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Motivators and Barriers to Participation of Ethnic Minority Families in a Family-Based HIV Prevention Program

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SUMMARY

Involving low-income, ethnic minority families in lengthy HIV prevention programs can be challenging. Understanding the motivators and barriers to involvement may help researchers and practitioners design programs that can be used by populations most at risk for HIV exposure. The present study discusses motivators and barriers to involvement in the Collaborative HIV Prevention and Adolescent Mental Health Project (CHAMP), using data from a sample of 118 families that participated at varying levels in the twelve sessions of the program. Most participants chose motivators that reflect their perceptions of individual and/or family needs ("CHAMP might help me, mine, and other families"), and of characteristics of the program, such as CHAMP staff were friendly, CHAMP was fun. Among barriers to involvement, respondents expressed concerns about confidentiality, and about being judged by program staff. Respondents also reported experiencing many stressful events in their families (e.g., death and violence in the family) that may have been barriers to their involvement. Knowing these motivators and barriers, researchers and practitioners can enhance involvement in HIV prevention programs.

Keywords

Involvement; motivators;	barriers; HIV	prevention	program;	African	American	families

Ethnic minority adolescents comprise the group at highest risk for contracting STDs (DiLorenzo & Hein, 1993; Jemmott & Jemmott, 1992), including HIV (CDC, 2002a), and economically vulnerable young females have the highest rates of pregnancy (Children's Defense Fund, 2000), further evidence of unprotected sex and risk for HIV exposure. This adverse picture has prompted behavioral scientists to develop a range of prevention research programs to target populations at highest risk for HIV infection, including adolescents, women, and families of color (CDC, 2002b; Pequegnat and Szapocznik, 2000). In general, these programs aim to increase protective knowledge and behavior, and to decrease both risk behavior and exposure to HIV.

The available research indicates that family relationships and processes are significantly associated with sexual behavior in adolescence (Biglan, Matzler, Wirt, Ary, Noell, Ochs, French, & Hood 1990; Black, Ricardo, & Stanton, 1997; Romer, Black, Ricardo, Feigelman, Kaljee, Galbraith, Nesbit, Homik, & Stanton 1994); however, programs that can reach adolescents in the context of their own families are still scarce (Pequegnat & Szapocznik, 2000). Therefore, building on the strength of ethnic families as a protective factor against high-risk sexual behavior, CHAMP represents an HIV prevention intervention that targets simultaneously the prevention needs of the entire family, while focusing on pre-adolescent youth.

Given the socioeconomic context in which many adolescents of color live, effective HIV prevention interventions usually require lengthy approaches, including multiple individual and group sessions (McCormick, McKay, Wilson, McKinney, Paikoff, Bell, Baptiste, Coleman, Gillming, Madison, & Scott, 2000; Pinto, 200, Pinto, 2000). Family-based interventions may require extended participation as urban families may have experienced significant life stressors, have fewer resources, and are less likely to be served by responsive providers and culturally relevant interventions (Boyd-Franklin, 1993; Flaskerud, 1986; Gary, 1982, Wahler & Dumas, 1989; Webster-Stratton, 1985).

Nonetheless, it may be difficult to attract, engage and retain low-income, ethnic minority families precisely for these reasons. Indeed, the literature on service utilization reveals that involvement of highly stressed families is low and that not enough is known about the factors that influence minority families to become involved (Bui & Takeuchi, 1992; Miller & Priz, 1991) and that not enough is known about the factors that influence minority families to become involved in preventative interventions (Pinto, 2003). Understanding the motivators and barriers to involvement in HIV prevention programs may help researchers and health practitioners design programs that can be used by the minority populations most at risk for HIV exposure.

THEORETICAL FRAMEWORK

The literature on service utilization consistently indicates that myriad motivators and barriers in the service system may influence involvement of individuals and families in medical and social services, including HIV prevention programs. Extensively used frameworks suggest that health-related behaviors, such as involvement in HIV prevention programs, is a social process managed within social networks, including families and services systems (see, for example, Pescosolido, 1991, 1992). Others indicate that enabling factors, such as the characteristics of a service or program, may facilitate or hinder the use of social and medical services (Andersen, 1968; Andersen & Newman, 1973).

Given the high risk context in which low-income families reside in neighborhoods with high HIV prevalence, McCormick et al. (2000) have proposed that separately or in combination multiple conditions may influence involvement in family-based prevention programs like CHAMP. These include both motivators and barriers. Program level motivators (e.g.,

monetary incentive), as well as individual and family level barriers—concerns about program content and life stressors—have been hypothesized as influencing family involvement.

Beyond factors that influence individual families to participate in HIV prevention programs, program level characteristics may be important influences on involvement. Therefore, the present study focuses on program level characteristics of CHAMP, and reports motivators and barriers reported by a sample of families that participated at varying levels in the twelve sessions of the program. This information may prove to be crucial to researchers and practitioners developing HIV prevention programs, and could inform strategies for addressing barriers and for enhancing motivators to participation in their programs.

MOTIVATORS TO INVOLVEMENT

In an attempt to clarify some of the motivators to participation in preventative programs, including CHAMP, a series of studies, using data collected from both program participants and program staff, have been conducted to identify motivators to involvement (Lynn, 2002; McKay, 1995; McKay, McCadam, & Gonzales, 1996; McKay, Nudelman, & McCadam, 1996; McKay, Stoewe, McCadam, & Gonzales, 1998; Pinto, 2003). These authors found that involvement was related to participants' understanding of the program's purposes, and their perceptions about the program staff. Participants also identified program logistics, scheduling, transportation to program site, commitment to their children, and concerns about HIV infection as critical issues related to their involvement.

Other studies also suggest that recruitment and service delivery strategies (Prochaska, Redding, Evers, 1997), and reminders from services providers (Larson, 1982) may also facilitate involvement in prevention programs. Monetary incentives have been also shown to be positively associated with recruitment and retention in HIV prevention programs. For example, Greenberg, Lifshay, Van Devanter, Gonzales, and Celentano (1998) found that the average number of paid sessions women participants attended was greater than the average of unpaid sessions attended.

Other concrete conditions that appear to facilitate involvement include health coaching, vouchers for medical office visits, materials resources, scheduling, time of year and to program sites (Montaño, Kasprzyk, & Taplin, 1997; Yen, Edington, McDonald, Hischl, & Edington, 2001). These findings suggest that these factors may also facilitate participation in HIV prevention programs and are explored in the current study.

BARRIERS TO INVOLVEMENT

The literature on service utilization covers barriers to participation that relate to both the characteristics of a program, and the stressors within a family system (McCormick et al., 2000; Pinto, 2003).

Program characteristics

These authors have suggested that concerns related to community skepticisms and HIV/AIDS stigma may deter involvement. The sensitive content of the program material and its duration also may be regarded as barriers (Stevenson & White, 1994). Other barriers found in the literature on service utilization relate to concrete obstacles, such as hard-to-reach locations and lack of information about the services rendered (Acosta, 1980; Baekeland & Lundwall, 1975; Boyd-Franklin, 1993, Windle, 1980) have been shown to influence negatively rates of utilization of mental health services. This literature also reveals that attitudes about professionals (as opposed to informal helpers) have been identified as important factors that influence engagement of minority families (Leaf, Bruce, Tischler, &

Holzner, 1985; Snow, 1983). Moreover, receptivity to services and previous experiences with unresponsive service providers have been shown to be associated with attrition (Muecke, 1983).

Life stressors

A range of life stressors may affect minority families in urban areas. These stressors have been described as distributed across three key domains (Tolan, Miller, & Thomas, 1987) are hypothesized as barriers to involvement in prevention programs. Induced transition stressors include situations that change the patterns of family behavior (e.g., mental illness). Developmental transition stressors refer to expected life changes that prompt reorganization of family structure (e.g., pregnancy). Circumscribed life events can be either short- or long-term, and include life events such being robbed and being arrested.

Since many urban, low income, families experience huge numbers of stressors from each of these domains, this has raised the question of whether or not the presence of multiple stressors is a barrier to participation in CHAMP. The knowledge that family stressors create difficulties in retaining participants in mental health services (Bui & Takeuchi, 1992; Cohen & Hesselbart, 1993; Kazdin, 1993) supports exploring family stressors as possible barriers to involvement in prevention programs, including CHAMP.

METHODS

All research procedures described below have been approved by Institutional Review Boards at Columbia University and the University of Illinois at Chicago.

Sample and Data Sources

The current study examines data from a cohort of 118 African American mothers who participated in both CHAMP (Collaborative HIV Prevention and Adolescent Mental Health Project), *and* another NIMH-funded study, KAARE (Knowledge About the African American Research Experience). Of all families that participated in CHAMP, a sample of adult women caregivers were randomly selected to participate in a more in-depth interview in the KAARE study. KAARE re-interviewed this sample of women regarding issues related to their perceptions about research, including motivators and barriers to their participation in CHAMP.

The mean age of participants was 33.3 years (SD = 7.7). More than half (54%) were between 19 and 35 years old. Seventy-three percent of respondents were not married at the time of interview; 92% were single and never married; and 8% were separated, divorced or widowed. Approximately 34% of respondents reported that their total income for the year prior to the interviews was less than \$5,000. All had completed either high school (90%) or some college (10%). More than half of all respondents (54%) were working outside the home. Even though the majority of respondents had a high school education, and worked for pay, 74% of all respondents reported that they were receiving public assistance at the time of their interviews.

Of the 118 African American mothers invited to participate in the CHAMP Family Program, 92 attended at least one session. Forty percent of mothers brought their children to nine each of the twelve CHAMP scheduled sessions. Eighty-nine percent attended at least half of the scheduled CHAMP sessions.

Data Collection Procedures

The women in this study were identified when they gave consent for their pre-adolescent children to participate in a study carried out in four inner-city public schools in the Midwest. Five hundred and fifty eligible youths were identified as eligible from the 4th and 5th grades. Research staff recruited the adolescents' mothers through personal contacts, telephone calls and home visits.

Trained community interviewers conducted individual interviews lasting approximately 90 minutes. Each participant received \$25.00. Research staff assisted participants by reading instrument items aloud. Data collection occurred at community sites. To ensure readability and cultural relevance, instruments were pilot-tested.

Using a cross-section research design, data were drawn from both CHAMP and KAARE. Four instruments were used to collect data for the current study: (1) Demographic Characteristics Questionnaire; (2) Program Motivators; (3) Program Barriers; and (4) the Family Stress Scale (Tolan, Miller, & Thomas, 1987).

Measures

In order to arrive at a fuller understanding of specific conditions that influenced involvement in CHAMP, the mothers in this sample were asked about both motivators and barriers to their involvement in CHAMP. These measures were derived from separate listings of motivators, and barriers—concerns about participation and major life stressors.

Motivators—Interviewers presented respondents a list of potential motivators for their involvement in CHAMP, such as "Money," "Friends were in it," "It seemed like fun." They were asked to mark those motivators that might have made them want to be in CHAMP.

Barriers—Barriers in this study have been conceptualized as including two separate categories. *Concerns about participation* in research projects refers to participants apprehensions and unease in the context of an HIV prevention program, and which might have hindered their involvement. *Major life stressor*, another category, refers to major events that might disrupt family life and thus may also have impeded, and/or made participation more difficult.

Concerns about participation—Respondents were presented a list of potential concerns about their involvement in CHAMP, e.g., "People would know my business," "Don't know anyone in CHAMP." They were asked to mark those concerns that might have made them not want to be in CHAMP.

Major life stressor—This variable was measured by using the Family Stress Scale (Tolan, Miller, & Thomas, 1987). This 21-item scale was used to identify major life stressors that might have occurred within the families attending CHAMP, such as "Had a family member die," "Had a new baby come into the family." Descriptive statistics were used to describe these motivators and barriers to involvement in CHAMP.

RESULTS

Table 1 summarizes the motivators to participation in CHAMP.

Many participants identified program characteristics as motivating their involvement. A total of 82 respondents (70%) marked "CHAMP might help me, mine, and other families" as an important motivator for their involvement in the program. Seventy six respondents (65%)

found that CHAMP staff were nice and friendly, and 67 (57%) found CHAMP to be a fun program with which to get involved. Others found that the food served during the program sessions (n = 38; 32%), as well as the monetary incentive (n = 33; 28%) were important motivators.

Many participants also found that personal and/or family needs were important motivators. Sixty five respondents reported that they wanted "to stop AIDS," 48 participants (41%) reported wanting their children to be in an after-school program like CHAMP, and 28 (24%) found that having friends in CHAMP was also a motivator to their involvement. Overall, participants perceived each factor listed as a motivator.

Table 2 summarizes the results for concerns about participation.

Thirty (25%) respondents marked "other people would know my business" as a concern that may have made them not to want to be in CHAMP. Nineteen (16%) respondents who did not know anyone in CHAMP, and 14 (12%) who did not want their children to participate in an after-school program, all indicated these as concerns for not getting involved. Most other concerns referred to program characteristics as follows. Nineteen (16%) respondents marked that CHAMP staff were strangers to them, 17 (14%) did not need CHAMP, 15 (13%) seemed to be concerned about involvement in a program about HIV/AIDS, and 13 (11%) thought that CHAMP seemed boring. Small percentages of respondents considered that CHAMP staff might think that they (n = 14; 12%), or their families (n = 11; 9%) might be "bad" as concerns about their involvement in CHAMP. Overall, no more than 25% of participants marked any of the concerns presented to them as barriers to involvement.

Table 3 reveals eight major life stressors experienced by the majority of families in the year prior to their involvement in CHAMP.

For each stressor presented, the majority respondents had experienced that stressor in their lives. More than half of the families (n = 72; 61%) experienced the death of a family member, and 48 (41%) of these families experienced the death of another relative. Forty (34%) families in the study experienced a family member being seriously ill or injured badly, and 32 (27%) had a family member being beaten or attacked in the past year. A quarter of the sample (n = 30; 25%) reported family members having trouble at work, in school, or with authorities, and 24 (20%) had been arrested or gone to jail or court. Twenty-four (20%) respondents reported that someone in their family had a major emotional problem. Moreover, an otherwise positive stressor, "having a new baby come into the family," but which can be a source of stress for many families, was marked by 24 (20%) respondents.

DISCUSSION

The literature on service/program utilization indicates that characteristics of a program may become motivators or barriers to family involvement in behavioral interventions. Several motivators we found reflect what has been found in others studies, such as perceptions of program content and staff, monetary incentives, and logistic conditions (McCormick et al., 2000; Pinto, 2003; Prochaska et al., 1997). However, participants in this study reported specific motivators that have not been cited in the reviewed literature. In relation to the program staff, respondents noted that "nice and friendly" facilitators were an important motivator to their involvement. They also noted that a program that is "fun," that gives food and money, and is scheduled as an after-school activity, all contributed to motivate them to become involved in CHAMP. Since CHAMP may provide fun in many ways, respondents may have perceived communication and socialization as sources of pleasurable feelings called "fun." CHAMP also builds activities around meals and other forms of recreation that

may have been perceived as fun, and thus as motivators. Also, as found in other studies, social influence in form of a friend in the program was another motivator to some respondents (Gardner, Hoge, Bennett, Roth, Lidz, Monahan, & Mulvey, 1993).

Some of these motivators, along other conditions known to influence involvement in prevention programs, have been tested elsewhere and found to be significant factors which influence both participation and completion of CHAMP (Pinto, 2003). Therefore, it is recommended that further studies, both to identify other motivators *and* to test them, be carried out as a matter of course in HIV prevention studies. Because involvement of ethnic minority families is usually low, this information will over time help researchers and practitioners better recruit and retain underserved populations.

Participants in this study identified several concerns about their involvement in CHAMP, which have not been reported in other related studies. The related literature shows that most concerns revolve around location, lack of information, and unresponsiveness from providers (Boyd-Franklin, 1993; Leaf et al., 1985; Muecke, 1983). These concerns were not found among CHAMP participants possibly because the program was developed and delivered within the community in which participants reside, and because CHAMP staff strive to help participants understand the content, the goals, and overall objectives of the program (Pinto et al., in press). Nonetheless, participants identify other concerns that need to be accounted for when engaging ethnic minority families.

Adult caregivers indicated that they had concerns about confidentiality, "other people would know my business," and about being judged by program staff. Moreover, they found that not knowing other families in CHAMP, nor the program staff, were also concerns that caused them hesitancy about participation in CHAMP. These concerns were not identified by the majority of respondents. Indeed, no one concern was noted by more than thirty families (25%). These and other, even less frequent concerns are nevertheless important, and must be addressed in HIV prevention programs.

The results also indicate that stressful events in the family were noted as possible barriers to involvement. These stressors reflect many of those already found in the related literature. Note, however, that large numbers of families identified very serious stressors (e.g., death and violence in the family), that may have occurred simultaneously. Single stressors usually do not remain isolated overtime, and a combination of different ones may appear in a family at any point over the course of attempting to involve a family in HIV prevention programming. Socioeconomically disadvantaged families are especially embedded in contexts of multiple stressors, which *together* may have an impact in several areas of family life, including their ability to participate in an HIV prevention program (Dohrenwend, 2000).

One may speculate that families that experience simultaneously more stressors may be less able to get involved and to attend lengthy HIV prevention programs. Therefore, future research needs to continue to identify the impact of stressors and to test how specific stressful events may hinder family participation. Knowing participants' specific sources of stress, researchers and practitioners will be able to provide interventions to help attenuate stress or make referrals to other programs that may be better equipped to help participants. In so doing, health professionals will be better able to recruit and retain families for HIV prevention programs.

It is not possible to discern from the results which sets of motivators and barriers influenced most families in their decisions to become involved in CHAMP. Although limited, these findings are crucial because they reveal various conditions that might facilitate or hinder involvement of ethnic minority families in HIV prevention programs. Nonetheless, other

conditions—motivators and barriers—not identified in this study may also influence involvement, and thus should be researched and addressed, in order to improve involvement of families of color in HIV prevention efforts.

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TABLE 1

Motivators for Participation in CHAMP

Motivator (n = 118)		%
CHAMP might help me, my family and other families		70
CHAMP people are nice and friendly	76	65
CHAMP seemed like fun	67	57
To stop HIV/AIDS	65	56
Wanted to be in an after-school program	48	41
They give you food	38	32
Money	33	28
Friends were in CHAMP	28	24

Note:

 $n = number \ of \ respondents \ choosing \ that \ motivator$

TABLE 2

Concerns About Participation in CHAMP

Concern (n = 118)		%
Other people would know my business		25
Don't know anyone in CHAMP		16
CHAMP people were strangers		16
Didn't need CHAMP	17	14
CHAMP is about HIV/AIDS	15	13
Didn't want to stay after school		12
CHAMP people might think I'm bad		11
CHAMP seemed boring		11
CHAMP people might think my family is bad		9

Note:

n = number of respondents choosing that concern

 $\label{table 3} \textbf{Families Reporting Major Stressors in the Past Year}$

Stressor (n = 118)		Families (%)
Had a family member die		61
Had another close relative die		41
Had a family member seriously ill or injured badly		34
Had someone in family been beaten or attacked		27
Had gotten in trouble at work, school, or with authorities		25
Had a new baby come into the family		25
Had a major emotional problem		20
Had been arrested, or gone to court or jail		20