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The Effect of Social Support on Mental and Behavioral Outcomes Among Adolescents With Parents with HIV/AIDS

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During the last decade, researchers and health care practitioners have suggested that parents who are infected with or have died from HIV/AIDS are associated with specific, detrimental effects on their adolescent children (aged 11-18 years).^{1,2} Adolescents whose parents are infected with or have died of HIV/AIDS are subject to stigmas associated with poverty and the disease.¹ In the case of adolescents orphaned as a result of HIV/AIDS the stigma associated with the disease heightens the likelihood of persistent, unresolved grief.³ Such grief may be expressed through fantasies of reunion, absence of overt expression, and persistent feelings of anger.¹ Symptoms of adolescents' unresolved grief include low tolerance for frustration, acts of rage, fighting in school, and truancy.⁴

Rotheram-Borus et al. mounted an intervention study aimed at improving the mental and behavioral outcomes of adolescents affected by HIV/AIDS and their parents.⁵ The parents of the adolescents in that study were vulnerable to drug abuse and poverty, which placed them at risk for depression,⁴ conduct problems, and other risk factors.^{6,7} We used the same study sample in an extension of the Rotheram-Borus study, to examine the affect of social support on adolescents' mental and behavioral outcomes. Adolescents in the intervention group reported significantly lower levels of emotional distress, fewer multiple problem behaviors, and fewer conduct problems.⁵ Adolescents in the intervention group also reported higher levels of self-esteem, which suggests that interventions may reduce the long-term negative affect of parents' HIV status on adolescents.

Social support is defined as the existence or availability of people who let an individual know that they care about, value, and love them.⁸ The link between social support and psychological well-being is well established, dating back to Durkheim.⁹ Lack of social *Objectives.* We examine the associations between social support and mental and behavioral outcomes among adolescents whose parents were infected with or died of HIV/AIDS.

Methods. Families (parents who were HIV infected and their adolescent children) were randomly assigned to a coping skills intervention or a standard care group. After completing the intervention, the parents and adolescents were assessed for 2 years.

Results. Adolescents who had more social support providers reported significantly lower levels of depression and fewer conduct problems; adolescents who had more negative influence from role models reported more behavior problems. Reductions in depression, multiple problem behaviors, and conduct problems were significantly associated with better social support.

Conclusions. Our findings underscore the complex relations between social support and mental and behavioral outcomes among adolescents affected by HIV. Future prevention programs must focus on increasing social support to reduce negative outcomes among adolescents affected by HIV as well as the need to reduce influence from negative role models. (*Am J Public Health.* 2007;97: XXX–XXX. doi:10.2105/AJPH.2005.084871)

support and lower perceived adequacy of social support have been linked to symptoms of depression.^{10–12}

One of the main challenges to objective research on adolescent social support has been the lack of a reliable, general, and convenient index of social support.8 Despite a diversity of measures of social support, which is matched by the diversity of conceptualizations,⁸ existing research among adolescents has been treated as a homogeneous mass.^{13–18} Researchers have examined the size of social support (number of support providers),¹⁹ frequency of contact with support providers,²⁰ perception of social support,²¹ influence from negative role models,²² and positive social support (positive behaviors by support providers),²³ but much more empirically derived evidence is needed to provide a basis for theoretical advances. Among a group of adolescents who suffered a stressful event, Bal et al. found that a higher perceived availability of social support was directly associated with fewer symptoms related to trauma.24

Building on the findings of Rotheram-Borus et al.,⁵ we considered the affect of the individual dimensions of social support. Because there are few empirical data on the relation between the mental and behavioral outcomes of adolescents affected by HIV/AIDS and social support, our primary objective was to study the association of adolescent mental and behavioral outcomes with the dimensions of social support for 2 years.

METHODS

Participants

Figure 1 illustrates the study design.⁵ Upon completion of the baseline assessment, 307 families were randomly assigned by a preprogrammed laptop computer to either the intervention group (parents living with HIV/ AIDS, n=153; adolescents, n=206) or the standard care group (parents living with HIV/ AIDS, n=154; adolescents, n=207). (A detailed intervention manual is available at: http://chipts.ucla.edu/interventions/manuals/ intervhra1.html.) The intervention was delivered in 2 modules: Module 1 to parents and Module 2 to both parents and adolescents. Module 1 was designed for parents and was focussed on helping them with disclosing their HIV status to their children. At baseline, 66 out of 206 adolescents were not aware



Note. From August 1993 to March 1995, the New York City Division of AIDS Services had a log of 95% of persons with who qualified for social welfare benefits in New York City. PLH were eligible for recruitment to our study if they were HIV positive, between 25 and 70 years old, had at least 1 adolescent between 11 and 18 who typically lived with them, their case manager evealuated the project as being in their best interest, and they lived through the recruitment period. Of the 619 potential participants, 155 (25%) died prior to being approached, 11 (1.8%) were ineligible because they were being severely ill or incarcerated, and 35 (5.7) were exluded based on case managers' recommendation. Of the 418 (68%) elibible, 65 (16%) were untraceable and 46 (11%) refused. Thus, 73% (n = 307/418) of eligible parents living with HIV/AIDS, were recruited, reflecting 87% (n = 307/353) of the traceable eligible parents living with HIV/AIDS. From the 307 parents living with HIV/AIDS, 413 adolescents were recruited with institutional review board approval, parental permission, and assent. Adolescents in the standard care group had access to referral services, counseling, and participated in the assessment interview over the 2 years of the study. Adolescent follow-up assessments were conducted every 3 months for more than 2 years; data is presented for just the first 2 years. The number of adolescents is based on disclosure at time of randomization.

Source. Adapted from Rotheram-Borus et al.⁵

FIGURE 1—Study design: New York City, 1993-1995.

of theeir parents' HIV status. As parents disclosed their status, their adolescents were invited to attend Module 2, which targeted both parents and adolescents. For adolescents, Module 2 addressed coping with parents' diagnosis, providing skills to reduce high-risk behaviors, and reducing emotional distress. Adolescents in the intervention group were assessed for 2 years only after they attended Module 2.

Outcome Measures

Adolescent depression was assessed using the Brief Symptom Inventory²⁵ depression subscale (Cronbach's α =.76), in which the adolescents' rate the level of severity—from 0 (not at all) to 4 (extremely)—across 6 items that reflect symptoms of depression.

Multiple problem behaviors, which reflect adolescents' risk behaviors (unprotected sexual intercourse, alcohol use, drug use, contact with the criminal justice system, trouble with peers, trouble at school, and not being enrolled in school), were scored by summing the presence (1) or absence (0) of these behaviors (range, 0-7).

Conduct problems, by contrast, were a measure of the adolescents' level of delinquent behaviors (e.g., robbed someone, threatened someone in order to steal from them) and were calculated by summing up across 18 identified delinquent behaviors (Cronbach's α =.61).

Independent Variables

Size of social support was measured by the number of people who provided support (support providers) reported by the adolescent (range: 0–15 people).

We used frequency of contact to capture the number of times per month adolescents were in contact with support providers; this was asked for each reported support provider. By summing across support providers and dividing by the number of support providers, we determined the average frequency of contact (range, 0-22 times per month).

Satisfaction with social support was measured using a 5-point Likert scale (1=very unsupportive to 5=very supportive). Adolescents reported their satisfaction for each support provider, which was then summed across providers and divided by the number of providers to determine the average satisfaction of social support (1=very dissatisfied to 5=very satisfied).

Positive social support measured the number of positive behaviors among support providers (e.g., helped when in trouble, provided crucial support, was supportive about parent's illness) as reported by the adolescents. It was assessed for each provider and averaged across the number of providers to determine the average positive social support score, which ranged from 0 (no positive support) to 4 (4 counts of positive support).

Negative role model influence (defined as perceived negative influence from any role model) captured adolescents' perception of the number of negative behaviors among support providers (e.g., doing drugs, having unprotected sexual intercourse, criminal activity). Negative behaviors were assessed for each provider and averaged to determine the

negative role model influence, ranging from 0 (no negative support) to 4 (4 counts of negative role model behaviors).

Past research has indicated that ethnicity, gender, and age may influence adolescent outcomes; therefore, they were considered in the analyses. Parental death as a result of HIV/AIDS was considered a time-dependent covariate, because parental death may have an affect on adolescent outcomes.⁵

Data Analysis

Before we estimated the associations of social support and adolescent outcomes, exploratory data analyses were performed to visualize data patterns. For example, each social support dimension was plotted against time (3, 6, 9, 12, 15, 18, 21, and 24 months) and stratified on depression status. To construct parallel plots, 100 adolescents were randomly selected at baseline assessment for each group (depressed vs nondepressed), and were plotted over time. The plots were used to determine proper trajectories of depression over time and were used to determine the time variable as either a linear or nonlinear variable (e.g., quadratic, piece-wise). Because social support by time indicated a rough dose-response group trend, time was treated as a continuous variable with a linear assumption.

Initially, a full model that consisted of all 5 social support variables was considered for each outcome, and nonsignificant social support variables were dropped. However, treating all the social support variables simultaneously in the model tended to obscure the effects of each social support predictor. Therefore, we performed sensitivity analyses with varying numbers of social support variables in each model. For example, association between depression and size of social support, control for frequency of contact, satisfaction with social support, negative role model influence, and positive social support (and their interactions terms) were assessed one at a time. The sensitivity analyses indicated robustness of the models in which each social support was assessed separately, and resulted in parsimonious models. Because the outcome variables did not follow normal distributions, log transformations were applied to each outcome.

We estimated mixed-effect models²⁶ to fit adolescent outcomes with each of the social support main effects, and potential confounders were controlled for. These models made it possible to follow individual adolescent trajectories. The outcome measures at each time were assessed during the 2-year study period. The Proc Mixed Procedure in SAS 9.1 (SAS Inc, Cary, NC) was used with an autoregressive covariance structure to account for repeated measurements (for 2 years). The correlations among adolescents in the same family were taken into account by including random intercept and slopes. The social support predictor indicated the pooled effect of social support on adolescent outcome, the time variable indicated the change in the outcome measure, and the social support by time interaction variable indicated trends in strength of the social support effect during the 2 years.

For each outcome, the key variables included each dimension of social support as the main predictor: social support by time interaction, social support by age interaction, social support by gender interaction, parental death as a result of AIDS, and parental death by time interaction. Only those variables that remained significant were retained in the final model.

The effect of social support was initially stratified on the intervention status. Because stratified analysis showed no difference in social support between the adolescents in the intervention group versus the standard care group, intervention effect was not considered. Ethnicity was initially considered in all the models. However, given that most of the participants were marginalized minorities (African American and Latino) parents, we found no significant difference across ethnicity. Because sensitivity analyses revealed that ethnicity did not contribute to any models, it was not included in our final models. Similarly, adolescents' family life stressors and self-esteem were not retained in the final models.

RESULTS

About half of the adolescent participants were girls. The mean age was 14.7 years (SD=2.0); almost all subjects (89%) were in

school. About half of the adolescents had experienced their sexual debut and had used alcohol by the age of recruitment into the study; two thirds reported no drug use ever. The sociodemographic characteristics of adolescents and parents in the intervention and standard care groups at recruitment are compared in Table 1. The comparisons indicated that randomization resulted in well-balanced groups, similar in sociodemographic characteristics, emotional distress, sexual and substance use risk acts, multiple problem behaviors, and conduct problems. Adolescents' social support dimensions (size [5.17 vs 5.27], frequency of contact [4.31 vs 3.89], satisfaction [0.94 vs 1.01], negative role model influence [0.76 vs 0.70], and positive support [2.42 vs 2.45]) were comparable between the standard care group and the intervention group, respectively.

Table 2 outlines the associations of adolescents' depression with size of social support. Adolescents who reported fewer social support providers reported significantly higher levels of depression (P=.024) during the 2 years of assessment; 1 additional support person was associated with a 0.014 reduction in adolescents' log depression score. However, the protective effect of having more social support providers tended to show a decreasing trend, which was indicated by a positive size-by-time interaction (P=.072). That is, for each follow-up assessment, the 0.014 reduction in depression score decreased by 0.002. When we examined the size-depression association by follow-up time, we found that higher size of social support was significantly associated with lower depression up to the 9-month follow-up (P=.035). By the 12month follow-up, the association was no longer significant (P=.092).

Regardless of the size of social support, adolescent depression decreased significantly during the 2 years (P<.001). This suggests that on average, adolescents scored 0.024 points less on their log-depression score at each follow-up period. Other factors significantly associated with depression included baseline levels of adolescent depression (P<.001); being male (P<.001); and being older (P<.001). Among adolescents who experienced parental death as a result of HIV/AIDS, we found a significant shift in

TABLE 1—Baseline Assessment Characteristics of Adolescents Randomized to the Intervention and Standard Care Groups: New York City, 1993–1995

	Parents		Adolescents	
Characteristics	Standard Care (n = 154), % or mean (SD)	Intervention (n = 153), % or mean (SD)	Standard Care (n = 207), % or mean (SD)	Intervention (n = 206), % or mean (SD)
Male	19%	20%	48%	47%
Mean age, y	37.99 (5.91)	38.12 (5.34)	14.75 (1.89)	14.57 (2.02)
Ethnicity				
African American	36%	33%	41%	35%
Latino	43%	47%	49%	50%
White	10%	12%	2%	4%
Other	12%	8%	9%	11%
Lifetime substance use				
Injection drug use	41%	33%	0%	0.5%
Alcohol use	79%	83%	49%	48%
Any drug use	77%	78%	39%	33%
Current substance use at baseline				
Abstinent alcohol and drugs	63%	60%	67%	67%
Injection drug use	6%	5%	0%	0%
Mean number drugs used	0.36 (0.74)	0.35 (0.73)	0.23 (0.47)	0.21 (0.47)
Lifetime sexual behavior				
Abstinent	0%	0%	50%	55%
Among active, median number sex partners	7	7.5	3	3
Current sexual behavior at baseline				
Abstinent	60%	54%	70%	71%
Among active, mean no. sexual partners	1.31 (1.85)	1.22 (1.14)	1.79 (1.54)	1.33 (0.71)*
Among active, 100% condom use	59%	65%	43%	34%
Social support				
Size	3.58 (2.32)	3.73 (2.58)	5.17 (3.10)	5.27 (3.40)
Frequency of contact	4.89 (6.34)	3.98 (5.30)	4.31 (4.75)	3.89 (4.44)
Perceived satisfaction	1.67 (1.49)	1.71 (1.46)	0.94 (0.94)	1.01(0.98)
Negative role model influence	0.79 (0.70)	0.70 (0.63)	0.76 (0.57)	0.70 (0.51)
Positive support	2.66 (1.06)	2.77 (1.04)	2.42 (0.99)	2.45 (0.89)
Brief symptom inventory	0.97 (0.77)	1.03 (0.70)	0.60 (0.56)	0.66 (0.58)
Multiple problem behaviors	0.69 (0.84)	0.76 (0.93)	2.13 (1.51)	2.05 (1.46)
Diagnostic status of their parents				
Asymptomatic	16%	20%		
Symptomatic	44%	40%		
AIDS	40%	40%		
Mean number physical health symptoms	14.27 (5.60)	14.52 (5.74)		
Mean number health distress	2.85 (1.02)	2.86 (1.03)		
Attends school currently		/	87%	91%
Conduct problems			1.69 (2.07)	1.56 (1.93)

*P<.05.

depression score (P=.016), which indicates a 0.061 increase in log-depression score.

Table 3 outlines the associations of conduct problems with size of social support among HIV/AIDS-affected adolescents. Adolescents who have more social support providers reported significantly lower levels of conduct problems (P=.046); however, this association decreased over time, which was indicated by a positive size-by-time interaction (P=.004). Regardless of the size of social support, adolescents reported significantly fewer conduct

TABLE 2—Associations of Depression and Size of Social Support Among Adolescents With Parents or Caregivers With HIV/AIDS: New York City, 1993–1995

Variables	95% Confidence Interval	Р
Baseline depression	0.299, 0.406	<.001
Size of social support	-0.027, 0.002	.024
Gender ^a	-0.150, 0.069	<.001
Age	0.013, 0.033	<.001
Time	-0.034, 0.014	<.001
Parental death as	0.011, 0.111	.016
result of AIDS		
Size by time	-0.000, 0.005	.072

Note. Analyses are on the basis of adolescents being assessed at multiple time points (3 months to 24 months). 95% of the adolescents were assessed at least once annually, which yielded 2158 observations in 2 years. Associations between depression and positive social support among adolescents yielded very similar results to the size of social support. ^aAdolescent girls were treated as the referent group.

TABLE 3—Associations of Conduct Problems and Size of Social Support Among Adolescents With Parents or Caregivers With HIV/AIDS: New York City, 1993–1995

Variables	95% Confidence Interval	Р
		-
Baseline conduct problems	0.325, 0.452	<.001
Size of social support	-0.049, 0.000	.046
Gender ^a	0.064, 0.228	.001
Age	-0.048, 0.008	.007
Time	-0.068, 0.029	<.001
Parental death as a result of AIDS	-0.027, 0.170	.153
Size by time	0.004, 0.013	.004

^aAdolescent girls were treated as the referent group.

problems during the 2 years (P<.001). Other adolescent factors associated with conduct problems included baseline levels of adolescent conduct problems (P<.001); being male (P=.001); and being younger (P=.007).

Table 4 outlines the associations of adolescents' multiple problem behaviors with negative role model influence. Adolescents who reported higher negative role model influence

TABLE 4—Associations of Multiple Problem Behaviors and Negative Role Model Influence Among Adolescents With Parents or Caregivers With HIV/AIDS: New York City, 19931995

Variables	95% Confidence Interval	P Value
Baseline multiple	0.288, 0.407	<.001
problem behaviors		
Negative role model	-0.040, 0.632	.085
influence		
Gender ^a	-0.015, 0.024	.648
Age	0.038, 0.166	.002
Time	-0.047, 0.018	<.001
Parental death as result	-0.025, 0.137	.177
of HIV/AIDS		
Negative role model	0.014, 0.051	.001
influence by time		
Negative support by age	-0.043, 0.000	.048

^aAdolescent girls were treated as the referent group.

reported more multiple problem behaviors (P=.085). Although the strength of this association was marginally significant, it increased with time, as indicated by a significant negative support-by-time interaction (P=.001). When we examined the trend of this association, higher negative role model influence was significantly associated with more multiple problem behaviors by the 6-month follow-up (P=.024). The association remained significant at the 24-month follow-up (P=.003).

During the 2 assessment years, we also observed a significant decline in adolescent multiple problem behaviors (P<.001). Other adolescent factors significantly associated with multiple problem behaviors included baseline levels of multiple problem behaviors (P<.001) and being older (P=.002). We also observed a significant negative role model influence-by-age interaction (P=.048), which indicated that the negative role model influence–multiple problem behavior association was weaker among older adolescents.

DISCUSSION

When confronting the challenges faced by parents living with HIV/AIDS, it is vital to

address the quality of life of their adolescent children. In this study, we found that adolescents who had more social support providers reported significantly lower levels of depression and fewer conduct problems during our 2 study years. There are important implications to these findings. First, our study indicates that adolescents affected by HIV cope better emotionally if they have more social support providers. When the 3 quartiles of the size of social support (1, 3, and 4 support providers) were plotted against depression over time, our plots indicated that adolescents who have 3 support providers reported significantly lower levels of depression up to the 9-month follow-up, compared with adolescents who reported 1 provider. Although adolescents who had 4 providers reported lower depression than those who had 3 providers, the differences were not significant, which suggests that 3 providers may be the threshold point. Research on the relation between mental health and behavioral outcomes and social support among adolescents affected by HIV/AIDS is limited, and our findings point to the need for future prevention programs to facilitate better social support for this unique group of adolescents.

We also found that the protective effects of social support tended to decline over time. There are at least 3 plausible explanations. First, the advent of highly active antiretroviral therapy (HAART) about 2 years into the study caused a profound effect on families who expected the parent to die within a year. All the parents in our study were eligible for HAART. This major shift in the quality of care for the parents may have significantly contributed to decreased emotional distress for the parents and adolescents. Similarly, the advent of HAART may have reduced the significance of having positive social support. When the parents started coping better, their quality of interaction with their adolescents may have improved. Thus, adolescents may have sought less support from their support providers. HAART may have replaced the social support that adolescents sought during the pre-HAART era. Unfortunately, because HAART became available 2 years after the study was initiated, we could not assess the "use of HAART" in our models.

The second explanation for why the protective effects of social support tended to decline over time could be that adolescents may have adapted to the challenges over time once they learned to cope with them and may have no longer relied heavily on social support. Third, our findings suggest that the initial protective effect of better social support may be short lived. Given that enhancing social support was not an element of the original intervention, we can only speculate. One way to assess this observation in future studies is to recommend incorporating sustainability of social support into the study. If having better social support is indeed protective against adolescents' negative outcomes, future prevention programs should be designed to ensure the sustainability of the protective effects of having better social support.

Similarly, our study found that adolescents who reported more negative role model influence also reported increasingly higher multiple problem behaviors; negative role model influence was significantly associated with multiple problem behaviors by the 9-month follow-up and remained significant. One explanation for this finding is that the effect of negative role model influence increases over time. Similarly, the protective effect of higher size of social support may be short lived and diminished by the 9-month follow-up, at which point the harmful effects of having negative role model influence become more evident. Future research among adolescents affected by HIV/AIDS should consider how different dimensions of social support interact within the context of depression and other negative outcomes.

We also found a significant association between parental death from HIV/AIDS and depression among the adolescents. The adolescents who experienced parental death as a result of HIV/AIDS reported a significant increase in their depression. This finding is consistent with existing adolescent literature, which suggests that parental death is a risk factor for adolescent depression.² Older adolescents also reported significantly higher levels of depression over time when compared with younger adolescents. This, again, is consistent with the existing literature.

Regardless of social support, adolescents' depression, multiple problem behaviors, and

conduct problems all declined over time. This is consistent with existing literature, which indicates that every major prevention trial has shown improvements that have been sustained over time across all participants, regardless of intervention status.^{27,28} Participation in the study itself may have served as a positive resource, even if subjects took part in the standard care group. An interviewer visited the adolescents every 3 months and repeatedly asked about mental, social, and behavioral factors. In a sense, being in a study and interacting with the interviewer may have acted as a form of social support. Because of study design limitations, we cannot determine the source of the social support from our measures. We did not have information about whether adolescents reported the study interviewer or intervention facilitators as social support providers.

Limitations

We acknowledge several limitations of the study. First, given that social support was not a focus of the original intervention, we cannot assess the affect of social support using a randomized controlled trial design. Future intervention programs that target adolescents affected by HIV should address the significance of social support. Second, the manner in which social support was measured presented challenges, mainly because of the lack of a reliable and convenient index of social support at the time the study was initiated.⁸ This may explain why 3 of the 5 social support dimensions that were assessed showed no association with adolescent outcomes. In addition, our measures lacked information on the source of support (e.g., peer, family, nonfamily), which would have contributed to our findings. Third, because HIV disclosure status was assessed indirectly through the parent assessment, analytic challenges prevented us from controlling for disclosure status in our analyses. For example, among the families who had more than 1 adolescent, we had instances where the older adolescent was aware of the parent's HIV status and the younger adolescent was unaware. We believe that the challenges adolescents affected by HIV/AIDS face (e.g., poverty, parental drug abuse) contribute to their depression, independent of their knowledge of the parent's HIV status.

We acknowledge that HIV disclosure in and of itself is a complex topic, and a time-toevent analysis that examines the affect of HIV disclosure on adolescents has been published separately.²⁹

Conclusion

Our study participants were unique in that the parents living with HIV/AIDS were predominantly African American and Latino single parents. In this challenging environment, we found the size of social support to be protective against depression and conduct problems among adolescents affected by to be a risk factor for depression, and negative role model influence to be a risk factor for multiple problem behaviors. There are scanty empirical data on social support and mental health and behavioral outcomes among adolescents who are affected by HIV, and few studies address social support within the context of parental death from AIDS. Our study underscores the need for future prevention programs to focus on the effect of social support in reducing negative outcomes among adolescents who are affected by HIV and the need to reduce negative role model influence. Future prevention programs should include social support as part of the original study design and clearly defined social support measures with specific hypotheses. Such prevention programs should also address the negative effect of experiencing parental death as a result of HIV/AIDS on adolescents.

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Contributors

S-J Lee originated the study and supervised all aspects of its implementation. M. J. Rotheram-Borus assisted with writing the manuscript and analyses. R. Detels assisted with the study development, writing, and analyses. N. Duan assisted with the study interpretation and analyses. All authors helped to conceptualize ideas, interpret findings, and review drafts of the manuscript.

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Human Participant Protection

This study was approved by the University of California's institutional review board.

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