figure 1: Adolescent Multiple Problem Behavior

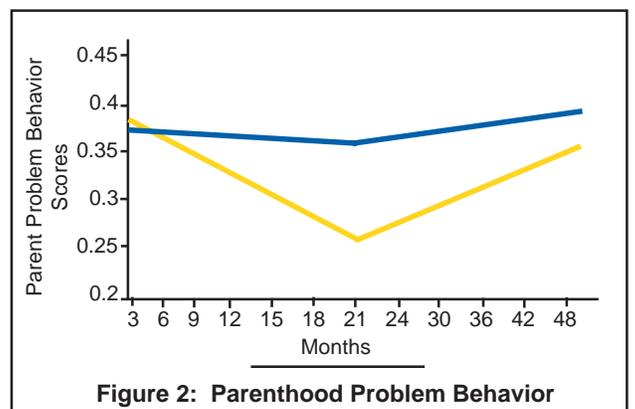
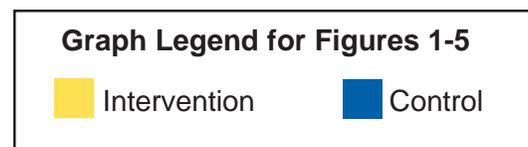


Figure 2: Parenthood Problem Behavior



IMPROVEMENTS ARE FOUND AT FOUR YEARS FOR PARENTS AND YOUTH

Over four years following the delivery of a coping skills intervention, fewer adolescents became teenage parents (Figure 3) and fewer parents were drug dependent in the intervention compared to the control condition. Intervention parents also tended to relapse less often into substance abuse and coped with a passive-withdrawal style less often (Figure 4).

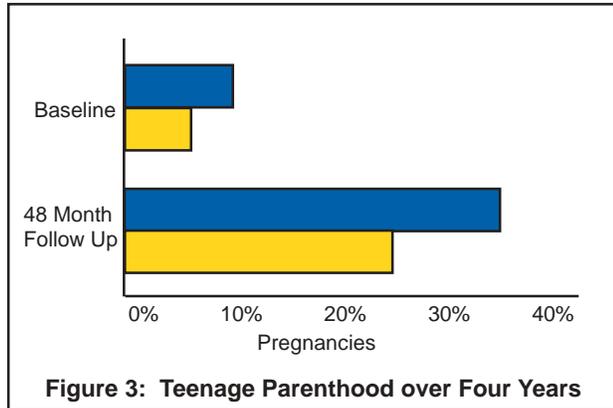


Figure 3: Teenage Parenthood over Four Years



HIV HAS AN INTERGENERATIONAL IMPACT

At six years, offspring of the adolescent children (who became teenage parents) were experiencing many difficulties. The babies, ages 18-36 months had somewhat low IQ, poor home environments, and often experienced disorganized and insecure attachments to their mothers. Offspring of teenagers in the intervention condition tended to have significantly higher IQ and better home environments than offspring of teenagers who did not get the intervention (Figure 5).

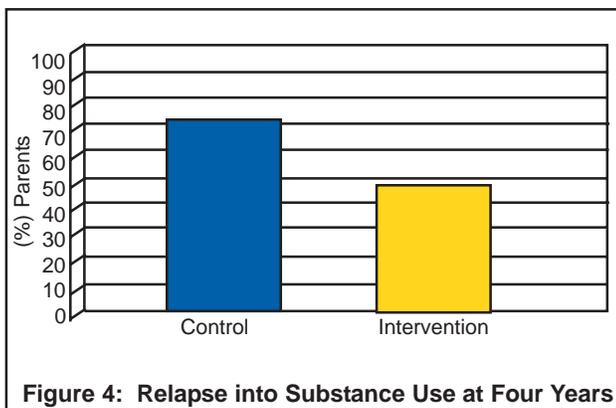


Figure 4: Relapse into Substance Use at Four Years

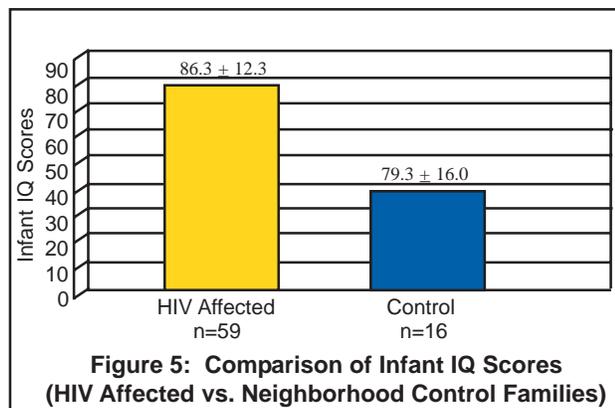


Figure 5: Comparison of Infant IQ Scores (HIV Affected vs. Neighborhood Control Families)

Additional Major Findings

- Parents disclose to most adolescents (75%), but not to children under age 12 years (30%).
- Mothers disclose more than fathers and disclose to daughters more than sons.
- Youth's behavior problems increase for about three years when parents disclose their serostatus.
- Disclosure is a natural process; rather than focusing on whether or not to disclose, parents must focus on how and when to disclose and prepare for the long-term negative consequences of disclosure.
- Parents living with HIV are likely to treat their sons and daughters in very different ways; sensitizing HIV-positive parents to their normative ways of responding may help them to parent more effectively.
- Bereaved adolescents and caregivers are in significant need of intervention.
- Custody plans are effective in identifying caregivers for children; placements appear stable.
- Sibling caregivers create an unstable custody arrangement, with significant costs to the adolescent.
- The parent's substance abuse has an immediate impact on youth's substance use, but the impact decreases when parents stop using.
- The parent's survival is predicted by improvements in mental health symptoms over time, having a relationship, and children. Unexpectedly, substance use is related to increased survival.
- Parents living with HIV believed they "made it for the cure", even when 45% were not utilizing HAART and 30% of the 55% using HAART were not adhering to their HAART medications.
- "Parentification" was common among youth of parents living with HIV (15%) and had both positive and negative consequences for youth.
- Psychiatric disorders are common among youth: 39% report an anxiety disorder and 20% a depressive disorder three years after parental death, similar to rates of youth in war situations.
- The initiation of pregnancy and substance use among youth is related to receiving an intervention and receiving educational counseling in school for teens.
- Most parents relapse into substance use over time.
- The impact of losing a parent to AIDS is long term, with the consequences of bereavement increasing over time.
- Offspring of adolescents of parents living with HIV have insecure attachment relationships with their parents, low IQ scores, and poor home environments; an intervention can improve these outcomes, even when completed many years earlier.
- Families under stress demonstrate even greater stress under conditions of trauma, such as the impact of September 11th terrorist attacks.



Project's Selected Publications

1. Rotheram-Borus, M.J., Lee, M.B., Leonard, N., Lin, Y.Y., Franzke, L. & Lightfoot, M.A. (in press). Four-year behavioral outcomes of an Intervention for parents living with HIV and their adolescent children. *AIDS*.
2. Murphy, D. A., Rotheram-Borus, M. J., & Marelich, W. D. (in press). Factor structure of a coping scale across two samples. *Journal of Applied Social Psychology*.
3. Lightfoot, M., Rotheram-Borus, M. J., Milburn, N., Swendeman, D. (in press). Prevention for HIV Seropositive Persons: Successive Approximation towards a New Identity. *Behavior Modification*.
4. Lightfoot, M. , & Rotheram-Borus, M.J. (in press). Predictors of Child Custody Plans for children whose parents are living with AIDS. *Social Work*.
5. Lester, P., Stein, J.A. , Bursch, B. (in revision). Developmental Predictors of Somatization in Adolescents of Parents with HIV: A 12ñ Month Follow-up. *Journal of Developmental and Behavioral Pediatrics*.
6. May, S., Lester, P., Iliardi, M., Rotheram-Borus, M.J. (in revision). Childbearing among adolescents of parents with HIV : Base rates predictors, and intervention effects. *Perspectives on Sexual and Reproductive Health*.
7. Lee, M.B. & Rotheram-Borus, M.J. (2002). Parents' Disclosure of HIV to Their Children. *AIDS*, *16* (16), 2201-2207.
8. Leslie, M. B., Stein, J. A., & Rotheram-Borus, M. J. (2002). The impact of coping strategies, personal relationships, and emotional distress on the health related outcomes of parents living with HIV. *Journal of Social and Personal Relationships*, *19*(1), 45-66.
9. Rotheram-Borus, M. J., Leonard, N. R., Lightfoot, M., Franzke, L. H., Tottenham, N., & Lee, S. J. (2002). Picking up the Pieces: Caregivers of Adolescents Bereaved by Parental AIDS. *Journal of Clinical Child Psychology and Psychiatry*, *7*, 115-124.
10. Lee, M. B., Lester, P., & Rotheram-Borus, M. J. (2002). The Relationship Between Adjustment of Mothers with HIV and their Adolescent Daughters. *Journal of Clinical Child Psychology and Psychiatry*, *7*, 71-84.
11. Rotheram-Borus, M. J., Stein, J. A., & Lin, Y. Y. (2001). Impact of parent death and an intervention on the adjustment of adolescents whose parents have HIV/AIDS. *Journal of Consulting and Clinical Psychology*, *69*, 763-773.
12. Rotheram-Borus, M. J., Lee, M. B., Gwadz, M., & Draimin, B. (2001). An intervention for parents with AIDS and their adolescent children. *American Journal of Public Health*, *91*, 1294-1302.
13. Lee, M., & Rotheram-Borus, M. J. (2001). Challenges associated with increased survival among parents living with AIDS. *American Journal of Public Health*, *91*, 1303-1309.
14. Pequegnat, W., Bauman, L. J., Bray, J. H., DiClemente, R., Dilorio, C., Hoppe, S. K., Jemmott, L. S., Krauss, B., Miles, M., Paikoff, R., Rapkin, B., Rotheram-Borus, M. J., Szapocznik, J. (2001). Measurement relevant to the role of families in prevention and adaptation to HIV/AIDS. *AIDS and Behavior*, *5*, 1-19.
15. Lightfoot, M., Robin, L., Rotheram-Borus, M. J., Murphy, D. A., Diaz, M. M., Lehane, J., & Rosen, L. R. (2000). Lifestyle choices of parents living with AIDS: Differences in health behaviors and mental health. *AIDS and Behavior*, *4*, 253-260.
16. Rotheram-Borus, M. J., Murphy D., & Coleman, C., & Swendeman, D. (2000). Counseling adolescents: Designing interventions to target routines, relationships, roles, and stages of adaptation. In M. A. Chesney & M. H. Antoni (Eds.), *Lessons from health psychology research: Translating a decade of innovations into clinical practice*. Washington, DC: The American Psychological Association Division of Health Psychology.
17. Rotheram-Borus, M. J. (2000). People living with AIDS: Variations in perceived pain associated with emotional distress and social identity. *AIDS Patient Care and STDs*, *14*, 1-7.
18. Rotheram-Borus, M. J., & Leonard, N. (2000). Training issues to deliver family interventions in clinical settings. In W. Pequegnat & J. Szapocznik (Eds.), *Working with families in the era of HIV/AIDS* (pp. 45-63). Thousand Oaks, CA: Sage Publications.
19. Rotheram-Borus, M. J., Rebchook, G. M., Kelly, J. A., Adams, J., & Neumann, M. S. (2000). Bridging research and practice: Community-researcher partnerships for replicating effective interventions. *AIDS Education and Prevention*, *12*, 49-61.
20. Rotheram-Borus, M. J., & Lightfoot, M. (2000). Helping adolescents cope with parental AIDS and its aftermath: A prevention program for families. In Pequegnat, W., & Szapocznik, J. (Eds.), *Working with families in the era of HIV/AIDS* (pp. 189-212). Thousand Oaks, CA: Sage Publications.
21. Murphy, D. A., Rotheram-Borus, M. J., & Joshi, V. (1999). Tuberculosis testing, knowledge, and medication adherence among HIV-infected adolescents and adults. *AIDS Care*, *12*, 59-63.
22. Stein, J. A., Riedel, M., & Rotheram-Borus, M. J. (1999). Parentification and its impact among adolescent children of parents with AIDS. *Family Process*, *38*, 193-208.
23. Gwadz, M., De Vogli, R., Rotheram-Borus, M. J., Diaz, M., Cisek, T., James, N. B., & Tottenham, N. (1999). Behavioral practices regarding combination therapies for HIV/AIDS. *Journal of Sex Education and Therapy*, *24*, 81-88.
24. Rotheram-Borus, M. J., Lightfoot, M., & Shen, H. (1999). Levels of emotional distress among parents living with AIDS and their adolescent children. *AIDS and Behavior*, *4*, 367-372.
25. Lee, M., Rotheram-Borus, M. J., & OiHara, P. (1999). Disclosure of serostatus among youth living with HIV. *AIDS and Behavior*, *3*, 33-40.
26. Rotheram-Borus, M. J., & Stein, J. A. (1999). Problem behavior of adolescents whose parents are living with AIDS. *American Journal of Orthopsychiatry*, *69*, 228-239.
27. Rotheram-Borus, M. J., Robin, L., Reid, H. M., Draimin, B. H. (1998). Parent-adolescent conflict and stress when parents are living with AIDS. *Family Process*, *37*, 83-94.
28. Rotheram-Borus, M. J., Draimin, B. H., Murphy, D. A., & Reid, H. M. (1997). The impact of illness disclosure and custody plans on adolescents whose parents live with AIDS. *AIDS*, *11*, 1159-1164.
29. Rotheram-Borus, M. J., Murphy, D. A., Miller, S., & Draimin, B. H. (1997). An intervention for adolescents whose parents are living with AIDS. *Clinical Child Psychology and Psychiatry*, *2*, 201-219.
30. Rotheram-Borus, M. J., & Gwadz, M. (1993). Sexuality among youths at high risk. *Psychiatric Clinics of North America*, *2*(3), 415-430.
31. Rotheram-Borus, M.J., Lester, P., Wang, P.W., Ching, Q. (in submission). Custody Plans Among Parents Living with AIDS. *AIDS*.
32. Leonard, N., Lester, P., Rotheram-Borus, M.J., Mattes, K., Ferns, B. (in submission). Successful Recruitment and retention of participants in behavioral longitudinal research. *AIDS Education and Prevention*.
33. Rotheram-Borus, M.J., Weiss, R. E., & Alber, S. (in preparation). The impact of parents drug use on their adolescent children.
34. Rotheram-Borus, M.J., Weiss, R.E., & Alber, S. (in preparation). The impact of parental bereavement on adolescents over time.



Project Talk: Teens and Adults Learning to Communicate

UCLA-NPI Center for Community Health
10920 Wilshire Boulevard, Suite 350
Los Angeles, CA 90024-6521

Phone: 310-794-8278
Fax: 310-794-8297

www.cch.ucla.edu