

Lessons Learned from “Integrating” Intensive Family-based Interventions into Medical Care Settings for Mothers Living with HIV/AIDS and their Adolescent Children

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Abstract Centers for Disease Control and Prevention (CDC) has recommended integrating behavioral interventions into medical care settings for persons living with HIV. Delivering an intensive, family-based intervention for mothers living with HIV (MLH) ($n = 173$) and their adolescent children ($n = 116$) integrated into medical care was problematic. Despite the fact that nearly half of MLH were recruited at HIV/AIDS clinics, community centers and children’s hospitals were the most popular and most successful sites for the delivery of the intervention. We provide recommendations for how to integrate intensive interventions into medical care, given the needs of MLH, their adolescents, and the organizations serving them.

Keywords Integrating interventions to medical care · HIV/AIDS · Secondary HIV prevention · Persons living with HIV · Family

Introduction

Since the mid-1990s HIV/AIDS care and prevention has become increasingly “medicalized” in the United States and other nations where anti-retroviral drug therapies are readily available. In response, the Centers for Disease Control and Prevention (CDC) issued recommendations in 2003 that HIV prevention interventions for persons living

with HIV/AIDS (PLH) be “integrated into medical practice” (CDC 2003). There have been a small number of prevention programs delivered and/or piloted at HIV clinical care settings of varying success which give credence to the CDC recommendations (Fisher et al. 2006; Knauz et al. 2007; Lightfoot et al. 2007; Richardson et al. 2004; Knauz et al. 2007). In addition, Koester and colleagues conducted a cross site evaluation of 15 other clinic based-projects that implemented similar interventions and/or demonstration projects funded under the Health Resources and Services Administration’s HIV Prevention with Positives in Clinical Settings Initiative (Koester et al. 2007). The purpose of the initiative was to determine whether prevention interventions delivered within medical care settings were effective in reducing risk behavior of PLH and to identify intervention models that were appropriate for various populations and care settings.

The delivery of more intensive cognitive behavioral interventions shown to improve emotional and social adjustment and to reduce behavioral risk for PLH (e.g., Healthy Living Project Team 2007; Kalichman et al. 2001; Rotheram-Borus et al. 2001, 2003, 2004) within medical care settings may be problematic. CDC recommends that medical providers refer patients for such interventions and recommends these interventions be “integrated” into clinical care sites. While CDC was not explicit as to what “integrated” means, given the focus on medical care settings, it would appear “integrated” at a minimum means “delivered” at locations where PLH receive HIV/AIDS care. Presumably, these more intensive behavior interventions would be delivered by other non-medical staff, such as case managers or psychotherapists who have experience with group-level interventions. The successful creation, delivery, and testing of such an approach for “integrating” intensive behavioral interventions has not yet been demonstrated.

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At face value, the HIV/AIDS care setting provides an ideal location for more intensive interventions; it is a known location where patients are coming for routine visits which could anchor intervention attendance. CDC has acknowledged that successful engagement with more intensive interventions requires convenience and accessibility for patients (CDC 2003). Integrating behavioral interventions into medical care settings appears to address this concern. Thus, to assess the feasibility of the CDC recommendations, we mounted a randomized control trial of an intensive family-based HIV prevention intervention for mothers living with HIV (MLH) and their adolescent children, “integrated” into clinical care settings and also community-based settings. This paper is an investigation into the preferences of the MLH and their adolescents for different delivery sites and the retention to the intervention at those different sites.

Methods

Participants

This study examines participation among MLH ($n = 173$) and their adolescent children ($n = 116$, drawn from 81 unique MLH), randomized to the intervention condition of an intensive cognitive-behavioral family-based HIV intervention (TALK LA). The total TALK LA intervention sample included 339 MLH and 257 adolescents; however, only those in the intervention condition were examined for this analysis. MLH were eligible if: (1) they were the mother or primary female caregiver of a child age 6–20; (2) they were HIV+, based on self-report (corroborated by the fact that the MLH is accessing services at known agencies where HIV care is available). Adolescent children ages 12–20 to whom the MLH had disclosed her serostatus were eligible to participate in the intervention. Participants were recruited in Los Angeles County, California from January 2005 to October 2006. MLH were recruited from HIV/AIDS clinics, general medical clinics, HIV/AIDS community-based organizations, peer referrals, and from the rosters of previous studies (refusal rate = 6.4%). Adolescents were recruited through their MLH.

Recruitment sites included settings where primary medical care was available (HIV/AIDS Clinics and Community-Based Medical Clinics) and where medical care was not directly available (HIV/AIDS Service Organizations, peer referrals, prior study participants). All MLH recruited into the study were receiving primary medical care for their HIV, and detailed information on where MLH received medical care was obtained from all study participants. Many MLH who were recruited from settings where primary medical care was not available, received primary

medical care from one of the participating medical care sites. HIV/AIDS care is extremely decentralized in Los Angeles, and all MLH in our study accessed resources at multiple agencies.

Intervention Design

The TALK LA intervention was delivered at a total of nine different sites, broken into four categories: HIV/AIDS Clinic, Children’s Hospital, Community Center, and University Campus. Two *HIV/AIDS Clinics* provided space on site in conference rooms. Two HIV/AIDS clinics were located inside the campus of a *Children’s Hospital*, and group sessions were held in rooms available to the community in the hospital, but not at the clinic itself. Space was provided at four *Community Centers*, all owned by a community-based general medical clinics (two such facilities were sufficiently large to house both clinic and community center spaces on one campus). Sessions were also held on a *University Campus* in private conference rooms. MLH were allowed to switch locations if they wished, and a discussion of switching is included in the results.

MLH chose their intervention location from a list of available locations in consultation with an intervention facilitator who called them on the phone to schedule a time, day, and location for their sessions. The availability of most sites was limited to certain times of the day and certain days of the week. Group facilitators worked with MLH to find a time, day of the week, and location for a group session which best accommodated the needs of the MLH. The intervention staff went to great lengths to accommodate the location preferences and scheduling needs of the MLH and their adolescents. In addition, MLH and their adolescents were able to change locations if they wished. Thus, throughout the process, MLH had their choice of intervention locations and were *not* assigned to a specific location.

A subset of MLH had the added opportunity to attend intervention sessions in the same building which housed their primary medical provider. Ninety-two MLH were recruited from sites where medical care was available, 68 of these MLH had this additional “ease of integration.” A sub-analysis of these 68 MLH was conducted and is presented in the results section.

The intervention was an 8-week program consisting of 16 small group sessions offered separately for MLH and their adolescents. Each group typically consisted of 5–8 participants led by one of the project’s trained facilitators, who were employed by the research project, and most of whom had therapy backgrounds (M.S.·W., M.F.T., Psy.D., Ph.D., B.A., and M.P.·H.). Sessions focused on topics relevant to families, including parenting, building a positive family environment,

healthy physical and emotional habits and topics specific to MLH, such as disclosure, stigma, medication adherence, and assertiveness with health care professionals. MLH were compensated for transportation costs and child care for the first 16 sessions they attended. Adolescents were provided with gifts valuing less than \$10 per session. Participants were welcome to attend additional sessions without incentives (45 of MLH and 11 of adolescents did so).

As with most intensive behavioral interventions, there were a complex set of inter-related goals. For the adolescents, intervention goals were: HIV prevention, increased emotional well-being, attaining appropriate developmental milestones, staying in school, delaying/preventing pregnancy, and reducing substance use. For MLH, intervention goals included: secondary HIV prevention, increased emotional well-being, improved doctor/patient communication, increased medication adherence, and reducing substance use. For the families as a whole (regardless of adolescent attendance), the intervention goals were: reduced family conflict, improved communication, and creating/maintaining developmentally appropriate family roles.

Measures

Demographic variables, including race/ethnicity, education, employment, age, and annual income were all based on self-reports. Health-related variables, including CD4⁺ count, annual number of doctor visits, and years since diagnosis, were also based on self-report. All self-reported data were collected in face-to-face interviews, conducted with laptop computers by trained field staff who were not part of the intervention team. Distance from home to medical care was measured by calculating the driving distance from the participant's home address to the address of the participant's primary medical care provider using a web-based mapping program. Distance to group was calculated by the same method. Data on intervention session attendance were collected on a participant level by intervention facilitators who kept rigorous logs of date, location, and participant attendance for all intervention sessions. *Location First Attended*, reported here, shows the distribution of the initial location where MLH elected to attend. *Switched locations* was coded yes for any MLH or adolescent who changed locations at any time during the study.

Data Analyses

A set of ANOVA analyses were conducted to assess the association between location first attended and overall attendance. In order to accurately assess the retention rate of participants at different intervention locations, the count

of sessions attended included only the sessions which were attended at the *Location First Attended* by any participant. For example, if a participant attended 4 sessions at an HIV/AIDS clinic then switched to a children's hospital for eight more sessions, for a total of 12 sessions, that participant is counted only once as attending four sessions at an HIV/AIDS clinic.

Results

Most MLH were women of color, who had low educational attainment, low household income, and few were employed (Table 1). On average MLH had been living with the disease for nearly a decade and had an average self-reported CD4⁺ count of 511. Median distance to primary care was 7.1 miles and median number of annual appointments to primary medical care was six. More girls than boys joined their MLH in the study. The majority were still in school, and the average age was under 15-years old.

MLH were recruited primarily from settings where clinical care was available; 53% came from either recruitment efforts held at HIV/AIDS clinics or community-based medical clinics where HIV/AIDS care was being provided as part of a larger continuum of care. Non-clinical settings provided the remainder of study participants.

Overall, 77% of MLH attended at least one session, and among women attending at least one session, 81% of them attended 12 or more of the 16 offered. Of the 116 eligible adolescents, 64% attended at least one session, and 66% of those adolescents attended 12 or more sessions. Two ANOVA models, not reported in Table 1, were run to examine the association between recruitment site and total number of sessions attended by MLH or adolescents. In neither model was there a significant association.

Over 60% of MLH selected community centers (owned by general medical clinics) as their intervention location. For adolescents, children's hospitals were the most often selected intervention location. ANOVA results reported at the bottom of Table 1 show the pattern of session retention as a function of location first attended. For MLH and adolescents, the location first attended was significantly associated with retention at that location. For both groups of participants, children's hospitals had the largest mean number of sessions attended, while HIV/AIDS clinics and university campuses had the least. In addition, a set of additional independent variables were entered into ANOVA models one at a time, looking at both main effect and interaction effects with location on attendance. For MLH, race/ethnicity, education, employment, age, distance to group, CD4⁺ count, income, annual appointments, and recruitment site were all entered (continuous variables

Table 1 Demographic information and intervention attendance for MLH and adolescents, Los Angeles County 2005–2007

MLH (<i>n</i> = 173)	<i>n</i>	%	Adolescents (<i>n</i> = 116)	<i>n</i>	%
Race/ethnic group					
Latina	109	63.01	Latina	61	53.98
African American	49	28.49	African American	33	29.20
Mixed ethnicity	6	3.47	Mixed ethnicity	15	13.27
White	5	2.89	White	2	1.77
Other	3	1.73	Other	1	0.88
Asian American	1	0.58	Asian American	1	0.88
Education					
8th grade or less	67	39.64	In school	95	84.07
Some high school	46	27.22	High school grade or GED	10	13.89
High school grade or GED	16	9.47	Gender		
Some college	33	19.53	Male	41	35.34
College graduate or higher	7	4.14	Female	75	64.66
Employment					
Currently employed	50	32.05			
Currently unemployed	47	30.13			
No, retired, or disabled	59	37.82			
Recruitment location					
HIV/AIDS clinic	66	38.15			
Community-based clinic	26	15.03			
HIV/AIDS organization	72	41.62			
Peer or other referral	9	5.23			
Continuous measures					
	Mean	SD		Mean	SD
Age	40.82	8.11	Age	14.85	2.32
Annual income (in dollars)	11786.29	8275.24			
Recent CD4 ⁺ Count	510.92	646.81			
Years since diagnosis	9.09	5.13			
Distance from home to MD	9.86	14.32			
Distance from home to group	9.35	10.45			
Annual number of MD visits	8.05	7.45			
Attendance results					
	<i>n</i>	%		<i>n</i>	%
At least one session	133	76.88	At least one session	74	63.79
12 or more sessions	108	62.43	12 or more sessions	49	42.24
Switched locations	41	24.70	Switched locations	9	7.76
Location first attended					
Campus	8	6.02	Campus	4	5.4
Community center	84	63.16	Community center	29	39.19
Children's hospital	33	24.81	Children's Hospital	34	45.95
HIV/AIDS clinic	8	6.02	HIV/AIDS clinic	7	9.46
ANOVA results on number of sessions attended as a function of location					
Location first attended	Mean	SD	Location first attended	Mean	SD
Campus	8.38	3.25	Campus	4.00	0.00
Community center	13.80	6.24	Community center	9.17	5.56
Children's hospital	17.03	6.33	Children's hospital	14.88	6.03
HIV/AIDS clinic	9.38	6.80	HIV/AIDS clinic	9.14	6.26
F-stat	6.40*		F-stat	7.80*	
R-square	0.13		R-square	0.27	

* $P < .01$

were dichotomized at the median). For adolescents, age, gender, race/ethnicity, education, and their MLH's recruitment location were all entered. In every model, the main effect of first location remained significant, while neither the main effect of the added independent variable nor the interaction with first location were ever statistically significant.

Distance to primary care was compared to the distance to intervention group. Median distance to group was 7.2 miles which is shorter than median distance to primary care. Moreover, among the 133 women who attended at least one session, 50% attended a session located closer to home than their doctor.

Nearly one-third of MLH who attended at least one session switched to another location at some time during the study, while only 12% of adolescents who attended at least one session switched. A series of cross-tabular associations were examined comparing switchers to non-switchers (not included in Table 1). The number of adolescents switching was too small to produce significant findings; for MLH, sample size was not restrictive. For MLH, switching was associated with the type of location to which participants switched. Forty-two percent of switchers relocated to children's hospitals, 32% switched to community centers, 26% switched to a university campus, and zero switched to HIV/AIDS clinics [$\chi^2 (n = 133) = 13.52, P < .01$]. Switching, however, was not associated with location first attended for MLH [$\chi^2 (n = 133) = 4.36, P > .10$]. Facilitators did not encourage switching, except in 10 instances (nine MLH, one adolescent) where a participant joined a group after the first session. In these cases, participants wanted to finish their course of treatment, and a new group was starting at a different location earlier than at the initial location; accordingly, facilitators encouraged them to try the new location.

Ninety-two of the MLH were recruited at clinical care settings. Of these MLH, 68 could attend sessions at the exact address where they received their primary medical care. We refer to this group as having "added ease" of integrating their intervention attendance to their personal HIV care. These MLH could have attended intervention sessions and gone to medical appointments at the same location on the same day, if they chose. Only 44% of MLH with "added ease" attended sessions integrated into their primary care setting; 32% attended sessions somewhere other than where they personally received primary care, and 22% did not attend sessions anywhere. Overall attendance was not impacted by "added ease;" 78% of MLH attended at least one session regardless [$\chi^2 (n = 72) = 0.0006, P > .10$]. Attending 12 or more sessions was not significantly associated with "added ease" [$\chi^2 (n = 72) = 0.02, P > .10$]. Moreover, type of location first attended was not associated with "added ease" [$\chi^2 (n = 72) = 5.6, P > .10$].

Discussion

There are several important findings to emerge from this study. First, there is a disconnect between where MLH were recruited and where they opted to attend intervention sessions, despite our best efforts to "integrate" our intervention into medical care settings. In particular, nearly half the MLH were recruited from HIV/AIDS clinics, yet this was among the least popular intervention delivery locations. Second, both MLH and their adolescents had a clear preference for community-based settings. The most frequently selected locations for MLH and adolescents were either community centers or children's hospitals. Third, ANOVA results revealed that children's hospitals retained both MLH and adolescents with the greatest success. Fourth, switching location was a rare event for adolescents, but nearly one-third of MLH switched locations at some point, universally avoiding switching to HIV/AIDS clinic locations. Finally, a subset of MLH in the sample had the "added ease" of attending sessions at the same physical location where they received their personal HIV care, yet less than half of these women opted to do so and approximately one-third opted to attend sessions someplace else.

Although other researchers have had success linking targeted safer sex interventions for persons living with HIV to primary medical care settings (Fisher et al. 2006; Lightfoot et al. 2007; Knauz et al. 2007; Koester et al. 2007; Richardson et al. 2004), HIV/AIDS care sites were not the preferred location for this more intensive family-based intervention. With the exception of the university campus location (which was not very popular), all of the intervention locations were "integrated" into medical care, even the community-based settings. The community centers were universally owned and operated by a community-based medical clinic that served HIV/AIDS patients as part of a larger continuum of care. Likewise, the two children's hospital locations, which were so successful, each housed a maternal HIV clinic within that hospital on specific days and times during the week. These results, therefore, should not be misinterpreted as implying that "integrating" intensive interventions into medical care in a global sense is untenable. Rather, a successful integration of these interventions must bear in mind the sensitivities of families affected by HIV/AIDS and the organizations which serve those families.

Structural or systems-level features made community centers and children's hospitals ideal intervention settings. These locations had rooms that could easily accommodate the intervention groups, and site staff were accustomed to handling the logistic needs of small groups. In contrast, HIV/AIDS clinics tended to be relatively small and crowded, with space largely allocated to exam rooms and personal offices.

From a psychological and social perspective, community centers and children's hospitals tended to be more family-friendly, which may make them more attractive and conducive to participant attendance. Although women and children receive services at HIV/AIDS clinics and service organizations in Los Angeles, these organizations predominantly serve men who have sex with men and do not have a focus on the needs of families. Community centers and children's hospitals were places frequented by families, regardless of HIV status. Because these locations are not associated primarily with HIV treatment, there is a reduced threat of HIV-related stigma, and MLH can feel comfortable bringing their children. These organizations also have many programs and activities geared toward families, which facilitates MLH and their children feeling welcomed.

Since half of the women in the sample visited their primary medical provider once every other month or less, routine medical visits could provide a place for referrals to the more intensive intervention, but no more. Intensive interventions, such as the one offered to these women, typically require weekly sessions and cannot easily be adjunctive to infrequent clinic visits. Accessibility of the intervention site is an issue for some mothers, but not all. Nearly half of MLH traveled more than 10 miles from home to medical care. Half of intervention attendees opted to participate in a group which met closer to their home than the location of their primary medical care provider, suggesting that easing the burden of transportation was important for many families who participated in this intensive intervention which met on a weekly basis.

The primary limitation of this study is that it was not originally designed to test MLH intervention location preference. Rather, the study was designed to be a replication of an earlier family-based intervention (Rotheram-Borus et al. 2001, 2003, 2004) adapted to meet the current needs of MLH and to be "integrated" into primary medical care. Delivering the intervention to families outside of their primary care emerged in response to the needs of our partnering agencies and participants. Moreover, facilitators had some influence on where families attended intervention sessions. They systematically tried to create groups that would include 4–8 members. If a group was too small or too large, newly enrolled participants were sometimes encouraged to attend particular locations to help create desirably sized groups. Facilitators, however, were deeply concerned with convenience, accessibility, and desirability of locations for MLH, because these issues affected attendance. Unfortunately, detailed records of who was encouraged to go where, when, and why were not kept. The logistical problems encountered in delivering the intervention spurred many of the post hoc questions which drive this paper, and hence, the data required to fully satisfy all inquiries were not foreseen.

While delivering intensive behavioral interventions at HIV/AIDS care locations would appear to accommodate the needs of families living with HIV, other more loosely "integrated" locations (community centers and children's hospitals) were the most popular intervention locations. To borrow the terminology of economists, we must be aware of demand-side as well as supply-side issues. Just because researchers and policy makers think interventions delivered at HIV/AIDS care sites would be a good idea does not guarantee that people will welcome such programs. In designing and mounting intensive behavior change interventions, especially family-based interventions for MLH, care needs to be taken not only to create programs geared toward the population but also to locate these programs in settings which meet the needs of MLH and their families. Families need interventions to be located in convenient, comfortable, family-friendly, private, and familiar settings. Community-based settings, such as community centers and children's hospitals accommodate these needs and will continue to play an integral role in families' fight against the disease.

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