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Nicholas Tarantino

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Under the Direction of Lisa P. Armistead, Ph.D.

ABSTRACT

Young people in the United States, particularly African American youth, are at heightened risk for HIV infection. One proven prevention strategy is to enhance family processes through a group-based behavioral intervention. Such interventions have garnered considerable evidence for their effectiveness. Moreover, they have become increasingly culturally-informed in order to engage specific vulnerable populations and more effectively address their unique risk factors. A group overlooked by these efforts is adolescent children of mothers living with HIV (MLH). The current study therefore investigated the structured adaptation of an evidence-based HIV prevention intervention for this population. Two main phases of the study were completed. First,

15 MLH and 13 children of MLH (aged 10 to 15 years-old) were queried through focus groups and individual interviews, respectively. This formative work revealed needed modifications to intervention content, format, and delivery, and guided the selection of measures used to evaluate the intervention. For feedback on the newly adapted intervention, a community advisory board (CAB), consisting of MLH, their adolescent children, individuals working with MLH, and program staff familiar with the original evidence-based intervention (total CAB members = 11), was convened. In the second phase of the study, 12 MLH-child dyads were recruited to participate in the intervention for the purposes of examining the feasibility, defined in terms of its preliminary efficacy and acceptability. As hypothesized, the newly formed Ms. Now (Moms Stopping it Now!) intervention improved protective family processes, including parent-child relationship quality and parental monitoring. Attendance at all sessions was high, and participants had excellent engagement scores. They also rated the Ms. Now program as highly satisfactory. Clinical and prevention implications are explored, and observations are made about the process of adaptation. Finally, recommendations for a larger-scale pilot test of the intervention are offered.

INDEX WORDS: HIV, parenting, prevention, adolescents, adaptation, parent-child communication

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DEDICATION

For Benton. Happy Birthday, bud.

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1   INTRODUCTION

In 2012, an estimated 35 million people were living with HIV and about 1.6 million died an AIDS-related death (UNAIDS, 2013). In the United States, communities of color are disproportionately affected, including African American women and young people (Centers for Disease Control and Prevention, 2013). Fortunately, those living with the virus who follow treatment recommendations can expect to live almost as long as uninfected individuals (Samji et al., 2013). More children now have the opportunity to grow up with their HIV-positive mother. Mothers living with HIV (MLH) often feel burdened by the virus, however, which affects parenting (Kotchick et al., 1997) and, potentially, child adjustment (Reyland, McMahon, Higgins-Delessandro, & Luthar, 2002). Because of intergenerational transmission of genetic and environmental risk factors (e.g., substance abuse, victimization, and poverty), the risk for HIV infection in uninfected children of MLH is likely high. In fact, in one New York City-based sample, 20% of behaviorally-acquired youth HIV cases had parents who were HIV-positive (Chabon, Futterman, & Hoffman, 2001) in a community where 2-5% of women were seropositive (New York State Department of Health, 1999). Despite the small but fruitful effort of a few studies aimed at understanding youth HIV risks in families affected by maternal HIV infection (Cederbaum, 2012; Cederbaum, Hutchinson, Duan, & Jemmott, 2013; Marhefka, Mellins, Brackis-Cott, Dolezal, & Ehrhardt, 2009; C. A. Mellins, Brackis-Cott, Dolezal, & Meyer-Bahlburg, 2005; O'Sullivan, Dolezal, Brackis-Cott, Traeger, & Mellins, 2005), this growing population of vulnerable youth is left without interventions targeting their specific sexual health needs. To date, only one published intervention, conducted in New York City and Los Angeles, had, in part, this aim (Rotheram-Borus, Stein, & Lester, 2006; Rotheram-Borus et al., 2011).

Healthy family functioning is critical for reducing youth HIV risk, and support for family-based HIV prevention interventions is growing. Unfortunately, only a few have undergone rigorous validation. One such evidence-based intervention is the Parents Matter! Program (PMP; Forehand et al., 2007). Grounded in social and behavioral theories, PMP targets specific components of parenting—including the parent-child relationship, parental monitoring, and sex-specific parent-child communication—in parents and their preadolescent and adolescent children, to reduce youth sexual initiation and risk. The success of this program has led to its adaptation in specific settings (e.g., South Africa and Kenya; Armistead et al., 2014; Poulsen et al., 2010) and national dissemination (K. S. Miller et al., 2010).

The current study adapted PMP and drew from other evidence-based interventions for families affected by maternal HIV infection. The central hypothesis that guided the adapted intervention is that by enhancing caregivers' capacity to care and addressing specific needs related to maternal HIV infection, short and long term youth risk factors, defined as their sexual attitudes, knowledge, behaviors, and intentions, will be reduced. Adaptation occurred in two phases: (1) formative work to aid intervention development and (2) a feasibility evaluation with a small sample of the target population. Formative research in the community occurred through qualitative focus groups and interviews with MLH and their children. This phase of the study also involved obtaining feedback on new and modified components of the adapted intervention from a community advisory board. The second phase of the study involved recruiting MLH-child dyads to participate in the intervention and evaluate its feasibility. The study concludes with recommendations for a large-scale pilot test of a newly formed intervention.

1.1 Youth HIV Prevention

1.1.1 HIV risk at the individual level

HIV is transmitted in young people primarily through unprotected anal or vaginal sex (CDC, 2013). At the individual level, several social, cognitive, and behavioral theories have been used to explain how attitudes, knowledge, intentions, and behaviors are predictive of sexual risk for infection in youth and how they can be used for HIV prevention (see Fisher & Fisher, 2000 for a review). Providing knowledge to young people about sex and sexual development, what HIV is and how it is transmitted, and the methods for preventing HIV is the most basic of interventions. Although its important, researchers have long known that imparting knowledge, alone, is not enough for producing significant behavioral change; thus, theories have been introduced that consider other internal and external forces that lead to risky behavior. The most prominent theories include the theory of planned behavior (Ajzen, 1985), Bandura's social learning theory and social cognitive theory (Bandura, 1975, 1986), and problem behavior theory (Jessor & Jessor, 1977). These theories have guided the development of behavioral interventions to prevent HIV among adolescents. Traditionally, such interventions target older adolescents and are specific to individual-level targets of intervention. Many are shown to be efficacious (DiClemente et al., 2004); however, adolescents face social contexts that influence their behavior, during and after receiving such interventions, that are likely to undermine the strength of the intervention. For example, a 16 year-old who develops skills to avoid peer pressure to have sex may not be well-positioned to use these skills if she experiences emotional distress caused by an unstable home environment. Family context may be particularly important for younger adolescents who spend more time with their parents than with friends outside of the home. Moreover, HIV prevention efforts are critical during early adolescence, as research has shown that delaying sexual debut reduces later sexual risk (Kalmuss, Davidson, Cohall, Laraque, & Cassell, 2003), and, practicing safe sex at first intercourse is a strong predictor of future

condom use (K. S. Miller, Levin, Whitaker, & Xu, 1998). Given that 72% of boys and 55% of girls have had vaginal intercourse by age 16 (Cavazos-Rehg et al., 2009), interventionists have turned their attention towards the role of families in preventing HIV risk behaviors, attitudes, and intentions among early adolescents.

1.1.2   Family as a tool for youth HIV prevention

Ecological theories of child development support the family environment as central to youth adjustment (e.g., Bronfenbrenner, 1986). This is particularly true during childhood and early adolescence. For example, studies find child problem behavior is more influenced by environmental factors earlier in development and increasingly more by genetic factors in late adolescence and early adulthood (Tarantino, Tully, et al., 2014). As Bronfenbrenner (1977) explained, children are embedded within (a) microsystems, interactions between children and their families, schools, and peer groups, (b) mesosystems, interactions between these settings, and (c) macrosytems that encompass broader environments such as their neighborhood and cultural context. According to the theory, families can support or hinder development both directly via microsystems, for example, through negative parent-child interactions (Tarantino, Lamis, Ballard, Masuda, & Dvorak, 2014), and indirectly via mesosystems, by serving as gatekeepers to larger social contexts (e.g., neighborhoods; Burton & Jarrett, 2000). Destructive parent behaviors and attitudes, parent psychopathology, parent-child conflict, divorce, and exposure to intimate partner violence have all been associated with a range of problems in childhood and adolescence (Brumariu & Kerns, 2010; Foster et al., 2008; Tajima, Herrenkohl, Moylan, & Derr, 2011; Tarantino, Lamis, et al., 2014; Thomas & Kelly, 2013; Waldron et al., 2014). Parents and the family environment are also responsible for child resiliency. Indeed,

families are in a unique position to combat youth sexual risk (Armistead, Kotchick, & Forehand, 2004).

Three aspects of family life are strongly associated with HIV risk during adolescence. First, parent-child communication is critical. Through parental provision of accurate information about risks, consequences, and responsibilities related to sexual behavior, adolescent sexual decision-making improves (Dittus, Jaccard, & Gordon, 1999). With respect to parent-child communication, frequency, breadth, and quality of communication are important. Frequency of discussions is positively associated with adolescents' condom use, communication with their sex partners about HIV prevention strategies, and self-efficacy to negotiate safer sex (DiClemente, Wingood, Crosby, Cobb, et al., 2001). A greater breadth of discussions (i.e., number of topics) is linked to a lower likelihood of recent unprotected sex among African American teens (Kapungu et al., 2010). In addition, when conservations with parents are perceived as open, receptive, and comfortable, youth are less likely to have sex or have risky sex (K. S. Miller, Forehand, & Kotchick, 1999). The time parents spend with their children reinforces their ability to have these types of discussions. Relative to other sources of sexuality information, parents can talk continuously to their children throughout development, build upon previous conversations, and be time-sensitive to when these discussions need to occur (e.g., tailoring conversations to child's development and functioning). By talking with adolescents about sex, parents give protective information, model how to have conversations about sensitive issues, and shape youth attitudes about safe sex, thereby increasing the likelihood adolescents will reduce their risk behaviors.

Second, parents have the ability to structure their children's social environments. Parents who provide structure in the form of monitoring and supervision have adolescents who engage in less sexual activity (Romer et al., 1994) with fewer sexual partners (K. S. Miller et al., 1999;

Rodgers, 1999) and use contraception more consistently (Rodgers, 1999). In addition, adolescents who perceived less monitoring by their parents were more likely to have an STI, engage with multiple sexual partners, have risky sexual partners, and not use contraception during the last time they had intercourse (DiClemente, Wingood, Crosby, Sionean, et al., 2001). High parental monitoring also delays sexual initiation (Huang, Murphy, & Hser, 2011). Monitoring likely works by restricting the amount of unsupervised time children have to engage in risky behaviors, including time spent with deviant peer groups, and by increasing parental involvement, a factor influenced by parent-child relationship quality. More recently, researchers have suggested that monitoring be approached differently; that is, emphasis should be placed not on improving parents' abilities to provide control and surveillance of their child, but in developing ways that facilitate children's free disclosure of their behavior to their parents (Stattin & Kerr, 2000). Important to this approach is the establishment of a strong parent-child relationship.

In fact, a strong parent-child relationship predicts risk reductions—young people who perceive their family to be supportive and involved, report having a good relationship with their parent, and who choose family support over other sources of support (e.g., friends), are less likely to engage in sexual behavior (Dittus & Jaccard, 2000; Scaramella, Conger, Simons, & Whitbeck, 1998) and related risks (Tarantino, Kuperminc, Parrott, & Latzman, 2013). Prospective research also demonstrates that a strong mother-adolescent relationship decreases the likelihood of adolescents having sex for the first time (McNeely et al., 2002). Relationship quality is often rated higher when parents are positive and responsive, rather than negative and harsh. This type of "nurturing-responsive" parenting is positively associated with self-control in early adolescents (Brody et al., 2005), a factor protective of youth sexual risk and other problem

behaviors (Wills et al., 2007). Adolescence is a time when young people begin to distance themselves for their parents and become increasingly independent. Sustaining a healthy relationship between parents and their children during this period likely attenuates adolescents' desire to strongly reject the protective attitudes and beliefs presumably held by their parents. Furthermore, adolescents who trust and feel connected to their parents may be more likely to talk to them about sensitive topics like safe sex without fear of rejection, disapproval, or punishment. They also are more likely to be open and honest with their parents about their behavior and whereabouts.

1.1.3   The Parents Matter! Program

Several family-based strategies have been incorporated into successful behavioral interventions to prevent HIV in youth. A recent review of these interventions for African American youth found that the majority led to at least one positive youth sexual risk outcome (Sutton, Lasswell, Lanier, & Miller, 2014). However, other researchers who qualitatively reviewed outcomes of 44 similar programs found that many lacked the methodological rigor to be adequately evaluated (Wight & Fullerton, 2013).

Methodological rigor is an important consideration when choosing an intervention for adaptation to a new setting or new population. Programs recommended by prevention experts are those based on strong evidence. The evidential strength of an intervention can be measured with four indicators (SAMHSA, 2009): (1) rigor of the evaluation design, (2) rigor and appropriateness of methods used to collect and analyze the data, (3) the magnitude and consistency of the effects of the intervention on targeted outcomes, and (4) generalizability of findings. Interventions demonstrating strong evidence are more likely to meet the requirements for an evidence-based intervention (EBI).

The Parents Matter! Program (PMP) is one of a few theoretically-driven, family-based EBIs for the prevention of youth sexual risk (Forehand et al., 2007). PMP is a five, 2.5 hour session, community-based intervention. Developers remark that PMP was created in response to the growing epidemic of HIV in the African American community, and they based their program on literature suggesting that youth HIV prevention efforts need to be conducted prior to sexual debut (Miller et al., 1998); thus, their target population was African American parents (mothers, fathers, and guardians) with children in the 4th or 5th grade between the ages of nine and 12.

Dittus and colleagues (2004) explain the conceptual basis for the intervention and its overarching hypothesis, which is that by modifying parenting and the family environment, adolescent HIV risk—defined as attitudes, intentions, and behaviors consistent with risk reduction—will diminish. Several theories were used to support this hypothesis: social learning theory and social cognitive theory (Bandura, 1975, 1985), problem behavior theory (Jessor & Jessor, 1977, and theory of planned behavior Fishbein & Azjen, 1975). PMP emphasizes response contingences and modeling (social learning theory; Bandura, 1975). Parents learn to reinforce their children's positive behavior (indirectly decreasing problem behavior) and model healthy attitudes and behaviors. PMP also seeks to enhance general child competencies. (problem behavior theory; Jessor, Donovan, & Costa, 1991). This is accomplished through strengthening parent-child relationship quality and by helping parents provide structure to their child's life (e.g., parental monitoring) in order to reduce opportunities for youth to engage in problem behavior. The role of attitudes and intentions in behavioral initiation or change (theory of planned behavior; Fishbein & Azjen, 1975) also guides PMP. By providing parents with information designed to promote changes in their attitudes about sexual risk, and by increasing parents' skills in discussing these attitudes with their children, PMP posits that youth will, in

turn, incorporate the protective attitudes of their parents and decrease their intention to have sex. Finally, PMP uses strategies to increase self-efficacy among adolescents and parents. Its goal is to increase parents' and teens' communication self-efficacy to promote well-informed and open parent-child conversations about sensitive issues, like sex and HIV.

There were several steps in developing the content of PMP (Long et al., 2004). First, in terms of format, a decision was made to use curriculum-based parent education groups. Such groups enable enough time to be spent on all topics, enhance interactions between parents and the building of social support, and lessen the burden of dissemination. At the outset, focus groups with African American parents were used to accomplish several aims, including (1) understanding how parents' values shape health-related communication; (2) identification of existing individual and community-level strengths; and (3) assurance that the language in and around the intervention was culturally sensitive. Following focus groups, intervention content was drafted by the research team. Subsequent to this step, a back and forth process of content modification took place between community advisory boards and the researchers. Eventually, groups piloting the intervention, as well as facilitators leading the intervention, provided additional feedback that was used to modify and finalize the curriculum. This resulted in the Enhanced Communication and Parenting Intervention, the main experimental arm of the efficacy trial of the intervention.

A brief description summarizing the goals and content areas for each of the five sessions follows (Long et al., 2004). Session one aims to explain group procedures, establish group cohesion, introduce the concept of "Pyramid of Success," increase group members' knowledge of teen development, and increase group members' awareness of their influence on child behavior. The content of session one includes psycho-education on child sexual development,

reasons for focusing on preteen/early adolescent sexual risk, and the importance of protective parenting. Session two focuses on increasing general parenting practices which are consistent with youth risk reduction, with content areas such as how to strengthen parent-child relationship quality (e.g., positive reinforcement, increasing parental involvement), general parent-child communication, and parental monitoring. Session three's goals and content are related to raising parents' awareness of adolescent sexual risk behaviors and emphasizing the importance of parents as sexual educators. Session four's goal is to enhance parents' comfort and openness in discussing topics related to sex with their adolescents by highlighting the inherent difficulties of talking to children about such topics, raising parents' awareness of their own sexual values and behaviors, and by providing skills specific to sex communication. The goal of the final session is to give parents an opportunity to practice their communication skills with their adolescent. This session also reviews major points made across all sessions and has a program graduation ceremony. In between each session, parents are also given homework assignments to build upon what they have learned in the previous session.

Given the significant attention paid to its development, implementation, and delivery, and the methodologies used in its evaluation (Ball, Pelton, Forehand, Long, & Wallace, 2004), it is unsurprising that PMP was shown to be efficacious (Forehand et al., 2007; K. S. Miller et al., 2011). The efficacy trial of the intervention was conducted with 1115 parent-child dyads residing in and around cities located in southeastern United States. Participants (parent-child dyads) were randomized to one of three intervention conditions: enhanced (five 2.5 hour sessions), brief (one 2.5 hour session), or general health (one 2.5 hour session). Six and twelve months following the intervention, parents in the enhanced intervention compared to those in the single-session or general health interventions had a greater, positive mean change in parental responsiveness to

parent-child communication about sex and frequency of this communication. Youth whose

parents were in the enhanced intervention, compared to the other conditions, also had lower risk

for sexual activity or intentions to have sex 12 months following the intervention. A second

examination of the intervention's efficacy revealed that compared to the control conditions,

parents in the enhanced arm increased in their perception of their child's readiness to learn about

sex 12 months post-intervention (K. S. Miller et al., 2011). The researchers also found the

intervention positively affected parent-child communication about HIV, abstinence, and condom

use, as well as the concordance of parent and child reports on communication of these topics.

1.2   Families Affected by Maternal HIV Infection

1.2.1   Maternal health

Given its influence on adolescent and family well-being, maternal health is an important

consideration when developing a family-based intervention. Despite advances in its treatment,

HIV infection can be still be a burden on one's physical health. For example, many people

experience neuropathic pain associated with HIV infection (Schütz & Robinson-Papp, 2013).

Sleep disorders (Reid & Dwyer, 2005) and gastrointestinal problems (Macarthur, 2013) are also

common. MLH who do not take antiretroviral medication or who take their medication

inconsistently, are at risk for even greater health concerns, including several life-threatening

conditions. Consistent with other research on racial and ethnic health disparities in the U.S.,

MLH of color are more at risk for severe HIV-related illnesses than White MLH (Murphy,

Marelich, Stritto, Swendeman, & Witkin, 2002).

Deficits in behavioral health are also associated with HIV infection. For instance, in a

study of primarily ethnic minority mothers with an early adolescent child, HIV infection was

associated with heightened risk for depression and anxiety (Brackis-Cott, Mellins, Dolezal, &

Spiegel, 2007). It has also been linked to emotional distress and substance use (Rotheram-Borus, Rice, Comulada, Best, & Li, 2012); and, as measured through biological indicators, MLH demonstrate an increased stress response when compared to mothers not living with HIV (MNLH; Glover, Garcia Aracena, Lester, Rice, & Rothram-Borus, 2010). Moreover, mental health difficulties are likely maintained by less adaptive coping strategies, based on the negative association between number of anxiety and depressive symptoms in women living with HIV and the use of active coping strategies (Catz, Gore-Felton, & McClure, 2002).

Low-income dwellers of urban communities of color are disproportionately affected by HIV in the United States. Accordingly, MLH are often exposed to several environmental stressors (before and after infection). MLH report experiencing poor housing, unsafe neighborhoods, racial and gender discrimination, and poverty (Greene et al., 2010). Living with HIV may limit available resources. For example, a longitudinal study of mothers found that MLH, compared to MNLH, had higher economic insecurity and lower rates of employment, even though they lived in comparable low-income communities (Rotheram-Borus, Rice, et al., 2012). Heightened exposure to violence and victimization often characterize the experiences of MLH. Researchers have hypothesized a link between childhood sexual abuse and HIV risk (Parillo, Freeman, Collier, & Young, 2001), and others note the risk intimate partner violence confers on HIV infection (Jewkes, Dunkle, Nduna, & Shai, 2010). In one study of HIV-positive women, 60% and 70% of the sample reported a lifetime history of sexual and physical abuse, respectively (Brady, Gallagher, Berger, & Vega, 2002).

Perceived HIV-related stigma is an additional and unique barrier to the health and well-being of MLH. A study found that MLH compared to MNLH demonstrated higher levels of perceived HIV-related stigma, and in turn, stigma was negatively associated with psychological

functioning (Clark, Lindner, Armistead, & Austin, 2004). Further, among men and women living with HIV, HIV-related stigmatization was related to increased depression, recent utilization of psychiatric care, a greater number of HIV-related physical symptoms, and poorer adherence to HIV treatment (Vanable, Carey, Blair, & Littlewood, 2006). Many MLH also experience HIV-related stigma that is enacted (i.e., overt discrimination) rather than "felt" (Bogart et al., 2008).

Despite the health risks associated with HIV-seropositivity, many MLH are resilient, and indeed, several studies have demonstrated their strengths. Rotheram-Borus, Rice, et al.'s (2012) longitudinal investigation comparing HIV+ to HIV- mothers living the same neighborhoods found MLH to be engaging in less risky sexual behavior than MNLH. MLH also reported less family conflict and violence, and more family cohesion, than their noninfected counterparts. In addition, women living with HIV have demonstrated high levels of spirituality, mastery (sense of control of their life), and social support (Simoni & Coopermanni, 2000). A large percent of a similar sample indicated that acquiring HIV was the impetus for personal growth in many domains, including spirituality, health-related behaviors, interpersonal relationships, and positive attitudes towards one's self (Siegel & Schrimshaw, 2000). Testing positive promotes self-reflection. It also exposes women to a new community of healthcare providers and potentially support networks. The acquisition of health-promoting skills, behaviors, attitudes, and support by MLH may enhance family functioning and child resiliency. For example, MLH who become more invested in their health and future after learning of their status can pass this attitude down to their children. It is the goal of this study to understand how the strengths of MLH can be used in the context of youth HIV prevention, while acknowledging the challenges these mothers face.

1.2.2   *Child adjustment*

Children of MLH can be negatively affected by their mothers' status via the effect of HIV infection on maternal health and family functioning. In addition, individual personality and behavioral attributes responsible for psychological difficulties and problem behaviors (including sexual risk) can be passed down from mother to child (Brook, Whiteman, & Zheng, 2002). Because transmission of HIV among women living in the U.S. most typically occurs via unsafe heterosexual sex (approximately 85% of all new infections) with remaining transmissions occurring mainly through injection drug use (CDC, 2009), children of MLH may be at heightened risk for HIV infection through genetic and environmental pathways responsible for risk behavior. For instance, substance dependence is estimated to be 40% heritable (Button et al., 2006). Even in early adolescence, substance use increases the risk for sexually-acquired HIV infection (Tolou-Shams, Feldstein-Ewing, Tarantino, & Brown, 2010). Genetic contributions also account for individual differences in putative environmental risks. Recently, significant genetic influences were reported on peer-group deviance (Tarantino, Tully, et al., 2014); in other words, youths have a genetic predisposition to select or be chosen by peer-groups known to increase HIV risk (Lansford et al., 2010). Few studies have linked specific risky sexual practices of parents to those of their children—however, the extant literature shows that parents reporting early sexual debut, inconsistent condom use, and multiple sexual partners are more likely to have adolescent children who engage in similar behaviors (Kotchick, Dorsey, Miller, & Forehand, 1999; Rojas, Kim, De L Rosa, Dillon, & Niyonsenga, 2010). Importantly, it is also true that socioeconomic factors, such as poverty and social adversity, often characteristic of communities most affected by HIV, transmit across generations (Wickrama, Conger, & Abraham, 2005), creating a difficult context for children of MLH to navigate sexual health decisions.

Numerous studies have compared child adjustment in families affected or not affected by maternal HIV infection, and results are mixed. In a four-year longitudinal study, children of MLH had higher and more sustained symptoms of depression than children of MNLH (Forehand et al., 2002). Esposito et al. (1999) also found maternal HIV infection to be a risk factor for child depression, as well as a risk factor for child anxiety and externalizing problems. A more recent study had similar findings (Rotheram-Borus, Rice, et al., 2012), and additionally noted that adolescent children of MLH had a greater increase in hard drug use overtime than children of MNLH. Conversely, others studies find no effect of maternal HIV infection on indicators of child mental and behavioral health (Leonard, Gwadz, Cleland, Vekaria, & Ferns, 2008; C. Mellins et al., 2003), and in fact, one investigation reported that among families residing in similar communities, children living with MLH had better mental health outcomes than children of HIV-negative mothers (Elkington et al., 2011).

1.2.3   Mother-to-child HIV disclosure

Children's awareness of their mothers' serostatus may explain these discrepancies. National estimates indicate that 56% of parents living with HIV have not told their child (Corona et al., 2006). Overtime, disclosure generally leads to improved mother, child, and family functioning (see Murphy, 2008 for a review), but studies of older youth and adolescents show this is not always the case. In fact, some even demonstrate that older youth of MLH who are aware of their mothers' serostatus have higher rates of sexual and related risks (i.e., frequent alcohol use; C. A. Mellins et al., 2005; Rotheram Borus, Draimin, Reid, & Murphy, 1997) than those unaware. In her review, Murphy (2008) suggests that negative outcomes are more likely to occur as result of disclosure if youth are older, are told to keep it a secret, and if the disclosure itself goes poorly (e.g., inappropriate timing).

MLH commonly decide not to disclose because they want to protect their children (Palin et al., 2009). A study of MLH who did disclose found that many did not regret it; those who did, had concerns related to the timing, context, preparation, content, and outcomes of the disclosure event (Murphy, 2003). Because disclosure can go well or poorly, and this perhaps predicts child and family well-being post-disclosure, and because the long-term effects of disclosure are generally positive, interventions have been created to promote safe and protective mother-to-child disclosure. The Teaching Raising and Communicating with Kids (TRACK) Program is a theoretically-driven and evidence-based intervention administered individually to MLH at home-visits over the course of three 1.5-hour sessions (Murphy, Armistead, Marelich, Payne, & Herbeck, 2011). Results of the randomized pilot trial of the intervention demonstrated that, compared to wait-list control participants, MLH receiving the intervention were more likely to disclose, had increased self-efficacy to disclose, increased parent-child communication, and improved emotional functioning; their children, compared to the children of control participants, had reductions in anxiety and depression and increases in happiness (Murphy et al., 2011).

Due to PMP's emphasis on parent-child communication about HIV, the current adaptation focused solely on children of MLH who are aware of their mother's status. Raising the topic of HIV among those unaware might cause confusion and conflict when MLH later reveal their status, as youth are given HIV prevention messages related to their own behavior without a rationale for why it is a personally significant issue for their mother. Given the challenge of disclosure and its potential for leading to negative child outcomes, it is important to reconsider the context of the initial disclosure. The TRACK Program uses an adapted version of disclosure theory to help understand disclosure outcomes (Derlega, 2002; Fishbein, 1979). As this theory is applied to the family environment (Murphy et al., 2011), positive outcomes are

most likely to occur if the parent-child relationship is strong pre-disclosure. Formative adaptation for this study included revisiting the decision to disclose and the actual disclosure event in order to learn whether it went well or poorly. Using this information, we devised ways to promote future MLH-child conversations about maternal HIV infection. Our intervention targeted parent-child relationship quality and the context surrounding having these continued discussions. By having mothers reintroduce disclosure in a safe, appropriate way, we aimed to (1) increase adolescents' understanding and acceptance of their mother's status, thereby strengthening the family environment; (2) provide relevant information for keeping youth safe from HIV (e.g., routes of transmission); and (3) use mothers' experience of living with HIV as a teachable moment for deterring adolescents from engaging in risky behaviors and avoiding risky situations. Each is posited to contribute to the ultimate goal of reducing youth HIV risk.

1.2.4   *MLH-child communication about sex and HIV*

In the context of HIV prevention, a potential strength of MLH is their knowledge of HIV and sexual risk and their ability to communicate this knowledge to their children. In one study, MLH were more likely to discuss HIV and had more frequent conversations about HIV than MNLH (O'Sullivan et al., 2005). The same study also revealed that early adolescent children of MLH were more comfortable discussing sex and drugs with their mother and felt their conversations about sex were of greater quality, than children of MNLH. However, another study, specific to MLH with older adolescent daughters, did not find mother's serostatus to predict parent-child communication about sex, HIV, and sexual risks (Cederbaum et al., 2013). Many factors could explain this difference, including child gender and age, characteristics of the MLH sample (e.g., geographic location), and measurement of communication (breadth/depth

versus comfort/quality). For example, it may be that MLH discuss the same number of HIV-related topics with their children but feel more knowledgeable than MNLH about the topics.

Qualitative studies provide additional context for this potential strength of MLH. In most cases, MLH express a strong desire to prevent their children from experiencing the same situations that put them at risk for HIV. A mother in Cederbaum's (2013) study noted,

> "And I believe that me telling them what I went through and some of the things that I did that they know they can't go that way; they just know that's not the right way and I just know I'm teaching them … I had to go that way so they would, so I could train them up right"

From the same study, it is apparent that older teens of MLH get risk reduction messages from their mother that provide the impetus for behavioral change.

> "It makes me think twice or maybe three times before you lay down and do it what you doing.; It make me not want to have sex, especially not with anybody. [name] you better not be having sex, you still young you know. You got to know your partners sex history.

MLH also indicated that having HIV has made them more aware of adolescent sexual development and the ways they can talk to their children about it. A mother in a different study noted, "I would not have talked to them about sex… With this disease, I had the chance to know more and also learn more about how one should treat one's kids during their puberty" (Murphy, Roberts, & Herbeck, 2011). It is evident that this is a strength of MLH that should be leveraged when adapting the intervention; at the same time, the difficulties of discussing HIV and the sensitive conversations between MLH and kids to which it can lead (e.g., how a mother acquired HIV, how long she is going to live), should also be addressed.

1.3   Conceptual Model

The conceptual model for this study is based on PMP (see Figure 1). It also draws from the TRACK program and its emphasis on mother-to-child HIV disclosure (Murphy et al., 2011). In summary, the long-term (distal) outcomes of the intervention are behavioral changes with a direct relationship to youth HIV risk reduction (e.g., fewer sexual partners). The short-term (proximal) outcomes consist of child characteristics that are predictive of the long-term outcomes, such as increases in protective attitudes related to sex and decreases in intentions to have sex. The primary targets of the intervention include aspects of the family environment known to influence the short-term child outcomes: parent-child relationship quality, parental monitoring, general parent-child communication, and specific parent-child communication about sex, sexual risks, and sexual development. Included also as a primary target of the intervention is the disclosure experience. Though disclosure has already occurred, reintroducing disclosure and continuing the process of disclosure in a protective family environment is hypothesized to reduce youth HIV risk (e.g., by increasing discussions about HIV and children's knowledge of HIV). The model also considers MLH and child characteristics, including their social environment, factors which are predictive of youth and family outcomes. These factors are included in the model as they may be potential barriers to the program's effectiveness.

PREDICTORS OF YOUTH HIV RISK

YOUTH OUTCOMES

Mother's Health
-Physical illness
-Emotional well-being
-Substance abuse

Social Context
-Social support
-HIV stigma/discrimination
-Exposure to violence/abuse
-Neighborhood-Perceived neighborhood quality
-Access to resources

Child Adjustment
-Emotional well-being
-Behavioral problems

Family Environment
-Relationship quality
-Parental monitoring
-General parent-child communication
-Parent-child communication about sex, sexual risks, and sexual development

Disclosure Experience
-Mother's self-efficacy to continue the disclosure process

Primary Intervention Targets

Proximal

Child Characteristics
-Attitudes about sex, HIV, sexual risks consistent with risk reduction
-Increased knowledge about sex, HIV, and sexual risk
-Reduced intentions to have sex

Distal

Delayed Sexual Debut

Changes to Sexual Risk Behaviors
-Fewer sexual partners
-Consistent condom use
-Ability to resist partner pressure to have sex and negotiate safe sex
-Avoidance of sex while under the influence

Figure 1 Conceptual Model of an HIV Prevention Intervention for Families Affected by Maternal HIV Infection

1.4   Adaptation of Evidence-Based Interventions

1.4.1   Guidelines for adaptation

The imperative to use empirically-supported treatments and interventions that are culturally relevant in the fields of clinical psychology, medicine, and prevention science has led to increasingly well-defined models for program adaptation and ways adapted interventions can be evaluated (Chen, Reid, Parker, & Pillemer, 2013; McKleroy et al., 2006; Solomon, Card, & Malow, 2006; Tortolero et al., 2005; Wainberg et al., 2007; Wingood & DiClemente, 2008). Core steps for adaptation common to many models are found in guidelines published by the Centers for Disease Control and Prevention (CDC; McKleroy et al., 2006), and have been used in previous adaptations of PMP (Poulsen et al., 2010). Guidelines are designed to be stepwise, but steps can occur simultaneously, and because adaptation and evaluation is an ongoing process, it may be necessary to go back to previous steps.

Step 1: Assess. First, it was necessary to assess the target population (e.g., demographics, social norms, location). Second, intervention possibilities from a list of known EBIs were explored. In this step, program adapters are expected to attend closely to the core components of existing interventions; that is, the components that are linked to the intervention's efficacy. Third, goodness-of-fit between the population and intervention was determined, as well as the organizational capacity for implementing the intervention. McKleroy and colleagues explain that "it must be confirmed that the EBI activities address the same risk factors, behavioral determinants, and risk behaviors that are identified in the target population (p. 67)." Finally, stakeholders, staff at local non-governmental organizations, were assessed for their knowledge of the target population and their potential to work as collaborators.

Assessment of the target population included their characteristics (e.g., predominantly low-income, African American female caregivers living with HIV) and needs that are above-mentioned, and where to locate members (i.e., NGOs and HIV clinics). An EBI that uses family-based strategies to prevent youth HIV risk was found to be the best fit for the population given the possible strengths of families affected by maternal HIV infection; that is, MLH are seemingly well-positioned to impart HIV-related knowledge and share their experience of living with HIV in order to shape the attitudes and intentions of their children in a way that is disease preventing and health promoting. Additionally, the behavioral determinants of child risk behavior in this population are believed to be related, in part, to family processes (e.g., maternal HIV disclosure, parent-child relationship quality), and thus a family-based intervention targeting these processes is appropriate. Stakeholders at NGOs and HIV clinics were recruited as collaborators.

Step 2: Select the intervention. This step involved selecting an EBI to be adapted. PMP was chosen as the primary intervention for several reasons. First, it has been rigorously evaluated and its effects are well-documented. Second, PMP was designed for and with African American families living in the South, specifically, Atlanta and Athens, GA, and Little Rock, AR. The current project sampled from a similar population of families living in Atlanta. Finally, PMP's targeting of early adolescents was attractive given research supporting the greater impact of HIV prevention efforts on this age group versus others (i.e., older youth). Because PMP was not designed for parents living with HIV, components of an evidence-based maternal HIV disclosure intervention (i.e., the TRACK program; Murphy et al., 2011) that directly address the ways in which HIV can affect family functioning were also incorporated into the adapted intervention.

Step 3. Prepare. In this step, changes were made to PMP to fit the risk factors and behavioral determinants of risk in the new population. McKelroy et al. (2006) recommended that

those conducting the adaptation consult with the developers of the EBI in order to maintain its core components and internal logic. Additionally, they recommend that a community advisory board should review the materials and offer suggestions on how they can be modified for the target population. A major focus of the current study was to decide through formative qualitative research with members of the target population how intervention content could be changed, amended, or removed. The co-developer of PMP served as a consultant on the adaptation, and materials were reviewed by a community advisory board consisting of community members familiar with providing services for MLH, as well as MLH and their adolescent children. Some members had previously participated in the focus groups and interviews. The community advisory board is also a form of member checking. Member checking is a process used in qualitative research to inform intervention development that involves presenting research findings to the target population in order to validate the results and strengthen members' ownership of the intervention (Varjas, Nastasi, Moore, & Jayasena, 2005).

Step 4. Pilot. This step is the second phase of the current study. It involved pilot testing the intervention with a small number of participants to assess feasibility and whether or not the intervention will likely result in producing its intended outcomes. McKelroy et al. remarked that "the pilot is unlikely to determine if the intervention is having the desired behavioral outcomes, but it is possible that there are some anticipated immediate outcomes that a pilot might be able to capture (e.g., intentions, knowledge, or attitudes.)" As suggested, brief pre-/post- assessments of core intervention targets were used to examine trends in outcomes (i.e., preliminary efficacy).

Researchers in the field of public health provide examples of how feasibility can be assessed to complement testing for preliminary efficacy in a pilot examination of an adapted evidence-based intervention (Bowen et al., 2009). Bowen and colleagues noted that a common

practice for assessing feasibility is to assess acceptability. They indicated that acceptability can

be measured by the extent to which program deliverers and recipients find the program "suitable,

satisfying, or attractive" with degree of program satisfaction as an outcome (Bowen et al., 2009).

Researchers of feasibility often create their own or use standardized measures of satisfaction that

are administered after each intervention session and/or are completed only after the last session

(e.g., Brothers, Harper, Fernandez, Hosek, & The Adolescent Trials Network for HIV/AIDS

Interventions, 2014). Qualitative and quantitative assessments of intervention leaders are also

useful to assess participant engagement (Brothers et al., 2014), an additional indicator of

acceptability. Finally, and most simply, acceptability can be assessed by counting how many

sessions each participant attends.

Step 5. Implementation. In the last step, the adapted intervention is implemented. Central

to this step is an ongoing monitoring and evaluation of the intervention. The current study

focused on preparing an intervention to be ready for this step of the adaptation.

1.4.2   *Adaptations for families affected by HIV*

Rotheram-Borus and colleagues have written about their experience of adapting an

evidenced-based intervention designed for adolescents and parents affected by parental HIV-

infection (Rotheram-Borus, Lee, Amani, & Swendeman, 2012; Rotheram-Borus et al., 2011).

Their original intervention was developed in the early 90s in New York City (Rotheram-Borus,

Stein, & Lester, 2006) and was later implemented in Los Angeles, South Africa, and Thailand

(Rotheram-Borus et al., 2012). A comprehensive program, it targeted several indicators of family

and adolescent well-being—such as maternal physical, behavioral, and emotional health, child

internalizing and behavior problems such as sexual risk and substance abuse, and parent and

child adjustment to maternal HIV infection—through a 24 session group-based intervention.

From their work, they introduced a set of five guidelines for adapting similar interventions (Rotheram-Borus et al., 2011). In summary, these include framing the intervention in terms of the strengths of living with HIV, ensuring that strategies are applicable to real-world situations, building parents' and adolescents' cognitive, affective, and behavioral skills, establishing social support for families, and addressing environmental barriers to intervention effectiveness.

As PMP was adapted, each guideline was considered. For example, the intervention was framed to leverage the strengths of MLH and empower them to prevent youth HIV risk (e.g., through helping MLH impart their knowledge of HIV to their children). In addition, we encouraged participants to exchange phone numbers, seek support from one another, and build a sense of community over the course of the intervention. This was facilitated by a "Support Card" given out during the first meeting. Skill-building was a main focus of PMP, and for the adaptation, new cognitive and behavioral skills were added to enhance specific components related, for example, to having continued parent-child discussions about maternal HIV infection. Finally, environmental barriers are partly addressed by the provision of referrals to community resources and an associated discussion on how to access those resources.

1. 5   Current Study

Guided by a structured model of adaptation and informed by theory and previous research with MLH and their children, the current study adapted an evidence-based intervention for mother-child dyads in order to decrease youth HIV risk. The study was completed in two phases: (1) formative research with MLH, their adolescent children, and community board members to aid in modifying the intervention and (2) a feasibility evaluation of the adapted intervention through assessment of its preliminary efficacy and acceptability. The central hypothesis guiding this study is that by following a structured process of adaptation, the core

components of an evidence-based intervention can be successfully incorporated into an adapted intervention that fits well with a new population. Further, through this process, it was hypothesized that the intervention would be feasible to implement on a larger scale.

2   METHOD

2.1   Phase I

2.1.1   *Design and procedures*

The main focus of Phase I was collecting qualitative data and modifying the intervention. Common to the process of adapting evidence-based interventions to new populations is the use of focus groups (Dévieux et al., 2005). Focus groups are useful for gathering information related to social norms, expectations, values, and beliefs (Ulin, Robinson, & Tolley, 2005). Through targeted debates and discussions, focus groups elicit attitudes that might not be reported in other settings. In the case of the current study, the group-based format allowed for MLH to discuss commonalities and differences in their experiences of living with HIV, raising an adolescent, and talking to their children about sex and HIV. In addition, focus groups served as a preliminary trial of MLH's willingness to share their thoughts and feelings with other MLH.

Individual interviews with adolescent children of MLH were also conducted. This method was chosen over a group-based format due to privacy concerns and the sensitive nature of the discussions (Krueger & Casey, 2009); that is, teenagers may have been uncomfortable talking about how they discuss sex (or not discuss sex) with their parents in front of other adolescents, and, though HIV-positive parents may understand the importance of maintaining the privacy of other group members, particularly with regard to disclosing others' HIV status, their children may not. Furthermore, it was expected that some children of MLH were told about their

mothers' status relatively recently, while others were told much longer ago, and children's initial reactions can be negative as compared to their thoughts and feelings as time passes (Murphy, 2008). For youth who were still experiencing a significant amount of distress about their mothers' illness, discussions with other youth about HIV may have been emotionally difficult; whereas among parents, it was likely that those who decided to attend the focus group will have prepared themselves emotionally for the discussion.

A set of four focus groups with three to five MLH each were conducted at Georgia State University's Psychology Clinic for Psychotherapy and Assessment, hereafter referred to as the Clinic. Groups were facilitated by two masters-level clinical psychology doctoral students trained in adult and child clinical interviewing. One facilitator was a non-Hispanic White male and the other was an African American female. A licensed clinical psychologist was on-call for emergency situations. After undergoing informed consent and completing the two-hour focus group, participants were paid $30 for their participation. Adolescent children of MLH who were assented and whose parents agreed to their participation completed a 45 to 60 minute individual interview held either at the Clinic or at their home, per participant preference. At either location, a masters-level clinician matched to the child's gender conducted the interview in a private setting, away from the child's mother or other family members. Child participants were given a $15 gift certificate to a local department store. Interviews and focus groups were digitally audio-recorded and transcribed for data analysis.

An additional component of this phase involved recruiting a community advisory board, as recommended for the adaptation process (McKleroy et al., 2006). After informed consent, MLH, children of MLH, staff from non-profit agencies serving MLH, and intervention experts participated in either a three-hour board meeting at the Clinic (adults only) or a 45 minute

individual meeting at home (adolescents only). Main changes or additions to intervention content area, delivery, and materials were reviewed with participants. Many community advisory board members were past focus group or individual interview participants, and thus the community advisory board served as a form of member-checking. Adults were given $60 and children a $30 gift card for their participation.

Recruitment for both phases occurred through a number of clinics and non-profit organizations aimed at providing referrals or services for those living with HIV in the Atlanta area. Participants were informed that participation in the study was voluntary and refusal to participate or withdrawal would not affect the services they received from these groups. MLH connected to recruitment sources were approached by organizational staff not affiliated with the current study (e.g., HIV clinic staff) and when feasible, recruitment advertisements in the form of flyers and pamphlets were distributed to sites with physical space for their display and disbursement. Depending on the site, with MLH permission, their names and phone numbers were shared by recruitment staff with our research team. Potential participants were then contacted discretely to schedule a consent/assent. Other sites passed along our information to potential participants and they contacted us directly

Both phases of the study involved the recruitment of MLH with an adolescent child who was aware of their HIV status. Given that the most African American adolescents are sexually active by age 16 (Cavazos-Rehg et al., 2009), and evidence indicates that prevention efforts may be most beneficial prior to sexual debut (Miller et al., 1998; Kalmuss et al., 2003), the intervention targeted early adolescents in the age range of 10 to 15. This age range differed from the original target for PMP, which was 9 to 12 year-olds. The older age range for the adapted intervention was driven by the fact that older youth are more likely to be told their mothers'

status than younger youth, particularly during the transition from childhood to adolescence (see

Murphy et al., 2008 for a review). Thus, participation in the study would have been severely

limited if PMP's age range was used. Modifications to the intervention incorporated the change

in target child age range as indicated by the formative data.

Inclusion criteria included MLH and child consent and assent, respectively. Participants

must also have been English-speaking and children must have lived most of the time with their

mother, who could also have been a non-biological guardian with custody of the child. HIV

positive children were excluded because (1) it would have been difficult to determine differences

in the outcome measures (parenting/family functioning and youth sexual risk) without taking into

consideration the effects of disease progression on child functioning; (2) HIV-infected youth

could have been unaware of their own status and this may have affected their risk outcomes; and,

(3) there would have been too few HIV positive children to conduct separate analyses with this

population. Additional exclusion criteria included: child does not meet screening criteria

(diagnoses with depression or suicide attempt, or cognitive/intellectual functioning < 74), and

psychosis of parent or child. MLH also provided information about their illness, including HIV

diagnosis date, to verify serostatus.

2.1.2   Participants

A total of 14 HIV-positive mothers and one grandmother (collectively referred to

hereafter as mothers) participated in one of four focus groups ($n = 15$). Mothers ranged in age

from 29 to 58 years-old ($M = 41.33$, $SD = 8.52$). All but one mother, who identified as White,

reported their race as African American or Black; none indicated their ethnicity as Hispanic or

Latina. Most mothers were unemployed (80%) with lesser proportions of mothers being

employed full-time (7%) or part-time (7%). Thirteen percent reported having less than a high

school education; 13% had a high school education or the equivalent; about half (47%) achieved some college education; and about a quarter (27%) had a technical, vocational, 2-year, or 4-year college degree. Their income levels were generally low. They indicated receiving the following monthly incomes: between $0 to $199 dollars (27%), $200 to $499 (7%), $500 to $999 (33%), $1000 to $1999 (27%), and $2000 to $2999 (7%). Eighty percent received government assistance and the rest did not. Most mothers indicated that they were either "single, never married" (53%) or "separated or divorced" (20%); others were "in a relationship," either living with (7%) or without (7%) a partner. No mother said she currently lived with the father of the target child. On average, mothers had two children (SD = 1.16, range = 1 to 7 children) and currently lived with two of their children (SD = 1.17, range = 0 to 5 children). Mothers' religious preferences were also reported. Most identified as either Baptist (60%) or Christian (non-denominational; 20%) with the remaining mothers indicating that they were a Jehovah's Witness (7%) or other (7%), or not religious (7%).

In terms of HIV status, most were not recently diagnosed. The mean number of years a mother had been living with HIV when she participated in the study was 13 (SD = 9.18, range = 17 years to less than 1 year). A majority of mothers said they had been diagnosed with AIDS (60%). The mean age of their target child when he or she was told of their mother's HIV status was 11 (SD = 2.38, range = 7 to 14 years-old). Mothers indicated that they had told their child on average 3 years prior to the focus group date (SD = 2.05, range = less than a year to 7 years).

The average age of adolescent participants individually interviewed was 13 years-old (SD = 1.98, range = 10 to 15 years-old). About half the teens were girls (54%) and the rest were boys. All but one girl who was biracial identified as African American or Black. No child was

identified as Hispanic or Latina. Adolescents educational attainment ranged from 5 grade to 10th grade (*M* grade of completion = 7.69, *SD* = 1.80.).

The community advisory board consisted of MLH (*n* = 5), four of whom were previous focus group participants. Two adolescent children of MLH also served as board members: a 16 year-old boy who was previously interviewed and 15 year-old girl who was not. Further, two women, each with several years of experience working at different non-governmental organizations that serve individuals living with or affected by HIV, joined the other community advisory board members. These women happened to be HIV-positive as well. A former facilitator of the Parents Matter! Program (PMP), who also had experience working with individuals living with HIV, was an additional member. All members were African American or Black except for one MLH who identified as White. Finally, the co-developer of PMP was present for the group meeting as well.

2.1.3   Measures

Focus group and child interview protocols that mirror each other were constructed in a way that is consistent with the process of adaptation (McKleroy et al., 2006; see Appendices A and B). The main focus of both was on the way in which maternal HIV infection affects the targets of the intervention. The primary targets are the core components of PMP and a specific component related to the HIV disclosure experience included in the TRACK program. In addition, contextual factors that may be influential to the intervention (included in the conceptual model; Figure 1) and deemed important for MLH and their children were also explored (e.g., social support).

Focus groups began with facilitators welcoming participants to the study and introducing themselves. A brief description of the study's aims then followed, along with group rules and

review of confidentiality and privacy restrictions. After this section, semi-structured protocols were used that followed a line of questioning beginning with open-ended, broad questions and followed up with probes that were less broad and could be either open-ended or close-ended. The advantages of this approach over others (e.g., structured; closed-ended questions only) include being able to get a breadth and depth of information from participants, promoting discussion and debate, and capturing participants' experiences that may be unexpected, yet useful for adapting the intervention (DiCicco-Bloom & Crabtree, 2006). Each participant was encouraged to contribute to the discussion, as the facilitators moderated participant interactions.

Individual interviews followed a similar structure. Adolescents were reminded that their responses would not be shared with their parents unless there was a concern for their safety. A brief description of the study was given, including information as to why they are being asked to participate and the importance of their answers. Adolescents were asked throughout the introduction of the interview if they had questions for the facilitator. Interviewers were encouraged to ask probing questions liberally throughout the interview given the tendency of adolescents to give brief responses.

2.1.4   Plan for analysis

Researchers recommend that two focus groups with eight to ten participants per group be conducted for every demographically or characteristically distinct feature of a population (e.g., men and women; African Americans and Caucasians; individuals living with and without HIV; Ulin et al., 2005). Given that this sample was homogenous (e.g., demographically similar [i.e., race, gender, and class] and shared HIV status), two groups would normally be sufficient for its aims. However, recent research on a similar topic with African American MLH and their adolescent children, found that MLH face many difficulties in attending a focus group (e.g.,

access to transportation; Cederbaum, 2013). In her study, Cederbaum was unable to achieve more than six participants per group, and she often had fewer. Thus, the current study had four focus groups with three to five participants per group in order to achieve a larger sample size. We conducted 13 semi-structured child interviews because methodological research suggests that the majority of major data themes are identified within approximately the first 12 interviews (Guest, Bunce, & Johnson, 2006).

A 6-phase thematic analysis, as described by Braun & Clarke (2006), was used to analyze the data using NVivo (version 9) software. The approach taken for identifying themes was mostly "top down" and not inductive; that is, themes were generated that were related to the overall research question (Braun & Clarke, 2006): how does being in a family affected by maternal HIV infection influence family-based HIV prevention intervention targets? This decision was due to our objective of adapting the intervention for a new population rather than working from the bottom up to generate new hypotheses. Nevertheless, new themes emerged that were not previously considered given the uniqueness of the sample and the few existing studies on the subject (e.g., Cederbaum, 2013).

Braun & Clarke's phases were completed by doing the following: (1) First, I familiarized myself with the data by reading all the transcripts, observing common patterns and potential themes, and listing initial ideas about the data. As suggested by the authors, transcriptions were done verbatim and the analyst was also one of the two transcribers; (2) Initial codes were generated by myself at the most basic level. Codes were specific and less broad than themes. As many as possible were generated; (3) Next, I searched for themes by reviewing the codes. Primary themes included the targets of the intervention (e.g., parent-child communication about sex) listed in the conceptual model. Subthemes were then created by grouping codes and

connecting subthemes to themes. In the end, a thematic map was created. (4) In this phase, the themes were refined through two levels of review. First, each coded data extract was read in its entirety with the goal of deciding whether the theme or subtheme it was under was coherent. If it was not, several actions could have been taken including creating a new theme, finding a theme that specific extracts would fit in better, or discarding the subtheme. The second level of review involved re-reading each with an eye towards the established thematic map. At this level, new extracts were coded and old extracts re-coded to fit with the themes; (5) Phase five involved defining each theme by overarching characteristics. (6) In this last phase, I provided evidence for each theme and subtheme and connected it to the research question through example data extracts.

2.1.5   Intervention development

Once major themes and subthemes were identified, changes were made to the content and delivery of the intervention. This process involved several steps. First, intervention content was reviewed in its entirety and broken down into the core components of the intervention. This also included a review of materials (e.g., videos and handouts). Second, any content that was inappropriate or unneeded, given the themes established from the qualitative data analysis, was removed. For example, it was determined that MLH did not need a section that strived to raise awareness of the HIV epidemic. Third, content was changed or added to be consistent with (a) the needs of MLH and their children and (b) relevant social and behavioral theories of behavior change. One part of this step was adding content from the TRACK program that aids MLH in discussing HIV with their children in the context of their own infection. This step also included a consideration of how the strengths of MLH can be fostered through the intervention to enhance parent-child communication about sex and HIV risk. Fourth, modified segments of the

intervention were reviewed by the community advisory board (CAB). CAB members provided

their input on the content and delivery of the intervention. Finally, remaining changes were made

and an intervention manual was finalized.

2.2 Phase II

2.2.1 Design and procedures

Phase II of the study used the same recruitment strategy as Phase I and recruited a

demographically similar sample of participants. Participants in this phase (n = 12 MLH-child

dyads) were recruited to take part in a feasibility evaluation of the adapted intervention. Even

though it is has been suggested that fewer than 10 participants would suffice for such an

evaluation (McKelroy et al., 2006), due to anticipated difficulties with retention, more

participants were recruited than were needed. Recruited MLH and adolescents provided

informed consent and assent, respectively, at their house. MLH and one target child then

completed an assessment on an Audio Computer Administered Self-Interview (ACASI) self-

administered on a laptop with assistance from an interviewer to assess pre-intervention

functioning. The ACASI was used to minimize bias in responding by providing participants with

a safe, non-confrontational medium for answering questions about sensitive information. It also

was accessible to participants with low literacy.

Following the initial assessment, MLH were invited to attend intervention sessions at the

Clinic in a private conference room. The conference room was large enough to accommodate

more participants than were in attendance and had multimedia functions that were used to

facilitate intervention delivery. Given the travel difficulties that many MLH face in Atlanta, a

decision was made to shorten the number of sessions of the intervention, from five 2.5-hour

sessions to three 3.5-hour sessions, separated by one week. All 12 participants were invited to

attend. Lunch was served halfway through each session. In addition, a 1.5-hour, one-on-one (dyad) home-visit with a group facilitator occurred with each family within one to three weeks following their last group sessions. This was done in order to incorporate the component of the intervention that includes the adolescent (i.e., practicing parent-child communication skills) in a way that respects the privacy of group members. Also, home visits were a way to tailor conversations about sensitive topics (e.g., sex) to the child's appropriate developmental level.

Following every session, participants completed a brief measure assessing their satisfaction with the session. At the final session (home-visit), they also completed an assessment of their overall satisfaction with the program. The measures were anonymously self-administered using pen and paper and collected by program staff not facilitating the intervention.

During the home-visit and immediately following the one-on-one session, MLH-child dyads completed an ACASI follow-up assessment of post-intervention functioning using the same measures used to assess baseline functioning. For the baseline and follow-up assessments, MLH receive $60 cash and children received a gift certificate worth $30. Assessments for MLH-child dyads at both time points lasted approximately 30 minutes. MLH were also given $100 for each intervention session they attended. Payments were made to compensate participants for their time and costs incurred due to participation (e.g., parking fees, childcare).

A standardized manual was used by facilitators trained in intervention delivery. Facilitators were one masters-level clinician and one outreach worker trained in providing services for African American families affected by HIV. One facilitator was an African American female and the other was a White male. Their training included conducting the intervention in its entirety. On-going, weekly supervision was provided to facilitators by a licensed clinical psychologist (and a PMP co-developer) during the pilot trial of the intervention.

In addition, an undergraduate research assistant trained in the study protocol served as a group helper during all intervention sessions and aided in monitoring intervention fidelity via a structured assessment.

2.2.2 Participants

Female caregivers were all African American mothers (M age = 40.75, SD = 9.85) of their 10 to 15 years-old child (M age = 12.50, SD = 1.31; M grade = 7.12, SD = 1.40). All lived in Atlanta or in a nearby suburb. On average, mothers had three children and currently lived with two of them. Forty-two percent reported had a co-parent, this included a boyfriend/partner (8%), ex-boyfriend/partner (17%), friend (8%), and daughter (8%). Only one mother said the co-parent lived with her and her child. Many parents endorsing having never been married (67%); others said that they were widowed (8%) or divorced or separated (25%). No mother said she had ever been married to the biological father of her child. Most of the sample (83%) were not currently in a relationship.

Mothers were generally low-income (M house monthly income = $1224.50, SD = 518.15), yet most said they had at least enough money to "make ends meet" at the end of the month (92%). Employment status for mothers was as follows: none were employed full-time; 17% were employed part-time; 58% were unemployed; and 25% were students. Approximately 17% had a high school degree or equivalent; 16% did not graduate high school; 25% had some college experience; 25% had a vocational, technical or 2-year degree; and 17% had a college degree.

In terms of HIV status, mothers on average had been living with the virus for 13.67 years (SD = 8.09). This ranged from two to 26 years. Forty-two percent of mothers had received an AIDS diagnosis. Mothers reported their CD4 count as well (M = 718.08, SD = 390.73), and most

(75%) said their viral load was undetectable. They indicated that they disclosed their status to their target child between less than a year to 11 years ago ($M = 2.54$ years, $SD = 2.87$).

2.2.3   Measures

2.2.3.1   Engagement

Program engagement was assessed following each intervention session. Facilitators rated all participants on a scale of engagement that ranged from (0) "most (greater than 50%) participants were not engaged at all" to (3) "most (greater than 50%) participants were very engaged" for each segment of the intervention. Each facilitator and the group helper provided these scores. Facilitators and the group helper met to resolve discrepancies in ratings and come up with a set of final ratings. Definitions for each item response were given. For example, a rating of three was defined as "almost no participation in non-session activities (for example, texting), attempting all activities, watching all videos, making eye contact with facilitators, and responding to at least one question." Facilitators also provided qualitative feedback regarding participant engagement after the home visit session.

2.2.3.2   Satisfaction

Participant satisfaction was assessed following each session using the Session Evaluation Form (SEF; Harper, Contreras, Bangi, & Pedraza, 2003). The SEF has 10 items on a 4-point scale that assess degree of satisfaction with the intervention by asking questions (e.g,. "Was the session interesting" and "Did you learn a lot") that have responses ranging from strongly agree (1) to strongly disagree (4). Two open-ended questions were also asked at the end of each session after the facilitators left the room related to what participants found to be most useful and what they would change in the session.

Global satisfaction with the intervention was assessed using the 8-item Client Satisfaction Questionnaire (CSQ-8: Larsen, Attkisson, Hargreaves, & Nguyen, 1979) completed following the last session. The CSQ-8 assesses participants' satisfaction with the intervention's procedures, quality and quantity of service, and outcome, as well as their general satisfaction. Response choices for each item are different and all are 4-point. For example, participants were asked "Did you get what you wanted from our program?" with response ranging from (4) "yes, definitely" to (1) "no, definitely"; and, "How would you rate the overall quality of the program" with responses ranging from (4) excellent to (1) poor.

2.2.3.3 *Preliminary efficacy*

To examine preliminary efficacy, the following indicators of family, mother, and adolescent functioning were examined pre- and post-intervention. They are based on the primary targets of the intervention (see Figure 1). Many of the measures come from the PMP efficacy trial. An extensive process occurred in order to make sure that the items were "reliable, valid, sensitive, age appropriate, and culturally relevant" (Ball et al., 2004). This included using items or scales previously used with African American samples, obtaining feedback from community advisory boards and grade school teachers on the relevancy of the items, and pilot testing the revised scales/items with a group of middle school students. Baseline assessments using these measures assessed current or lifetime (youth sexual activity) functioning. The post-intervention assessment asked participants to respond to their functioning since beginning the intervention.

Quality of **general parent-child communication** was assessed by asking MLH-child dyads to complete a 10-item scale developed for PMP using items modified from a previous scale (Barnes & Olson, 1985). A 3-point response for each item is used—not at all true (1), a little true (2), and very true (3)—for questions such as, "My son/daughter [mother] and I can talk

about almost anything." Three items were reverse-coded; items are summed; and higher total scores equal better quality general parent-child communication. In the baseline sample of PMP, Cronbach's alpha was .79 for parents and .70 for kids (on a briefer-5 item version). This abbreviated version was used with children in the PMP efficacy study as some of the items require a somewhat complex understanding of how a child talks with his/her parent.

Parent-child communication about sex topics was assessed using two scales from PMP (Ball et al., 2004). The first is a 17-item scale (15-item scale for youth) that assessed frequency of discussing sex topics. Two items were originally included that did not relate to sex (i.e., exercise and diet) and were excluded for the current study. Reponses for each item (e.g., "How many times have you talked to [target child] about what sex is?") include (0) "never," (1) "once or twice", and (2) "lots of times." Items were summed with higher scores equaling greater frequency of discussions. Cronbach's alphas for the PMP sample was .91 for parents and .90 for children (however, due to gating, some children received fewer items). Items were also dichotomized to 0 = "never" and 1 = "once or twice" or "lots of times" and summed to create a breadth of communication about sex topics variable. The second scale used to assess parent-child communication about sex topics measured perceptions of MLH responsiveness to this sort of communication. The 20- (parents) or 6-item (adolescents) measure asked parents and adolescents to rate on a 3-point scale ("not at all true," "a little true", or "very true" for parents; "no," "don't know," or "yes" for adolescents) a series of questions such as "If my son/daughter asked me [If I asked my mom] a question about a sex topic, I [she] would get mad or angry." Several items are reversed coded and items were summed to reveal a scale where higher scores equal greater caregiver responsiveness to parent-child sex communication. In modified versions of these scales used in the efficacy trial of PMP, and across four assessments, Cronbach's alpha equaled .80 for

parents and .70 for adolescents (Forehand et al., 2007). Six question yes or no questions were also asked of mothers regarding what topics they discussed with their adolescent that were related to their own HIV status (e.g., "Have you talked to your child about how you were infected?"). These items were summed to create a count variable. In addition, adolescents were given two items related to parent-child communication about sex: "Who would be the first person you would go to if you had questions about sex" and "Where do you get most of your information about sex?" Each allowed one response out of a list of individuals (e.g., mother, father, and friends).

Parent-child relationship quality was assessed using a 12- (parents) or 5-item (adolescents) scale developed for PMP (Ball et al., 2004). On each scale, items had a 3-point response scale, ranging from (0) "not at all true" to (1) "a little true" to (2) "very true." Sample questions were "Mom [Target child] and I spend a lot of time together" and "Mom [Target child] shows me that she [he or she] loves me." Cronbach's alphas for the baseline PMP sample equaled .87 for parents and .77 for adolescents.

Parental monitoring was assessed using items drawn from a previously used scale (K. S. Miller et al., 1999) and adapted for PMP. Five items for MLH and four items for adolescents asked questions related to the amount of time MLH spend supervising their children (e.g., "How often does your parent know where you go when you are not at home; How often do you know where your child is when he/she is not home?). Response options included (0) "never," (1) "sometimes," (2) "a lot," or (3) "often." Responses for each item were summed to give a total score reflecting degree of parental monitoring. In the PMP baseline sample, Cronbach's alpha was .82 and .78 for parents and adolescents, respectively.

To assess **mothers' self-efficacy to continue the disclosure process**, MLH were asked 8 items related to their degree of confidence discussing maternal HIV infection-related topics with their adolescent. These questions were developed for the TRACK program (Murphy et al., 2011). Many are specific to disclosure (e.g., "How confident are you that could disclose your status to your child" or "How confident are you that you can pick a time and date to disclosure your status to your child"). Since MLH already disclosed their status in the current study, items were reworded to reflect ongoing disclosure conversations and the confidence MLH feel in continually talking about their status with their adolescent child. For example, questions asked "How confident are you that you can continue to talk to your child about your status" and "How confident are you that you can answer any questions your child may have about your HIV infection, including how you got it and how long you will live." Reponses ranged from 0 (not confident at all) to 5 (extremely confident).

Adolescents were asked six questions about their **attitudes about sexual risk topics** drawn from a scale created for PMP. Each question start with "It's important that teens…" and end with "… before they have sex." Topics included knowing how to obtain and use condoms, talking to adults and sexual partners, understanding how girls/women get pregnant, and knowing how alcohol and drugs affect decision-making. An additional item was added for this study that asked about knowing the facts of HIV (e.g., how people get HIV). Responses included 0 = "not at all true," 1 = "a little true," and 2= "very true." Items were summed for scale score where a higher score equaled an attitude more consistent with sexual risk reduction. A second scale constructed with items from PMP was also used. It had six items related to how worried adolescents would feel about the consequences of sex if they had sex. For example, one item read, "If I had sex I would worry about getting a disease." Responses also included 0 = "not at all

true," 1 = "a little true," and 2= "very true" and were similarly summed for scale score where a higher score equaled a greater degree of worry about sex outcomes.

HIV knowledge as assessed by asking adolescents 16 yes/no items related to HIV transmission and HIV myths created for a previous adaptation of PMP (Armistead et al., 2014). Sample items included "HIV is transmitted by kissing; … coughing; … by a mosquito that has bitten someone with HIV." Correct items are scored 1 and items that are not true are scored 0. A count variable was created for total number of correct responses.

Pre-coital sexual behavior and sexual activity and intentions was assessed using 35 items developed for PMP. Items began with assessing pre-coital sexual behavior with an adolescent of the opposite sex (e.g., "Have you ever hugged a boy/girl" or "Have you ever willingly let a boy/girl put his/her hands under your clothes? Willingly means you gave permission or said it was OK. It also means you did it because you wanted to, and not because someone made you.") Skip patterns were used to gate out children from answering more sensitive questions about intentions when they answer "no" to the question, "Have you ever thought about having sex with a boy/girl?". Affirmative responses to four items related to sexual intentions (e.g., "I think I'm ready to have sex"; response = "not at all true," "a little true," and "very true") were summed to yield a total intentions score. Those surpassing gated questions were asked about sexual activity (e.g., "Have you ever willingly had sexual intercourse with a girlfriend/boyfriend? Sexual intercourse is when a boy or man puts his penis in a girl's or woman's vagina").

2.2.4   Plan of analysis

Reports on participants' satisfaction and engagement with the intervention were presented for each session to describe acceptability. This included average answers for each item

of the SEF, average engagement ratings (for the session as whole and for each segment of the session), and a summarized description of facilitators' open-ended responses related to participants' engagement for each session. A report of item-level percentages for the CES-8 are also reported to describe participants' overall satisfaction with the program.

Analysis of pre-/post-intervention data for the purpose of establishing preliminary efficacy was mainly descriptive. Means and standard deviations for each continuous variable (parent-child relationship quality, parent-child communication [general and sex-specific], responsiveness to sex communication, parental monitoring, mothers' self-efficacy to re-disclose, and adolescents' attitudes, knowledge, and sexual intentions) at both time points was computed. Rates of pre-coital sexual behavior and sexuality activity among adolescents was examined at the item-level and presented in percentages (e.g., percent of adolescents who have had oral sex). A paired t-test was also conducted to examine the significance of intervention effects on continuous outcomes.

3   RESULTS

3.1   Phase I: Formative Work

3.1.1   Focus groups and individual interviews

Several subthemes emerged from the qualitative data that were used to inform modifications made to the intervention. They are grouped hierarchically under broader themes, which are the intervention targets (e.g., parent-child communication about sex). The subthemes that emerged also provided a specific understanding of the potential barriers to the implementation of the adapted intervention. Examples are given for each theme and subtheme.

Whereas mothers and older adolescents were more vocal, younger adolescents gave shorter responses. This is reflected in the examples presented.

3.1.1.1 Parent-child communication about sex

All mothers indicated that they had talked to their child about at least some topics related to sex, sexual risks, or sexual development. Differences emerged in what topics they discussed, the depth and breadth of their communication, and when and how often conversations occurred. These differences were often shaped by their personal experiences, child gender and age, and broader family factors, such as parent-child relationship quality. In part because of their experiences of living with HIV, all appeared motivated to protect their children from sexual risks and be active in improving their child's health and well-being.

3.1.1.1.1 Mothers' attitudinal barriers to communication
Whereas most mothers had positive attitudes towards communication about sex and sexual risks with their early adolescent children, a few voiced concerns typical among many parents. One was the belief that talking about sex leads to sex. A recently diagnosed 32 year-old African American mother struggled with the idea of giving information about condoms to her 15 year-old son.

> …how do I teach him to, you know. I don't really want to be graphic to make it seem because I'm teaching him this, I'm condoning it. But at the same time, I don't want you to do it and then be clueless about it. So I don't want to condone it but I want you to be safe if you do.

A related belief more frequently reported was that talking about sex should not occur until a child is "ready" to learn about sex and safe sex. Mothers had different opinions about the timing with some having specific benchmarks (e.g., when a girl starts menstruating; when a boy's

muscles develop), and others had more vague ideas of when it should occur. The implicit, and sometimes explicit, assumption was that talking to them too early could lead to increases in curiosity and potentially sexual debut.

A second attitude was that sexual activity as a teenager is scary, an attitude heightened by mothers' personal experiences. Consequently, they wanted to prevent their kids from engaging in sexual behaviors by only describing the dangers of sex. A 42 year-old African American mother most vocally embracing this attitude said the following:

> Well [when] I talk to my daughter and her friends about sex I use scare tactics. And I'm not saying that it's right but that's what I use. I tell her about every disease that there is and I tell her none is small. All of them can cause you to be sterile.

It was difficult to ascertain the influence of this attitude on child behavior. Some adolescents brushed off the warning. Nonetheless, one teen girl said that her parent's use of "scare tactics" caused her to avoid sexual situations.

Another barrier to communication, the most common, occurred in parents who took a punitive attitude towards adolescent sexual behavior, that is, that early sexual feelings are wrong, and teens should be punished for engaging in any sexual behavior. Many times this belief was connected to teenage pregnancy. It was unclear whether mothers actually had punitive attitudes towards sex or whether it was just their child's perception; youth were more likely to report this maternal attitude than mothers. Regardless, such attitudes led to teens avoiding or fearing conversations with their mothers. One 15 year-old African American girl felt frustrated by not being able to talk to her father or HIV-positive mother about sexual urges.

> Participant: … all she told me was like: "I know your body changing." Like, 'cause she told me that she don't have a feeling, 'cause I told her that girls my age have the feeling

to have sex. Like, I was like, "because it's like a feeling that goes on, like…" And she

was like, "I never had that feeling before." Because… she started having sex when she

was 12, so I was like, "maybe cause you started too soon." But I know I have a feeling,

but I just don't do it, I just take showers and stuff to get [rid of] it. Like, it's a physical

feeling, but she don't understand.

Interviewer: So who do you talk to about having urges in your body?

Participant: I told her, but she don't understand! So, I told my dad, no, she told my dad,

and he flipped out about it. He was like, "Just hop your butt in the shower! You don't

need to do that!" And all of that. And I was like, "OK."

Interviewer: So what do you think? Is that working for you?

Participant: No, 'cause the feelings, like, the feelings like disappear but then they came

back this morning. I'm like, but I don't talk to nobody about it.

As shown, her attempts to talk with her parents left the girl feeling confused by sensations that

are a part of typical adolescent development and closed the door future discussions.

3.1.1.1.2 Mother and child comfort with sex communication

Many, but not all mothers, reported feeling at least fairly comfortable with having

conversations about a sex with their adolescent child. As a 51 year-old African American mother

with a 10 year-old child said, "It's not hard for me to talk to my daughter. I don't go too far

because she's so young. I try to keep it age-appropriate with her." Although mothers said they

talked about a variety of topics, it appeared they were most comfortable with talking about

sexual risks. For example, parent-child communication about condom use was more prevalent

than discussions about topics related to puberty, except perhaps menstruation (girls only).

Mothers said they were motivated to have these conversations because of concerns related to

teenage pregnancy and sexually transmitted infections. Across gender and age, many youth confirmed that they had talked to their moms about these topics.

As is typical of adolescents, children of MLH expressed discomfort with such discussions about sex. The most commonly cited reason was simply that it was or would be awkward. When responding to the question what made it uncomfortable to talk to their moms about sex, youth would say things like "I don't know, it's my *mom* " or "'cause she's my mom." For some, their comfort was also influenced by their fear of negative repercussions such as being punished or yelled at, as mentioned previously.

Although in general, children were less comfortable than mothers with this sort of communication, there were within group differences; namely, boys expressed more discomfort than girls. The gender difference was reported by both mothers and adolescents. Consistent with the literature (Wilson & Koo, 2010), the group with the most open and comfortable communication was mothers and older (13 to 15 years-old) adolescent girls. Even though she indicated that she was extremely angry with her 13 year-old daughter for having sex, a fact confirmed by her daughter, a 36 year-old African American mother was also proud that her daughter was comfortable enough to talk to her about it. Daughters also revealed their comfort. As a 15 year-old put it, "I don't really mind 'cause I feel like I pretty much can talk to her about most of everything." This attitude was different for young girls. The two youngest adolescents (10 year-olds) in the study were both girls and neither reported feeling comfortable talking with their mothers about sex.

Despite a desire to keep them safe, for mothers, talking with boys about similar issues was harder. Referring to her 15-year-old son, an African American mother reported feeling unprepared and uncomfortable when it came to discussing condoms with her son.

…for a female it's hard for me to talk to my son about sex because I don't just want to

just talk to you about it. You know, "okay, lets make sure you have the right condoms

size; let me make sure you're putting it on correctly." And, you know, he's not going to

want to show me all this.

The majority of boys expressed similar difficulties. Even though they said they could talk to their

moms about most subjects, "male stuff" was different. Not all boys had this sort attitude, and at

least one said he was comfortable with talking about sex with his mother; however, he still

seemed reluctant to initiate the talk. As he put it, "I wouldn't ask her but like you know if it come

up… [he would talk about it]."

Regardless of their comfort with mother-son communication, most boys indicated a

desire to talk with men about sex and sexual development issues; however, few reported that

they did. A second source for information, which was less favorable than talking with a man,

was another adult woman. Two male teens in the study, 14 and 15 years-old, reported feeling

more comfortable talking with a grandmother and a female family friend, respectively, than with

their mothers.

3.1.1.1.3 Protective effect of status on communication

A proposed strength of MLH is their knowledge and experience of living with HIV,

which can be used to shape their children's attitudes and behaviors in a way that prevents youth

HIV infection. Indeed, MLH had unique perspectives on the topics of sex, sexual risks, and

sexual development that, more often than not, they reported increased their motivations to keep

their kids safe from HIV via parent-child communication about sex. A few mothers were also

motivated to keep, not only their child safe, but also their community. They engaged in work

with non-profit organizations, attended support groups, and were active in community events

such as the Atlanta AIDS Walk. Sometimes their children were engaged with these activities too.

Many mothers voiced concern for their children not to engage in risky lifestyles or behaviors, as they had done when they were younger. This included a desire to inform their kids about the dangers of drug and alcohol use and unsafe sex. Consistent with prior reports (Murphy et al., 2011), some mothers were aware of their ability to protect their children from these risks through sharing their experiences with them, and they cited living with HIV as the impetus for becoming more protective of their child's well-being. They made statements such as "I don't want my daughter to end up like me" and "[I don't want my child to] be in my predicament." Some mothers were even thankful they were living with HIV for this reason. A 59 year-old grandmother with a 15 year-old granddaughter said the following.

> You know, but I'm glad that... I guess in a lot of ways, I'm glad that I got HIV. I can teach her, you know, how I wanted her to be instead of how she should be or how I was, you know, because I mean, well, I started having sex late… but it was like once I got a taste of it, that was it.

Mothers varied in how much detail they gave their child about how they were infected. Although mode of HIV transmission was not explicitly queried by facilitators, most mothers seemed to have been infected via sexual contact with one, possible two, exceptions—one mother said it was through a blood transfusion, another was not sure if it was through sex or injection drug use. Child age was a factor, with older youth getting more information about their mothers' experiences than younger youth. Mothers who disclosed less information usually were worried that their child was not old enough to hear about it and made statements such as "I just don't wanna put too much on her." Those who went into more detail often did so as a way to prompt discussions about sexual risks. One 46 year-old African American mother said, "That's why when I told her, I told her all the different ways you can get it and how you can contract HIV."

Another African American mother, age 32, was asked if her son had questioned her about how she was infected or if she wanted him to know and initiated the conversation. She responded:

> I wanted them to know 'cause I tell my son if you gonna be sexually active come to me. There are certain things that I can teach you. I know I am not your father…I can't teach you what a man can teach you but I can teach you what I can teach you as a woman. I can't give the father figure thing. I don't know how to be a man. I don't know how to teach you what a man can teach you so I can only teach you what I know.

This passage also highlights the openness to sex communication that a few mothers had with their sons. In addition, it is an example of how these mothers persisted in having such discussions despite perceiving obstacles related to parent-child gender differences.

3.1.1.1.4 Association with relationship quality

A few adolescents indicated that talking to their mothers about sex would be easier and they would feel more comfortable doing so if they had better communication about other topics with their mothers, in addition to a better parent-child relationship. Both factors were additional targets of the intervention (see below), and thus these children's statements were in line with the assumption that greater family functioning, in general, would lay the foundation for an increased willingness on the parts of both parents and teens to discuss sensitive topics, such as sex, sexual risks, and sexual development. For example, a 15 year-old African American girl said, "I probably end up telling [about sex] when I'm ready… if we get closer," and an 11 year-old African American boy insisted that it would be easier to talk to his mother about sex topics "if… we like bonded more."

3.1.1.2   Parent-child relationship quality and communication (general)

These targets for the adapted intervention are grouped together here because of their overlap. It was also difficult separating the two during data analysis. For example, when asked to describe their relationship or how to improve their relationship, many parents and teens responded in terms of how they communicated (e.g., "we are open with each other").

It was common for mothers and teens to indicate that parent-child relationships were "good." Generally, this occurred in families who spent more time together and had positive interactions, communicated regularly, and had low levels of conflict. Youth commonly responded in terms of the fun activities they did together (e.g, "Me and my mom have so much fun. Every time we go out, we have fun".). A 15 year-old African American boy was asked about his relationship with his mother.

> Participant: She's good.
>
> Facilitator: And why is she good?
>
> Participant: She's fun. Sometimes she gets mad at me when I do something stupid or
>
> wrong… But she's a good parent.

When parent-child conflict arose, it was usually from typical situations such as difficulties with school performance and behavior, and behavior around the house. Conflict over riskier situations, such as stealing and sexual activity, was rarer but also reported. As expected, it appeared that youth had better relationships with their parents when their parents were more involved in their lives.

3.1.1.2.1   "Big Breaks"
Given the high prevalence of substance abuse among individuals living with HIV, it was unsurprising that almost half of mothers in this study reported a history of alcohol and drug-

related problems. Although not directly assessed, it appeared that all but one of in this subgroup of women were in long-term recovery; one was recently recovered. For many, substance abuse problems either directly or indirectly led to a period of physical separation from their child. This included mothers being incarcerated, undergoing inpatient drug treatment, losing custody of their child, or voluntarily having someone else (usually a grandmother) care for their child while they were using, often when they were "on the streets."

In addition to (and possibly because of) the potential negative mental and behavioral health consequences of exposing children to maternal substance abuse, breaks, or what we termed "big breaks," occurred in the relationships of some mothers and teens. For a few, this was a significant challenge to having a healthy parent-child relationship with good communication. Breaks had similar effects on youth. Some adolescents seemed to be angry and had low levels of trust in their mothers. Others reported a loss of closeness due to a separation. A 15 year-old African American girl responded accordingly to the following questions.

Facilitator: How do you think you could have a better relationship with your mom?

Participant: I don't know. I just don't think it's there.

Facilitator: Do you think the time that you guys had apart that's…

Participant: Affected me. I do. 'Cause when she be like, "Give me a kiss on the cheek," I be like, "No." But she my momma so I don't know why am I feeling that way?

Mothers also felt the challenges of repairing relationships with their children after periods of separation. One 49 year-old White mother was in prison for 11 years before getting her daughter back, who was 15 years-old at the time of the study and also interviewed. She talked about how she was learning to be a parent again. In describing how she was trying to foster a new relationship with her daughter, she said the following:

…she just got all this anger and I asked her one day I said, "Are you mad at me for

something? Tell me. Get it out." And she couldn't tell me. She said, "I just don't wanna

talk about. I just don't wanna talk about it." And she just, I mean, they're just like

holding this in and just like lashing out at everything, doing everything, just going wild.

Her response echoed the attitudes of some adolescents. Whereas they were able to discuss, to

some degree, sensitive topics like HIV and sex with their mothers, conversations about these

breaks seemed to be harder for them, likely due the emotional pain they brought up. Regardless

of such difficulties, mothers with histories of child separation were optimistic about mending

relationships with their children and were motivated to do so.

3.1.1.2.2   Teen suggestions for improvement

Near the end of each interview, youth were asked if they had suggestions for how they or

other kids with HIV-positive mothers could have better relationships with their mothers. Many

offered advice. A common theme was that mothers spend more time with their teens doing

activities such as having dinner, playing sports, and going to the movies, mall, or amusement

park together. Some specifically wanted more one-on-one time with their mothers. It was

somewhat surprising to hear this suggestion from youth regardless of child age and gender.

The second most commonly expressed idea was related to communication. Many youth,

particularly girls, believed mothers and teens should be more open with each other. A biracial 15

year-old girl said the following when asked how HIV-positive mothers could get along better

with their teen children.

Mostly trying to be open and honest… Usually it's kinda hard cause kids like they feel

kinda like sometimes they're not able to talk to their parents. And like their parents

should kinda make them feel more comfortable with being able to talk to them and being

open and like just being honest.

A final suggestion was voiced by an African American 13 year-old girl who seemed to have been exposed more than others to her mothers' substance abuse. She touched on the negative impact of her mother's behavior on her own behavior and their relationship. When asked how mothers could get along better with their teenage children, she said the following:

> If they [mothers] could try to change their ways too. Like they expect us to change. Like when my mom was messing up and stuff, I was like, you know, forget it. I'm making errors, I'm getting in trouble in school, so like, she'll like pay more attention to me.

The teen's description implies that she felt that her mother was a hypocrite. This made it hard for her see her as a role model. This passage also highlights the negative impact of maternal substance abuse on child behavior (i.e., school difficulties).

3.1.1.2.3 Influence of maternal HIV infection

Maternal HIV infection seemed to vary across dyads with respect to its effect on parent-child relationship quality. A few mothers stated that, when first diagnosed, they avoided contact with their children for fear of infecting them; however, overtime, this fear and behavior went away. A common youth response reported by mothers and teens when mother-to-child disclosure occurred was children starting to try to care for their mothers, a response previously studied (Tompkins, 2007). One mother called her child "mommy's little nurse." Prompted by worry, youth reportedly reminded their mothers to take HIV medication, reviewed their HIV lab work, and helped around the house. Some MLH said this brought them closer to their children. In one family, the teen girl seemed to be overly worried and invested in her mother's well-being.

A second youth response, indicated by the 32 year-old African American mother of two teens who was diagnosed a few months prior to the focus group, was different than most others. She felt as though her infection—discovered after it had progressed to AIDS and led to a two month hospitalization—caused a significant disruption in her relationship with her 15 year-old

daughter and 14 year-old son. According to her, they became more distant and began acting out. The mother indicated that when she first found out, the teens had to live with a relative, and she was afraid to let them visit her in the hospital. She attributed relationship difficulties to this period of time, as she believed they felt abandoned. She also believed that her lack of HIV knowledge and inability to communicate about HIV effectively with her children contributed to disruptions in their relationships. She stated the following.

> We were always like really close 'cause I was a single parent so it was just me my son and my daughter. But then when we, when I was at the hospital I realized I wasn't going to be getting out any time soon and so you know my kids they were moved out of their schools…so everything kinda shifted for them. And then it was to the point where I really didn't want them to come visit me at the hospital because I'm so used to them seeing me a certain type of way that I didn't want them to see me with all the IV's in and the machines in. … I couldn't really interact with them so now we're trying to rebuild the bond but I think I freaked them out.

3.1.1.3   Discussion of mother's HIV status

A new core component of the adapted intervention is parent-child communication about maternal HIV infection. To gain an understanding of this topic, we asked mothers and children to describe the initial disclosure event and its impact on child and family functioning, how often they have talked about the mother's HIV infection since the initial disclosure, and the potential barriers to and facilitators of this sort of communication.

3.1.1.3.1   The impact of disclosure
Many moms struggled with the decision to tell their child. Commonly cited reasons against disclosure were that their child was not old enough; they did not want to upset or scare

their child; or they felt their child would reject them. However, no mother expressed a significant amount of regret for disclosing, although some were regretful about how they disclosed (e.g., inappropriate timing).

Children reacted to the initial disclosure event in different ways. Some mothers said their child "brushed it off" and did not react much; others said their child was very upset. Different reactions were reported among children with a few confirming their mothers' report of it being "no big deal" to them, while others indicated that it led them to feel sad, angry, and/or shocked. No child expressed being upset in hindsight that their mother had told them. One even reported feeling relief. As indicated below, however, it seemed children often felt (and have continued to feel) worried about their mother's health, including being fearful of her death.

For some, because of how the disclosure took place, their worry was likely amplified. One 13 year-old girl said her mother impulsively told her when the mother was intoxicated, about three months prior to the interview. She stated, "…she [the mother] was like 'You know, I'm HIV positive.' And she was like, 'I probably don't even have that much time to live.'" Unsurprisingly, the child reported feeling sad and thought about her mother dying "now and then."

Previous parent-child separations also likely influenced how children reacted. A 49 year-old African American mother said the following.

> … he gets attitude. Someone brought it to my attention. It's like, "well, you know, you
> was in his life for 12 years on and off, maybe he don't want to think about it 'cause he's
> so afraid that it might bring thoughts of him losing you." But I don't want him to think
> that way, you know…And I don't want him to have to fear like that. And then recently
> you know he's always been up under my mom, me, or my niece but he don't hang out

with his friends and he always just want to be right there watching me. And I'm so afraid

it's because of fear.

Typical of others with this awareness, this mother had a desire to reduce her child's fear. The

passage also shows the dialectic that existed for a few youth: anger and frustration towards their

mother on the one hand, clinginess and worry on the other.

3.1.1.3.2 Continuing the disclosure process

Participants ranged widely in how often they reported having continued discussions about

maternal HIV infection. Discrepant informant reports were also observed; mothers were more

likely than youth to report having repeated conversations. A significant minority of teens said

that after their mothers had told them, they rarely, if at all, had talked about it again. For

example, one 15 year-old adolescent boy indicated that his mother told him when he was eight

years-old, and that was the last time they spoke about it. Conversely, some families seemed to

talk about it much more frequently.

Mother who indicated having more frequent conversations with their child appeared that

to have ample HIV-related support and were more open about their status in general. As

previously discussed, some mothers wanted to share their experience of living with HIV in order

to protect their child from sexual risks. A desire to protect the child motivated continued

conversations about the topic. For example, when asked about the frequency of talks related to

her HIV-related experiences, a 59 year-old African American grandmother responded, "Oh, I

talk to them about it all the time. Because she's coming up on that promiscuous age."

Mothers who talked less frequently about their HIV status indicated why this was the

case. Some believed that their child had no need for more information. One 46 year-old African

American mother of a 12 year-old son reported that her 23 year-old daughter also lived in the

house and was positive too so HIV was "normal around our house." Thus, she did not feel the

need to talk about it more with her son. Families with less frequent discussions were more isolated and less open about the mother's HIV status than other families. An 11 year-old had this to say when asked how often, after their initial talk, she and her mother discussed the mother's experience of living with HIV.

>Participant: Well we talked about it a couple of days ago when she told me you guys were coming to talk to me about [it]. She was like, "they are going to ask you some questions like about what HIV is and what it does to you, and how you can get it and stuff." I was like, "okay, well just tell me what the stuff is so I can at least be productive" 'cause I didn't know what none of it was.

>Facilitator: When else have you talked about it?

>Participant: Well that's pretty much it, we really don't mention it like that.

>Facilitator: So you don't really talk about it that much?

>Participant: And very few people in my family know it.

Finally, a few mothers felt they had already answered all the questions their children had about their illness, and, therefore, they discontinued discussions about it. Moreover, because their children seemed less distressed about the infection than they did immediately following the initial disclosure, mothers did not feel the need to help their child cope with painful emotions, nor did they want to bring up past painful emotions. As a 46 year-old African American mother said, "It ain't facing her, you know, right now."

Differences also arouse in how much detail was given to children by their mothers related to their infection. Mothers who had more frequent conservations also provided more detail, compared to mothers who had less frequent conversations. Many, but not all, told their child they acquired HIV via unprotected sex. One mother did not want to share this information because

she feared her child would be angry at his father who infected her. Another mother told her child the various ways a person could get HIV but did not disclose how she acquired it. Details on topics such as HIV transmission (in general), whether the child could get HIV from the mother, mother's health status, and mother's HIV medical treatment were more likely to be given than other details (e.g., how the mother was infected; what it's like living with HIV). Similar to hesitations about the initial disclosure, mothers cited reasons for not disclosing more detail—for example, my child is not ready or the right age; I do not want to burden the child; and, I want to keep some information private.

In addition to facilitating talks about HIV, mothers' HIV status was linked to a greater degree of knowledge related to sexual risks and sensitivity to these risks. Mothers were highly aware of modes of HIV transmission, sexual risk factors, and, not surprisingly, the medical and psychological consequences of living with HIV.

3.1.1.3.3   Child comfort

Many teens felt at least somewhat comfortable discussing their mother's HIV status, however, for many, similar to the topic of sex, they were reluctant to initiate the conversation. Child comfort was influenced by mother's degree of acceptance towards living with the virus. An 11 year-old African American girl shared her insight into what made it easier for her to talk to her mother about her mother's HIV infection. She noted, "I don't think [she has] a problem talking about it, but if she did, and I thought that she did, then I wouldn't be able to talk about it." Similarly, children in families in which HIV was less of a secret and the mother was more open about her status felt more comfortable discussing it further.

Similar to conversations about sex, and perhaps for similar reasons, boys were more uncomfortable discussing their mother's experience of living with HIV than girls. They had difficulty in elaborating their feelings about the topic. When asked what made it uncomfortable,

an 11 year-old boy mentioned the difficulties in "talking about like guys and like that she meet and stuff" and stated that "every time when she met someone and wanted to go out on a date I was like 'no, don't do that' and stuff." It appeared he was making the connection between HIV and his mother's sexual behavior. Two older teen boys stated that they actively resisted discussions with their mother because of their discomfort. Referring to his mother's insistence on discussing HIV with him, one of the African American teen boys (14 years-old) had this to say.

> Participant: Like [she] tried to sit me down and have a conversation and I just tell her, like, I just don't feel like talking about that.
>
> Facilitator: Does that work?
>
> Participant: Mhm [agreement], she tells me like cool but you need to know about it. I'm like…But if I wanted to know about it, I wouldn't want to know from you. Like telling me that is kinda uncomfortable.
>
> Facilitator: … who would you want to get information about it from?
>
> Participant: Anybody, anybody but my mom. That's like, that's awkward conversation.

The second teen (15 years-old) with a similar attitude revealed how these conversations could affect a teen's relationship with his or her HIV-positive mother. When asked how discussions about HIV could be easier and more comfortable, he stated:

> I mean it's really up to that teen if he wants to talk to his mom about it. I mean I think they should have that conversation. I mean if he really doesn't feel comfortable having that conversation, I think [the mother] really shouldn't bring it up or even have the talk with him 'cause it's just going to make him more distant from you. He's not gonna wanna even like be in the same room as you if you want to keep bringing it up.

Despite his resistant attitude, it is also apparent that he acknowledged the importance of having at least some knowledge and communication about maternal HIV infection.

3.1.1.3.4 Protective effect on adolescent risk behavior

A few older female adolescents indicated that because they were aware of their mother's status, had information about the virus from continued parent-child discussions about HIV, and witnessed and heard about their mother's experience of living with HIV, they had changed their own attitudes and behaviors; that is, they expressed feeling a greater need to protect themselves from HIV. Similar to an attitude advocated by MLH, they felt a desire to not "follow in the footsteps" of their mother. One African American 15 year-old girl said:

> …it kinda makes me cautious about the things I do, like, and how much I get tested and stuff like that. And it makes me more cautious of like… sex and stuff like that. And it just kinda makes me more knowledgeable about what's going on with her and like, um, like everything that she goes through and stuff like that…And then, like, it makes me, you know, I don't know, it makes me more cautious about what I do, so I won't do the same thing.

Most other youth, however, denied or did not report this sort of impact on their behaviors or attitudes, particular in families where conversations about the mother's experience of living with HIV were less detailed or non-existent or the child was younger and not sexually active.

3.1.1.4 Parental monitoring

Although a decision was made to de-prioritize traditionally defined parental monitoring (i.e., maternal surveillance and control of teens) as an intervention target, observations on the topic were still made. One common attitude among mothers was an intense need to protect their children from the dangers of their communities, including peer pressure. Consequently, most

mothers reported a high degree of monitoring and many identified themselves as being overprotective. Although less frequently reported, some had concerns about their particular neighborhoods, which heightened their protective attitudes. Mothers reported knowing at all times where there child was, who they were with, and what they doing. Some indicated that they did not allow their children to go to other people's homes by themselves; they would not allow sleepovers; and they would always need to meet or talk with friends' parents. Some with younger adolescents, particularly girls, would not allow them out of their sight outside of their home, and only allowed them to play near their home.

Due to the risks that they were exposed to earlier in life, mothers often reflected on personal experiences when discussing this need to protect their children. An African American mother of a 13 year-old explained the following.

> I keep her close. You know, because I know, I grew up with ten brothers. And I left home at 19 to come to Atlanta to go to college. And I've been on my own. I'm 51 now. I've been on my own from 19 to now, and I've had a lot of experiences, you know, and I just keep her close to me. You know, because she can't make decisions like that this early in life whereas a teenager can, you know, right from wrong.

Another African American mother (29 years-old) discussed in detail her own experiences of being a teenager when she was a few years older than her 10 year-old daughter. She said:

> I rebelled. I was hot. I was out there with boys. I did everything I could to piss my mom off. I put myself on birth control at 15, like, you know, I had made up my mind that I was gonna lose my virginity.

She had fears that her daughter would engage in similar behaviors. She went on to say:

You're gonna start to get the feelings… I'm not gonna pretend like it doesn't. So she's going on birth control. But I feel like as far as freedom, I think roughly a 14, 15 year-old should have a little leeway far as, like you drop them off at the movies or something. But for pre-teens no, you're chaperone, like, you're gonna chaperone. But once they're a little bit older, yeah, you give them a little bit more freedom. But you still need to, you know, they need to have cell phones; they need to be checking in with you because, you know, they get that little itch.

While many mothers identified with this sentiment, some were less worried about their children because they saw differences between themselves when they were teens and their children. They often made statements like "thank God my daughter is not like me."

Almost all mothers in the study were unemployed and therefore they spent much of their time at home with their children. This enhanced their degree of monitoring and parental involvement. Moreover, children of the few parents who did work or were in school, typically were engaged after-school programs until the mother came home.

Despite their protective attitudes and behaviors, gaps in monitoring were still reported by mothers. For example, a 36 year-old African American mother indicated that her 13 year-old daughter recently had sex in her apartment while the mother was at a class. Some mothers also struggled with the balance of providing firm restrictions about where a child can go outside of the home versus allowing the child some freedom to go out. One 36 year-old African American mother attributed her own strictness in this regard to her older 20 year-old daughter (not in the study) leaving the family home at age 16. This left the mother feeling unsure about the balance that is needed to raise her younger 15 year-old daughter who was in the study.

Youth typically confirmed their parents' report that their mothers closely monitored their behavior. A couple of exceptions arose, with male adolescents who indicated that they will sometimes lie to their mothers about their whereabouts. When asked what they were doing, for both boys, it was hanging out with friends and playing basketball. They indicated that they lied so that their mothers would not worry. Also, they reported that it was a hassle to consistently let their mothers know what they were doing.

3.1.1.5 *Other considerations for implementation*

Potential contextual influences to the delivery and effectiveness of the adapted intervention were also explored and three subthemes were generated.

3.1.1.5.1 Access to resources
Socioeconomic status was not directly assessed via qualitative interviews. However, as is noted (Table 2), all families were low-income, and many mothers were unemployed. Despite these barriers, families seemed generally adept at navigating government assistance programs to obtain financial and healthcare resources. No family indicated that they were in dire need of financial help. Many mothers had access to resources as a result of their HIV status. For example, non-profit organizations aimed at assisting individuals living with HIV in the Atlanta area, including one specifically for mothers, subsidized safe housings and provided childcare and mental health services. Other mothers were familiar with local events designed to aid individuals in finding these and other services. Mothers less familiar with navigating HIV-related services were typically less open about their status. Similarly, they had less exposure to others living with HIV (e.g., via support groups) who could presumably help them find such services.

3.1.1.5.2 Social support

Mothers ranged in the amount of social support they received—some appeared to be fairly isolated, and others seemed very connected to support systems. Most were the sole caregivers of their child, but some mothers reported other supportive adults in the child's life such as grandmothers and fathers. Families were often their primary source of support. Generally, for most, immediate family members were aware of the mother's HIV status, but mothers varied by which other relatives they told. With a few exceptions of long-term family conflict, typically seen between mothers and their mothers (i.e., the child's grandmother), many mothers reported having good relationships with their family members. However, for some, historically, this was not true. These mothers indicated that some family members initially treated them poorly upon learning they were positive. Overtime, according to the mothers, they gained greater acceptance in their families.

The second most common source of support reported by mothers was support groups. About half of the mothers said they had attended or still attend support groups for HIV-positive individuals. Attending groups, they explained, was most helpful when they were first diagnosed and under a great deal of distress. A few mothers stated a desire to have support groups for mothers or children of mothers living with HIV, however, only one mother stated that she had taken her child or been to such a group.

To assess the degree of HIV-related social support adolescents received, they were asked whom they could talk to about their mother's status. Many could name at least one person, such as an older sibling, father, or grandparent. However, it was common for teens to report that their mothers had not identified which people were "safe" to talk with about it. Only a couple of kids said they were able to talk with their friends. Surprisingly, some adolescents reported that their mother did not tell them to keep her status a secret. Nonetheless, these teens, usually older ones,

indicated that they did not talk to others about it because, for example, it was "family business" and private. Moreover, regardless of having identified HIV-related social support, many teens in the study were unlikely to report seeking support.

3.1.1.5.3 Mothers' trauma history

Although not asked by facilitators, a few women in the study indicated having histories of childhood and adult trauma, such as molestation and sexual assault. Some mothers made connections between these events and parenting; for example, they linked sexual trauma to a strong desire to protect one's child from similar victimization.

3.1.2 Resulting initial intervention

Guided by the data gathered during focus groups and individual interviews, two theories—the theory of planned behavior (Azjen, 1985) and attachment theory (Bowlby, 1969; Diamond, Diamond, & Levy, 2014)—were chosen as overarching theoretical frameworks for the adapted intervention. These theories were used to guide changes made to PMP, including the use of additional intervention strategies. The two theories were selected because they predict changes in parent and child behavior via the family environment in ways that are consistent with the targets of the original intervention. Moreover, they are helpful in explaining the unique needs and strengths of families affected by maternal HIV infection, and how these needs and strengths are related to the program's intended outcomes. For example, the theory of planned behavior posits that the attitudes, norms, and perceived control related to engaging in a specific behavior influence one's intention to engage in that behavior. A goal of the program is to increase parent-child communication about sex. We do this by shaping attitudes and norms which promote communication and by giving mothers opportunities to enhance their perceived ability to communicate. In turn, adolescent children who take on the protective attitudes of their mothers,

are in a family environment that has protective norms against risky sex, and who feel like they have the ability to negotiate risky situations, are predicted to be less likely to engage in sexual risk behavior. Attachment theory (Bowlby, 1969), as it has been applied to working with parents and adolescents (Diamond et al., 2014), is also useful when considering the needs of these families and our intended program outcomes. The theory predicts that adolescents with a secure mother-child attachment and good relationship quality, one characterized by trust, parental care responsiveness, and open communication, are less at risk for HIV infection than youth with insecure attachment, as was the case for some adolescents interviewed. With less secure attachment, it is posited that adolescents will not turn to their mothers for advice (e.g., on how to stay safe from HIV) or want to honestly disclose personal information. They also may not want to spend time with their mothers which limits mothers' abilities to influence and monitor their child's behavior.

These theoretical underpinnings were incorporated into a comprehensive spreadsheet that also included each component of the Parents Matter! Program (PMP) segmented into its intervention targets, materials and activities used, length, and session number. An additional segment was used to note results from the qualitative analysis of focus groups and interviews pertinent to the component. Next, proposed modifications were included such as removing part or all a component, lengthening it, or changing it in a way to be consistent with the qualitative findings. This step involved a consideration of new materials and activities used. As an example, Session 2 of PMP had a component titled, "Parents are Important." Due to fewer and longer sessions in Ms. Now, it was moved to Session 1. The activities in this component originally included watching a video titled "How are your parents important to you," discussing a figure called the Pyramid of Success, and reflecting on proverbs., These activities strived to raise

awareness of the importance parents in the lives of children and enhance motivation to practice protective parenting strategies. From the focus groups, we learned that many MLH had difficult past experiences with their families of origin, as well as current relationship problems with their children. In order to address these issues, we lengthened the section and added a discussion and exercise. Drawing from evidence-based, theory-driven strategies used in Attachment-Based Family Therapy (Diamond, Diamond, & Levy, 2013), parents were asked to reflect on difficulties of their own childhood, in order to garner motivation to change intergenerational patterns of parenting problems, as well to build empathy for their children and began the process of rebuilding the parent-child relationship.

Once the comprehensive "modifications chart" was completed, new intervention manuals were created based on the existing Parents Matter! Program manuals. The manuals were designed not to be read verbatim. Instead, their purpose was to serve as a structure for the intervention and a guide for facilitators. During the process, new materials and exercises were also obtained or created such as a video, role-play scripts, cognitive restructuring exercise, participant handouts, and fact sheets. Next, a PowerPoint presentation to be used for all group sessions was made. The presentation served several functions, such as providing overviews of intervention content, orienting participants to materials, and facilitating activities.

3.1.3   Community Advisory Board (CAB) feedback

Adult CAB members met once for three hours. Members were presented with a condensed version of the intervention. Feedback was requested mainly on its new or modified content, older content considered possibly outdated or irrelevant, appearance, and delivery.

Overall, CAB participants were very receptive to Ms. Now. They liked its name and appearance, connected with its reoccurring themes, and said they found it to be relevant to their

lives. Many confirmed findings observed in the focus groups and individual interviews on topics such as those related to the existence of gender differences in parent-child communication, "big breaks" in the parent child-relationship caused by parental separation and substance abuse, strengths of living with HIV, including how it affects parent-child communication about sex, positive effects of HIV-related social support on mother well-being, children's worry related to mothers HIV status, and how often, and with how much detail, they discussed their experiences of living with HIV with their children. In addition, participants found the old materials and content to still be relevant and useful. Of all parts, they specifically connected to and enjoyed the following: (1) the emphasis that the newly added video ("Many Women, One Voice: African American Women and HIV") had on HIV stigma; (2) the notion that mothers can be "advocates" for child sexual health; (3) the "Pyramid of Success" diagram demonstrating the needs and goals of adolescents; (4) the script created for a section titled "Big Breaks;" (5) the use of a Support Card to foster social support; (6) example thoughts in the cognitive restricting exercise; (7) the pros and cons list of "continuing the disclosure process;" (8) identification of a "safe person" for their children to talk with about their status; and (9) the role-plays involving children asking their mothers personal questions about their past sexual experiences and HIV.

Participants also offered a few specific suggestions for change or improvement. They wanted to include the characteristic of "family values" to the necessary child characteristics part of the "Pyramid of Success" and the child goal of "being a role-model." In the newly added section titled "Big Breaks," they encouraged us to further emphasize the importance of mothers being open with their children and receptive to their needs, despite historically being secretive and closed off with them. CAB members came up with novel strengths of living with HIV not reported in the focus groups. They also volunteered typical questions, difficult ones, that they

were asked by their children related to HIV (e.g., "Why didn't you use a condom?") that could be used in a role-play. One participant noted that the "safe person" in the picture art used in a slide should be changed to be an African American individual. Previous to the CAB meeting, changes were made to a role-play based on a belief that they were too presumptuous of women's sexual behavior. For example, they read a hypothetical situation in which a mother and a father had sex after dating for two weeks and their 15 year-old child asks the mother how long she and the father waited to have sex. On the contrary, mothers thought the scenarios were realistic and added a greater difficulty to the exercise. Lastly, the newly added component titled, "What Does Having HIV Mean to Me," which involved psychoeducation and a cognitive restructuring exercise, was simplified due to participants having difficulty understanding it.

Other suggestions were very helpful but unfortunately not feasible for the current program. For example, one HIV-positive NGO worker suggested that young adults with parents living with HIV be recruited to talk with young adolescents about their experiences with mother-to-child HIV disclosure to provide support.

Two adolescents CAB members were interviewed separately at their homes for about 45 minutes. The intervention structure was explained, and the content was reviewed with an emphasis on the components that would directly affect them (e.g., practicing parent-child communication). Main findings from the previous individual interviews were presented as well.

Both teen members seemed open to the idea of the intervention and believed it was important for teens to stay safe from HIV. However, the 16 year-old adolescent boy was a little resistant to some of the targets of intervention, namely, parent-child communication. For example, when asked if it was important for HIV-positive mothers to talk to their teens about HIV, he replied by saying that he would not mind being asked to talk about it, but that he

probably would not respond to his mother. This was consistent with the difficulty that boys interviewed in the earlier portion of Phase I expressed. When probed further, similar to the individual interview findings, he was unable to identify why he was uncomfortable talking about HIV talks. However, it seemed most related his mother talking to him about her personal experience with sexual risks. As a consequence, perhaps, he had little knowledge of his mothers' experiences of living with HIV, such as how she was infected. When told about the parent-child communication exercises that would occur last session (the home visit), which is related broadly to peer pressure, the teen said he was willing to talk about any topic but that "serious" topics might make him laugh or be harder to talk about. He did, however, note that his mother discussed condoms with him. This is consistent with the finding that mothers are more likely to talk about safe sex and less likely to talk about other issues related to sex, sexual development, or HIV. Accordingly, the teen said it was a lot easier to talk about condoms and safe sex with his mother than it was to talk about HIV. He also confirmed the importance of having someone else he could talk with about these issues; for him, it was his grandmother.

He had less feedback on other topics. He described his relationship with his mother as "good." The only recent conflict between them had to do with his desire to get a tattoo. No significant parent-child separations were reported. When asked about parental monitoring, he said his mother generally knows where he is and whom he is with, and he maintains contact with her via a cellphone. He gave no feedback on the appearance of the intervention or its name and had no further suggestions for intervention content.

The 15 year-old female CAB member also said she had a good relationship with her mother. She said she enjoyed spending time with her (e.g., by having a "girls' day out") and reported that they rarely had conflict. She also revealed that they communicate frequently about

a variety topics. The teen CAB member's reflection on her mother's HIV status was consistent with the qualitative findings. She expressed feeling "shocked" when she first found out three or four years ago but no longer felt that way. However, she said she still felt a little worried about her mother's health. Unlike the teenage male CAB member, she said she talked "every now and then" about her mothers' HIV status with her mother. She also expressed feeling comfortable with having these conversations. Further, she was knowledgeable about her mothers' status and experience of living with HIV. In addition to HIV, the teen also reported that her mother had spoken with her more than once about sex, safe sex, sexual development, and her mother's sexual values (e.g., waiting until marriage to have sex), a much broader range of topics than reported by the teen boy CAB member. It was therefore unsurprising to hear that this teen would feel comfortable talking about "anything" with her mother during the parent-child intervention session. However, she had no particular topics that she wanted to discuss.

When asked about HIV secrecy, it appeared that her mother was very open in general about her status. Her mother received many HIV-related services and participated in HIV support groups and programs. The teen said she could talk to her other family members including her sister and aunt about her mother's status. Consistent with other adolescent interviews, the openness mothers had with their HIV status and their level of HIV-related support likely influenced how comfortable children felt in talking to their mothers about HIV.

This teenage CAB participant's suggestions were generally similar to ones given during individual interviews with teens earlier. Parents should be aware of peer pressure that teens face, and MLH should communicate more frequently with their teens in order to have a better relationship with them.

After CAB feedback was gathered, final changes were made to the intervention. Table 1 shows the core components of the Parents Matter! Program (PMP), their descriptions and theoretical support. Included in this chart is a summary of modifications or additions made to PMP in the adapted Ms. Now program. These changes were reflected in the finalized intervention manuals and PowerPoint presentation.

Table 3.1 *Modification of Parents Matter! Program (PMP) Core Elements to Create Ms. Now*

Core Elements of PMP	Description	Theoretical Support	Changes Made Based on Formative Work	Measure(s) to Evaluate Preliminary Efficacy
Provide information to increase parents' awareness of youth sexual behaviors	Provide information through videos, mini-lectures, written information, and discussions	Theory of Planned Behavior	Reduce section due to MLH having a high awareness of youth sexual risk behaviors	Attitudes about Sexual Risk Topics (Ball et al., 2004)
Provide information to increase parents' awareness about their important and unique roles as sex educators, as well as to build their confidence	Provide information through videos, mini-lectures, written information, and discussions Provide opportunities for parents to see and practice strategies	Theory of Planned Behavior	None	Parent-Child Communication (Barnes & Olson, 1985; Ball et al., 2004)
Provide parents with information, examples, and opportunities to build positive parenting skills	Provide information through videos, mini-lectures, written information, and discussions Help parents generalize information through discussions Provide opportunities for parents to learn skills through demonstration and practice Model techniques	Theory of Planned Behavior Attachment Theory	Reduce section on parental monitoring because of (1) research suggesting other parenting behaviors are more important in reducing risk such as parent-child relationship quality, and (2) many MLH reported sufficient monitoring	Parent-Child Relationship Quality (Ball et al., 2004); Parental Monitoring (Miller et al., 1999); Parent-Child Communication (Barnes & Olson, 1985; Ball et al., 2004)

	through interactions with participants			
Provide parents with information, examples, and opportunities to build skills and confidence necessary to communicate with youth about sexual issues	Provide information through videos, mini-lectures, written information, and discussions Provide opportunities for parents to learn skills through demonstration and practice	Theory of Planned Behavior Attachment Theory	Add discussion questions that help MLH think about how living with HIV affects their sexual values and communication with youth about sexual issues; Add examples of "teachable moments" related to HIV that lead to parent-child discussions about sex to enhance this type of communication	Parent-Child Communication about Sex Topics (Ball et al., 2004); Responsiveness to Sex Communication (Ball et al., 2004)

Proposed New Core Elements of Ms. Now	Description	Theoretical Support	Changes Based on Qualitative Findings	Measures to Evaluate Preliminary Efficacy
Provide parents with information, examples, and opportunities to build skills and confidence necessary to communicate with youth about their experience of living with HIV (i.e., continuing the disclosure process)	Provide information through videos, mini-lectures, written information, and discussions Provide opportunities for parents to learn skills through demonstration and practice Model techniques through interactions with participants	Theory of Planned Behavior Attachment Theory	Add new sections that aim to (1) reduce negative HIV-related cognitions; (2) raise awareness of the importance of communicating about HIV with youth; (3) provide MLH with HIV knowledge; (4) improve self-efficacy related to continuing the disclosure process; and (5) address the need for a safe adult that youth can talk to about their mother's HIV status	Disclosure Self-Efficacy (Murphy et al., 2011)

Provide parents with information, examples, and opportunities to further strengthen the parent-child relationship and mend disrupted relationships	Provide information through mini-lectures, written information, and discussions Provide opportunities for parents to learn skills through demonstration and practice Model techniques through interactions with participants	Attachment theory	Add new sections that aim to (1) build empathy in MLH for their child's experience of disrupted attachment, and (2) increase conversations about topics related to disrupted attachment (e.g., loss of custody, substance abuse, and incarceration)	Parent-Child Relationship Quality (Ball et al., 2004)

3.2   Phase II: Feasibility of Ms. Now

In this next phase of the study, the adapted intervention was evaluated in terms of its acceptability to participants, defined in terms of retention, satisfaction, and engagement, and its preliminary efficacy.

3.2.1   Acceptability

3.2.1.1   Retention

Retention was high. Attendance for each session was as follows: session 1 (92%), session 2 (75%), session 3 (83%), and session 4 (100%; M percent of retention across sessions = 88%). Participants said they missed sessions because of family emergencies, doctor's appointments, and new job requirements. Eight out of 12 participants (67%) attended all four sessions, and 10 (83%) attended at least three.

3.2.1.2   Satisfaction

Participants reported on their satisfaction using Session Evaluation Forms (SEF) after each group meeting and home visit (Table 2). As shown, participants rated each session highly. Among other qualities, they perceived it to be enjoyable, interesting, and relevant. It was noticeable that participants on average found Session 3 the most satisfactory.

Table 3.2 *Average Satisfaction Ratings By Session Based on Session Evaluation Form*

Item	Session *M* (*SD*)			
	1	2	3	4
Learned a lot	1.09 (.30)	1.22 (.44)	1.00 (.00)	1.17 (.39)
Able to apply	1.36 (.50)	1.22 (.44)	1.10 (.32)	1.08 (.29)
Given an opportunity to participate	1.09 (.30)	1.22 (.44)	1.00 (.00)	1.08 (.29)
Well organized	1.00 (.00)	1.22 (.44)	1.00 (.00)	1.08 (.29)
Interesting	1.09 (.30)	1.11 (.33)	1.00 (.00)	1.08 (.29)
Presenter stimulated my interest	1.18 (.40)	1.11 (.33)	1.00 (.00)	1.08 (.29)
Relevant	1.09 (.30)	1.22 (.44)	1.00 (.00)	1.08 (.29)
Enjoyable	1.09 (.30)	1.22 (.44)	1.00 (.00)	1.08 (.29)
Would recommend to others	1.18 (.40)	1.33 (.30)	1.00 (.00)	1.08 (.29)
Comfortable	1.18 (.40)	1.22 (.44)	1.00 (.00)	1.17 (.39)

Note: *N* = 11, 9, 10, and 11* for Sessions 1, 2, 3, and 4 (home visit), respectively.
1 = *Strongly Agree*; 2 = *Agree*; 3 = *Disagree*; 4 = *Strongly Disagree*.

Following the last session, participants indicated their overall satisfaction using the CSQ-8 (Table 3). Although all participants completed the last session, one did not complete the CSQ-8 due to an error. Similar to their evaluation of individual sessions, participants rated the program as highly satisfactory. For example, 91% answered the following question, "How would rate the quality of the program?" with the response "Excellent."

Table 3.3 *Participant Satisfaction with Ms. Now Based on the Client Satisfaction Questionnaire*

Item	N (%)
How would rate the quality of the program?	
Excellent	10 (91%)
Good	1 (9%)
Fair	0 (0%)
Poor	0 (0%)
Did you get what you wanted from our program?	
Yes, definitely	9 (82%)
Yes, generally	1 (9%)
No, not really	1 (9%)
No, definitely	0 (0%)
To what extent has your program met your needs?	
Almost all of my needs have been met	7 (63%)
Most of my needs have been met	4 (37%)
Only a few of my needs have been met	0 (0%)
None of my needs have been met	0 (0%)
If a friend were in need of a similar help, would you recommend our program?	
Yes, definitely	10 (91%)
Yes, I think so	1 (9%)
No, I don't think so	0 (0%)
No, definitely	0 (0%)
Has our program helped you to deal more effectively with you or your child's problem?	
Yes, it helped a great deal	8 (73%)
Yes, it helped	3 (27%)
No, it didn't really help	0 (0%)
No, definitely	0 (0%)
In an overall general sense, how satisfied were you with our program?	
Very satisfied	10 (91%)
Mostly satisfied	1 (9%)
Indifferent or mildly dissatisfied	0 (0%)
Quite dissatisfied	0 (0%)
If you were to seek help again, would you come back to our program?	
Yes, definitely	10 (91%)
Yes, I think so	1 (9%)
No, I don't think so	0 (0%)
No, definitely	0 (0%)

3.2.1.3   Engagement

Two facilitators and one group helper debriefed after each group meeting and ranked all participants as a group on an engagement scale, ranging from 0 to 3. On average, Sessions 1 and 2 had an engagement score of 2.60. Session three had the highest engagement score (2.90). Engagement was generally highest in the beginning, decreasing towards the end of each session. Participants seemed more engaged during role-play activities and when the topic was sex.

The facilitator and helper also discussed participant engagement in the fourth session (home visit). Participants appeared very engaged and were willing to complete all components of the session. They reviewed intervention materials, shared personal experiences, discussed previous homework assignments, and seemed motivated to complete the parent-child communication exercises. Whereas the majority of adolescent children were very engaged with this activity as well, a few were less engaged, evidenced by their brief responses to mothers' questions. These teens likely felt the experience was awkward due to the presence of facilitators. Others, however, felt the environment was safer for communication with facilitators present.

3.2.2   Preliminary efficacy

As shown (Table 4), many but not all outcomes shifted in the intended direction; that is, the intervention had the effect of changing parenting practices and child attitudes and knowledge in a direction consistent with youth HIV risk reduction. It was notable that decreases occurred in mother report of responsiveness and communication about sex (breadth), and child report of attitudes (importance). Likely due to sample size, only four changes were statistically significant ($ps < .05$; increased child report of parent-child relationship quality and monitoring) or approached significance ($ps < .09$; increased mother report of monitoring and number of topics related maternal HIV infection discussed).

Table 3.4 *Ms. Now Preliminary Efficacy Outcomes* (*N* = 12 dyads)

	Pre- *M* (*SD*) / Post- *M* (*SD*)	Pre- *M* (*SD*) / Post- *M* (*SD*)	*t*	*p*-value
	Mother	Adolescent	Mother / Adolescent	
Family Variables				
Communication about Sex (Breadth)	13.83 (1.34) / 13.58 (2.07)	11.08 (3.65) / 11.42 (3.50)	.51 / -1.48	
Communication about Sex (Frequency)	23.08 (5.50) / 23.58 (6.02)	17.25 (6.93) / 18.75 (6.78)	-.37 / -1.61	
Responsive to Sex Communication	32.17 (3.51) / 32.00 (4.63)	6.33 (2.42) / 6.75 (2.96)	.12 / -.66	
Communication (General)	14.58 (4.12) / 15.00 (3.44)	5.58 (2.23) / 6.17 (2.04)	-.56 /-1.48	
Relationship Quality	19.50 (4.72) / 20.75 (2.96)	9.75 (2.80) / 10.83 (2.33)	-1.34 / - 3.46	-- /.01
Parental Monitoring	8.75 (2.83) / 10.00 (2.37)	5.42 (1.73) / 9.92 (2.15)	-1.92 / -9.00	.08 / <.01
Mother Variables				
Maternal HIV Topics Discussed	4.75 (1.22) / 5.33 (.78)		-2.03	.07
Disclosure Self-Efficacy	36.00 (7.03) / 38.50 (2.03)		-1.23	
Child Variables				
Attitudes About Sex (Worry)		2.50 (1.73) / 2.83 (1.85)	-1.08	
Attitudes About Sex (Importance)		12.25 (4.04) / 12.17 (3.99)	.22	
HIV Knowledge		10.92 (1.73) / 11.00 (2.26)	-.19	
Sexual Intentions*		4.75 (.96) / 5.25 (1.26)	-2.03	

*n = 4 due to question gating

To explore whether or not outcomes were influenced by intervention dose, a second set of paired samples t-tests was conducted with only participants who had attended all sessions ($n = 8$ dyads). Most effects remained the same with four notable exceptions. Child attitudes (importance) and mother report of communication about sex (frequency and breadth) improved; indeed, the frequency communication variable approached statistical significance $t(7) = -2.30$, $p = .055$. Also, mother report of responsiveness no longer decreased pre- to post-intervention.

Additional parent-child communication about sex items answered by adolescents were examined separately in percentages. When asked who would be the first person they would go to if they had a question about sex, 50% said their mothers at baseline compared to 75% at post-intervention. Similarly, when asked where they get most of their information about sex, 42% said their parents (mother was not an option) at baseline compared to 67% at post-intervention.

Changes in baseline to post-intervention rates of adolescent pre-coital sexual behavior on the following items were reported: having ever kissed a boy or girl increased from 42 to 50%; having ever allowed a boy or girl to put their hands under your clothes remained the same at 17% while having ever put your hands under the clothes of another boy or girl increased from 8 to 17%; having ever undressed to show a boy or girl your private parts or having ever had a boy or girl undress to show you his or her private parts remained the same at 8%; and having ever touched a boy's or girl's private parts or had your private parts touched by a boy or girl increased from 8 to 17%. Because the low rates of adolescents who did not endorse this last item, most participants did not answer sexual activity questions. Of the two teens who were asked if they ever put their mouth on another boy or girl's private parts, neither said they did; however, one said they allowed a boy or girl to put his or her mouth on their private parts. When asked by the computer-assisted questionnaire, this adolescent denied having sexual intercourse (vaginal sex).

At follow-up, no new adolescents endorsed having oral sex and no one had yet to report sexual intercourse.

3.2.3   Qualitative feedback on intervention sessions

Participants were asked what they liked about each group session and what they would change after the session without the facilitators present. Only a couple of changes were requested. Some participants after the third session voiced a desire to have their adolescent children present during part of the group portion of the program. They indicated that they believed it would be helpful for them to learn similar skills (e.g., communication), gain information about HIV, and receive support from other adolescents with mothers living with HIV. The second change indicated by one participant was that the program should include more information as to why some adolescents engage in riskier behaviors (e.g., having sex at a young age) than others. Across sessions, participants seemed very pleased with the program. Comments included statements regarding feeling very comfortable in the session, connecting with the facilitators, being interested by the material, and feeling well-supported by group members.

Mothers and teens were also asked about their experience doing the parent-child communication exercise during the home visit. Most gave positive feedback, such as believing in the importance of having more direct parent-child communication, and none gave negative feedback or suggestions for improvement. Remarkably, despite some feeling seemingly uncomfortable during the exercise, teens indicated that they enjoyed having the conversations with their mothers. Many reported that they typically do not have such discussions. According to some, the format (i.e., direct, one-on-one, conversation) was helpful.

3.2.4 Fidelity

To measure the degree to which facilitators completed each activity of the intervention, a checklist was made for all activities. The group helper kept track of accomplished activities during the session and reviewed the audio-taped sessions afterwards for further accuracy. Overall, the intervention was implemented with high fidelity. Facilitators completed 98% (51/52), 100% (42/42), and 97% (37/38) of the activities in sessions 1, 2, and 3, respectively.

4   DISCUSSION

HIV-negative adolescent children of mothers living with a HIV (MLH) are a population potentially vulnerable to HIV infection. Whereas a growing body of research addresses their risk factors and unique needs and strengths under a lens of HIV prevention (Cederbaum, 2012; Cederbaum et al., 2013; Marhefka et al., 2005; Mellins et al., 2005; O'Sullivan et al., 2005), the development of evidence-based preventive interventions for this group, with one exception (Rotheram-Borus et al., 2006), has not occurred. Results of the current study demonstrated the feasibility of developing such an intervention through a structured process of adaptation. Important themes emerged from the formative phase of the investigation that aided in this process and which are helpful in understanding families affected by maternal HIV infection. As anticipated, MLH seemed well-positioned to serve as a tool for youth HIV prevention but also had challenges influential of family-based intervention targets. Guided by the theory of planned behavior and attachment theory, considerations were made in the development of Ms. Now to strengthen its effects on mother, adolescent, and family factors that are consistent with risk reduction. Its preliminary efficacy was shown via hypothesized shifts in many of these factors from pre- to post-intervention. Due to the high degree of retention, engagement, and satisfaction

of MLH and adolescents in the small pilot test of the program, a larger larger-scale evaluation of its efficacy is proposed.

4.1 Developing Ms. Now

The steps followed during the adaptation of Ms. Now (McKleroy et al., 2006) proved valuable to its development. Information was gathered and analyzed (focus group and individual interviews); modifications were made to intervention content and delivery; and the newly formed Ms. Now program was reviewed by relevant stakeholders to confirm the accuracy of the information previously obtained and to gain additional feedback. Without this structure, critical opportunities to improve the intervention would have been missed. Below the results of the formative work are discussed, including how they were used to aid in intervention development.

4.1.1 Implications of the formative research

4.1.1.1 Parent-child communication about sex

Due to the well-documented benefits of parent-child communication about sex, sexual risks, and sexual development on youth HIV risk reduction, and its significant role in the Parents Matter! Program, much attention was given to the topic during the formative phase of the study. On the whole, MLH were well-versed in sexuality information. Moreover, they used this knowledge to educate their children, primarily for the purpose of keeping them safe. Compared to parents not singled out for being HIV-positive, this is relatively unusual. For example, in a nationwide sample of mothers, a little more than half reported that they had discussed sex with their 10 to 14 year-old child (Wilson & Koo, 2010). A similar proportion of mothers with an early adolescent child in a second study indicated having a discussion about safe sex with their child (Jerman & Constantine, 2010). A lack of breadth of parent-child communication (i.e.,

number of different topics discussed) is also reported among general populations, even among families with middle to late adolescent children (Beckett et al., 2010). Our finding of MLH having a more proactive approach to adolescent sex education, relative to other parents is consistent with previous studies. For example, O'Sullivan and colleagues (2005) addressed this question quantitatively, and found, in a sample of MLH and their 10 to 14 year-old children, that MLH talked more frequently about sex with their children and their children felt more comfortable having such conversations than did families with HIV-negative mothers. Although many adolescents interviewed in the current study still felt discomfort with sex talks, some did not.

As hypothesized, one reason for the apparent high rates of parent-child communication among these families was related to the experience of living with HIV. In part, MLH were motivated to talk about sex because they wanted to protect their children from the same sexual risks they were exposed to as an adolescent or young adult. Similar to other qualitative investigations (Cederbaum, 2012; Murphy et al., 2011; Vallerand et al., 2005), a theme emerged that had do with MLH not wanting their child to "follow in their footsteps." For a significant number of mothers, this could mean alcohol and drug use, incarceration, sex work, early sexual experiences, or other risky behaviors and situations. Moreover, there was an association for some between mother-to-child HIV disclosure and sex communication; that is, the HIV disclosure event was leveraged as a teachable moment for youth about HIV transmission routes and risk factors for infection. Finally, MLH had a wealth of knowledge related to HIV and other sexual risks, likely due to repeated exposure to healthcare professionals, which may have enhanced their communication self-efficacy.

Despite these strengths, MLH also had challenges to discussing sex that were informative of intervention development. First, while the number of sex tops these families discussed was likely higher than in other samples, such talks were still somewhat limited to sexual risks. Some mothers, confirmed by their children, took the approach of using simple and direct commands (e.g., "Don't get pregnant;" "Always use a condom"). Such messages are important; however, a broader discussion that includes other topics like those related to sexual development are likely more effective at reducing risk. Kapungu and colleagues (2010), for example, found a negative association between number of sex topics discussed between African American mothers and their adolescent child and youth risk behavior (Kapungu et al., 2010). A combination of not knowing what to say, not having the confidence to say it, and believing that others (e.g., school) will do it for them, likely contributed to this deficit in breadth. Second, a related challenge was voiced by a small number of families; mothers had a punitive attitude towards sexual behavior and used "scare tactics." In an effort to protect their children, influenced by their own experiences, mothers described only the dangers of sex, and they would get angry (at least according to teens) when children disclosed sexual feelings or experiences. This combination may not be conducive to preventing youth risk behavior. A recent review of threat-based messaging found that threats only work to influence behavior when individuals also have high levels of self-efficacy (Peters, Ruiter, & Kok, 2013). Resisting conversations about sexual behavior that include opportunities to enhance adolescents' self-efficacy to avoid risky behaviors or situations (via role-plays, for example), coupled with the use of sex scare tactics, could leave adolescents feeling helpless to the potential hazards of sexual initiation. Indeed, a study of family communication showed a positive association between discussing only the consequences of HIV and youth sexual risk, whereas discussing HIV prevention strategies demonstrated a negative

association (Nappi, McBride, & Donenberg, 2007). A balance is likely needed for MLH between providing firm rules about sexual activity at a young age, along with appropriate consequences for breaking these rules, and being supportive and open to discussing normative sexual development.

A final challenge to MLH-adolescent discourse found in the formative work was related to gender. Consistent with research documenting child gender-based differences in rates of parent-child communication about sex (e.g., Jerman & Constantine, 2010; Miller et al., 2009), boys received less information about sex and sexual risks than girls. A commonly held belief is that daughters are at greater risk than boys (Wilson & Koo, 2010). However, in the current sample, while to some degree this attitude was also voiced, it seemed gender differences had less to do with a greater desire to protect daughters than sons from risk and more to do with general discomfort with talking to sons. Part of this discomfort was related to self-efficacy. MLHs reported not feeling confident in their ability to approach discussions about sex with sons (e.g., what to say; how to say it). Others have found similar deficits (Wilson & Koo, 2010).

Qualitative findings were used to inform the inclusion of this communication prevention strategy in the following ways. First, because mothers were generally knowledgeable of sexual risks, and indeed some were overly invested in espousing such risks via "scare tactics," intervention portions designed to enhance risk awareness were shortened or removed. Second, to capitalize on their knowledge of sexual risks and previous experience communicating these risks to their youth, and to improve maternal self-esteem and self-confidence, living with HIV was introduced and discussed as a parenting strength, particularly with regard to protecting adolescents from HIV. A section with cognitive restructuring exercise was added to help MLH challenge irrational or unhelpful thoughts related to HIV, parenting, and parent-child

communication. Third, existing strategies (e.g., presentation of research findings; use of puberty fact sheets; parent-child communication exercises) were retained to broaden the number of sex topics discussed in families (i.e., not just the negative consequences of sex) and increase mothers' mother-son communication efficacy. Finally, the notion of finding other supportive adults to talk to one's child was emphasized and put also in the context of HIV-related support. This "safe person" once identified could talk to adolescents about a variety of topics they did not feel comfortable talking to their mother about. Interviewed adolescent boys, in particular, expressed a desire for such an individual.

4.1.1.2   *Parent-child relationship quality and communication (general)*

Confirmed by adolescents interviewed in our study, a good relationship involving trust, closeness, open communication, and mutual respect is the foundation for mothers and teens to discuss sensitive topics like sex and HIV (Henrich, Brookmeyer, Shrier, & Shahar, 2006). Indeed, among MLH and older adolescent daughters in a separate study, relationship satisfaction was positively associated with parent-child communication about sexual risks (Cederbaum et al., 2013). A supportive and responsive parent-child relationship is also related to reduced sexual risk behaviors such as fewer sex partners, later age of sexual debut, and lower rates of unprotected sex (Hutchinson, Jemmott, Jemmott, Braverman, & Fong, 2003; B. C. Miller, Norton, Fan, & Christopherson, 1998; Voisin, 2002). A goal of our adapted intervention was to improve family relationships to prevent youth sexual risk. Despite many mothers and adolescents describing their relationships as "good," a closer examination of their history revealed some serious challenges to teens feeling connected with their mothers.

The separation of MLH from their sons and daughters due to maternal substance abuse or incarceration presented challenges to the parent-child relationship, and this finding led to

significant changes to Ms. Now. Such experiences can have long lasting negative effects on

parent-child relationship quality (Murray & Murray, 2010; Solis, Shadur, Burns, & Hussong,

2012), at least in part due to disruption of parent-child attachment. For instance, infants with an

alcohol-dependent parent, versus infants without a non-alcohol-dependent parent, show higher

rates of insecure mother-child attachment (Eiden, Edwards, & Leonard, 2002). This effect likely

exists with older children and adolescents as well. Young adult children of alcoholics (ACOA),

for example, are more likely to report worse relationships with their mothers (e.g., less trust,

greater alienation, and greater emotional longing) than non-ACOAs (Kelley, Pearson, Trinh,

Klostermann, & Krakowski, 2011). Families with an incarcerated parent demonstrate similar

characteristics (Shlafer & Poehlmann, 2010). Subsequently, insecure attachment during

childhood and adolescence has been associated with a variety of poor mental and behavioral

health outcomes (e.g., depression; Kelley et al., 2011), including HIV risk (Feeney, Peterson,

Gallois, & Terry, 2000).

MLH and some children of MLH also reported adolescent behavior consistent with

insecure attachment. This behavior was linked in part to mothers' HIV status. For example,

children worried about losing their mother (possibly again), either through illness or

abandonment. A few were clingy and acted as caregivers with their mothers, while at the same

time they expressed anger towards them. Many also indicated wanting closer relationships with

their mothers through greater parental involvement and more open communication. These

findings are consistent with a previous study demonstrating lower parent-child relationship

satisfaction among teen daughters of HIV-positive mothers versus teen daughters of HIV-

negative mothers (Cederbaum et al., 2013). Additional research should examine whether or not

and in what way adolescent children of MLH are at greater risk for insecure attachment than other children and how this affects protective parenting practices.

To improve relationship quality, a decision was made to use strategies from an evidence-based intervention designed to repair parent-child attachment difficulties. While Attachment-Based Family Therapy (ABFT) was created specifically to treat adolescent depression, its developers remark on its potential to address other childhood problems via influencing the family environment (Diamond et al., 2013). Indeed, other interventions with this focus are known to reduce adolescent substance use, delinquency, and internalizing problems (i.e., Multidimensional Family Therapy; Liddle, Rowe, Dakof, Henderson, & Greenbaum, 2009). Ms. Now included two components drawn from ABFT. The first instructed MLH to reflect on personal experiences with their parents during childhood that caused them to feel lonely, abandoned, rejected, or sad. The goal was to foster a sense of empathy for their child's experiences and motivate them to take action to repair parent-child relationship disruptions. The second component had mothers review and discuss a printed handout with steps for discussing disruptions. Mothers also had the opportunity to read a script modified from ABFT's manual that involved an MLH discussing with her teenage son a period of time in her life when she was using drugs and her child was living with a grandmother. Although the ABFT manual is more comprehensive than what was introduced to mothers in Ms. Now, its primary intervention strategy is to prepare and facilitate this discussion. The current program strived to introduce mothers to the idea of repairing their relationship and enhance their efficacy and motivation to approach the topic with their child.

4.1.1.3   Discussing mothers' HIV status

Our study was the first to conceptualize mother-to-child disclosure as a continuing process associated with youth HIV risk reduction. The proposed process includes maternal provision of additional information related to mothers' personal experiences with HIV (e.g., how she was infected), repeated parent-child discussions about these experiences, and sharing information about HIV prevention methods. Qualitative findings informed our use of strategies to facilitate this process.

Consistent with prior studies (Murphy, 2003; Murphy, 2008), initial mother-to-child HIV disclosures reportedly occurred in many different ways and had distinct effects on child adjustment. For most families, this event occurred years before their participation in the study, and on average, youth now seemed to be adjusting well (e.g., none reported being very distressed), despite some still feeling worried about their mother's health. They voiced concerns reported elsewhere in the literature, such as fear of their mother dying or getting sick (Vallerand, Hough, Pittiglio, & Marvicsin, 2005). However, their worries seemed less severe than has been previously reported (Vallerand et al., 2005), which is perhaps a consequence of the times—namely, mothers are healthier, and arguably, there is less HIV-related stigma than in past decades. Two teen siblings acted out as a response to disclosure, not an uncommon response (Vallerand et al., 2005; Rother-Borus et al., 1997). They were older when they were told, which others have noted is a risk factor this reaction (Mellins et al., 2005). Their mother's lack of HIV knowledge may have further contributed to them acting out. She had difficulty explaining HIV to her children, and they perhaps felt confused and upset. Making sure mothers had adequate knowledge of HIV and felt confident responding to their child's fears were therefore important aims to address in Ms. Now.

Similar to the initial disclosure event, we found variability in the degree to which disclosure continued in families. One way to conceptualize these differences is by using an approach-avoidance framework. Researchers have noted that individuals living with HIV disclose their status to others based on whether they choose to pursue approach or avoidance goals (Chaudoir, Fisher, & Simoni, 2011). Related to continuing the current disclosure process, mothers' approach goals included wanting to protect children from sexual risks. Consistent with prior research (Murphy, Steers, & Dello, 2001), it was notable that mothers who were more open about their status, in general, and had more social support, often had an approach-oriented style to child disclosures. Many mothers fell into this category. On the other hand, avoidance goals, including a desire to prevent negative child reactions (e.g., getting angry at the father for infecting the mother with HIV; burdening him with uncomfortable information), mirrored what other mothers have stated as reasons against the initial disclosure event (Vallerand et al., 2005). Also, some MLH simply found no reason to continue the disclosure process, which is a novel finding. They felt as though their child had enough information about it. Moreover, it seemed that because their child was not overtly showing signs of distress, as was the case perhaps following the initial disclosure event, these MLH did not feel the need help their child cope with their illness by providing ongoing information.

Adolescents generally felt comfortable discussing their mothers' HIV status with them with the exception of a few adolescent boys. Although it was difficult to unravel reasons for this discomfort, it appeared, understandably, that they equated discussions with their mothers about HIV to discussions about their mothers' past sexual behavior. Interestingly, the boys said it was easier to talk about sex and condoms (related to their own behavior) than their mothers' status.

To our knowledge, ours is the first study to document this occurrence. Most other adolescents were receptive to such conversations; nevertheless, they usually would not initiate the discussion.

Knowing someone living with HIV has been shown to effect sexual risk behavior (Burkholder, Harlow, & Washkwich, 1999). In our study, it appeared that for some adolescents, gaining further information about their mother's status had this hypothesized effect. Because they reflected on their mother's experiences and the consequences of living with HIV, they made decisions to be sexually cautious, such as wanting to get tested if they were sexually active, use condoms, and be more selective in choosing a sexual partner. Other investigations with older adolescent children of MLH have reported similar adolescent attitudes and behavioral intentions (Vallerand et al., 2005; Cederbaum, 2012). Nevertheless, larger longitudinal investigations are necessary to quantify the effect that having repeated and broad conversations about maternal HIV infection, not just a one-time talk, has on youth HIV risk outcomes.

Our intervention attempted to strengthen the family environment in order to encourage a healthy continuation of the disclosure process to produce positive family outcomes. This involved several changes to the Parents Matter! Program. Following the first session, which targeted the broader family context (i.e., parent-child relationship quality and communication, parental monitoring), the second session was largely dedicated to the topic of HIV. First, we incorporated a cognitive restructuring exercise that challenged harmful cognitions related to HIV and parenting (e.g., "My son will never listen to me about HIV"), followed by a discussion of the strengths of living with HIV. Some strengths were elicited from program participants, and others were drawn by facilitators from previous focus groups and relevant research (Siegel & Schrimshaw, 2000). Second, we introduced the idea of continuing the disclosure process. In this section, we started with requesting mothers to reflect on their previous disclosure experiences

and the ways in which they went well and poorly. We then presented research findings showing the negative association between parent-child discussions about HIV and adolescent sexual risk behaviors. In addition, a modified version of a pro's and con's of disclosure list created through previous formative research with MLH and used in an evidence-based mother-to-child disclosure intervention (Murphy et al., 2011) was incorporated. In the third section, we added an HIV knowledge game with updated research findings that would be helpful for mothers to tell children (e.g., the average life expectancy of someone living with HIV). Finally, in the last section, targeted towards enhancing mother-to-child disclosure, we added a role-play exercise previously used (Murphy et al., 2011). It included personal questions that MLH reported were commonly asked by children and were hard to answer (e.g., Why did you get infected?). In this session, we introduce the homework assignment of finding a "safe person" for their adolescent to talk to about their HIV status.

4.1.1.4   *Parental Monitoring*

The provision of parental monitoring, that is, an awareness of where children are when they are not at home or not with their parent, who they were with, and what they doing, is a strong predictor of youth sexual risk outcomes such as delayed sexual initiation (Huang et al., 2011). Focus group MLH and interviewed youth all reported a high degree of monitoring. At least for some mothers, past experiences, including exposure to sexual risks, contributed to them feeling overprotective. Many had strict rules about their child spending time outside the home. Further, monitoring was increased by an unintended side effect of unemployment; mothers spent a significant amount of time at home with their children. Since most mothers were unemployed, on the whole, more monitoring likely occurred in these families than would in others.

A debate exists on the relevancy of traditional conceptualizations of parental monitoring. Some believe they should be redefined to capture the degree to which adolescents freely report their whereabouts to their parents as opposed to parental solicitation of information or the provision of rules related to monitoring (e.g., where a child can go; Stattin & Kerr, 2000). These authors argue that other family variables such as parent-child communication, relationship quality, and attachment perhaps deserve more attention than parental monitoring because they may be good predictors of whether or not children are open and honest with their parents about their whereabouts. For this reason and because many MLH already reported high levels of parental monitoring, the section on parental monitoring in the Parents Matter! Program was removed. In its place, we were able to strengthen the sections on relationship quality, communication, and maternal HIV infection. We did however maintain a brief homework assignment that reminded parents to practice monitoring (i.e., asking kids where they are, who they are with, etc.). Subsequent studies should evaluate the degree to which adolescent children of MLH disclose, without being asked, their whereabouts and whether this is influenced by the other family variables targeted in the Ms. Now (e.g., relationship quality).

4.1.1.5 Other considerations for implementation

As anticipated, other important themes emerged from our qualitative findings which were considered in the adaptation process. First, MLH had limited financial resources. However, all seemed to receive government assistance, and because of this assistance, many did not report serious financial difficulties. Access to healthcare resources were also described as sufficient/present, including mental health counseling for mothers and children. This finding should be interpreted with caution. A second ongoing research study, being simultaneously conducted by our research team that includes a more comprehensive assessment of MLH and

child mental health functioning, has found high rates of depression and suicidality among families, potentially a consequence of low access to effective treatment. To increase access to these resources, a resource list was given to all participants. Given that some but not all participants were "resource savvy," they were also encouraged through the use of a "Support Card" to call each other for support, which could include navigating access to programs offering assistance. Future studies should more comprehensively assess the HIV-related resources available to MLH in order to provide them with referrals.

A high level of social support is a robust predictor of health and well-being (Gielen, McDonnell, Wu, O'Campo, & Faden, 2001), particularly for individuals living with HIV, due to the stigmatizing nature of the illness. Our qualitative findings revealed that mothers generally felt well-supported. Predictably, those with more support were more open about their status. The group format of the focus group offered insight into mothers' degree of openness to receiving HIV-related support from others. No MLH reported feeling uncomfortable. Further, during recruitment, no MLH voiced hesitation prior to participation, and no MLH declined participation due to not wanting to be around other MLH. Many felt it was important to receive support in this format. Despite that a significant number of women had prior experiences with support groups, none had participated in a group specifically for mothers of adolescent children.

There also seemed be a need for additional HIV-related support for youth. Similar to a prior study which found that only 25% of MLH have identified a safe person for their child to talk to about their illness (Murphy et al., 2001), a safe person was not typically named among current families. Surprisingly, unlike older reports (Murphy, Roberts, & Hoffman, 2002), some youth were not told to keep their mother's status a secret; although, none said that they had told others about it. This may reflect mothers' greater acceptance of the disease, perhaps a

consequence of a broader social acceptance and improved treatment of HIV, than has been previously indicated. Identification of a safe person was an added intervention strategy.

A final consideration was mothers' history of traumatic experiences, including victimization. Consistent with prior research (Brady et al., 2002; Gielen et al., 2001), MLH in the current study reported significant traumatic events such as childhood molestation and rape. More women indicated being involved in situations which are associated with high rates of trauma exposure (e.g., sex work). These experiences likely shape how MLH talk with their adolescents about sexual risks. For example, one MLH had said it made her more protective of her daughter and motivated to keep her safe through a discussion of risks. This is in line with a recent study which found that early adolescent children of mothers who had a sexual abuse history reported higher rates of parent-child communication about sex than adolescent children of mothers without a sexual abuse history (Anthony et al., 2014). Nevertheless, exposure to other forms of victimization (i.e., intimate partner violence) and unsafe situations have been found to hinder the effects of family-based HIV prevention interventions on communication outcomes (Tarantino, Goodrum, et al., 2014). Because it was unclear what influence victimization or traumatic experiences would have on the implementation of Ms. Now, and due to its relatively narrow aims, they were not explicitly addressed in the intervention. There were, however, opportunities for mothers to share this information and relate it to current parenting practices. For example, mothers were asked to reflect on personal experiences that shaped the sexual values they want to impart to their child.

4.1.2   Finalization of Ms. Now

The task of summarizing the qualitative findings into suggestions for specific changes to the Parents Matter! Program was complicated. As recommended (McKleroy et al., 2006),

retaining core intervention components was prioritized. In the case of the current adaptation, a new core component (i.e., continuing the disclosure process) was added. The most common and seemingly critical suggestions gleaned from the formative work (e.g., a need to repair disrupted parent-child relationships) resulted in the most significant changes. Less salient suggestions resulted in the least significant changes. All modifications had to correspond to sections that could be delivered within the allotted hours of the intervention. In keeping with relevant theory, decisions about which strategies to use for each new or modified section were made. Also guided by theory, the "flow" of the intervention had to be considered. For example, it was important to address parent-child relationship quality prior to communication about HIV. We recommend that future studies follow our process of adaptation by creating a comprehensive table that lists all sections of the intervention, in order, linking qualitative findings to core components to theory to specific strategies to the goals of these strategies, and finally, to time allotted for each section. It is also recommended that developers rank each qualitative suggestion by its relative importance to the program's intended outcomes.

The use of a community advisor board (CAB) was essential to finalizing Ms. Now. Members were able to verify qualitative findings and confirm our use of new or modified strategies based on these findings. Moreover, because the Parents Matter! Program was created almost two decades ago, it was helpful to have them evaluate the relevancy of materials. They also gave feedback on its presentation. If possible, future adaptations should allow for additional time with a CAB to fine tune intervention content and enhance the community's ownership over the program.

4.2   Feasibility Evaluation

Overall, as hypothesized, based on the collaborative approach to intervention development and adaptation, the 12 mothers who participated in Ms. Now were very satisfied with the adapted intervention. When they learned about the developmental needs of teenagers, expressed the difficulties and joys of being a mother living with HIV, and practiced new skills with the assistance of trained facilitators, they felt comfortable and supported in group and individual settings. It was a completely new experience for all mothers, and they were eager to participate. The goals of Ms. Now fit well with mothers' expectations for the program. We had strong buy-in for the intervention's family-based approach to preventing HIV in youth through strengthening family processes. MLH were open to trying each new strategy, particularly those that involved more active participation such as role-plays. They saved and referred to materials distributed during previous sessions, highlighted topics they found most important, and came prepared with questions about challenges they faced over the course of the week, often ones related to primary intervention targets like parent-child communication. Further, at most times, they appeared very engaged with the content and facilitators. Of utmost importance, it was evident that MLH were forming relationships with each other and intended to stay connected following the end of Ms. Now. Despite the group component consisting of three four hour-long sessions in the middle of a weekday, most MLH made the effort to attend; and those that did not, were in circumstances beyond their control (e.g., death of a family member) and expressed being upset that they missed out. Adolescents of MLH, though involved directly in a much smaller capacity than mothers, also found it be useful, enjoyable, and interesting.

Beyond being acceptable to participants, the pre-/post-intervention assessment revealed promising trends in the effect of the intervention on attitudes, knowledge, and behavior which

are consistent with youth HIV risk reduction. Although statistical significance should be interpreted with caution given the small sample size, significant improvements were demonstrated in child report of parent-child relationship quality and parental monitoring. The first finding is unsurprising given that Ms. Now incorporated evidence-based strategies aimed at repairing disrupted parent-child relationships previously unused in the Parents Matter! Program (PMP), and in general, had a greater emphasis on enhancing relationship quality than PMP. Indeed, no prior outcome studies of PMP or PMP-adapted programs have reported significant intervention effects on relationship quality (e.g., Forehand et al., 2007; Armistead et al., 2014). It is a promising effect. More so than other intervention targets (e.g., parent-child communication about sex), parent-child relationship quality should theoretically have a broader influence on child problem behavior (Ditto et al., 2004; Jessor & Jessor, 1977), that is, behaviors beyond risky sexual behavior.

A significant improvement in child report of parental monitoring is a more surprising finding, because the section on parental monitoring was mostly removed from the program. Two explanations are proposed for this effect. First, MLH were asked to discuss their experiences of living with HIV throughout the program at the same time they were asked to consider youth sexual behavior. For many mothers, this discussion may have reminded them of unmonitored risky situations they faced when they were their child's age, providing the impetus to increase their monitoring practices. The second explanation is related to improvements in parent-child relationship quality. Because teens' trust and understanding of their mothers increased over the course of the intervention, they may have been more likely to freely and honestly tell them their whereabouts when not at home. Honest communication from children regarding their activities is consistent with Stattin and Kerr's (2000) reconceptualization of parental monitoring and studies

testing their framework (Fletcher, Steinberg, & Williams-Wheeler, 2004). More studies that include measures assessing the degree to which children initiate disclosures of their whereabouts to MLH, as well as the truthfulness of such disclosures (e.g., How often do mothers *really* know where you are?), are needed to confirm this explanation.

A third effect that approached significance was an increase in mothers' report of the number of topics related to her HIV status discussed with her child from pre- to post-intervention. To our knowledge, ours is the first intervention to document this effect. The increase may have been mediated by an increase in mothers' self-efficacy to continue the disclosure process, which showed an improvement (non-significant) as well. Our use of strategies drawn from an evidence-based disclosure intervention (i.e., TRACK) likely contributed to mothers' enhanced self-efficacy (Murphy et al., 2011). In the future, targeting additional topics (e.g., mothers' exposure to HIV-related discrimination), as well as the depth of conversations, would further strengthen the continuation of mother-to-child disclosure.

Other results were less encouraging. Unlike the PMP efficacy trial (Forehand et al. 2014), and the increases we found in child report of sex communication, decreases in mother report of parent-child communication about sex (breadth; i.e., number of topics discussed) and responsiveness to sex communication were found. Although these shifts were minor, they deserve attention. One possibility of a negative intervention effect is due to measurement error. MLH reported on having ever (lifetime) talked about each topic related to sex at both time points. An item-level examination of the data revealed that some mothers at Time Two reported not discussing a topic that they had previously discussed at Time One. By definition, any endorsement of communication at time one should also be endorsed at Time Two. If only new topics discussed are considered in the analyses, breadth of topics reported by MLH increases

significantly from pre- to post-intervention. Another explanation for the minor negative shifts in these family variables has to do with ceiling effects. MLH reported high levels of communication and responsiveness at baseline. For example, all mothers at baseline said they talked to their child at least once about sex, covering 14 out of 15 topics on average, over their lifetime. Thus, there was little room for improvement across the two assessments, and by chance, a decrease was also possible.

Mean differences in parent-child communication about sex outcomes in the intended direction grew when participants who had attended all four sessions were examined. Similar to effects found in the Parents Matter! Program trial (Forehand et al., 2007), this outcome might be influenced by intervention dose. An additional evaluation with a larger sample could clarify what amount of intervention is needed (i.e., how many sessions to attend) in order to induce the intended effects. Ideally, this would be the lowest dose possible to account for attrition.

As hypothesized, adolescents reported more knowledge of HIV facts and a greater degree of worry related to sex consequences following Ms. Now. However, there was a minor decrease in how important they felt it was for teens to gather relevant information (e.g., how to use a condom; facts about pregnancy) prior to having sex. Similar to MLH's report of communication (breadth and responsiveness), adolescents at baseline had very high scores on this attitude scale prior to the intervention, and therefore, the ceiling effect likely contributed to the unexpected change in attitudes. Future family-based interventions with youth of MLH may instead want to address other social cognitions also predictive of HIV risk in this population (e.g., those related to gender roles: Bowleg et al., 2011).

One way to measure the effects of a prevention program like Ms. Now is to assess the absence of behavior over time. Although it was a short interval between pre- and post-

intervention assessments (five to eight weeks), no new adolescents reported engaging in sexual behavior (oral or vaginal sex). There were however a few minor increases in rates of pre-coital behavior, ranging from more (i.e., kissing) to less (i.e., touching a boy or girl's private parts) developmentally appropriate behaviors. In either case, while it would seem that a somewhat noteworthy increase was present (from 42% to 50% and 8% to 17%, respectively), because of the small sample, only one new case reported either behavior. Unfortunately, due to item gating, only four adolescents at baseline were asked items related to sexual intentions. Intentions also showed a very minor and not statistically significant increase.

4.3   Further evaluating Ms. Now: Recommendations for an RCT

The next step in the adaptation process is implementation (McKleroy et al., 2006). The purpose of a feasibility study such as ours is to provide evidence, as we have done, for the implementation of a larger scale efficacy trial (Bowens et al., 2009). An efficacy trial should include several key components. It should be a randomized controlled trial (RCT) large enough to compare the effects of Ms. Now to a control condition on main and secondary outcomes while controlling for a number of individual differences that could influence outcomes, such as demographics (e.g., child gender), child and mother mental health functioning, and family exposure to contextual risk factors (e.g., violence; Tarantino et al., 2014). Baseline, post-intervention, and follow-up assessments of these outcomes should occur over a period of time determined by the likelihood of youth becoming sexually active in order to evaluate the long-term impact of the intervention on program goals (i.e., youth sexual risk prevention and reduction; Figure 1). Almost all adolescents in our feasibility study were not sexually active, and their average age was 12.5. Since over 40% of African American ninth graders have had sex

(CDC, 2013), the follow-up period should be at least two years to be able to assess whether or not Ms. Now participation delays sexual debut.

A larger scale RCT of the Ms. Now program will require substantial time to establish community partnerships for the purposes of recruitment and community buy-in. In the current study, progress towards the adaptation timeline was limited because of difficulties establishing these relationships. Most often we recruited from non-governmental organizations (NGOs). Staff at these NGOs were often burdened by job demands. Appropriately, they were also protective of the individuals they served, which included being cautious of who they referred to our study. The process undertaken by recruitment staff to develop relationships with NGO staff was time consuming and involved contacting staff from different organizational levels, conducting study presentations at NGOs, and having repeated informal correspondence via phone calls, emails, and lunch meetings. One common suggestion for developing relationships with NGOs is to provide services to them or their clients in exchange for participant referrals (Begun, Berger, Otto Salaj, & Rose, 2010). Because of our limited resources, the provision of formal services was not possible. Also, offering direct services to their clients, our potential participants, such as mental health counseling, would have biased the results of our intervention. Creative and immediate ways to give back to NGOs for their assistance with recruitment should be considered. Working with some medical clinics was also a challenge. We found at least one was reluctant to collaborate because of existing relationships with other researchers. In the future, it may be helpful to contact other research teams for the purpose of collaboration and mutual recruitment. Having to get approval from a separate institutional review board (IRB) was also a barrier. Because the process can often take a long time, all IRB approvals should occur prior to the start of the recruitment. In addition, a wide net of diverse recruitment sources (e.g., NGOs,

medical clinics, and advertisements on public transportation) should be established ahead of time in case of one or more fail to meet recruitment expectations, as was the case in the current study. Finally, in terms of recruitment, a form of respondent driven sampling (RDS) is recommended. Due to concerns from our IRB, we were unable to implement this strategy. RDS involves giving a certain number of coupons to each participant. Coupons are then distributed to people they know who may meet eligibility criteria. Participants who recruit others are reimbursed. This technique is particularly useful for hard-to-reach populations, including low-income individuals living with HIV (Magnani, Sabin, Saidel, & Heckathorn, 2005). Researchers should work with their IRB to address concerns (in our case, paying participants to recruit) to generate mutually agreed upon compromises for using RDS.

Due to the structured process of adaptation and feasibility evaluation, only one relatively major programmatic change is recommended for the RCT of Ms. Now. Greater involvement of adolescents should be considered. A decision was made in the early stages of adaptation to exclude adolescents from the group portion of the intervention, unlike the Parents Matter! Program. This was done due to privacy concerns and a need to tailor parent-child communication exercises to be age appropriate. While the latter concern is still valid and could still be addressed via an individual family meeting, the first concern may not be as relevant as previously assumed. Indeed, MLH wanted their children to meet other adolescents in similar situations to gain support from them. They also desired an opportunity for their teens to learn the same material as they had learned. Incorporating an additional child-only group meeting, perhaps run simultaneously and separate from a parent meeting, might accomplish these goals. Unlike the Parents Matter! Program, this child group would be structured with specific objectives (e.g., increase understanding of mothers' HIV status; increase motivation to discuss parent-child relationship

disruptions; increase HIV-related social support; increase facilitator-child alliance). A greater inclusion of adolescents is consistent with strategies used by other evidence-based family interventions targeting parent-child communication and relationship quality (e.g., Diamond et al., 2013; Liddle et al., 2009).

A final consideration for a scaled up trial of Ms. Now is deciding the best way to enhance parent-child communication about sex. Mother and teen participants in our current study reported discussing a high number of topics related to sex, approximately 14 out of 15 (mothers) and 11 out of 13 (child), and discussed these topics with moderate frequency. This is clearly a strength of HIV-affected families, and was not seen in other studies (Forehand et al. 2007; Armistead et al., 2014). Less consistent across family members was their report of parental responsiveness to sex communication. Whereas mothers' indicated high levels of responsiveness, youth reported only a moderate degree of responsiveness. In other words, mothers felt they were open and receptive and did not have a punitive attitude during discussions about sex. Many teens believed that their mothers were not as approachable as they indicated. This gap should be addressed in future iterations of Ms. Now by focusing less on quantity and frequency of communication and more on quality. Such a strategy may include giving mothers additional feedback on the manner in which they approach parent-child communication about sex, for example, the degree to which they appear upset or angry when youth ask question about sexual development and volunteer information about their sexual or romantic feelings.

4.4   Limitations

Our study was not without limitations. Foremost are concerns with generalizability. Ms. Now was adapted from an evidence-based intervention (PMP) designed for African American families. This is reflected in many ways. For example, African American parents and youth are

present in program videos; African proverbs are used; and the content has been reviewed and evaluated by African American families for relevancy. The vast majority of mothers living with HIV in Atlanta are African American, thus we believed PMP would be an appropriate intervention. However, because services for MLH are limited, particularly programs for children of MLH, we included MLH of other ethnicities in the formative phase of the study with the aim of making Ms. Now accessible to mothers of all ethnicities. Future interventionists desiring to use Ms. Now with other groups (e.g., Latino mothers) or want its videos to show individuals of more diverse ethnicities, can use materials created by PMP developers for this purpose. We also decided to only include mothers or female caregivers because most caregivers living with HIV are women. Only a few recent studies have examined parenting in the context of paternal HIV infection (e.g., Letteney, Krauss, & Kaplan, 2012), and therefore more formative work is required to understand their strengths and challenges as caregivers striving to prevent youth HIV risk. Finally, generalizability was limited to parents with an early to middle adolescent child. Due to their increasing independence from families, including older adolescents in the Ms. Now program would require more direct intervention with adolescents than is currently used.

Although adaptation and feasibility studies are necessarily smaller in scope (McKleroy et al., 2006; Bowen et al., 2009), limitations of this approach should be noted. First, no control group was used which precludes causal conclusions about the effects of Ms. Now. Second, the sample size was small. This restricted our ability to detect smaller intervention effects. It also prohibited a thorough examination of within group differences (e.g., child age and gender) that may have influenced these outcomes. Third, we only assessed short-term outcomes. Indeed, we examined post-intervention effects immediately after the parent-child session. This could have affected our findings in two ways. We may have found greater improvements in main

intervention outcomes (e.g., relationship quality) than if we waited because families had been primed to respond positively. Conversely, if the follow-up period was longer, MLH and youth would have had longer time to practice and use communication skills and build their relationship, perhaps prompting better outcomes on family variables. Furthermore, as previously discussed, the short timeframe was unable to capture youth sexual behavior outcomes.

Another limitation relates to experimenter (researcher) bias. The focus groups were led primarily by a White man. Since all focus group mothers were women, and all but one identified as Black or African American, it is possible that some felt less comfortable being open, honest, and direct about some of the issues discussed, particularly those related to the intersection of race and HIV; although, reviewing focus group transcripts provided no evidence of explicit participant discomfort related to the male facilitator's race or gender. In addition, two female African American facilitators and one group helper were always present as research partners in the formative and feasibility phases of the study to increase participants' comfort and understanding, and inform research findings, interpretations, and conclusions. Researchers were also responsible for administering both the pre-/post-intervention assessments and facilitating the group and parent-child intervention sessions. Precautions were taken to minimize biased responding on the part of participants through the use of the audio computer-assisted laptop interview. Both facilitators also left the room following each session when participant satisfaction was assessed qualitatively. Nevertheless, it is possible that acceptability and preliminary efficacy outcomes were enhanced due to participants wanting to provide favorable responses.

4.5 Conclusions

The family environment for a thriving population of MLH is one ripe for raising healthy children. Over the course of creating Ms. Now, we learned much about this environment. More so perhaps than ever before, mothers are doing well. Yet, they still encounter the same trials faced by all parents, regardless of HIV status. Raising adolescents presents exceptional challenges, above all, keeping them healthy and safe as they navigate new developmental milestones such as going through puberty and forming closer and more influential peer relationships. HIV and other sexual risks are topics no mother is entirely comfortable talking about with her child. In this regard, MLH had a wealth of knowledge, awareness, and motivation to facilitate such conversations, and in fact, they often did. Difficulties still remained related to the messages they gave and whether or not they were talking to a male child. Adolescents of MLH also had the same concerns voiced by teenagers in other families; namely, while they often believed mothers are good sources of sexuality information, they were uncomfortable about approaching them for advice, support, or information. Moreover, teens were uncertain how their mothers would react if they did approach them.

A program such as Ms. Now that centrally targets parent-child communication about sex is therefore still an appropriate intervention approach for youth affected by maternal HIV infection. Indeed, leveraging mothers' experiences of living with HIV through ongoing disclosures offers an advantage to this group not available to other parents. Ms. Now was also formed to address broader family risk factors. We learned that being an MLH implies a heightened probability of past exposure to substance abuse and other risky situations that may lead to difficulties in forming and maintaining solid parent-child bonds and relationships, as well as providing protective parenting practices. Many MLH are thus similar to other parents with histories of addiction or incarceration. Ms. Now was adapted to help families start to rebuild the

parent-child relationship foundation in trust, closeness, and open communication, with the hope that they will continue to strengthen their relationships overtime, and if needed, participate in additional family-based interventions designed for this purpose (e.g., Multidimensional Family Therapy; Liddle et al., 2009). Although a larger trial is required to confirm our findings before disseminating it, Ms. Now is novel program that offers theory-driven evidence-based prevention strategies tuned to the distinct needs and strengths of families affected by maternal HIV infection.

Our study also confirmed how a large amount of useful information can be gathered through a thorough and reflective adaptation process in order to improve the fit of an evidence-based intervention for a specific population. If the Parents Matter! Program (PMP) was simply disseminated to families affected by maternal HIV infection without this information, many opportunities for enhancing it would have been missed. Each step of the process was important. Participants in the feasibility evaluation were connected to the modifications made to PMP in such a way that enhanced its acceptability and perhaps efficacy. Moreover, families felt a sense of ownership of the program because it was created by and for them. For an underserved group with an illness that continues to be highly stigmatized, this is vital to the provision of needed and desired prevention services.

REFERENCES

Ajzen, I. (1985). From intention to actions: A theory of planned behavior. In J. Kuhl & J. Beckman (Eds.), *Action Control: From Cognition to Behavior* (pp. 11-39). New York: Springer-Verlag.

Anthony, E., Hipp, T., Darnell, D., Armistead, L., Cook, S., & Skinner, D. (2014). Caregiver–Youth Communication about Sex in South Africa: The Role of Maternal Child Sexual Abuse History. *Journal of Child Sexual Abuse, 23*(6), 657-673.

Armistead, L., Cook, S., Skinner, D., Toefy, Y., Anthony, E. R., Zimmerman, L., . . . Chow, L. (2014). Preliminary results from a family-based HIV prevention intervention for South African youth. *Health Psychology, 33*, (7):668-676.

Armistead, L., Kotchick, B. A., & Forehand, R. (2004). Teenage pregnancy, sexually transmitted diseases, and HIV/AIDS. In L. Rapp-Paglicci, C. Dulmas & J. Woodarski (Eds.), *Preventive Interventions for Children and Adolescents* (Vol. 227-254). New Jersey: Wiley and Sons.

Ball, J., Pelton, J., Forehand, R., Long, N., & Wallace, S. A. (2004). Methodological overview of the Parents Matter! Program. *Journal of Child and Family Studies, 13*(1), 21-34.

Bandura, A. (1975). *Social Learning Theory*. Englewood Cliffs, NJ: Prentice-Hall.

Bandura, A. (1986). *Social foundations of thought and action: A cognitive social theory*. Englewood Cliffs, New York: Pretince Hall.

Barnes, H. L., & Olson, D. H. (1985). Parent-adolescent communication and the circumplex model. *Child Development, 56*, 438-447.

Beckett, M. K., Elliott, M. N., Martino, S., Kanouse, D. E., Corona, R., Klein, D. J., & Schuster, M. A. (2010). Timing of parent and child communication about sexuality relative to children's sexual behaviors. *Pediatrics, 125*(1), 34-42. doi: 10.1542/peds.2009-0806

Begun, A., Berger, L., Otto Salaj, L., & Rose, S. (2010). Developing effective social work university-community research collaborations. *Social Work, 55*(1), 54-62.

Bogart, L., Cowgill, B., Kennedy, D., Ryan, G., Murphy, D., Elijah, J., & Schuster, M. (2008). HIV-Related Stigma among People with HIV and their Families: A Qualitative Analysis. *AIDS and Behavior, 12*(2), 244-254.

Bowen, D., Kreuter, M., Spring, B., Cofta-Woerpe, L., Linnan, L., Weiner, D., . . . Fernandez, M. (2009). How we design feasibility studies. *American Journal of Preventive Medicine, 36*(5), 452-457.

Bowlby, J. (1969), Attachment. New York: Basic Book/

Bowleg, L., Teti, M., Massie, J., Patel, A., Malebranche, D., & Tschann, J. (2011). 'What does it take to be a man? What is a real man?': ideologies of masculinity and HIV sexual risk among Black heterosexual men. *Culture, Health & Sexuality, 13*(5), 545-559.

Brackis-Cott, E., Mellins, C. A., Dolezal, C., & Spiegel, D. (2007). The mental health risk of mothers and children: the role of maternal HIV infection. *The Journal of Early Adolescence, 27*(1), 67-89. doi: 10.1177/0272431606294824

Brady, S., Gallagher, D., Berger, J., & Vega, M. (2002). Physical and Sexual Abuse in the Lives of HIV-Positive Women Enrolled in a Primary Medicine Health Maintenance Organization. *AIDS patient Care and STDs, 16*(3), 121-125.

Brody, G. H., Murry, V. M., McNair, L., Chen, Y.-F., Gibbons, F. X., Gerrard, M., & Wills, T. A. (2005). Linking changes in parenting to parent–child relationship quality and youth self-control: The strong African American Families Program. *Journal of Research on Adolescence 15*(1), 47-69. doi: 10.1111/j.1532-7795.2005.00086.x

Bronfenbrenner, U. (1986). Ecology of the family as a context for human development: Research perspectives. *Developmental Psychology, 22*(6), 723-742.

Brook, J., Whiteman, M., & Zheng, L. (2002). Intergenerational transmission of risks for problem behavior. *Journal of Abnormal Child Psychology, 30*(1), 65-76.

Brothers, J., Harper, G., Fernandez, M. I., Hosek, S., & The Adolescent Trials Network for HIV/AIDS Interventions. (2014). EVOLUTION—Taking Charge and Growing Stronger: The Design,

Acceptability, and Feasibility of a Secondary Prevention Empowerment Intervention for Young Women Living with HIV. *AIDS Patient Care and STDs, 28*(1), 33-42.

Brumariu, L., & Kerns, K. (2010). Parent–child attachment and internalizing symptoms in childhood and adolescence: A review of empirical findings and future directions. *Development and Psychopathology, 22*(01), 177.

Burkholder, G., Harlow, L., & Washkwich, Jacque-Lynne. (1999). Social stigma, HIV/AIDS knowledge, and sexual risk. *Journal of Applied Biobehavioral Research, 4*(1), 27-44.

Burton, L., & Jarrett, R. (2000). In the mix, yet on the margins: The place of families in urban neighborhood and child development research. *Journal of Marriage and Family, 62*(4), 1114-1135.

Button, T. M. M., Hewitt, J., Rhee, S., Young, S., Corley, R., & Stallings, M. (2006). Examination of the causes of covariation between conduct disorder symptoms and vulnerability to drug dependence. *Twin Research and Human Genetics, 9*(1), 38-45.

Catz, S. L., Gore-Felton, C., & McClure, J. B. (2002). Psychological distress among minority and low-income women living with HIV. *Behavioral Medicine, 28*(2), 53-60.

Cavazos-Rehg, P. A., Krauss, M. J., Spitznagel, E. L., Schootman, M., Bucholz, K. K., Peipert, J. F., . . . Bierut, L. J. (2009). Age of sexual debut among US adolescents. *Contraception, 80*(2), 158-162.

CDC. (2009). *HIV Surveillance Report: Diagnoses of HIV infection and AIDS in the United States and Dependent Areas, 2009.*

Cederbaum, J. A. (2012). The Experience of Sexual Risk Communication in African American Families Living With HIV. *Journal of Adolescent Research, 27*(5), 555-580.

Cederbaum, J. A., Hutchinson, M. K., Duan, L., & Jemmott, L. S. (2013). Maternal HIV serostatus, mother–daughter sexual risk communication and adolescent HIV risk beliefs and intentions. *AIDS and Behavior, 17*(7), 2540-2553.

Centers for Disease Control and Prevention. (2013). HIV Surveillance Report, 2011; vol. 23. Retrieved 3/19, 2014, from

http://www.cdc.gov/hiv/pdf/statistics_2011_HIV_Surveillance_Report_vol_23.pdf

Chabon, B., Futterman, D., & Hoffman, N. D. (2001). HIV infection in parents of youths with behaviorally acquired HIV. *American Journal of Public Health, 91*(4), 649-650.

Chaudoir, S. R., Fisher, J. D., & Simoni, J. M. (2011). Understanding HIV disclosure: A review and application of the Disclosure Processes Model. *Social Science & Medicine, 72*(10), 1618-1629. doi: http://dx.doi.org/10.1016/j.socscimed.2011.03.028

Chen, E. K., Reid, M. C., Parker, S. J., & Pillemer, K. (2013). Tailoring evidence-based interventions for new populations: a method for program adaptation through community engagement. *Evaluation & the Health Professions, 36*(1), 73-92. doi: 10.1177/0163278712442536

Clark, H., Lindner, G., Armistead, L. P., & Austin, B.-J. (2004). Stigma, disclosure, and psychological functioning among HIV-infected and non-infected African-American women. *Women & Health, 38*(4), 57-71.

Corona, R., Beckett, M., Cowgill, B., Elliott, M., Murphy, D., Zhou, A., & Schuster, M. (2006). Do children know their parent's HIV status? Parental reports of child awareness in a nationally representative sample. *Ambulatory Pediatrics, 6*(3), 138-144.

Derlega, V. J. (2002). Perceived HIV-related stigma and HIV disclosure to relationship partners after finding out about the seropositive diagnosis. *Journal of Health Psychology, 7*(4), 415.

Dévieux, J. G., Malow, R. M. R., R. , Jean-Gilles, M., Samuels, D., Ergon-Pérez, E., & Jacobs, R. (2005). Cultural adaptation in translational research: field experiences. *Journal of Urban Health, 82*, 82-91.

Diamond, G. S., Diamond, G. A., & Levy, S. (2014). Attachment-Based Family Therapy for Depressed Adolescents. American Psychological Association: Washington, D.C.

DiCicco-Bloom, B., & Crabtree, B. F. (2006). The qualitative research interview. *Medical Education, 40*(4), 314-321.

DiClemente, R. J., Wingood, G., Crosby, R., Cobb, B., Harrington, K., & Davies, S. (2001). Parent-adolescent communication and sexual risk behaviors among African American adolescent females. *The Journal of Pediatrics, 139*(3), 407-412.

DiClemente, R. J., Wingood, G., Harrington, K., Lang, D., Davies, S., Hook, E., . . . Robillard, A. (2004). Efficacy of an HIV prevention intervention for African American adolescent girls. *JAMA: the Journal of the American Medical Association, 292*(2), 171.

DiClemente, R. J., Wingood, G. M., Crosby, R., Sionean, C., Cobb, B. K., Harrington, K., . . . Oh, M. K. (2001). Parental monitoring: association with adolescents' risk behaviors. *Pediatrics, 107*(6), 1363-1368.

Dittus, P. J., & Jaccard, J. (2000). Adolescents' perceptions of maternal disapproval of sex: relationship to sexual outcomes. *Journal of Adolescent Health, 26*(4), 268-278.

Dittus, P. J., Jaccard, J., & Gordon, V. V. (1999). Direct and nondirect communication of maternal beliefs to adolescents: adolescent motivations for premarital sexual activity. *Journal of Applied Social Psychology, 29*(9), 1927-1963. doi: 10.1111/j.1559-1816.1999.tb00158.x

Eiden, R. D., Edwards, E. P., & Leonard, K. E. (2002). Mother–infant and father–infant attachment among alcoholic families. *Development and Psychopathology, 14*(2), 253-278.

Elkington, K., Robbins, R., Bauermeister, J., Abrams, E., McKay, M., & Mellins, C. (2011). Mental health in youth infected with and affected by HIV: the role of caregiver HIV. *Journal of Pediatric Psychology, 36*(3), 360-373.

Feeney, J., Peterson, C., Gallois, C., & Terry, D. (2000). Attachment style as a piedictor of sexual attitudes and behavior in late Adolescence. *Psychology & Health, 14*(6), 1105-1122.

Fishbein, M. J. (1979). Concealment and disclosure: Some effects of information control on the person who controls. *Journal of Experimental Social Psychology, 15*(2), 114.

Fishbein, M. J., & Azjen, I. (1975). *Belief, attitude, intention and behavior: An introduction to theory and research.* Reading, MA: Addison-Wesley.

Fisher, J. D., & Fisher, W. A. (2000). *Theoretical Approaches to Individual-Level Change in HIV Risk Behavior: Handbook of HIV Prevention*.

Fletcher, A., Steinberg, L., & Williams-Wheeler, M. (2004). Parental Influences on adolescent problem behavior: revisiting Stattin and Kerr. *Child Development, 75*(3), 781-796.

Forehand, R., Armistead, L., Long, N., Wyckoff, S., Kotchick, B. A., Whitaker, D., . . . Miller, K. S. (2007). Efficacy of a parent-based sexual-risk prevention program for African American preadolescents: a randomized controlled trial. *Archives of Pediatrics & Adolescent Medicine, 161*(12), 1123-1129.

Forehand, R., Jones, D. J., Kotchick, B. A., Armistead, L. A., Morse, E., Morse, P. S., & Stock, M. (2002). Noninfected children of HIV-infected mothers: A 4-year longitudinal study of child psychosocial adjustment and parenting. *Behavior Therapy, 33*(4), 579-600.

Foster, C. E., Webster, M. C., Weissman, M. M., Pilowsky, D. U., Wickramaratne, P. J., Rush, A. J., . . . King, C. (2008). Course and severity of maternal depression: associations with family functioning and child adjustment. *Journal of Youth and Adolescence, 37*(8), 906-916. doi: 10.1007/s10964-007-9216-0

Gielen, A. C., McDonnell, K. A., Wu, A. W., O'Campo, P., & Faden, R. (2001). Quality of life among women living with HIV: the importance violence, social support, and self care behaviors. *Social Science & Medicine, 52*(2), 315-322. doi: http://dx.doi.org/10.1016/S0277-9536(00)00135-0

Glover, D., Garcia Aracena, E., Lester, P., Rice, E., & Rothram-Borus, M. (2010). Stress biomarkers as outcomes for HIV+ prevention: participation, feasibility and findings among HIV+ Latina and African American mothers. *AIDS and Behavior, 14*(2), 339-350.

Greene, S., Tucker, R., Rourke, S., Monette, L., Koornstra, J., Sobota, M., . . . Watson, J. (2010). "Under My Umbrella": the housing experiences of HIV positive parents who live with and care for their children in Ontario. *Archives of Women's Mental Health, 13*(3), 223-232.

Guest, G., Bunce, A., & Johnson, L. (2006). How many interviews are enough? An experiment with data saturation and variability *Field Methods, 18*(1), 59-82.

Harper, G., Contreras, R., Bangi, A., & Pedraza, A. (2003). Collaborative Process Evaluation. *Journal of Prevention & Intervention in the Community, 26*(2), 53-69.

Henrich, C. C., Brookmeyer, K. A., Shrier, L. A., & Shahar, G. (2006). Supportive relationships and sexual risk behavior in adolescence: an ecological–transactional approach. *Journal of Pediatric Psychology, 31*(3), 286-297. doi: 10.1093/jpepsy/jsj024

Huang, D., Murphy, D., & Hser, Y.-I. (2011). Parental monitoring during early adolescence deters adolescent sexual initiation: Discrete-time survival mixture analysis. *Journal of Child & Family Studies, 20*(4), 511-520. doi: 10.1007/s10826-010-9418-z

Hutchinson, M. K., Jemmott, John, Jemmott, L. S., Braverman, P., & Fong, G. (2003). The role of mother–daughter sexual risk communication in reducing sexual risk behaviors among urban adolescent females: a prospective study. *Journal of Adolescent Health, 33*(2), 98-107.

Jerman, P., & Constantine, N. A. (2010). Demographic and psychological predictors of parent–adolescent communication about sex: A representative statewide analysis. *Journal of Youth and Adolescence, 39*(10), 1164-1174. doi: 10.1007/s10964-010-9546-1

Jessor, R., Donovan, J. E., & Costa, F. M. (1991). *Beyond adolescence: Problem behavior and young adult development.* New York: Cambridge University Press.

Jessor, R., & Jessor, S. (1977). *Problem behavior and psychosocial development: a longitudinal study of youth.* New York: Cambridge University Press.

Jewkes, R., Dunkle, K., Nduna, M., & Shai, N. (2010). Intimate partner violence, relationship power inequity, and incidence of HIV infection in young women in South Africa: a cohort study. *Lancet (London, England), 376*(9734), 41-48.

Kalmuss, D., Davidson, A., Cohall, A., Laraque, D., & Cassell, C. (2003). Preventing sexual risk behaviors and pregnancy among teenagers: Linking research and programs. *Perspectives on Sexual and Reproductive Health, 35*(2), 87-93.

Kapungu, C. T., Baptiste, D., Holbeck, G., McBride, C., Robinson-Brown, M., Sturdivant, A., . . . Paikoff, R. (2010). Beyond the "birds and the bees": gender differences in sex-related

communication among urban African-American adolescents. *Family Process, 49*(2), 251-264. doi: 10.1111/j.1545-5300.2010.01321.x

Kelley, M. L., Pearson, M. R., Trinh, S., Klostermann, K., & Krakowski, K. (2011). Maternal and paternal alcoholism and depressive mood in college students: Parental relationships as mediators of ACOA-depressive mood link. *AddictiveBbehaviors, 36*(7), 700-706.

Kotchick, B. A., Dorsey, S., Miller, K. S., & Forehand, R. (1999). Adolescent sexual risk-taking behavior in single-parent ethnic minority families. *Journal of Family Psychology, 13*(1), 93-102.

Kotchick, B. A., Forehand, R., Brody, G., Armistead, L., Simon, P., Morse, E., & Clark, L. (1997). The impact of maternal HIV infection on parenting in inner-city African American families. *Journal of Pamily Psychology, 11*(4), 447-461.

Krueger, R. A., & Casey, M. A. (2009). *Focus groups: a practical guide to applied research* (4th ed.). Thousand Oaks, CA: Sage.

Lansford, J., Yu, T., Erath, S., Pettit, G., Bates, J., & Dodge, K. (2010). Developmental precursors of number of sexual partners from age 16 to 22. *Journal of Research on Adolescence, 20*(3), 651-677.

Larsen, D., Attkisson, C. C., Hargreaves, W., & Nguyen, T. (1979). Assessment of client/patient satisfaction: Development of a general scale. *Evaluation and Program Planning, 2*(3), 197-207.

Leonard, N., Gwadz, M., Cleland, C., Vekaria, P., & Ferns, B. (2008). Maternal substance use and HIV status: adolescent risk and resilience. *Journal of Adolescence, 31*(3), 389-405.

Letteney, S., Krauss, B., & Kaplan, R. (2012). Examining HIV-Positive Parents' Disclosure to Their Children: A Biopsychosocial Approach. *Social Work in Public Health, 27*(4), 345-360.

Liddle, H., Rowe, C., Dakof, G., Henderson, C., & Greenbaum, P. (2009). Multidimensional family therapy for young adolescent substance abuse: Twelve-month outcomes of a randomized controlled trial. *Journal of Consulting and Clinical Psychology, 77*(1), 12-25.

Long, N., Austin, B.-J., Gound, M., Kelly, A., Dunn, R., Harris, S., & Miller, K. S. (2004). The Parents Matter! Program intervention: content and the facilitation process. *Journal of Child and Family Studies, 13*(1), 47-65.

Macarthur, R. (2013). Management of noninfectious diarrhea associated with HIV and highly active antiretroviral therapy. *The American Journal of Managed Care, 19*(12 Suppl), s238-s245.

Magnani, R., Sabin, K., Saidel, T., & Heckathorn, D. (2005). Review of sampling hard-to-reach and hidden populations for HIV surveillance. *AIDS, 19*, S67-S72.

Marhefka, S. L., Mellins, C. A., Brackis-Cott, E., Dolezal, C., & Ehrhardt, A. A. (2009). Perceptions of adolescents' sexual behavior among mothers living with and without HIV: Does dyadic sex communication matter? *Archives of Sexual Behavior, 38*(5), 788-801. doi: 10.1007/s10508-007-9284-y

McKleroy, V., Galbraith, J., Cummings, B., Jones, P., Harshbarger, C., Collins, C., . . . Carey, J. (2006). Adapting evidence-based behavioral interventions for new settings and target populations. *AIDS Education and Prevention, 18*(4 Suppl A), 59-73.

McNeely, C., Shew, M. L., Beuhring, T., Sieving, R., Miller, B. C., & Blum, R. W. M. (2002). Mothers' influence on the timing of first sex among 14- and 15-year-olds. *Journal of Adolescent Health, 31*(3), 256-265. doi: http://dx.doi.org/10.1016/S1054-139X(02)00350-6

Mellins, C., Smith, R., O'Driscoll, P., Magder, L., Brouwers, P., Chase, C., . . . Matzen, E. (2003). High rates of behavioral problems in perinatally HIV-infected children are not linked to HIV disease. *Pediatrics, 111*(2), 384-393.

Mellins, C. A., Brackis-Cott, E., Dolezal, C., & Meyer-Bahlburg, H. L. (2005). Behavioral risk in early adolescents with HIV+ mothers. *Journal of Adolescent Health, 36*(4), 342-351.

Miller, B. C., Norton, M. C., Fan, X., & Christopherson, C. R. (1998). Pubertal development, parental communication, and sexual values in relation to adolescent sexual behaviors. *The Journal of Early Adolescence, 18*(1), 27-52.

Miller, K. S., Forehand, R., & Kotchick, B. A. (1999). Adolescent sexual behavior in two ethnic minority samples: the role of family variables. *Journal of Marriage and Family, 61*(1), 85-98.

Miller, K. S., Levin, M. L., Whitaker, D. J., & Xu, X. (1998). Patterns of condom use among adolescents: the impact of mother-adolescent communication. *American Journal of Public Health, 88*(10), 1542-1544.

Miller, K. S., Lin, C., Poulsen, M., Fasula, A., Wyckoff, S., Forehand, R., . . . Armistead, L. (2011). Enhancing HIV communication between parents and children: efficacy of the Parents Matter! Program. *AIDS Education and Prevention, 23*(6), 550-563.

Miller, K. S., Maxwell, K. D., Fasula, A. M., Parker, J. T., Zackery, S., & Wyckoff, S. C. (2010). Pre-risk HIV-prevention paradigm shift: the feasibility and acceptability of the parents matter! Program in HIV risk communities. *Public Health Reports (Washington, D.C.: 1974), 125 Suppl 1*, 38-46.

Murphy, D. A. (2003). Regrets and advice from mothers who have disclosed their HIV+ serostatus to their young children. *Journal of Child and Family Studies, 12*(3), 307.

Murphy, D. A., Armistead, L., Marelich, W., Payne, D., & Herbeck, D. (2011). Pilot trial of a disclosure intervention for HIV+ mothers: the TRACK program. *Journal of Consulting and Clinical Psychology, 79*(2), 203-214.

Murphy, D. A., Marelich, W. D., Stritto, M. E. D., Swendeman, D., & Witkin, A. (2002). Mothers living with HIV/AIDS: Mental, physical, and family functioning. *AIDS Care, 14*(5), 633-644.

Murphy, D. A., Roberts, K., & Hoffman, D. (2002). Stigma and ostracism associated with HIV/AIDS: Children carrying the secret of their mothers' HIV+ serostatus. *Journal of Child and Family Studies, 11*(2), 191-202.

Murphy, D. A., Roberts, K. J., & Herbeck, D. M. (2011). HIV-Positive mothers' communication about safer sex and STD prevention with their children. *Journal of Family Issues*. doi: 10.1177/0192513x11412158

Murphy, D. A., Steers, W. N., & Dello, M. (2001). Maternal disclosure of mothers' HIV serostatus to their young children. *Journal of Family Psychology, 15*(3), 441-450.

Murray, J., & Murray, L. (2010). Parental incarceration, attachment and child psychopathology. *Attachment & Human Development, 12*(4), 289-309.

Nappi, C. M., McBride, C. K., & Donenberg, G. R. (2007). HIV/AIDS communication among adolescents in psychiatric care and their parents. *Journal of Family Psychology, 21*(4), 637-644. doi: 10.1037/0893-3200.21.4.637

New York State Department of Health. (1999). *AIDS in New York State, 1998-1999*. Albany, NY.

O'Sullivan, L. F., Dolezal, C., Brackis-Cott, E., Traeger, L., & Mellins, C. A. (2005). Communication about HIV and risk behaviors among mothers living with HIV and their early adolescent children. *The Journal of Early Adolescence, 25*(2), 148-167.

Palin, F., Armistead, L. P., Clayton, A., Ketchen, B., Lindner, G., Kokot-Louw, P., & Pauw, A. (2009). Disclosure of maternal HIV-infection in South Africa: description and relationship to child functioning. *AIDS and Behavior, 13*(6), 1241-1252.

Parillo, K., Freeman, R., Collier, K., & Young, P. (2001). Association between early sexual abuse and adult HIV-risky sexual behaviors among community-recruited women. *Child Abuse & Neglect, 25*(3), 335-346.

Peters, G.-J. Y., Ruiter, R. A. C., & Kok, G. (2013). Threatening communication: a critical re-analysis and a revised meta-analytic test of fear appeal theory. *Health Psychology Review, 7*(sup1), S8-S31. doi: 10.1080/17437199.2012.703527

Poulsen, M., Vandenhoudt, H., Wyckoff, S., Obong'o, C. O., Ochura, J., Njika, G., . . . Miller, K. S. (2010). Cultural adaptation of a U.S. evidence-based parenting intervention for rural Western Kenya: from parents matter! To families matter! *AIDS education and prevention, 22*(4), 273-285.

Reid, S., & Dwyer, J. (2005). Insomnia in HIV infection: a systematic review of prevalence, correlates, and management. *Psychosomatic Medicine, 67*(2), 260-269.

Reyland, S. A., McMahon, T. J., Higgins-Delessandro, A., & Luthar, S. S. (2002). Inner-city children living with an HIV-seropositive mother: Parent–child relationships, perception of social support, and psychological disturbance. *Journal of Child and Family Studies, 11*(3), 313.

Rodgers, K. B. (1999). Parenting Processes Related to Sexual Risk-Taking Behaviors of Adolescent Males and Females. *Journal of Marriage and Family, 61*(1), 99-109.

Rojas, P., Kim, S., De L Rosa, M., Dillon, F. R., & Niyonsenga, T. (2010). Intergenerational associations between consensual childhood sexual experience and adult substance abuse among Latina mothers and daughters. *International Journal of Womens Health, 9*(2), 213-222.

Romer, D., Black, M., Ricardo, I., Feigelman, S., Kaljee, L., Galbraith, J., . . . Stanton, B. (1994). Social influences on the sexual behavior of youth at risk for HIV exposure. *American Journal of Public Health, 84*(6), 977-985.

Rotheram-Borus, M., Lee, S.-J., Amani, B., & Swendeman, D. (2012). *Adaptation of interventions for families affected by HIV family and HIV/AIDS : Cultural and contextual issues in prevention and treatment*.

Rotheram-Borus, M., Rice, E., Comulada, W. S., Best, K., & Li, L. (2012). Comparisons of HIV-affected and non-HIV-affected families over time. *Vulnerable Children and Youth Studies, 7*(4), 299-314.

Rotheram-Borus, M., Stein, J., & Lester, P. (2006). Adolescent Adjustment over Six Years in HIV-Affected Families. *Journal of Adolescent Health, 39*(2), 174-182.

Rotheram-Borus, M., Swendeman, D., Lee, S.-J., Li, L., Amani, B., & Nartey, M. (2011). Interventions for families affected by HIV. *Translational Behavioral Medicine, 1*(2), 313-326.

Rotheram Borus, M. J., Draimin, B. H., Reid, H. M., & Murphy, D. A. (1997). The impact of illness disclosure and custody plans on adolescents whose parents live with AIDS. *AIDS, 11*(9), 1159-1164.

Samji, H., Cescon, A., Hogg, R. S., Modur, S. P., Althoff, K. N., Buchacz, K., . . . Design of Ie, D. E. A. (2013). Closing the gap: increases in life expectancy among treated HIV-positive individuals in the United States and Canada. *PLoS ONE, 8*(12), e81355. doi: 10.1371/journal.pone.0081355

Scaramella, L. V., Conger, R. D., Simons, R. L., & Whitbeck, L. B. (1998). Predicting risk for pregnancy by late adolescence: a social contextual perspective. *Developmental Psychology, 34*(6), 1233-1245.

Schütz, S. G., & Robinson-Papp, J. (2013). HIV-related neuropathy: current perspectives. *HIV/AIDS -
Research and Palliative Care, 5*, 243-251. doi: http://dx.doi.org/10.2147/HIV.S36674

Shlafer, R. J., & Poehlmann, J. (2010). Attachment and caregiving relationships in families affected by
parental incarceration. *Attachment & Human Development, 12*(4), 395-415. doi:
10.1080/14616730903417052

Siegel, K., & Schrimshaw, E. (2000). Perceiving benefits in adversity: stress-related growth in women
living with HIV/AIDS. *Social Science & Medicine, 51*(10), 1543-1554.

Simoni, J. M., & Coopermanni, N. A. (2000). Stressors and strengths among women living with
HIV/AIDS in New York City. *AIDS care, 12*(3), 291-297.

Solis, J. M., Shadur, J. M., Burns, A. R., & Hussong, A. M. (2012). Understanding the Diverse Needs of
Children whose Parents Abuse Substances. *Current Drug Abuse Reviews, 5*(2), 135-147.

Solomon, J., Card, J. J., & Malow, R. M. (2006). Adapting efficacious interventions: advancing
translational research in HIV prevention. *Evaluation & the Health Professions, 29*(2), 162-194.
doi: 10.1177/0163278706287344

Stattin, H., & Kerr, M. (2000). Parental monitoring: a reinterpretation. *Child Development, 71*(4), 1072-
1085.

Sutton, M. Y., Lasswell, S. M., Lanier, Y., & Miller, K. S. (2014). Impact of parent-child communication
interventions on sex behaviors and cogntive outcomes for Black/African-American and
Hispanic/Latino Youth: A systematic review, 1988–2012. *Journal of Adolescent health, 54*(4),
369-384. doi: http://dx.doi.org/10.1016/j.jadohealth.2013.11.004

Tajima, E., Herrenkohl, T., Moylan, C., & Derr, A. (2011). Moderating the effects of childhood exposure
to intimate partner violence: the roles of parenting characteristics and adolescent peer support.
Journal of Research on Adolescence, 21(2), 376-394.

Tarantino, N., Goodrum, N., Armistead, L., Cook, S., Skinner, D., & Toefy, Y. (2014). Safety-related
moderators of a parent-based HIV prevention intervention in South Africa. *Journal of Family
Psychology, 28*(6), 790-799.

Tarantino, N., Kuperminc, G., Parrott, D., & Latzman, R. (2013). Family Support mediates the association between substance use severity and suicidal ideation in early adult emergency department patients. *International Journal of Mental Health and Addiction, 11*(6), 672-681.

Tarantino, N., Lamis, D. A., Ballard, E. D., Masuda, A., & Dvorak, R. D. (2014). Parent–Child Conflict and Drug Use in College Women: A Moderated Mediation Model of Self-Control and Mindfulness. *Journal of Counseling Psychology*. doi: 10.1037/cou0000013

Tarantino, N., Tully, E., Garcia, S., South, S., Iacono, W., & McGue, M. (2014). Genetic and environmental influences on affiliation with deviant peers during adolescence and early adulthood. *Developmental Psychology, 50*(3), 663-673.

Thomas, H., & Kelly, A. (2013). Parent-child relationship quality and adolescent alcohol use. *Australian and New Zealand Journal of Psychiatry, 47*(11), 1093-1093.

Tolou-Shams, M., Feldstein-Ewing, S., Tarantino, N., & Brown, L. K. (2010). Crack and cocaine use among adolescents in psychiatric treatment: associations with HIV risk. *Journal of Child & Adolescent Substance Abuse, 19*(2), 122-134.

Tortolero, S. R., Markham, C. M., Parcel, G. S., Peters, R. J., Escobar-Chaves, S. L., Basen-Engquist, K., & Lewis, H. L. (2005). Using intervention mapping to adapt an effective HIV, sexually transmitted disease, and pregnancy prevention program for high-risk minority youth. *Health Promotion Practice, 6*(3), 286-298. doi: 10.1177/1524839904266472

Ulin, P. R., Robinson, E. T., & Tolley, E. E. (2005). *Qualitative Methods in Public Health: A Frield Guide for Applied Research*. San Francisco, CA Jossey-Bass.

Vallerand, A., Hough, E., Pittiglio, L., & Marvicsin, D. (2005). The process of disclosing HIV serostatus between HIV-positive mothers and their HIV-negative children. *AIDS Patient care and STDs, 19*(2), 100-109.

Vanable, P. A., Carey, M. P., Blair, D. C., & Littlewood, R. A. (2006). Impact of HIV-related stigma on health behaviors and psychological adjustment among HIV-positive men and women. *AIDS and Behavior, 10*(5), 473-482. doi: 10.1007/s10461-006-9099-1

Varjas, K., Nastasi, B. K., Moore, R. B., & Jayasena, A. (2005). Using ethnographic methods for development of culture-specific interventions. *Journal of School Psychology, 43*(3), 241-258. doi: http://dx.doi.org/10.1016/j.jsp.2005.04.006

Voisin, D. (2002). Family ecology and HIV sexual risk behaviors among African American and Puerto Rican adolescent males. *American Journal of Orthopsychiatry, 72*(2), 294-302.

Wainberg, M., McKinnon, K., Mattos, P., Pinto, D., Mann, C., Oliveira, C. S. d. S., . . . Cournos, F. (2007). A model for adapting evidence-based behavioral interventions to a new culture: HIV prevention for psychiatric patients in Rio de Janeiro, Brazil. *AIDS and Behavior, 11*(6), 872-883.

Waldron, M., Vaughan, E. L., Bucholz, K. K., Lynskey, M. T., Sartor, C. E., Duncan, A. E., . . . Heath, A. C. (2014). Risks for early substance involvement associated with parental alcoholism and parental separation in an adolescent female cohort. *Drug and Alcohol Dependence*(0). doi: http://dx.doi.org/10.1016/j.drugalcdep.2014.02.020

Wickrama, K. A. S., Conger, R. D., & Abraham, W. T. (2005). Early adversity and later health: the intergenerational transmission of adversity through mental disorder and physical Illness. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences, 60*(Special Issue 2), S125-S129. doi: 10.1093/geronb/60.Special_Issue_2.S125

Wight, D., & Fullerton, D. (2013). A review of interventions with parents to promote the sexual health of their children. *Journal of Adolescent Health, 52*(1), 4-27.

Wills, T., Murry, V., Brody, G., Gibbons, F., Gerrard, M., Walker, C., & Ainette, M. (2007). Ethnic pride and self-control related to protective and risk factors: Test of the theoretical model for the strong African American families program. *Health Psychology, 26*(1), 50-59.

Wilson, E. K., & Koo, H. P. (2010). Mothers, fathers, sons, and daughters: gender differences in factors associated with parent-child communication about sexual topics. *Reproductive Health, 7*, 31-31. doi: 10.1186/1742-4755-7-31

Wingood, G. M., & DiClemente, R. J. (2008). The ADAPT-ITT model: a novel method of adapting evidence-based HIV Interventions. *Journal of Acquired Immune Deficiency Syndromes, 47*, S40-S46.

APPENDIX A

Individual Interview Protocol for Administration to Kids/Teens

I. Introduction [Interviewer introduces his/herself and asks child to give only their first names. Thanks participant for coming].

II. Description of confidentiality and interview agenda (5 minutes)
We're working on a project designed to help families communicate and get along so kids and teens can stay healthy. You have been asked to participate because you are between 10 and 15 years old and your family has been affected by HIV.

Today, you will be asked to share your thoughts and feelings about your family and some issues faced by both parents and kids (teens). We will be asking questions about how you and your parents deal with these issues. Today's interview should last about an hour. You do not have to answer any question if it makes you uncomfortable, and you can leave the interview at any time without penalty. If you decide to leave the interview, you will still receive the $15 gift card to pay you for your time. Everything said in here will be kept confidential. This means that whatever is said in here will only be used by project staff and only in ways that protect your identity.

Before we get started, there are some reasons we are required by law to tell what has been said in here to people outside this interview. If you say anything that leads us to believe that you are in danger of hurting yourself or someone else, or if child or elder abuse is revealed, then we will need to share that with people who can help keep everyone safe. These are the only circumstances under which we would break our promise of confidentiality.

Do you have any questions?

Because of your age, you are undergoing many changes. You may be more involved with friends and hanging out with your parents less. Physically, there are many changes as well, such as puberty. Many teens are faced with new choices and are torn between wanting do what they like and needing help from their parents. We are trying to develop a program that will help families learn strategies to make this easier. One of the most important things we are trying to do is to help parents talk with their children (teens) and to stay involved in their lives. We hope to know how parents and kids/teens talk about topics such as HIV, pressure from friends, and sexual development.

The program we are developing will be offered to parents and their children between the ages of 10 and 15 years old. Often projects like this can do a lot of good, but they don't always talk to parents, and especially kids/teens, before running the program. We believe we can learn a great deal of information from you to help us developed it. Your input can really help us to know how to make this program work best for families like yours. <u>You are the expert!</u>

III. Icebreaker (What grade are you in? What's your favorite subject? What do you like about?)	
IV. Family life. (15 minutes)	
(Key concepts: relationship quality, unsupervised time away from mom, general communication)	
A. What do you like to do in your free time?	<u>Probes</u> -Tell me about your best friend. -What do you do afterschool?
B. Tell me about your mom.	<u>Probes</u> -What types of activities do you do together? -Tell me about the last time you and your mom did something fun together.
C. Do you have any brothers or sisters?	<u>Probes</u> -Do they live with you? -What are they like? -Is there anyone else that you live with? - How often does your family eat dinner together? Watch TV together?
D. What kinds of rules do you have in your house?	<u>Probes</u> -What happens when you don't follow the rules? -Tell me about a time when you and your mom didn't get along. -Does your mom always know where you are?
E. Besides your mom, who would be the first adult you could turn to if you needed help?	<u>Probes</u> -Who else is there?
F. Tell me about your neighborhood.	<u>Probes</u> -How safe do you feel?

V. HIV/HIV disclosure (15 minutes)	
(Key concepts: parent-child communication about HIV status, child knowledge of HIV, HIV-related social support and stigma)	
	<u>Probes</u>
A. We're interested to know what it's like having a mom with HIV. Tell me about when your mom told you she has HIV	-How old were you?
	-Where was it?
	-How did you feel when she told you?
	-How do you feel about it now?
	-Have you talked about HIV since? How often?
	<u>Probes</u>
B. What have you learned about HIV from your mom?	-Has anyone else talked to you about it?
	-What questions do you have about HIV?
	-How do you stay safe from getting HIV?
	-Who told that?
	<u>Probes</u>
C. Who can you talk to about your mom's HIV?	-How do you feel talking about HIV with other people?
	-Is there anyone you can't talk with about it? Why not?
	<u>Probes</u>
D. How do you feel about people with HIV?	-What have you heard other people say about people with HIV?

VI. Sexuality and Peer Pressure (15 minutes)	131
(Key concepts: parent-child communication about sex, effect of status on communication)	
A. Kids and teens your age sometimes start learning about puberty, which is how their bodies are developing. Sometimes they also start learning about "hooking up" with other boys and girls, or having sex. These next questions might make you feel a little uncomfortable. You don't have answer them if you don't want to. Remember, your answers won't be shared with your mom unless you're in danger of being hurt or you're hurting someone else.	
Has your mom talked to you about puberty?	Probes -What has she told you about it? -Where do kids/teens usually get this information?
B. What does your mom say about having a boyfriend or girlfriend at your age?	Probes -Tell me about any rules your mom has about you dating. -Are their differences between what she says and what other adults say?
C. Tell me what your mom says about getting pregnant (getting a girl pregnant) at your age.	
D. Tell me what your mom has told you about having sex.	Probe **- How comfortable do you feel discussing sex with your mom?** -Has anyone else talked to you about sex before? -What have you learned about safe sex? From who? -What makes it hard for kids/teens to talk about sex with their parents? -Where should kids learn about these things?
E. What has your mom told you about safe sex?	Probes -What does she say about condoms?

VII. Emotions and stress

What makes you worry the most in the world?

<u>Probes</u>

- Tell me about a time when you were real sad? Angry?

VIII. Wrap up. (5 minutes)

Thank you talking with me today. You have been very helpful.

Before we end, do you have any ideas for us on how kids/teens and their moms can get along better?

How they can talk with each other about issues like HIV and sex?

Do you have any questions for us?

You have given us a lot of important information that we can use to make our program better for kids/teens like you and their families.

<u>Probes</u>

- What do parents need to know about teenagers?

- Tell me how you could have a better relationship with your mom.

APPENDIX B

Focus Group Protocol for Administration to Parent Focus Groups

I. Introduction [*Group leaders introduce themselves and thank participants for coming*].

II. Description of confidentiality and focus group agenda (5 minutes)
We're working on a project designed to help families find ways to communicate and build good relationships so children and teens can stay healthy. You have been asked to participate in today's discussion group because you are the parent of a child between the ages of 10 and 15 years old and your family has been affected by HIV. We would like your help so we can develop a program that is best for other parents. Today you will be asked to share your thoughts and feelings about raising children, family communication, and issues faced by both parents and children. Today's group should last 1.5 hours. You do not have to answer any question if it makes you uncomfortable, and you can leave the group at any time without penalty. If you decide to leave the group, you will still receive the $30 to compensate you for your time. Everything said in here will be kept confidential and anonymous. This means that whatever is said in here will only be used by project staff and only in ways that protect your identity. For example, you each will get an ID number to identify your voice on the audiotape and your name, if you choose to use it, will not be included in the transcribed script. We ask that each of you respects the privacy of other group members, and that you do not discuss what was said in here outside the group.

Before we get started, there are some reasons we are required by law to disclose what has been said to people outside this group. If anyone says anything that leads us to believe that any one of you or your children is in danger of hurting themselves or someone else, or if child or elder abuse is revealed, than we will need to share that information with the people who can help keep everyone safe. These are the only circumstances under which we would break our promise of confidentiality.

Any questions about today's group and the rules of confidentiality I just discussed?

Since all of you are parents, you know that your child is growing up quickly and undergoing many changes. They are becoming more involved with their friends and more independent from their parents. Also, adolescents are experiencing puberty. It is a time when they become aware of their sexuality and may be the first time they experiment with sex and sexual behavior. Because of their growing independence and physical maturity, many teens are faced with choices that they never had before. But physical maturity or age doesn't necessarily prepare kids to make safe, responsible adult decisions. We are trying to develop a program to help parents guide their children through this time and stay connected to their kids. We know topics such as sex, HIV, and other others (like using drugs) can be difficult to bring up with children and teens.

We also know projects like these can do a lot of good, but sometimes people making the projects don't always talk to people like you beforehand. We believe we can learn a great deal of information from talking with parents. Your input can really help us to know how to make this program work best. <u>You are the experts.</u>

III. Parental Introductions including their first name and the names of their children; Icebreaker (5 minutes)	
IV. Family life. (15 minutes) *(Key concepts: relationship quality, parental monitoring, general communication)*	
A. Tell me about your children.	Probes -What do they like to do? -What types of activities do you do together? -What do they do after-school?
B. What kind of rules do you have in the house?	Probes -When can your child be difficult? -How is discipline handled in your family?
C. When you think about your most difficult times, who do you turn to for help? D. Tell me about your neighborhood	Probes -Who helps you take care of your kids?
V. HIV/HIV disclosure (25 minutes) *(Key concepts: parent-child communication about HIV status, child knowledge of HIV, social support vs. secrecy, teachable moments)* A. How did you go about disclosing your status to your child?	Probes -How did your child react? -How often have you talked about it since you first disclosed? -What have you told your child about HIV? How prepared do you feel to talk about HIV?

B. What has your child asked you about HIV?	<u>Probes</u> -What exactly does your child know about HIV? -How comfortable do you feel talking about HIV with your child? **-What has your child asked you about how you became HIV-positive?** -At what age should a child/teen be told about HIV transmission?
C. Who can your child talk to about HIV?	<u>Probes</u> -Do you worry he/she will tell others your status?
D. Who can you talk to about living with HIV?	<u>Probes</u> -Do you know other parents living with HIV? -Do you feel there's a stigma about being a mom with HIV? -How safe do you feel in your neighborhood?
VI. Children's sexuality education and sexual risks. (25 minutes) *(Key concepts: parent-child communication about sex, effect of status on communication, monitoring)*	
A. Tell me about how you talk to your child about sexual development.	<u>Probes</u> -What have you told your child about puberty? Sex? Safe sex? -How prepared do you feel to discuss his/her questions about sex? -When should kids learn about sex? -Where else should they learn this information?
B. How do you think being positive affects talking about sex with your children?	

C. What do you know about your child's sexual behavior?	
D. What have you told your child about drugs and alcohol?	<u>Probes</u> - How do you tell your child/teen to deal with peer pressure?
VII. Wrap up and structure of the program. (15 minutes)	
A. As you probably guessed, we're very interested in how families talk about serious health concerns like HIV and sex. What kinds of things would make it easier for you to talk to your child about these issues?	<u>Probes</u> -More information? More skills?
B. We plan on having a multiple day workshop in a group setting like this for moms like you. What do you think about that? C. Thank you all very much for your comments. You've been very helpful. Do you have any questions for us before we leave today?	