HIV PREVENTION COMMUNICATION IN FAMILIES
AFFECTED BY HIV/AIDS

BY
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DISSERTATION
Submitted in the partial fulfillment of the requirements
for the degree of Doctor of Philosophy in Community Health
in the Graduate College of the
University of Illinois at Urbana-Champaign, 2012

Urbana, Illinois

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ABSTRACT

Introduction: Parents have been considered an underutilized resource for educating children about HIV prevention. Parents and other family members can play a critical role in prevention efforts by using effective parenting practices, communicating their values and expectations, and modeling strategies that reduce the risk of acquiring HIV. Despite the potential protective role of parent-child communication on adolescent sexual and drug use behavior, much remains unknown about the processes and contexts in which these communication encounters occur.

Methods: This study examined parent-adolescent communication about HIV prevention in families affected by HIV. Specifically, the project used a mixed method approach to identify the strategies parents living with HIV/AIDS use to discuss HIV prevention with their 10-18 year old uninfected adolescents. Whereas in-depth interviews shed light on what motivates and/or prevents parents from discussing HIV prevention with adolescents, a questionnaire was used to collect information on theoretical concepts previously identified as important to health behavior and health communication research. Overall, the major aims of this project were as follows: 1) to identify facilitators and barriers to talking about HIV prevention in a family context, particularly those that may be unique to families affected by HIV/AIDS, 2) to describe the strategies parents living with HIV/AIDS use to communicate about HIV prevention, and 3) to compare parents’ perceived effectiveness of those strategies to what current health behavior research deems effective parent-adolescent communication.
**Results:** Parents reported frequent conversations about HIV-related topics, but also faced a number of barriers when deciding whether or not to talk and how much information to discuss with adolescents. Parents who reported lower levels of HIV disclosure were less likely to communicate about HIV prevention with their children in bivariate analyses, however this association did not remain significant in multivariate analyses. Parents who reported higher levels of HIV-related stress were more likely to report using passive strategies to discuss prevention information (in both bivariate and multivariate analyses). Overall, parents indicated a great need and desire for social and professional support when engaging in prevention conversations, emphasizing the important role of HIV care teams and support programs in providing parents with effective communication training.

**Conclusion:** This project identifies ways to better support parents with HIV/AIDS in their efforts to communicate with adolescents about safer sex, drug use, and HIV infection. Findings from this study are applicable to researchers and practitioners involved in HIV prevention and/or management of HIV disease. Results suggest that parents with HIV do experience unique barriers to parent-adolescent communication, but that existing HIV prevention programs could be tailored to meet the needs of these families with relatively modest effort. Future studies with larger sample sizes are needed to replicate the quantitative aspects of these findings.
DEDICATION

To Dale E. Brashers

Gifted scholar, phenomenal mentor, and loyal friend.

You have left an indelible imprint on my life and scholarship, both personally and professionally. Thank you for your generosity, poise, energy, compassion, and for many jokes along the way.
ACKNOWLEDGEMENTS

This project would not have been possible without the support of a number of individuals and organizations. I would like to thank my doctoral advisor, Dr. Janet Reis, for her incredible wisdom and patience, for being both encouraging and realistic, and for being willing to embrace a student outside of her department as one of her own. I would also like to thank my other committee members for their support and thoughtful comments, including Dr. Sari Aronson, Dr. Reginald Alston, and Dr. Peter Mulhall. It is difficult to express how helpful each of you has been at various aspects of this process.

Friends and family members provided the much needed moral support to see this project to completion. My husband, Patrick, has celebrated every milestone along the way, and continues to amaze me with his love and support. To the extended “Draper Household,” I thank you for being coffee shop companions, late night study buddies, comic relief, and for much needed graduate and medical school debriefing sessions.

Finally, to the families who were willing to share their stories and experiences and the organizations that helped with recruitment, I cannot thank you enough. Please know how important our conversations have been in shaping my understanding of research, medicine, and a holistic view of HIV treatment and care.
RESEARCH SUPPORT

This study was completed with support from the National Institute of Mental Health (NRSA Predoctoral Training Grant F30 MH086364) and the Sherri Aversa Memorial Foundation Dissertation Completion Award. Funding was also received from the Graduate College, College of Medicine, and Department of Communication at the University of Illinois at Urbana-Champaign.

Thank you to the following individuals who provided assistance with recruitment and/or data collection and management: Cindy Goetting, Pam Talbott, Kathleen Weber, Sally Urwin, Angie Shanksy, Sarah Kubicka, Sarah Coleman, Esmeralda Rosales, Eileen Podlasek, Natalie Bradford, Brad Engelbarts, Michelle Moore, Nadine Schneider, Markisha Foster, Natasha Shrikant, and Samantha Hack-Ritzo.

Part of the data in this document were collected by the Women’s Interagency HIV Study (WIHS) Collaborative Study Group Chicago Consortium (Kathleen Weber). The WIHS is funded by the National Institute of Allergy and Infectious Diseases (U01-AI-35004, U01-AI-31834, U01-AI-34994, U01-AI-34989, U01-AI-34993, and U01-AI-42590) and by the Eunice Kennedy Shriver National Institute of Child Health and Human Development (U01- HD-32632). The study is co-funded by the National Cancer Institute, the National Institute on Drug Abuse, and the National Institute on Deafness and Other Communication Disorders. Funding is also provided by the National Center for Research Resources (UCSF-CTSI Grant Number UL1 RR024131). The contents of this document are solely the responsibility of the author and do not necessarily represent the official views of the National Institutes of Health.
**TABLE OF CONTENTS**

CHAPTER 1: INTRODUCTION ........................................................................................................ 1
CHAPTER 2: LITERATURE REVIEW ............................................................................................ 9
CHAPTER 3: METHODS ............................................................................................................. 27
CHAPTER 4: QUALITATIVE RESULTS ....................................................................................... 61
CHAPTER 5: QUANTITATIVE RESULTS .................................................................................... 167
CHAPTER 6: DISCUSSION ........................................................................................................ 200
REFERENCES .......................................................................................................................... 225
APPENDIX A: RECRUITMENT FLIER .................................................................................... 238
APPENDIX B: LETTER TO RECRUITMENT ORGANIZATIONS .............................................. 239
APPENDIX C: TELEPHONE RECRUITMENT SCRIPT .......................................................... 240
APPENDIX D: INFORMED CONSENT FORM ........................................................................ 241
APPENDIX E: FAMILY TREE ................................................................................................ 242
APPENDIX F: INTERVIEW SCRIPT ....................................................................................... 243
APPENDIX G: QUESTIONNAIRE ............................................................................................ 246
APPENDIX H: TRANSCRIPTION TEMPLATE .......................................................................... 255
APPENDIX I: CODEBOOK EXCERPT .................................................................................... 256
APPENDIX J: CODING AGREEMENT SHEET ....................................................................... 258
APPENDIX K: OUTLINE OF ANALYSIS FOR REGRESSION MODELS ................................. 259
APPENDIX L: SIGNIFICANT CORRELATION VALUES FOR PREDICTORS ...................... 266
CHAPTER 1: INTRODUCTION

Background on HIV/AIDS

On June 5th, 1981 the Centers for Disease Control and Prevention (CDC) published a report documenting five cases of *Pneumocystis carinii pneumonia* (PCP), a rare form of pneumonia generally only seen in individuals with severely compromised immune systems. All five men were young, previously healthy homosexuals living in Los Angeles (CDC MMWR, 1981). The authors concluded that these cases were indicative of a “cellular-immune dysfunction related to a common exposure that predisposes individuals to opportunistic infections” (CDC MMWR, p.3). Reports of rare cancers and pneumonia had also been detected in other parts of California and in New York, with most of the cases being identified in previously healthy homosexual men. A year later, this condition became known as *gay-related immune deficiency* (GRID) and widespread panic began to develop (Altman, 1982).

Within a few months, 20 states had reported cases of GRID, however, a small number of heterosexual men and women were now identified (CDC MMWR, 1982). In efforts to more accurately capture the nature of the epidemic, the term GRID with was replaced with AIDS, *acquired immune deficiency syndrome*. Main risk factors identified were being homosexual, a heroin addict, having hemophilia (a blood-clotting disorder often requiring blood transfusions), and/or being of Haitian descent. These risk factors soon became known as the “4-H Club” (Gallo, 2006). The association of AIDS with homosexuality and drug use, along with the fear and limited knowledge of transmission, contributed to the stigmatization of the disease from the very beginning (Grmek, 1990).

By 1984, researchers identified the virus that causes AIDS, which was later termed *human immunodeficiency virus* (*HIV*) (Kaiser Family Foundation, 2007). It became recognized
that HIV was transmitted through four major bodily fluids: blood, breast milk, vaginal fluid, and semen. Various HIV prevention efforts and service organizations began to materialize, but the number of HIV infections and AIDS-related deaths continued to rise.

**Current Epidemiology**

Today, 30 years into the epidemic, it is estimated that over one million people are living with HIV in the United States (CDC, 2010a). Though the number of new infections per year is no longer rising, 56,300 Americans become infected annually. Of those infected, 53% are thought to acquire HIV via male-to-male sexual contact, 31% by heterosexual contact, and 16% by intravenous (IV) drug use. In terms of race and ethnicity, African Americans, Hispanics, and Latinos are disproportionately affected. African Americans account for almost 50% of the new infections each year, whereas Hispanics and Latinos account for an additional 20% of annual infections. This makes prevention efforts tailored to the needs of these populations particularly important. Current estimates place the lifetime risk of being diagnosed with HIV infection at 1 in 16 for African American men and 1 in 30 for African American women (CDC, 2010a).

Advances in biomedical knowledge have contributed to a detailed understanding of the course of HIV infection. It is now known that once HIV enters the body it attacks the immune system by targeting specific cells, CD4 T-cells. Over time the virus replicates (viral load increases) and destroys more and more T-cells, eventually rendering the immune system incapable of fighting off other bodily infections. These infections, which a healthy immune system can usually fend off, are called opportunistic infections.\(^{1}\) In general, the higher the T-cell count and lower the viral load of an HIV-infected patient, the less likely he/she is to develop opportunistic infections. When a person infected with HIV has a CD4 cell count below 200

\(^{1}\) The average CD4 T-cell count for a healthy individual with a normal immune system is 800-1050 cells/μL (Bartlett & Gallant, 2007).
cells/μL, a CD4 cell percentage of less than 14, or has been diagnosed with an AIDS-defining illness, they are typically classified as having progressed from HIV to AIDS (CDC, 1992). AIDS-defining illnesses include conditions like rare fungal infections, cancers, and/or wasting syndrome caused by HIV infection. Best estimates surmise that, if left untreated, HIV infection would result in death from AIDS-related complications within 10 to 11 years (Bartlett & Gallant, 2007).

Medical Management

Although AIDS still ranks among the top 10 causes of death for African Americans (CDC, 2010a), the availability of antiretroviral therapy (ART) in the mid-1990’s and the ability to treat AIDS-related opportunistic infections have lessened AIDS-related mortality considerably (Steiner, Boyd-Franklin, & Boland, 1995). Whereas AIDS was once referred to as a death sentence with little hope of medical intervention, it is now regarded as a chronic illness (Edgar, Noar, & Freimuth, 2008). Today, there are 25 drugs approved to treat HIV and many patients manage their infection with as little as one pill per day (Gulick, 2010). This is in stark contrast to the early treatment regimens, which often involved taking over two dozen pills at specific times throughout the day with precise nutritional instructions (Chesney, Morin, & Sherr, 2000). Recent evidence reports that the average life expectancy after HIV diagnosis has increased from 10.5 years in 1996 to 22.5 years in 2005 (Harrison, Song, & Zhang, 2010). Studies also suggest that the life expectancy for HIV-infected individuals being treated appropriately with ART will soon approach that of the general population (Bhaskaran et al., 2008).

Current treatment guidelines vary as to when to recommend an HIV+ individual begin medication, but the worldwide standard is to start ART when a person meets the clinical definition of AIDS, has symptomatic HIV disease, and/or has a CD4 cell count of less than 350
cells/μL (Gulick, 2010). The average HIV+ patient sees a clinician every 3-6 months and has their CD4 cell count and viral load monitored to help with treatment decisions and oversee disease progression (Bartlett & Gallant, 2007). Initiating treatment too early risks long-term problems with medication adherence, unknown toxicities and side effects, and/or the emergence of drug-resistant strains of HIV (Gulick, 2010). In addition, clinical symptoms are relatively infrequent in early HIV disease and HIV+ individuals often feel worse from taking medication than they feel from HIV infection. Potential side effects of medications include diarrhea, headaches, fatigue, nausea and vomiting, hypersensitivity reactions, lipodystrophy (fat redistribution), and glucose intolerance (American Public Health Association [APHA], 2004; Sacajiu, Raveis, & Selwyn, 2009). On the other hand, not initiating treatment early enough risks increased viral loads, decreased immune function, and the heightened possibility of transmission in the community (Gulick, 2010). Thus, the shift in the HIV illness paradigm from acute to chronic disease has been cause for celebration, but has also led to a variety of long-term challenges.

**HIV/AIDS Case Management**

Many of the challenges in HIV management and care focus increasing attention on the psychosocial and behavioral aspects of living with HIV disease. For example, issues surrounding medication adherence, health literacy, access to health care and HIV-related services, the need for social support, and the high proportion of HIV+ individuals with mental health and/or substance abuse issues call for an increasingly multidisciplinary approach to the management of HIV disease (Edgar et al., 2008). As Steiner et al. (1995) assert, patients with chronic illnesses like HIV may have “periods of ‘normality,’ but there are also often crises, when familial, psychological, medical, economic, and social resources are heavily taxed” (p.7).
One such response to the need for both psychosocial and medical services for HIV has been the designation of federal funds to provide HIV/AIDS case management services. HIV/AIDS case managers are professionals who, at the most basic level, coordinate care for HIV+ individuals. Though the concept of case management existed long before HIV, it was quickly adapted address the complex needs of the AIDS epidemic (DHHS, 2008). Rather than provide direct services like legal aid or mental health therapy, most case managers focus on the following functions (DHHS, 2008):

- Assessing client service needs
- Determining client eligibility for benefits and services
- Coordinating various support services
- Providing disease management in the form of education, appointment or reminders, and/or routine reporting to health care providers
- Client advocacy
- Supportive counseling (not therapy)

A variety of federal agencies currently fund HIV case management services and research, including the Centers for Disease Control and Prevention (CDC), Centers for Medicare and Medicaid Services (CMS)/Medicaid, U.S. Department of Housing and Urban Development (HUD)/Housing Opportunities for Persons with AIDS (HOPWA), Health Resources and Services Administration (HRSA)/Ryan White HIV/AIDS Treatment Modernization Act, National Institutes of Health (NIH)/National Institute on Drug Abuse (NIDA), and Substance Abuse and Mental Health Services Administration (SAMHSA).

In part because of the plethora of organizations providing case management and their multiple jurisdictions, an HIV+ individual may have 5 or 6 different case managers to coordinate
their different services. For example, someone who is eligible for the Ryan White AIDS Drug Assistance Program (ADAP) may have a case manager who focuses on medication adherence. If the same individual is also in need of temporary housing, they may be assigned a housing case manager. Similarly, a SAMHSA-funded case manager may be called upon to help coordinate mental health counseling (DHHS, 2008). This estimate does not include the health care professionals who are providing direct services to HIV+ patients, which adds another layer of complexity to disease management and care. Recent efforts have tried to coordinate this flexible, yet often fragmented system of HIV care under one set of recommendations (DHHS, 2008). It is hoped that these recommendations will provide case managers and HIV/AIDS care teams with a centralized location to access current and effective case management strategies and services.

Despite the sometimes segmented nature of the HIV/AIDS case management system, case management services have greatly contributed to the basic psychosocial and medical needs of families affected by HIV/AIDS. Case management has been shown to effectively link HIV+ individuals to services for housing, mental health, and substance abuse, as well as provide individuals with income assistance, health insurance, and financial assistance with medications (DHHS, 2008). Since anywhere from 45-65% of HIV+ individuals are unemployed (Dray-Spira, Gueguen, & Lert, 2008), case managers have also had a strong role in helping HIV+ clients seek employment services and/or apply for disability coverage (for those unable to work). All of these factors contribute to a multi-faceted view of health and well-being for individuals living with HIV or AIDS.

**Significance & Purpose of the Study**

Given that individuals with HIV are living longer and healthier lives, there is a current need for research that addresses the long-term needs of families affected by HIV/AIDS, as well
as provides these families and their health care teams with quality information about how to prevent further infection in their communities. Whereas previous studies have established that family communication is an effective means of preventing HIV risk behavior, only recently has attention been turned to utilizing this knowledge to protect families who are already affected by HIV/AIDS.

The purpose of the following study was to investigate how parents living with HIV/AIDS communicate about HIV prevention in a family setting. The term “HIV prevention communication” was used to refer to any instance where two individuals discussed ways to prevent HIV infection. In the context of this study, it referred to parents living with HIV or AIDS discussing prevention-related information with adolescents between the ages of 10 and 18. The study was organized around three specific aims:

1. To identify facilitators and barriers to talking about HIV prevention in a family context, particularly those that may be unique to families affected by HIV/AIDS.
2. To describe the strategies parents living with HIV/AIDS use to communicate about HIV prevention.
3. To compare parents’ perceived effectiveness of those strategies to what current health communication/health behavior research deems effective parent-adolescent communication.

Each chapter in this document will address a unique aspect of the research process. Whereas this chapter summarized the major epidemiological, medical, and psychosocial aspects of HIV disease, Chapter 2 will provide a review of the current literature on HIV risk in adolescents, parent-adolescent communication, and the promise of family-based communication research efforts. It will also introduce the guiding frameworks of the study. Chapter 3 will present a
detailed study methodology, including the rationale for conducting a mixed methods study and the steps taken in data gathering and analysis. In Chapters 4 and 5, the results of the study interviews and questionnaire data will be presented, along with demographic information about the sample. Finally, Chapter 6 will key findings and discusses the broader implications of these findings for future research, behavioral interventions, and for clinical health care teams. By exploring parent-adolescent communication about HIV prevention in families affected by HIV/AIDS, it is hoped that researchers and practitioners alike will gain knowledge of how parents and adolescents can better communicate with one another about HIV and HIV prevention.
CHAPTER 2: LITERATURE REVIEW

Chapter Overview

The following chapter draws upon the relevant psychological, health behavior, health communication, family studies, and epidemiological literature. Key findings will be used to emphasize the following points: 1) adolescents continue to be at high risk for HIV and other sexually transmitted infections (STIs), 2) family members, and specifically parents, are in a unique position to initiate HIV prevention discussions with adolescents, and 3) though family-based research has shown great promise in influencing adolescent sexual behavior, much remains to be known about the strategies such families use to engage in HIV prevention discussions, particularly for families affected by HIV. After highlighting relevant literature findings, the chapter concludes by detailing the theoretical underpinnings, research questions, and hypotheses guiding the study design.

Adolescents and HIV Transmission

Of the new HIV cases in the United States each year, at least 25% of these infections occur in persons younger than 24 years of age (CDC, 2004). The majority of adolescents (over 90%) acquire HIV infection through sexual transmission, with the next largest percentage of adolescents being infected by risky drug use behavior (NIH, 2006; Rotheram-Borus, O’Keefe, Kracker, & Foo, 2000). This makes prevention efforts that delay the initiation of sexual activity, promote safer sexual practices, and prevent drug use the most effective methods of decreasing adolescent acquisition of HIV infection. Of added concern, the percentage of sexually active adolescents who report using condoms consistently and effectively varies widely, ranging from 35 – 61.5% (CDC, 2008; Illinois Department of Public Health, 2000; Manlove, Ikramullah, & Terry-Humen, 2008). Misconceptions about how to effectively prevent STIs are widespread
among adolescents, whereas adolescent concern about contracting HIV is low (DiClemente, Crosby, & Wingood, 2002). Nationally, only approximately 13% of high school students have been tested for HIV (CDC, 2008). This combination of characteristics (inconsistent condom use, lack of effective prevention knowledge, and low perceived risk, among other factors) leads to a dangerous situation whereby adolescents are engaging in unsafe sex and drug use behavior with sometimes limited and/or faulty knowledge about how to protect themselves from HIV infection.

**HIV Prevention and Families Affected by HIV/AIDS**

Youth who have HIV-infected parents are among the highest risk for contracting HIV themselves (O’Sullivan et al., 2005). Chabon and Futterman (1999) found that, among adolescents who acquired HIV through sexual behavior, 20% had a mother living with HIV. Compared to adolescents who did not have a mother living with HIV, adolescents who had a mother living with HIV were more likely to have sex at younger age, report risky sexual behavior (including sex exchanged for money, drugs, or living accommodations), have multiple (10 or more) sex partners, and report sexual abuse (Chabon, Futterman, & Hoffman, 2001). Living with an HIV-infected parent, therefore, may lead to behavioral, psychological, or social problems that leave youth especially vulnerable to acquiring HIV infection themselves (Green & Smith, 2004). These problems likely arise from a complex interaction of multiple factors. For example, youth growing up in a home where one or more parents are living with HIV oftentimes must cope with the stress, stigma, and potential death of a parent, as well as with impoverished social conditions, such as increased substance abuse, poor educational facilities, and disruptive family situations (Mellins et al., 2007).
Mellins et al. (2007) identified three main mechanisms by which adolescents with mothers living with HIV may be at risk for premature onset of sexual activity and unsafe sex or drug use behavior: (a) increased risk for mental health problems, (b) parent-child relationship factors (e.g., parental monitoring, supervision, and communication), and (c) the context of the adolescent’s living situation. Communication may be involved in each of these domains, although very little is known about the strategies HIV-affected families use to communicate about risk for HIV (O’Sullivan et al., 2005). Considering many parents intentionally avoid disclosing their HIV status to their children (Green & Smith, 2004), it has been suggested that these parents might also evade discussing HIV prevention information with adolescents (Letteny & Laporte, 2004). This lack of HIV prevention information, or lack of effectively delivered HIV prevention information, could serve to exacerbate the risk of adolescents living in families directly affected by HIV/AIDS.

At the same time, however, there is some evidence that mothers living with HIV may be more comfortable discussing HIV and HIV prevention information with their children, and may discuss such information more frequently than mothers who are not infected with HIV (O’Sullivan et al., 2005). Similarly, adolescents from HIV-affected families were more likely to report being comfortable discussing sex and drugs than adolescents from uninfected families, although they were not more likely to report being comfortable discussing HIV. Clearly, there are complicated communicative interactions that take place between parents living with HIV and their children. These interactions may be colored by the parent’s current health status, whether or not the parent has disclosed his or her HIV status to the child, as well as cultural, situational, and contextual factors that might prevent or facilitate HIV prevention discussions.

**HIV Prevention and the Broader Parent-Adolescent Communication Literature**
Regardless of parental HIV status, family-based research is recognized as an emerging approach to HIV prevention (DiClemente, Crosby, & Wingood, 2002). Both CDC and NIMH have emphasized the integral role of parents in affecting adolescent sexual risk behavior (Perrino, Gonzalez-Soldevilla, Pantin, & Szapocznik, 2000). Parents are considered a distinctive resource for communicating prevention information to adolescents because they have a proximal, long-term, and vested interest in adolescent development and behavior (Perrino et al., 2000). As Dittus, Miller, Kotchick, & Forehand (2004) assert, parents have a “unique ability to engage their children in dialogues…that occur early and are continuous, (i.e. not one-time events), sequential (i.e. build upon one another as the child’s…experiences change), and time-sensitive (i.e. information is immediately responsive to the child’s questions and anticipated needs…). (p.9).

Parent-adolescent communication about sexual behavior has been associated with a number of protective factors, including (a) later onset of sexual activity, (b) greater likelihood of using contraceptives, (c) less chance of pregnancy among girls, and (d) a decreased risk of HIV transmission (Baumeister, Flores, & Martin, 1995; Darling & Hicks, 1982; Fox, 1981; Furstenberg, 1971; Leland & Barth, 1993). Similarly, several studies have demonstrated that adolescents who have frequent, open, and supportive communication about drug use with their parents have a decreased likelihood of using drugs and tend to have more positive attitudes towards abstinence (Baumrind, 1991; Kafka and London, 1991). Overall, these studies document that parent-adolescent communication should a) occur early in adolescence (before onset of sexual activity) (Dittus et al., 2004), b) take place frequently (Dittus, Jaccard, & Gordon, 1999), c) be comprehensive (employing a variety of topics) (Dutra, Miller, & Forehand, 1999), d) have good quality (Dittus et al., 2004), and e) occur within supportive parent-child relationships (Dittus & Jaccard, 2000). In addition, conversations
are more likely to be effective if they are interactive as opposed to dominated by the parent (DiIorio, McCarty, & Pluhar, 2008), and if the parent is open, competent, and comfortable during sexual communication discussions (Whitaker, Miller, May, & Levin, 1999). Cultural differences also exist in family communication about HIV, with African Americans, Hispanics, and low-SES families (who are at the most risk for acquiring HIV) reporting less communication and less accurate knowledge than their non-minority counterparts (Tinsley, Lees, & Sumartojo, 2004).

Even within the wealth of prevention literature on parent-adolescent communication among parents not affected by HIV, the majority of studies have tended to examine (a) whether or not prevention conversations took place, or (b) the frequency of such conversations (Nappi, McBride, & Donenburg, 2007). Such studies have tended to overlook the content, context, quality, and emotional tone involved in discussing HIV prevention (Nappi et al., 2007). From the studies available that do investigate content of parent-adolescent discussions, topics range from sex and basic facts about reproduction to discussions of sexual values, masturbation, and homosexuality (see Table 1).
Table 1

**Content Discussed During Parent-Adolescent Conversations About HIV Prevention**

<table>
<thead>
<tr>
<th>Authors</th>
<th>Study Design</th>
<th>Content Discussed</th>
</tr>
</thead>
</table>

Although the evidence summarized above speaks to parents’ impact on adolescent decision-making and risk behavior, the extent to which these findings apply to families affected by HIV remains largely unknown. The confluence of the central role of parents as communicators of behavioral values and norms, along with the reality that many women living with HIV are living longer and having children (Murphy, Marelich, Dello Stritto, Swendeman, & Witkin, 2002), makes it important to understand how communication among parents living with HIV and their children is or is not broached.

**Barriers and Facilitators to Parent-Adolescent Communication**

In reality, there are many barriers that prevent parents from discussing HIV prevention with their children. Home-based discussions about HIV and HIV prevention oftentimes are limited by parents’ skill and comfort level discussing sensitive topics (Boone & Lefkowitz, 2007; Meschke, Bartholomae, & Zentall, 2002; Reis, 1996). In addition, parents are generally not good predictors of whether or not adolescents are sexually active and thus may underestimate the need
for and age at which sexual communication should take place (Jaccard, Dittus, & Gordon, 1998). Jaccard, Dittus, and Gordon (2000) classified these and other barriers into five main factors that prevent parents from effectively communicating with adolescents about sensitive topics, including (a) lack of parental knowledge or communication skills, (b) parental beliefs that the discussion will go poorly, (c) lack of parental confidence (self-efficacy), (d) situational constraints, and (e) the fear of encouraging sexual behavior.

Parents living with HIV or AIDS may face additional barriers when communicating about HIV prevention, such as feeling “inexperienced” when discussing behavioral risk, or being reluctant to give advice to adolescents because of “mistakes” they made when they were younger (Brackis-Cott, Mellins, & Block, 2003, p. 64). Families affected by HIV/AIDS also must confront issues of stigma, disclosure, secrecy, perceived social isolation (Steiner et al. 1995), and uncertainty about the course of their illness, among many other competing life concerns (Brashers et al., 2003). At the same time, however, parents living with HIV/AIDS may be more knowledgeable about HIV infection and more likely to realize the importance of preventing HIV infection, which may serve to facilitate HIV prevention discussions with adolescents (O'Sullivan et al., 2005). These factors, combined with the unique structure of many families affected by HIV/AIDS, speak to both the complexity and importance of finding effective strategies for discussing HIV prevention among parents living with HIV/AIDS (Pequegnat, 2001). Studies that explore new and innovative ways for parents to engage in HIV prevention discussions are an important step towards designing up-to-date and contextually relevant parent-adolescent communication interventions (Tinsley, Lees, & Sumartojo, 2004). A summary of communication strategies currently reported in the literature can be found in Table 2.
Table 2

*Strategies Reported for Parent-Adolescent HIV Prevention Communication*

<table>
<thead>
<tr>
<th>Authors</th>
<th>Study Design</th>
<th>Parental Strategies Reported</th>
</tr>
</thead>
</table>
| Whalen, Henker, Hollingshead, & Burgess (1996) | Mixed        | Humor (good-natured joking)  
Directiveness (dominating)  
Negative feedback (criticism, disagreement)  
Emotional expressiveness (intensity of emotion) |
| O’Sullivan, Meyer-Bahlburg, & Watkins (2001) | Qualitative  | Initiate discussion at puberty  
Initiate discussion when child interested in opposite sex  
Initiate discussion as situations arise  
Postpone discussions indefinitely  
Focus on consequences of sexual behavior  
Emphasize child’s responsibility in sexual encounters |
| Nwoga (2000)                     | Qualitative  | Story-telling                                                                               |
| Pluhar, Jennings, & DiIorio (2006) | Qualitative  | Resources (books, videos, media, etc.)  
Role-modeling  
Step-by-step approach (age-appropriate information)  
Referring to religion & spirituality  
Being honest or “real”  
Using persuasive arguments  
Being reactive (letting child ask) or avoidant |

**Effectiveness of Strategies for Communicating about HIV Prevention**

Research that has examined the strategies parents use to communicate with adolescents about sexual behavior has rarely addressed which communication strategies are more effective. Effective messages are those that are accepted by their target audience and are often measured by a change in attitude, intention, or behavior (Witte & Allen, 2000). From the limited effectiveness studies that exist, it is known that many mothers wait until their daughters ask about sex to discuss safe sexual behavior, a strategy that both the researchers and the mothers themselves deemed largely ineffective (O’Sullivan, Meyer-Bahlburg, & Watkins, 2001). Many parents also report focusing on rules, discipline, and consequences when discussing sexual activity or drug use with adolescents (Ennett et al., 2001; Miller-Day, 2002), whereas evidence-
based parenting interventions like the Parents Matter! Program aim to promote open, supportive, comprehensive, and timely communication practices (CDC, 2008; Dittus, Miller, Kotchick, & Forehand, 2004).

Without research that allows for exploration of effective parent-adolescent communication strategies, parents may perpetuate maladaptive strategies for discussing HIV prevention and safer sexual behavior. Given that communication behaviors are generally regarded as modifiable, studies that describe and identify effective communication patterns are a promising approach for interventions targeting parent-adolescent communication (Riesch, Anderson, & Kreuger, 2006). Indeed, Lefkowitz, Sigman, and Au (2000) found that mothers who underwent a communication skills training program were able to conduct more interactive conversations about sexuality and AIDS with their adolescents, compared to mothers who did not participate in the experimental training program. The mothers in the experimental group had a greater level of AIDS knowledge, acted less judgmental, asked an increased number of open-ended questions during conversation, and decreased the amount of time they spoke (to allow the adolescent to have greater participation in the conversation). A summary of effective and less effective parent-adolescent communication characteristics that have been reported in the literature can be found in Table 3.
Table 3

*Characteristics of Effective versus Ineffective Parent-Adolescent Communication*

<table>
<thead>
<tr>
<th>Authors</th>
<th>Study Design</th>
<th>Effective</th>
<th>Less Effective</th>
</tr>
</thead>
<tbody>
<tr>
<td>Many2</td>
<td>Various</td>
<td>Frequent discussions</td>
<td>Infrequent discussions</td>
</tr>
<tr>
<td>Miller, Levin, Whitaker, &amp; Zu (1998)</td>
<td>Quantitative</td>
<td>Conversations before the onset of sexual activity</td>
<td>Delayed conversations (late in adolescence)</td>
</tr>
<tr>
<td>Dutra, Miller, &amp; Forehand (1999)</td>
<td>Quantitative</td>
<td>Comprehensive conversations (various topics)</td>
<td>Narrow conversations (limited topics)</td>
</tr>
<tr>
<td>Dutra, Miller, &amp; Forehand (1999)</td>
<td>Quantitative</td>
<td>Conversations perceived as good quality</td>
<td>Conversations perceived as poor quality</td>
</tr>
<tr>
<td>Dittus &amp; Jaccard (2000)</td>
<td>Quantitative</td>
<td>Occur within supportive parent-child relationships</td>
<td>Occur within unsupportive parent-child relationships</td>
</tr>
<tr>
<td>Crawford, Thomas, &amp; Zoller (1993)</td>
<td>Quantitative</td>
<td>High parental HIV knowledge</td>
<td>Low parental HIV knowledge</td>
</tr>
<tr>
<td>Guilamo-Ramos, Jaccard, Dittus, &amp; Collins (2008)</td>
<td>Quantitative</td>
<td>High parental self-efficacy (confidence)</td>
<td>Low parental self-efficacy (confidence)</td>
</tr>
<tr>
<td>Whitaker, Miller, May, &amp; Levin (1999)</td>
<td>Quantitative</td>
<td>High parental comfort level discussing HIV prevention</td>
<td>Low parental comfort level discussing HIV prevention</td>
</tr>
<tr>
<td>Miller, Kotchick, Dorsey, Forehand, &amp; Ham (1998)</td>
<td>Qualitative</td>
<td>Open conversations</td>
<td>Closed conversations</td>
</tr>
<tr>
<td>Hepburn (1983)</td>
<td>Qualitative</td>
<td>Direct conversations</td>
<td>Indirect conversations</td>
</tr>
<tr>
<td>Many3</td>
<td>Qualitative</td>
<td>Interactive conversations</td>
<td>Didactic conversations (dominated by parent)</td>
</tr>
</tbody>
</table>

2 A number of studies have examined frequency of parent-adolescent communication about HIV prevention. The majority have found that more frequent conversations have a protective effect on adolescent attitudes about sex and/or adolescent sexual behaviors. A non-exhaustive list of these authors includes: Dilorio, Kelly, & Hockenberry-Eaton, 1999; Dittus, Jaccard, & Gordon, 1999; Furstenberg, Moore, & Peterson, 1985; Karofsky, Zeng, & Kosorok, 2001; Lehr, Dilorio, Dudley, & Lipana, 2000; Leland & Barth, 1993; Pick & Palos, 1995; Romer et al., 1999.

3 Authors looking at the effectiveness of interactive versus didactic HIV prevention conversations include: Lefkowitz, Kahlbaugh, Au, & Sigman, 1998; Lefkowitz, Kahlbaugh, & Sigman, 1996; Lefkowitz, Romo, Corona, Au, & Sigman, 2000; Pluhar, 2001.
Theoretical Underpinnings

DiLorio et al. (2008) noted that “behavioral theories and theories of communication might be useful in providing a context in which to raise research questions and test hypotheses” on parent-child discussions about HIV (pp.185-186). This study draws upon both health behavior and health communication theories, using well-tested concepts from the Unified Theory of Behavior (UTB) and the Normative Model of Interpersonal Communication (NMIC). The UTB is a general theoretical framework that integrates the core constructs of empirically supported health behavior theories in order to predict a given health behavior (Fishbein et al., 2001). It is a relatively new framework, although its constructs are based in decades of previous psychological and public health research. It has recently been found to be effective in predicting the frequency of parent-adolescent HIV risk communication (Guilamo-Ramos, Jaccard, Dittus, & Collins, 2008).

Unified Theory of Behavior (UTB)

The UTB posits that parents will be more likely to discuss HIV prevention with their children if they (a) perceive many advantages and few disadvantages to talking with their children about HIV prevention (parental behavioral beliefs), (b) feel “normative pressure” (social norms) to engage in prevention discussions, (c) believe that engaging in HIV prevention discussions will maintain (not damage) their self-image, self-esteem, or self-concept, (d) have a positive emotional reaction (feel relaxed and comfortable) when talking about HIV prevention, and (e) report a high degree of self-efficacy for engaging in HIV prevention discussions with adolescents (Guilamo-Ramos et al., 2008). Though additional factors (e.g., parental skill level, 

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environmental factors) may moderate parental intentions to perform a behavior, the above five broad classes of variables are thought to be immediate determinants of whether or not a parent intends to discuss HIV prevention with his or her child. An operational definition of each of these classes of variables is given below, as detailed by Guilamo-Ramos et al. (2008).

**Parental behavioral beliefs.**

Parental behavioral beliefs (also commonly referred to as parent expectancies) refer to the perceived parental advantages and disadvantages of performing a given behavior. For this study, parental behavioral beliefs refer to parents’ perceived advantages and disadvantages of engaging in conversations about HIV prevention with adolescents. According to the UTB, parents who perceive many advantages and few disadvantages to talking with their children about HIV prevention will be more likely to (a) intend to discuss HIV prevention with their children and (b) report discussing HIV prevention with their children.

**Normative influences.**

Normative influences refers to parental social norms. Parental intentions to discuss HIV prevention information with adolescents are affected by (a) parental perceptions of how many “other parents” (or parents like them) have discussed HIV prevention with their children, and (b) their perceptions of how much people important to them (e.g., a parent, a significant other, a close friend) would approve or disapprove of the parent talking about HIV prevention with his/her adolescent. For example, the UTB predicts that parents will be more likely to discuss HIV prevention with their children if they think many other parents have discussed HIV prevention with their children and that others who are important to them would approve of them having such conversations.
**Self-concept / self-image / self-esteem.**

This class of variables is a broad category covering perceptions of the self. It assumes that parents have an idea or projection of their self-image and how particular behaviors might alter or affect that self-image. The UTB predicts that parents will be less likely to perform behaviors that will project a self-image that is undesirable to the parent and more likely to perform behaviors that project a self-image that is desirable to the parent. For example, the UTB predicts that parents who think engaging in a conversation about HIV prevention with their adolescent would portray them as a competent and responsible parent would be more likely to have a discussion than parents who think that engaging in such a conversation might portray them as unprepared or unknowledgeable.

**Emotion.**

This class of variables recognizes the affective aspects of behavior. In contrast to the previous classes, which are cognitive in nature, emotion-centered variables focus on the emotional reactions a parent may have to performing a given behavior. For example, a parent who has a strong negative emotional reaction when thinking about discussing HIV prevention with their child would be less likely to have a conversation than a parent who has a strong positive emotional reaction. Thus, this class of variables refers to both the strength of emotional reaction and also to the valence or direction of that arousal (i.e., positive or negative) (Ekman & Davidson, 1994).

**Self-efficacy.**

The concept of self-efficacy stems from Alfred Bandura’s Social Learning Theory (1975, 1986) and has been used in thousands of behavioral studies (Guilamo-Ramos et al., 2008). It refers to one’s self-confidence (or perceived confidence) in performing a given behavior. For example, the UTB predicts that parents who have a high level of confidence engaging in HIV
prevention conversations with adolescents would be more likely than parents of lower perceived confidence to discuss HIV prevention with their adolescent.

Since the UTB is a general theoretical framework, its proponents advocate adapting it to specific populations and contexts and using “qualitative and exploratory work” to identify beliefs unique to the community members at hand (Guilamo-Ramos, Jaccard, & Casillas, 2004, p.121). The current study seeks to use specific constructs from this framework (e.g., parental behavioral beliefs, parental self-efficacy) to identify potential correlates of parent-adolescent HIV prevention communication, particularly those that might be unique to parents living with HIV/AIDS.

Normative Model of Interpersonal Communication (NMIC).

The second approach guiding the design of the proposed study is the Normative Model of Interpersonal Communication. Rather than focusing solely on identifying predictors of communication, a normative model can be used to describe, categorize, and explain communication encounters that have already occurred, including situational and contextual factors. A normative approach to interpersonal communication posits that there are certain message characteristics that are better designed than others – they reach their target audience and are deemed both appropriate and effective (Goldsmith, 2001). Messages that are well-designed are more likely to facilitate communication and overcome barriers, resulting in more effective communicative encounters (Goldsmith, 2004). Thus, a normative examination of communication draws attention to three often neglected tenets of conversational encounters: 1) conversational meaning should be examined, instead of only identifying whether or not conversations have occurred or which conversational topics have been discussed, 2) communication practices should be evaluated to discover what messages work in specific situations, contexts, cultures, and communities, and 3) the current focus on predicting
conversations should be expanded to include explaining communicative encounters (e.g., why some messages are perceived to be more adaptive or effective than others). Specific to parent-adolescent communication, the NMIC is useful because it encourages researchers to provide a thoughtful analysis of conversations that have already taken place (e.g., which HIV prevention conversations work, in what contexts or situations, why, and for whom).

Whereas constructs from the UTB were used in this study to identify specific advantages and disadvantages to communication reported by HIV+ parents, the NMIC was used to guide an in-depth and nuanced explanation of the strategies parents used to discuss HIV prevention, including why certain communication strategies were perceived as more effective than others (Brashers, Goldsmith, & Hsieh, 2002). Discussion characteristics examined stemming from the NMIC included (a) the content of discussions, (b) the strategies parents use for discussing such topics, and (c) the perceived parental effectiveness of those strategies. Identifying parental strategies currently used and perceived to be effective in discussing HIV prevention is an important first step towards laying the groundwork for a theoretical framework of parent-child communication about HIV prevention information, as well as future communication interventions which attempt to increase communication skills among parents living with HIV/AIDS. Figure 1 indicates key constructs that were examined stemming from the UTB (not shaded) and the NMIC (shaded in grey).
Research Questions & Hypotheses

Influenced by the previously mentioned theories and models, this study employed a mixed methods approach to examine how parents living with HIV/AIDS communicate with their sons and daughters about HIV prevention. For the qualitative portion of the study, the following three research questions were posed:

**RQ1**: What helps and/or hinders parents living with HIV/AIDS from engaging in conversations about HIV prevention with adolescents?

**RQ2**: What strategies do parents living with HIV/AIDS use to engage in prevention conversations and which do they deem to be the most effective?

**RQ3**: How might these strategies overlap and/or differ from those used and found to be effective in the larger HIV prevention literature?
For the quantitative portion of the study, the following two hypotheses were proposed:

**H1:** Parents will report focusing the content of HIV prevention discussions around how they believe they were personally infected.

**H1a:** Parents who think they were infected with HIV by sex will be more likely to report discussing sex frequently with adolescents than parents.

**H1b:** Parents who think they were infected with HIV by drug use will be more likely to discuss drugs frequently with adolescents.

**H2:** Limited disclosure of HIV status and high HIV-related stress will be identified as barriers unique to parents living with HIV/AIDS.

**H2a:** Parents who report limited disclosure of their HIV status to their children (as measured by the HIV Disclosure scale) will report less frequent discussions about HIV prevention with their adolescent(s).

**H2b:** Parents who report a high degree of HIV-related stress and avoidance of HIV (as measured by the Impact of Event scale) will report less frequent discussions about HIV prevention with their adolescent(s).

These research questions and hypotheses were addressed using both quantitative and qualitative methods, with careful attention devoted to the mixed methods nature of the study. Parents living with HIV/AIDS who had adolescents between the ages of 10 and 18 were interviewed and completed a questionnaire to assess the facilitators and barriers to conversation, and the strategies used discussing HIV prevention and testing with adolescents. Whereas the qualitative component was viewed as the most informative part of the study, the responses on the quantitative questionnaire were used to complement the interviews and provide a means for comparing this study to previous quantitative studies of parent-adolescent HIV prevention communication.

The long-term objective of this project is to facilitate development of family-based HIV prevention programs to enhance communication between parents and children affected by HIV. By providing theoretically-driven research that explores parent-adolescent communication
among parents living with HIV, the findings from this study may identify ways to help parents more effectively communicate with their adolescent children about safer sex, drug use, and HIV infection.

**Chapter Summary**

Overall, this chapter illustrated key findings in the literature that provided the background and rationale for embarking upon a study of this nature. Literature specific to families affected by HIV/AIDS and the broader parent-adolescent communication literature was reviewed in efforts to highlight how the wealth of information already available on parent-adolescent communication might be useful in informing interventions for specific groups of parents (e.g., parents living with HIV/AIDS). Major theories guiding the study, the UTB and the NMIC, were explained in efforts to (a) provide a conceptual framework for the reader, and (b) examine how two theories from different but overlapping fields might be used in conjunction with one another. Finally, the major study research questions were described, as well as the preliminary hypotheses. The following chapter will detail the methodological design employed to examine these objectives.
CHAPTER 3: METHODS

Chapter Overview

The purpose of this mixed methods study was to investigate the strategies parents living with HIV/AIDS use to discuss HIV and HIV prevention in a family context, including what factors facilitated or prevented parent-adolescent conversations, as well as which strategies were deemed to be the most effective. This chapter’s specific purpose is to describe the research methodology employed in this study. As such, the chapter details (a) the paradigmatic framework and guiding assumptions of the study (b) the rationale for conducting a mixed methods study, (c) participant sampling and recruitment, (d) ethical considerations, (e) how data were collected, including the specific instruments used, and (f) how data were analyzed and synthesized, including the rationale for using a grounded theory based approach to inquiry. The chapter closes by summarizing the timeline of investigation before setting the groundwork for the following chapters on presentation of results.

Paradigmatic Framework & Guiding Assumptions

As is a general standard in qualitative research and becoming increasingly common in mixed methods studies, the beginning of this chapter offers information on the researcher’s background, research experiences and qualifications, and the paradigmatic assumptions guiding the study focus and design. This reflexive stance is important because it gives the investigator an “opportunity to understand how his or her own experiences and understandings of the world affect the research process” and informs others of the researcher’s inclinations and subjectivities (Morrow, 2005, p.253). Background information and research experiences relevant to the study at hand include (a) the researcher’s current enrollment in a joint MD/PhD program and, (b) previous training as a laboratory scientist working with STIs, including HIV. From these
experiences comes a natural positivist tendency to work at a very detailed level with numeric data, hypotheses, fitting data into categories, and statistical inferences. However, the researcher has spent the past four years as a graduate student in a community health program, which has afforded a variety of opportunities to examine current thoughts and trends in health behavior. The courses taken in preparation for this study were very consciously selected for a study on communication and health behavior, consisting of basic courses in research methods, behavioral theory, and statistics, as well as specific courses in qualitative methodology, grounded theory, mixed methods research, and health communication theory. Overall, these courses have solidified and expanded the researcher’s knowledge of quantitative methods and experimental design, as well provided an understanding of the importance of examining the lived experiences of participants in their sociocultural contexts.

One of the guiding theories selected for this study, the UTB (Fishbein et al., 2001), closely aligns with the positivist and post-positivist tendency to focus on causal pathways, isolated variables, and predictions of behavior (Bloomberg & Volpe, 2008). This theory rests on the underlying assumption that individuals act rationally when making behavioral decisions. Inherent to this rational thought process is the notion that (a) people generally desire to avoid illness and value health, and (b) people believe and expect that a specific health action available to them (e.g., communicating about HIV prevention) will prevent illness (Janz, Champion, & Strecher, 2002). The other theory, the NMIC, is more in line with a constructivist worldview. It has an inductive focus on the process of communication and rests on the assumptions that (a) reality is a social, cultural, and historical construction, (b) people cultivate subjective meanings of their personal experiences, and (c) a researcher’s role is to understand these multiple meanings from the perspectives of those they study (Bloomberg & Volpe, 2008).
Throughout this document, traditional positivist terms have been used for sections detailing quantitative methods and Lincoln & Guba’s “parallel criteria” (2000) have been chosen as a framework for evaluating the qualitative methodology of this study. For those not familiar with qualitative methods, the parallel criteria provide the loosely fitting correlates to the quantitative terms “internal validity,” “external validity,” “reliability,” and “objectivity,” but their definitions are tailored to the differential aims and goals of qualitative work. Though some contest the usefulness of and/or have moved beyond using these criteria to evaluate rigor in the qualitative research process (Morrow, 2005), they prove particularly useful for mixed methods studies because of their historical emergence from and ease of relation to quantitative terms. Disagreement exists on where to currently place the parallel criteria in terms of paradigmatic thought, as they have been identified by some as stemming from a postpositivist paradigm while others classify them as more constructivist in nature (2005).

Overall, however, boundaries between paradigms are beginning to be less firm than they previously were (Denzin & Lincoln, 2005). Many mixed methods researchers have adopted pragmatism as an alternative or “middle-ground” paradigmatic stance (Greene, 2007), which endorses the following approaches to methodology:

1) A genuine respect for the various research philosophies but a refrain from whole-heartedly using one explicit philosophy or paradigm (Greene, 2007).

2) The belief that the research problem or questions should drive methodological decisions.

3) An acknowledgement that methods can (and sometimes should) be combined creatively to more completely understand a research problem (Bloomberg & Volpe, 2008).
4) A focus on conducting research to provide “practical applications and workable solutions” (Bloomberg & Volpe, 2008, p.10), particularly relevant to the intervention-focused disciplines of public health and medicine.

As high quality research in any tradition involves being transparent about the process (Morrow, 2005), portions of this chapter are also used as an opportunity to reflect on the “ebb and flow” of the research process, including the challenges encountered while conducting research with a difficult-to-reach population.

**Mixed Methods: Purposes and Rationale**

This project used a mixed methods design to examine the strategies parents with HIV use to discuss HIV prevention. Mixed methods studies employ both qualitative and quantitative techniques during data collection and data analysis (Teddlie & Tashakkori, 2003). Due to their methodological diversity, such studies produce knowledge neither method could provide in isolation (Greene, 2007). In this study, data from semi-structured interviews and questionnaires were analyzed to provide a comprehensive assessment of (a) the facilitators and barriers to initiating HIV prevention discussions with adolescents, (b) the strategies used for engaging in HIV prevention discussions, (c) which strategies were perceived to be more effective than others.

Though studies with mixed methodologies have been in existence for quite some time, methodologists have recently emphasized the need for intentional and thoughtful mixing of methods, noting that it is essential for researchers to identify their purpose for mixing methods (Greene, 2007). The primary purpose of mixing methods in this study was to use quantitative methods (structured questionnaires) to complement the overall qualitative nature of the study (in-depth interviews). It was hoped that the combined use of quantitative and qualitative methods would (a) allow the quantitative findings from this study to be compared with previous studies
using similar questionnaires (b) allow for convergence of findings between data sources, and (c) provide a more in-depth, nuanced, and comprehensive view of HIV prevention discussions than is typically captured by questionnaires alone.

Mixed methodology is especially appropriate for a study on communication within HIV-affected families. In a methodological review of research involving families with ill parents, Romer, Barkmann, Schulte-Markwort, Thomalla, and Riedesser (2002) assert that a combination of qualitative and quantitative evaluation is *necessary* for studying complex family processes like parent-child communication. Qualitative methods have often been underutilized in HIV/AIDS research (Kanekar, Sharma, & Wray, 2009; Pequegnat et al., 1995) and are well-suited for exploratory study (Babbie, 2001). Whereas the questionnaire used in this study served as a concrete way to identify parental strategies used during HIV prevention conversations, potential correlates of HIV prevention discussions, and how *often* parents communicated about HIV prevention with adolescents, the interviews were used to provide a deeper understanding of *how* the strategies were implemented and whether or not they were deemed effective.

**Participants: Sampling and Recruitment**

**Sampling**

Participants consisted of parents or guardians living with HIV/AIDS in Illinois and Indiana. They were reimbursed $30 for their participation in the study and were able to participate if they met the following inclusion criteria: (a) self-reported diagnosis of HIV or AIDS, (b) parent or guardian of at least one child ages 10-18 who is not infected with HIV, (c) 21 years of age or older, (d) ability to complete the interview and questionnaire in English, (e) no apparent dementia, and (f) reported living with or having frequent (at least monthly) contact with their adolescent for the past year. Criteria “d” and “e” above were included because the nature of this type of study (i.e. in-depth interviews and filling out questionnaires) required normal
cognitive function and the ability to read, understand, and respond in English.

Though the number of AIDS cases in Illinois is the sixth highest in the nation (Illinois Department of Public Health [IDPH], 2008), it is not known how many persons currently living with HIV/AIDS are parents of uninfected adolescent children in Illinois or in Indiana. Previous studies indicate that 75% of women living with HIV are mothers and that the average number of children per woman is 2.6 (Forsyth, 1995). The majority of children born to mothers living with HIV are not infected themselves (Bauman, Camacho, Silver, Hudis, & Draimin, 2002). Due to the fairly limited number of participants who may have fit the inclusion criteria and the exploratory nature of much of this research, convenience sampling was employed in this study.

**Diversity of the Sample**

One of the goals of the study was to recruit a diverse sample of parents living with HIV/AIDS. Since HIV/AIDS disproportionately affects minority populations (CDC, 2004), efforts were made to reflect this diversity when recruiting potential participants. Men and women ages 21 and older of all racial and ethnic backgrounds were eligible to participate in the study. Most recent evidence suggests the following distribution of AIDS cases by race and ethnicity in Illinois and Indiana (see Table 4).
Table 4

*Distribution of AIDS Cases by Race and Ethnicity in Illinois & Indiana*

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>White</td>
<td>25.3</td>
<td>44.7</td>
</tr>
<tr>
<td>Black/African American</td>
<td>57.3</td>
<td>40.1</td>
</tr>
<tr>
<td>Hispanic/Latino</td>
<td>16.1</td>
<td>9.9</td>
</tr>
<tr>
<td>Asian / Native American</td>
<td>1.1</td>
<td>1.3</td>
</tr>
<tr>
<td>Other</td>
<td>.3</td>
<td>3.9</td>
</tr>
</tbody>
</table>

Conversations with the supporting organizations for this study confirmed the likelihood of recruiting a sample largely made up of minority populations. In addition, the Illinois Department of Health (IDPH, 2008) estimates that 81% of AIDS cases are men and approximately 19% are women. From the literature on families affected by HIV/AIDS, however, it is known that many families affected by HIV/AIDS consist of single mothers and their children (Forsyth, 1995). Some of the organizations that assisted with recruitment were chosen because they offered programs specifically for women and children, whereas others were chosen because they indicated that they served a higher percentage of males than females. The researcher’s best guess was that approximately 40% of the sample would consist of men living with HIV/AIDS and the other 60% would consist of women. It was hoped that this gender dynamic would contribute to further research on father-adolescent sexual communication.

**Recruitment**

Recruitment took place in two rounds. Organizational efforts began in January 2008. Five HIV/AIDS-related organizations were located throughout Illinois and Indiana that might be interested in advertising a study of this nature to their clients. Organizations of a diverse nature were intentionally sought out, including an HIV/AIDS clinic at a hospital, a public health

department, a research institute with an established cohort of HIV-positive women, and two community-based non-governmental organizations (NGOs). Some of these organizations were known to serve urban populations, whereas other served a mix of and suburban and rural populations. Contacts at these organizations included a variety of administrators and health care providers, including social workers, counselors, physicians, nurses, and HIV case managers. These individuals were key players in not only providing eligible clients the opportunity to participate, but also in helping the researcher to immerse herself in and adapt to the world of HIV services and care.

After preliminary visits, meetings, and phone conversations explaining the nature of the study and the overall goals of the research, all five organizations pledged their support and commitment to helping with recruitment efforts. Below is a brief description of each organization, their general geographic location, and the types of services they provide.

1. **Organization #1, Various regions of IL.** This organization is well-known for its advocacy efforts on behalf of HIV affected children, youth, and families. They hold state-wide, federally funded retreats for families affected by HIV/AIDS. These retreats, which typically serve 200 family members, allow families from all over Illinois to come together in a therapeutic setting for recreation, skill-building, and HIV education. The researcher serves as a camp counselor at their annual summer retreats. This experience provided a unique opportunity to develop rapport with many of the service providers and families affected by HIV/AIDS prior to enlisting their support for the study.
2. **Organization #2, Central Illinois.** This HIV/AIDS clinic serves approximately 300 HIV patients living in seven counties in Central Illinois. The researcher attended weekly HIV Comprehensive Care meetings over the course of a semester. She developed rapport with the social workers, public health case managers, and physicians involved in HIV care, as well as some of the HIV community prior to embarking upon this study.

3. **Organization #3, Central Illinois.** This is a not-for-profit primarily volunteer-run organization that offers housing services, rent and utility assistance, nutritional services, and support groups for persons living with HIV/AIDS. The organization serves around 300 clients in Central Illinois.

4. **Organization #4, Northern Illinois.** This is a nationally recognized multidisciplinary group of investigators working together to study HIV pathogenesis, psychosocial, and clinical aspects of HIV infection among women. They estimated that approximately 76 mothers/legal guardians would be eligible for the study and that recruiting a large proportion of African American patients was highly feasible.

5. **Organization #5, Central Indiana.** This organization is one of the largest HIV/AIDS service organizations in Indiana and is considered to be a leader in HIV prevention and care. They have offered supportive services to thousands of persons infected with and affected by HIV/AIDS. Supportive services include health insurance, housing, medical/dental/vision referrals, medication management, nutritional services, legal assistance, and social and educational support.

   Once agreement to participate in recruitment efforts had been established, Institutional Review Board (IRB) applications were submitted and approved. Recruitment began in February 2009. In most cases, organizations handed out or posted fliers informing those interested about
the study. One of the organizations preferred to contact eligible participants on their own and schedule them for interviews (this was their institutional policy). The fliers advertised that a study was being conducted to learn how parents talk to kids about HIV prevention and emphasized that interviews would be confidential (see Appendix A). A toll-free phone number and an e-mail address were listed where parents could get more information about the study. If parents called in, were interested, and met the eligibility criteria for the study, an interview time and location were arranged.

The first five interviews were collected as pilot data, in efforts to gauge the comprehensibility of the interview script and questionnaire, as well as to elicit participant feedback on how the study materials might be improved. While participants indicated that they enjoyed the study session and the opportunity to speak about communicating with their children, they had no suggestions for improvement of the interview questions or questionnaire. Parents in the pilot interviews did suggest, however, that it would be valuable to allow participants to bring a friend, relative, or partner with them to the interview if they wanted, as it may (a) make participants feel more comfortable discussing potentially sensitive information, (b) give the researchers a more complete picture of family communication dynamics, and (c) give family members, partners, or friends a chance to learn from one another and talk in depth about a topic they didn’t normally have the opportunity to reflect on. These suggestions were incorporated into the study protocol.

While the researcher theoretically had access to more than enough parents living with HIV/AIDS to reach the targeted sample size of 50 parents, initial study recruitment was slow. After seven months of enrollment, only 16 interviews had been conducted. This provided an opportunity to focus on transcribing and preliminary analysis, however it was also at this point
that a second round of recruitment was planned and the IRBs amended. For the second round of recruitment, HIV-related websites were used to generate a list of the majority of HIV/AIDS service organizations in Illinois and Indiana. HIV/AIDS service organizations included organizations that provided some form of support – food, housing, medical or dental care, mental health services, medication, education, etc. to individuals living with HIV or AIDS. This list consisted of 184 organizations total, 166 in Illinois and 18 in Indiana. Each organization was mailed a letter (see Appendix B) explaining the purpose of the study, that IRB approval had already been obtained, how they could help (e.g., by raising clients’ awareness about the study), and contact information (should they wish to contact the researchers for further information). Also included in each packet were a handful of fliers, so that interested organizations could distribute the study information to their clients.

The second round of recruitment resulted in a much larger response. Within two weeks a number of e-mails and phone calls were received, both from potential participants as well as from organizational contacts extending invitations for the researcher to attend various HIV-related events (parenting classes, food drives, educational fairs, etc.). The researcher also continued to maintain contact with and actively recruit from the initial recruitment organizations. Ultimately, 29% of the sample came from the initial five organizations, while the remaining 71% came from a variety of HIV organizations throughout Illinois and Indiana. As a part of the second round of recruitment, snowball sampling was also incorporated (where participants would be given 2-5 fliers at the end of their study session and told they could pass them along to other potentially interested friends, relatives, or support group members).

Recruiting from a variety of organizations resulted in a diverse group of parents living with HIV/AIDS who had access to a variety of HIV-related services. All locations were within
four of the researcher’s current location and a private location for conducting interviews was secured in each geographic location. Due to the relative proximity of potential participants, the researcher was able to drive to conduct interviews. Interviews over one hour away were often coordinated to avoid unnecessary trips.

**Ethical Considerations**

Adhering to moral standards and a code of professional ethics is paramount in any research endeavor (Bloomberg & Volpe, 2008), and particularly salient when working with socioeconomically disadvantaged populations, minority populations, and the terminally or chronically ill. As Rubin & Rubin (2005) note, “interviewers have an obligation going beyond any rules set up by IRBs to deal ethically with their conversational partners, respect interviewees, and honor any promises made (p.97).” Though this study was deemed no more than minimal risk by all relevant IRBs, various precautionary measures were put in place to protect participant well-being. Central measures included (a) providing a comfortable and private interview environment, (b) ensuring participation was voluntary, (c) keeping data confidential, and (d) being supportive and empathetic, as well as providing avenues where participants could get further information and support.

**Interview Environment**

Part of building trust and demonstrating respect for participants includes carefully attending to the interview environment. Participants in this study were regarded as “conversational partners” rather than passive research subjects (Rubin & Rubin, 2005, p.97). Parents who called in and expressed interest in the study were given an overview, screened to make sure they were eligible, and (if so) scheduled for a study session in a private interview environment. A summary of the telephone recruitment script can be found in Appendix C.
Care was taken to put participants at ease during interviews by being friendly, respectful, and appreciative of their time and help. During initial phone calls, parents were asked where they would feel the most comfortable being interviewed and were given example locations where previous interviews had been conducted (at a nearby HIV-related organization, in participants’ homes, in a private room at a public library). They were also told (as suggested in the pilot interviews) that they could bring a significant other, friend, or family member with them to the interview if they would like, though this occurred infrequently. In a small subset of cases, the recruiting organizations preferred to have participants interviewed in a room in their own facility, in which case participants were not given a choice of interview location. The atmosphere in these locations was both friendly and already familiar to participants, with colorful pictures hanging on the walls and pamphlets on desks promoting HIV services and care.

Regardless of interview location, efforts were made to keep the interview environment private and relaxed. Participants were not interviewed in clinic exam rooms or in hospital settings, as to avoid the anxiety that can sometimes accompany medicalized settings. In a fair number of cases participants ate lunch or drank coffee while being interviewed. The researcher purposefully chose to sit next to participants rather than across from them at tables, as to make the environment seem more friendly and conversational. The researcher dressed casually for the interviews and invited interviewees to do the same. Emphasis was placed on the interviewer’s role as “someone interested in their experiences as parents” rather than her role as a researcher or graduate/medical student.

In instances where children or other people were in close proximity (but not actually in the interview room), participants were asked if they would prefer to pick a substitute word for HIV throughout the interview, such as “sick” or “positive” or “not feeling well.” This option
was only chosen twice -- once in the case of a mother who had disclosed her HIV status to her children but not to her son’s girlfriend, who happened to be watching a movie in the next room. The other case was a mother being interviewed in a library reading room that overlooked the children’s area, where her son was using the computer. The mother had not yet disclosed her status to her son and was afraid he might step in unexpectedly at some point during the interview. Such precautionary measures were appreciated by participants and helped to build rapport before the interview questions began, even for participants who didn’t choose this option.

**Informed consent**

Potential participants were informed prior to participation that the study dealt with sensitive questions about HIV and HIV prevention communication with adolescents. Once they arrived at the interview location (or the interviewer arrived at their home), a friendly greeting was exchanged and participants were asked to read over the informed consent form while the researcher finished setting up. The consent form contained the following information (see Appendix D): (a) a brief description of the study, including how long the interview and questionnaire would take to complete, (b) a brief review of the eligibility criteria for the study, (c) that participation was completely voluntary and participants could skip questions or withdraw at any time without penalty, (d) that participants would be reimbursed $30 for their participation, even if they withdrew early (e) the risks and benefits associated with the study, and (f) how to contact the researcher and the IRB (via toll-free phone and e-mail) for any questions they might have about the study. By signing the consent form, participants also indicated that they were willing to have their voices audio-recorded during the interview.

After having time to review the consent form on their own, the researcher verbally summarized the major points for participants (e.g., that participation was voluntary, that by
signing the informed consent form they were agreeing to have their voice audio-taped, etc.). The researcher also encouraged participants to ask questions about the consent process and to let her know if anything seemed unclear. Participants signed one copy of the consent for the researcher to keep and the other was given to the participant so that he/she would have a written summary of the study. Once the consent forms were signed, an “audio-check” was performed. Audio-checks consisted of the researcher speaking the participant’s study number into the tape recorder and playing it back for the interviewee to hear. This served to (a) make sure the batteries in the tape-recorder were working, and (b) make sure the participant understood that the interview was being tape-recorded.

Confidentiality

One of the largest social and psychological risks in a study of this nature would be a breach of confidentiality, particularly when it came to participants’ HIV status. Though knowledge about HIV transmission has improved since the early days of the epidemic and efforts to decrease HIV-related stigma have been moderately successful (Herek, Capitanio, & Widaman, 2002; Colbert, Kim, Sereika, & Erlen, 2010), the stigma and discrimination felt by individuals living with HIV/AIDS is still concrete and real. To minimize breaches of confidentiality in this study, all data were kept in a secure location. Study materials were kept in a locked briefcase (when in the field) or in a locked office (when being stored). The informed consent forms were the only documents with participant names on them and these forms did not have the participant’s study number. In addition, no linkage of participant responses was possible, as there was no key linking a given participant’s name to his/her interview or questionnaire. The audio-tapes, transcripts of interviews, paper questionnaires, and any computer files generated for data analysis only included the participant’s study number and pseudonym (not the participant’s real
name or identifying information). Signed informed consent forms were kept separate from all other paper materials for the study in a locked office drawer. Finally, findings were summarized such that they could not be used to identify individual participants in the study.

**Being supportive and empathetic**

Davies and Dodd (2002) assert that empathy, or the ability to understand what another person is feeling, plays a central but often neglected role as an ethical standard in qualitative work. Empathetic listening can be used to help build a supportive interview environment and can be demonstrated using both verbal and non-verbal cues (Rubin & Rubin, 2005). Efforts to employ empathy in this study included (a) engaging with participants (being interested in their lives and asking them follow-up questions to better understand their experiences), (b) checking for understanding (summarizing what participant’s said in their own words and asking them to verify interpretations), (c) being non-judgmental and sensitive when participants revealed personal or potentially embarrassing information (not acting surprised, acknowledging the difficult experiences participants had been through), and (d) allowing participants to voice the stories they felt were important, even if such topics sometimes deviated from the original research questions.

While being supportive and empathetic can be viewed under the umbrella of ethical considerations, supportive and empathetic listening can also be categorized as a potential benefit to research participants. A major focus of this study was allowing parents living with HIV/AIDS to share their concerns and experiences discussing HIV prevention information with their adolescent children. Previous research on parents with HIV/AIDS has found such experiences to be meaningful and therapeutic to study participants, as it allows them to discuss HIV and their concerns about their children in a safe and welcoming environment (Brackis-Cott, Mellins, &
Various personal interactions with families affected by HIV have also indicated that many families welcome the opportunity to provide advice that could be used to benefit other families affected by HIV, the HIV prevention researchers, and health care professionals involved with HIV prevention and care. Thus, parents in this study were willing to reveal oftentimes very personal information and trust that these experiences would be both protected and used for a greater good.

At the conclusion of their interview parents were given a list of HIV-related resources and support organizations in their specific area. The composition of the referral list varied by area but typically included organizations that provided HIV education, testing, and care, mental health services, domestic violence shelters, and drug rehabilitation programs. Taking care not imply that parents needed a particular resource on the list, the researcher stated that the list was being given to all study participants and that the resources could be used for them, for friends or family, or hung on the refrigerator where their adolescent(s) could access the information if needed. Detailed information about how the data were collected and which instruments were used are summarized in the section below.

**Data Collection**

On the day they were scheduled to interview, participants met the researcher for their study session. Each study session consisted of four main parts: (a) obtaining informed consent, (b) drawing a family tree, (c) undergoing a semi-structured interview, and (d) filling out a questionnaire. At the end of their study session parents were thanked for their participation, asked if they had any questions, given the list of various support agencies in the area, and reminded of how to get in touch with the research team should they have any further questions.
Instruments Used

Family tree.

After informed consent was obtained, participants were asked to describe who was in their family. Based on Boyd-Franklin’s (2000) notion of families as “families of choice,” participants were asked to include anyone in their tree who they considered their immediate family (not just biological family members). In the majority of instances, however, only biological family members were given. The family tree served as (a) a way to get to know participants and talk about enjoyable topics before delving into more personal and sometimes sensitive questions, and (b) a visual way for the interviewer to keep track of the multiple family members, their ages, and their gender throughout the length of the interview. The family tree also provided a place to jot important events or dates throughout the course of the interview. A sample family tree is included in Appendix E. Once the family tree had been completed, the interview questions commenced.

Interview script.

Semi-structured interviews were used to examine three main factors associated with parent-adolescent HIV prevention discussions, stemming from the UTB and NMIC. The interviews explored how these factors (e.g., parental behavioral beliefs, discussion strategies used, facilitators and barriers) might be tailored to parents living with HIV/AIDS. Therefore, the interview script (included in Appendix F) asked parents to describe their behavioral beliefs about discussing HIV prevention, the strategies they used for discussing HIV prevention with adolescents, which methods they believe are effective versus ineffective, and the facilitators and barriers to initiating such discussions.
The interview script was constructed after a thorough review of the relevant psychological, medical, health behavior, health communication, and family studies literature. Questions were worded (where relevant) to be consistent with previous qualitative measures of parent-adolescent HIV risk communication. Once the interview script had been revised based upon the pilot interviews, it was reviewed by both HIV content experts and experts in instrument development. The finalized version of the script was then used to interview participants. Interviews were constructed to last approximately one hour to allow for sufficient depth of participant responses. At the conclusion of the interview, participants were asked to fill out a structured questionnaire.

**Questionnaire.**

The questionnaire (see Appendix G) included demographic information (such as age, gender, race/ethnicity, relationship status, education level, CD4 count and viral load) and scales for the domains of interest. Major domains stemming from the UTB and NMIC included: (a) frequency and content of HIV prevention communication, (b) parental self-efficacy for discussing HIV prevention information, (c) importance of discussing HIV prevention, and (d) strategies used for discussing HIV prevention information. Many of these domains have been consistently examined in the broader parent-adolescent communication literature, but have not yet been systematically assessed in parents living with HIV/AIDS. Thus, the questionnaire was used to place the range of participant responses for this study amidst a larger body of parent-adolescent sexual communication literature. Ultimately, this will help to generate future questions and hypotheses about the strategies parents living with HIV/AIDS use to discuss HIV prevention, and how they may differ from those employed by parents who are not infected.

Two additional domains (e.g., degree of disclosure of HIV status and HIV-related
subjective stress) have been previously reported in the HIV/AIDS behavioral literature, but have not been studied along with HIV prevention communication. These measures were included in the questionnaire to explore if the extent to which one discloses his/her HIV status (see H2a) and avoids thoughts about having HIV (see H2b) might be related to discussing (or avoiding discussing) HIV prevention information with adolescents. Overall, the questionnaire consisted of 18 questions and took about 15 minutes to complete. Scale items were adapted and/or created based on an extensive review of the literature, as well as conversations with HIV professionals, members of the HIV community, and experts in behavioral research and instrument design. For items or constructs taken from previously validated questionnaires, the reliability and validity information are provided. A brief description of each scale follows.

1. **HIV Disclosure Scale.** This scale was created by Sowell, Seals, Phillips, & Julious (2003) to assess the extent to which 322 HIV-infected women had disclosed their status to various people in their lives, such as their children, relatives, friends, health care providers, employers, and sexual partners. Extent of disclosure was defined as having disclosed to “none,” “some,” or “all” of the individuals listed in the scale. The scale included an item where individuals could indicate that a particular category was not applicable to them (e.g., if they were not employed, their parents were deceased, etc.), as well as an item where they could indicate they had not disclosed to anyone. Reliability and validity information was not provided.

2. **PACS (Parent-Adolescent Communication Scale).** This scale, created by Sales et al. (2006) for use in HIV/STD prevention interventions, was validated on 522 African American females (a population disproportionately affected by HIV/AIDS). The scale assesses the content and frequency of parent-adolescent communication about sex and
HIV/STD prevention. It was found to have good internal consistency (Cronbach’s alpha = .88 - .90), test-retest reliability, and solid evidence for convergent and discriminant construct validity (Sales et al., 2006). The original scale was five items, eliciting the extent to which parents and adolescents had discussed (1) sex, (2) how to use condoms, (3) protection from STDs, (4) protection from the AIDS virus, and (5) protection from pregnancy. For the purposes of this study, four items were added to assess communication about (1) drug use, (2) getting tested for STDs, (3) getting tested for the AIDS virus, and (4) the parent’s own HIV or AIDS status. The combination of these nine items formed the basis for the majority of questions asked in the rest of the questionnaire. Item response options were measured on a four point scale where parents could indicate how often they had talked about each topic (ranging from “never” to “often”).

3. **Self-efficacy Scale.** This scale was created to assess how confident parents were discussing each of the nine items above with their adolescent(s). Wording and response options were created to be congruent with previous measures of parental self-efficacy about sexual communication (DiLorio et al., 2001). Item responses were measured on a four point scale ranging from “not sure at all” to “completely sure” that parents could talk about various sex, drug, and HIV-related topics.

4. **Importance of Communication Scale.** The importance scale was created to assess how much parents wanted their adolescents to know about the nine communication items above. Item responses were measured on a four point scale ranging from “not at all important” to “very important.”

5. **Strategies Scale.** This scale was created based on a review of existing literature and conversations with communication content experts. Items were created to reflect the
range of communication strategies reported in current parent adolescent communication studies. Eight main strategies were identified, ranging from active strategies (where a parent would bring the topic up him or herself) to more passive strategies (where a parent would rely on others to bring the topic up). Parents were asked to identify how often they had used these strategies on a four point scale ranging from “never” to “often.”

6. **Impact of Event Scale: A Measure of Subjective Stress.** This scale was originally developed by Horowitz, Wilner, & Alvarez (1979) as a measure of reactions to stressful life conditions. It is a generic scale where researchers or clinicians can insert a particular event or condition of interest (e.g., HIV diagnosis). The scale has been widely used in studies examining patient responses to chronic illness and has recently been used to assess HIV-related stress in families affected by HIV/AIDS (Wight, Beals, Miller-Martinez, Murphy, & Aneshensel, 2007). The nine item avoidance subscale was used in this study to gauge how frequently parents avoided thinking and talking about having HIV. It has been found to have good internal consistency (Cronbach’s alpha = .91 - .92) for persons living with HIV/AIDS (Wight et al., 2007). For the remainder of this document it will be referred to as the “HIV-Related Stress Scale,” since the version used in this study measured stress related to being diagnosed with HIV.

**Data Analysis & Synthesis**

**Overview**

The overall data analysis for this project can be summarized in the following seven steps: (1) transcribing the interviews and checking the transcripts for accuracy, (2) cleaning and organizing the transcripts using NVivo, (3) coding the interview data using a modified grounded theory approach (4) refining and organizing emergent themes and clarifying their relationships, (5) coding the interviews for contextual characteristics, (6) entering the questionnaire data and
generating descriptive statistics and correlations between scales, and (7) drawing overall inferences and conclusions based upon both qualitative and quantitative data. Though presented in a linear fashion, much of the data analysis occurred iteratively.

**Step 1. Transcribing and checking accuracy**

Audio-recorded interviews were transcribed using Express Scribe (©NCH Software), a free digital transcription software. Interviews were transcribed verbatim with the exception of verbal fillers (“ums,” “ahs,” “you knows,” etc.). Any identifying information was deleted and names were replaced with pseudonyms to protect participant confidentiality. If participants expressed emotion or spoke in a tone of conversation that seemed relevant to the interview, the transcriber captured these instances in parentheses (e.g. [Laugh] ). Any portions of the audiotapes that were difficult to hear were marked with asterisks and “unclear” and were listened to by another person in the research team. Since multiple transcribers were involved with data transcription, a random 10% of transcripts were double-checked for accuracy by a separate member of the research team. No major discrepancies between transcripts were found. At the beginning of every transcript a brief summary of the interview was written, as well as any field notes or reflections pertinent to the interview. A sample transcription template can be found in Appendix H.

**Step 2. Cleaning and organizing data using NVivo**

Once all interviews had been transcribed and data had been checked for accuracy, the hard copies of the audiotapes and transcripts were stored in a locked cabinet to protect the confidentiality of participant responses. The electronic versions of the transcripts and the scanned family trees were then imported into NVivo Version 8.0 (QSR International Ltd., Doncaster, Victoria, Australia). NVivo is a qualitative data analysis software using for storing, coding, and retrieving qualitative data. It was selected and proved useful to this study due to its
(a) ability to handle large amounts of text, (b) capacity to integrate quantitative and qualitative data sources, and (c) origins in facilitating grounded theory design (Bringer, Johnston, & Brackenridge, 2004). It should be noted that, though the software was used for organizing, storing, and retrieving data in one central location, the “autocode” feature was not used. Thus, all results from this study represent manual coding efforts subjected to human interpretation.

Altogether the interviews represented 4,794 minutes (80 hours) of audio-tape and 1,723 pages of single-spaced text. Coding proceeded using a modified grounded theory approach. The rationale for this approach and details about the coding process are given in the section below.

**Step 3. Coding the interviews using a modified grounded theory approach**

**Background and rationale for grounded theory.**

Grounded theory can be classified as one of five major methodological traditions in qualitative research (Creswell, 1998). Stemming from the field of sociology, grounded theory provides a systematic method for the identification of emerging trends and themes. Starks & Trinidad (2007) describes the overall goal of grounded theory as “developing an explanatory theory of basic social processes” in answer to the question “how does the basic social process of [X] happen in the context of [Y environment]?” (p.1373). Or, in the case of the current study “how does communicating about HIV prevention happen in the context of living with HIV/AIDS?” This particular coding approach fit nicely with the contextual focus of the NMIC.

One of the core foci of grounded theory is that codes, categories, and themes emerge *inductively*; in essence they are “grounded” in the data (Glaser & Strauss, 1967). Then, the various dimensions, conditions, causes, contexts, and consequences of each category are examined, compared against one another (constant comparative analysis), and the possible relationships between them specified (Glaser, 1978). While grounded theory is most often thought of as theory-generating, it can also be used to compliment or extend existing theories or
frameworks, so long as the data are not forced to fit preconceived notions or categories (Corbin & Strauss, 2008). As will be presented in the results chapter, much of the utility of grounded theory in this study came from identifying ways in which one might extend, tailor, or look in new ways at some of the constructs of already existing theories of communication and behavior, with a particular focus on parents living with HIV/AIDS. Finally, though the version of grounded theory used in the present analysis was most closely guided by Corbin & Strauss (2008) and Charmaz (2006), it should be noted that alterations were sometimes made to account for (a) working with mixed methods data and (b) working with an interdisciplinary team of researchers stemming from various disciplinary perspectives. In this case, the study might best be described as using a modified grounded theory approach or as using specific components of grounded theory, such as the constant comparative technique (Cutcliffe, 2005).

**Initial Coding.**

During initial coding (or “open” coding), the transcripts were read incident by incident (an incident generally referred to a given thought which spanned two to three lines), or in some cases, line by line. The purpose of initial coding was to remain close to the data and open to various theoretical directions (Charmaz, 2006). Coding progressed systematically, focusing on codes and categories from one specific aim at a time. Thus, concepts dealing with the facilitators and barriers to discussing HIV prevention were coded first, followed by those pertaining to the strategies parents used to discuss HIV prevention with adolescents, followed by notions of what it meant to have effective (versus ineffective) conversations about HIV and prevention. Wherever possible, participant’s own words were incorporated into category names, referred to by Glaser (1978) as “in vivo” coding. Analytic memos were kept in NVivo throughout this
process. Memos are “informal analytic notes” that describe or “fill out categories” and are an important middle step between coding and writing up results (Charmaz, 2006, p.72).

2nd round of coding.

Once coders agreed upon higher level categories, a more focused round of coding began. In focused coding, the most useful early codes were selected and compared or “tested against extensive data” (Charmaz, 2006, p.42). “Useful” generally referred to the most significant and/or most frequent codes, or the ones with the most explanatory potential. For example, codes pertaining to using books, television, brochures, and pamphlets to discuss HIV occurred quite often and across all three specific aims. These were categorized as “using supportive resources” and this became one of many categories focused on during subsequent analysis.

Also during this round of coding, notes and thoughts from initial memos were combined and elaborated upon to produce a more formalized codebook. Since not all members of the research team had access to or were familiar with NVivo, the codebook was used to facilitate team-based analysis and captured agreed upon definitions and meanings. The codebook format followed that specified by MacQueen, McLellan, Kay, & Milstein (1998) and included the following parameters: 1) code mnemonic, 2) a brief definition, 3) a full definition, 4) inclusion criteria (when to use the code), 5) exclusion criteria (when not to use the code), and 6) exemplar quotes. A seventh parameter was also added called “potential relationships to other codes.” This became a designated space in the codebook to summarize the inter-relationships between codes, a summary memo of sorts. It was also place to specify the properties and dimensions of a category (the who, what, where, when, why, how, and with what consequences that Corbin and Strauss (1998) refer to as axial coding). An excerpt from the codebook has been included in Appendix I.
**Consistency checks.**

Consistency checks were implemented during each round of coding. During preliminary analysis, the author and four other coders familiar with grounded theory and qualitative methods reviewed and coded the first several transcripts independently. These coders consisted of graduate students and one faculty expert coming from the fields of community health, social work, and communication. Once the transcripts had been coded, the team met to discuss the major insights from the interviews. While the research team was not looking to have a numeric count of agreements or disagreements at this stage, what was sought after was basic interpretive convergence—such incidents were generally coded similarly, that these code names were grounded in the data, and that team members could see where one another were coming from conceptually, even if the terminology differed. For example, all coders noted the importance of family background or upbringing (acknowledging generational influences) in shaping how parents chose to discuss HIV prevention with their children. This was agreed upon as a code highly related to the specific aim that focused on barriers and facilitators to prevention conversations.

Upon generally agreeing on a number of basic codes and the larger categories they fit into, the author chose specific categories to pursue for focused coding and constructed the codebook for each category. This decision was based on (a) which categories seemed to be most related to the three specific aims of the study, (b) which categories occurred repeatedly across interviews, and (c) which categories were the most relevant to the guiding theories of the study. If a given category or subcategory referred to a concept well-established in the parent-child communication literature (e.g., parental monitoring, DiClemente et al., 2001), the already-
established term was adopted at this point, in efforts to make the results more translatable to previous theories and studies.

Once the codebook had been completed, a separate faculty expert served as another coder for inter-rater reliability checks. This step served the following purposes: 1) it provided a level of coder agreement on content recognized by those invested in practical HIV applications and family-based interventions (Hruschka et al., 2004), and 2) it served as a concrete way to check for mistakes made when using computer software (e.g., that examples hadn’t been inadvertently “dragged and dropped” into the wrong category when using this feature in NVivo). The faculty member met with the author multiple times, discussed individual codes and larger categories, and was provided with the codebook for each category (with descriptions of all relevant codes and subcategories included). The faculty member then selected at least a random 10% of references (exemplar quotes) under each category, and double-checked them (see Appendix J). This individual also read through any references marked as ambiguous and or “not sure where to place” (an additional .5-3.5% of references, depending on the category). The number of agreements and disagreements were tallied and at least 95% agreement was reached in each category. This is considered more than satisfactory agreement (Hrushka et al., 2004; Miles & Huberman, 1994).

The few coding disagreements were discussed and either kept under the current category or switched to a related category. For example, when coding what parents' perceived as effective conversation, many parents referred to “giving educational facts” as a good way to talk to

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6 The terms “category,” “code,” “concept,” “theme,” and “subcategory,” are used by various authors in a number of different ways. Some authors provide a specific and purposeful definition for each term, whereas others use the terms more interchangeably. This jargon is further complicated by the use of separate terminology by qualitative coding software systems, such as “free nodes,” “tree nodes,” “references,” and “sources.” In this study, the specific aims of the study were referred to as “domains,” the major categories were called “categories” (synonymous with themes), and the headings under categories were called “subcategories” (synonymous with concepts).
adolescents. Interview data for all parents revealed 99 examples where this strategy was perceived as effective and 10 of these references were checked by another coder. Of the 10 references checked in this category, one discrepancy arose. One coder interpreted the reference as referring to the importance of knowledge globally and the other contended that this parent was referring to using educational facts. Upon closer examination of the context of the quote (by going back to the original transcript), it was agreed that the parent was referring to using educational facts. The reference was kept in its original category and was expanded to include more contextual information. By means of this iterative process, 100% agreement was reached for all categories.

**Step 4. Refining and organizing emergent themes and clarifying their relationships**

Once categories were agreed upon and the basic coding structure finalized, attention was turned to how these categories and subcategories might relate to form a larger picture of parent-adolescent prevention communication. It was at this point (a year and a half after the study began) that the literature was revisited on health behavior and communication theories, as well as any more recent empirical findings in family-based communication. The literature was used to re-familiarize the researchers with potentially relevant concepts rather than to dictate the structure of how results would be presented (Corbin & Strauss, 2008). Parts of the original theories that seemed well-suited to the data were kept and those that didn’t were modified, extended, or discarded. Negative case analysis was also conducted at this point, whereby extreme cases or those that did not fit the normal patterns of data analysis were sought out and compared against the final structure to look for alternate explanations and make sure findings did not require further refinement (Charmaz, 2006; Corbin & Strauss, 2008). For example, if a category was reported as both a facilitator and a barrier, those examples were re-examined to see
if there were discernable characteristics or conditions where the phenomenon might be viewed as helpful versus hampering.

**Step 5. Coding the interviews for contextual variables**

During initial coding, it was noticed that many parents spoke of contextual factors that were not asked about in the questionnaire, but that may be important for readers to gauge (a) some of the living conditions, contexts, and experiences these parents faced, and (b) how the findings presented in this study may or may not be relevant to other samples or populations. Though the parents in this study are by no means representative of all parents living with HIV/AIDS with an adolescent child, enough parents mentioned certain characteristics that they were examined more closely. Thus, all interviews were combed through to look for instances such as substance use and abuse, sexual abuse, previous incarceration, homelessness, and separation from children. The “query” feature in NVivo was also used here (similar to a key word search) to look for any examples that may have been missed by hand. These results are presented along with the demographic information and can be found in the following chapter.

**Step 6. Entering questionnaire data and generating descriptive statistics and correlations**

Questionnaire responses were entered into SPSS Version 15.0 (SPSS Inc., Chicago, IL), a standard statistical analysis software package. All data entry was double-checked for accuracy by a separate member of the research team. Once data had been entered and checked, descriptive statistics were generated. Independent two-sample *t* tests and ANOVAs were run (as appropriate) to compare subgroups of parents on variables of interest. Pearson’s *χ²* tests were conducted for categorical responses. Finally, correlations were generated between the extent of disclosure scale and the frequency of communication scale (PACS), as well as between the HIV-related stress scale and the frequency of communication (PACS) scale. This provided
information on whether or not these two factors were associated with the frequency of HIV prevention discussions in this sample.

**Step 7. Drawing overall inferences and conclusions**

Since mixed methods studies rely on both qualitative and quantitative data when drawing overall inferences and conclusions, a preview of how each research question or hypothesis was addressed is given below:

1. **RQ1:** Analysis for RQ1 focused on identifying what helps and/or hinders parents living with HIV/AIDS from engaging in HIV prevention conversations with adolescents. A list of facilitators and barriers was generated, along with a count of how frequently each was mentioned in the interviews. Facilitators or barriers were described in detail, with supporting quotes given to illustrate key points. Inferences for this question relied predominantly on interview data, but were complemented by the questionnaire scales on HIV disclosure and HIV-related stress.

2. **RQ2:** Analysis for RQ2 focused on the variety of strategies parents used to communicate about HIV prevention and whether or not they were perceived to be effective. A comprehensive list of effective versus less effective strategies used by parents living with HIV/AIDS was generated from the interview data. Each strategy was described and supporting quotes and frequencies given. The inferences for this question relied predominantly on the interview data, but were complemented by the strategies scale in the questionnaire.

3. **RQ3:** Analysis of RQ3 focused on comparing parental perceived effectiveness of discussion strategies to strategies deemed to be effective in evidence-based research interventions like the Parents Matter! Program. Effective communication included encounters that were open, supportive, comprehensive, and timely, among other factors. The analysis for this question
will be incorporated into the discussion chapter (Chapter 6). Implications for the guiding frameworks of the study are also discussed.

4. **H1**: This analysis focused on the content of HIV prevention discussions. The frequency/content scale (modified PACS scale) from the questionnaire was analyzed to describe how many parents report focusing conversations on sexual behavior versus drug use. The content was then compared to the method by which the parent believes he/she was infected with HIV (to see if any interesting trends emerged between content of discussions and mode of HIV transmission).

5. **H2**: Analysis for H2 also relied on quantitative data. A one-way ANOVA was run to examine the extent to which disclosure to one’s children (none, some, or all) was associated with the frequency of communication scale (PACS). Correlations were also generated between the HIV-related stress scale and the frequency of communication (PACS) scale. This provided data on whether or not these two factors were associated with the frequency of HIV prevention discussions.

**Summary Timeline**

This study was completed over a two year period, beginning in December of 2008 and ending in December of 2010. While data procedures have been detailed in the preceding sections of this chapter, Table 5 provides a visual timeline of how the research process progressed.
Table 5

Summary Timeline of Investigation

<table>
<thead>
<tr>
<th>Dec 08-Jan 09</th>
<th>Feb – July 09</th>
<th>Aug 09-Jan 10</th>
<th>Feb– May 10</th>
<th>June-Dec 10</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interview script and questionnaire constructed</td>
<td>1st round of data collection with HIV+ parents (n=16)</td>
<td>2nd round of data collection with HIV+ parents (n=74)</td>
<td>Continued 2nd round of coding</td>
<td>Refined quantitative data analysis</td>
</tr>
<tr>
<td>Expert review of instruments</td>
<td>Entered questionnaires</td>
<td>Entered questionnaires</td>
<td>Refined qualitative data analysis</td>
<td>Synthesized results</td>
</tr>
<tr>
<td>Revised Instruments</td>
<td>Transcribed/ coded 1st round of interview data</td>
<td>Transcribed/ coded 2nd round of interview data</td>
<td>Analyzed Questionnaire data</td>
<td>Wrote up findings</td>
</tr>
</tbody>
</table>

Chapter Summary

This chapter summarized the various steps of the research process, beginning with a synopsis of the current worldviews and paradigms that helped to frame the research focus (i.e., how parent-adolescent communication happens in the context of living with HIV/AIDS). From post-positivist roots came a desire to add to the wealth of quantitative literature on parent-adolescent communication about HIV risk communication, but to do so in a population for which little information currently exists. From a constructivist and clinical perspective came a desire to understand the lived experiences of parents facing a highly stigmatized chronic illness and the nuances and challenges associated with parenting in this unique environment. Finally, from pragmatism came an anchor in mixed methodology, an appreciation for combining methods in creative ways, and a reminder that researchers have a responsibility to translate philosophy into action.

The mixed methods approach chosen for this study relied primarily on interview data, with a questionnaire used to (a) complement the information found in interviews and (b) maintain consistency with previously used scales. A total of 90 parents living with HIV/AIDS...
were recruited from various locations throughout Illinois and Indiana. They underwent in-depth interviews and completed structured questionnaires detailing the strategies they used to discuss HIV with adolescents, as well as what facilitated or hindered these discussions. Data analysis proceeded using a modified grounded theory approach, guided most closely by the traditions of Corbin & Strauss (2008) and Charmaz (2006). Ethical considerations, including how potential risks were minimized to protect participant well-being, were reviewed within the context of creating a comfortable and supportive interview environment.

Data were analyzed and synthesized in a series of seven steps, beginning with data entry, proceeding through various stages of coding, and ending with specifications for data synthesis. Conclusions were drawn from both qualitative and quantitative findings. The following chapter will summarize the sample demographics, along with the results of the qualitative portion of the study.
CHAPTER 4: QUALITATIVE RESULTS

Chapter Overview

This study examined how parents living with HIV/AIDS describe their communicative interactions with adolescents, particularly when it comes to conversations about protecting one’s self from HIV. Guided by the frameworks of the UTB and NMIC, the overall study aims were to: 1) identify facilitators and barriers to talking about HIV prevention in a family context, particularly those that may be unique to families affected by HIV/AIDS, 2) describe the strategies parents living with HIV/AIDS use to communicate about HIV prevention, including which strategies they perceive as effective versus ineffective, and 3) compare parents’ perceived effectiveness of those strategies to what current health communication/health behavior research deems effective parent-adolescent communication. The purpose of this chapter is to present the findings from the 90 participant interviews.

The chapter is divided into two main sections. The first section describes the sample in terms of demographic characteristics and contextual information. The second section outlines the results from the qualitative interviews, using emergent categories, subcategories, and exemplar quotes to illustrate important points. Emphasis is placed on understanding the range of strategies parents used when talking to adolescents, highlighting those that may hold special relevance for families affected by HIV. Findings from the questionnaires are presented in the following chapter (Chapter 5) on quantitative results.

As a whole, the qualitative and quantitative results chapters correspond to the first and second research questions of the study (identifying facilitators and barriers and describing what constitutes effective conversation). The relation of these views to the guiding theories of the study and the broader parent-adolescent communication literature (RQ#3) will be described in
the discussion chapter (Chapter 6). Overall, it is hoped that the current chapter will provide a better understanding of how parents in this sample viewed and evaluated their conversations with adolescents about HIV prevention.

**Demographic and Contextual Information**

**Interview Characteristics**

As noted previously, parents were interviewed in a variety of settings. Almost half of participants (44%) chose to be interviewed in their homes. Another 26% preferred to be interviewed in private rooms in a public library and 21% were interviewed in the AIDS service organization that recruited them. The remaining 9% of interviews took place in university buildings or secluded areas of public locations (e.g., coffee shops, outdoor areas of restaurants). Most parents were interviewed alone, however a small subset (7%) were interviewed with someone else present. Of this 7%, in two cases (4 participants), the parents were part of the same HIV support group and both eligible for the study. These parents requested to be interviewed together. Also, one participant brought his wife (HIV-) with him for moral support. In the final case, a participant brought her younger sister (HIV-) with her, who also had children in the age range of the study. Though HIV- individuals were not counted as participants for purposes of this study, they were welcome to participate in conversation throughout the study session.

Interviews lasted an average of 53 minutes, with the shortest interview being 20 minutes and the longest one lasting 2.2 hours. Interviews where parents had not disclosed their HIV status or talked to their children about prevention were generally shorter and joint interviews were generally longer. Geographically speaking, the overwhelming majority (87%) of
interviews were conducted in Illinois, with only 13% of parents being interviewed in Indiana. Of the Illinois interviews, most (62%) were conducted in the Chicago area.

**Demographic Information**

**Parents.**

Of the 116 individuals who contacted the researchers to express interest in this project, 90 of them met the inclusion criteria and completed the study. The majority of these participants (93%) were biological parents, whereas the remaining 7% were primary caregivers and/or legal guardians, including five grandparents and one aunt. Approximately two-thirds of participants were mothers (69%) and the remaining one-third (31%) were fathers. The average age of participants was 46 years. Table 6 summarizes some of the basic demographic characteristics of parents in this sample.
Table 6

*Demographic Characteristics of Parents*

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>No. of Participants</th>
<th>% of N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>62</td>
<td>69</td>
</tr>
<tr>
<td>Male</td>
<td>28</td>
<td>31</td>
</tr>
<tr>
<td>Agea</td>
<td></td>
<td></td>
</tr>
<tr>
<td>27-39</td>
<td>21</td>
<td>24</td>
</tr>
<tr>
<td>40-49</td>
<td>38</td>
<td>43</td>
</tr>
<tr>
<td>50-65</td>
<td>30</td>
<td>34</td>
</tr>
<tr>
<td>Race/Ethnicity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>African American or Black</td>
<td>69</td>
<td>77</td>
</tr>
<tr>
<td>Caucasian or White</td>
<td>9</td>
<td>10</td>
</tr>
<tr>
<td>Hispanic or Latino</td>
<td>9</td>
<td>10</td>
</tr>
<tr>
<td>Asian</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Other</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Highest Level Education Completed</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than high school</td>
<td>26</td>
<td>29</td>
</tr>
<tr>
<td>High school or GED</td>
<td>55</td>
<td>61</td>
</tr>
<tr>
<td>4 year college degree</td>
<td>7</td>
<td>8</td>
</tr>
<tr>
<td>Advanced degree</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Relationship Status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>35</td>
<td>39</td>
</tr>
<tr>
<td>Dating</td>
<td>13</td>
<td>14</td>
</tr>
<tr>
<td>Long-term relationship</td>
<td>24</td>
<td>27</td>
</tr>
<tr>
<td>Married</td>
<td>16</td>
<td>18</td>
</tr>
<tr>
<td>Other</td>
<td>2</td>
<td>2</td>
</tr>
</tbody>
</table>

* 1 missing case

Of special note, this sample was predominantly African American (77%) and had relatively low levels of education. The overwhelming majority of parents (90%) had a high school education or less. In terms of relationship status, approximately half (53%) considered themselves to be single or dating, whereas the rest reported being in a long-term relationship, married, or “other.” Of those currently in relationships, only 32% currently lived with their significant others.
Parents also reported on their HIV-related medical background, including the year they were diagnosed and their perceived mode of infection. The majority of the parents in this sample had been living with HIV or AIDS for quite some time. The average number of years since diagnosis was 13, though time since diagnosis ranged from 2 years to 30 years. Over 90% of parents had been diagnosed with HIV more than five years ago. The youngest age at diagnosis was 16 and the oldest was 57, with average age of diagnosis of 33 years. Table 7 presents an overview of the medical characteristics of parents in this sample.
Table 7

HIV-Related Medical Characteristics of Parents

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>No. of Participants</th>
<th>% of N</th>
</tr>
</thead>
<tbody>
<tr>
<td>No. yrs. since diagnosed with HIV</td>
<td></td>
<td></td>
</tr>
<tr>
<td>0-5 years</td>
<td>8</td>
<td>9</td>
</tr>
<tr>
<td>6-10 years</td>
<td>24</td>
<td>27</td>
</tr>
<tr>
<td>11-15 years</td>
<td>36</td>
<td>40</td>
</tr>
<tr>
<td>&gt; 15 years</td>
<td>22</td>
<td>24</td>
</tr>
<tr>
<td>Mode of transmission(^a)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sex</td>
<td>64</td>
<td>72</td>
</tr>
<tr>
<td>Drug use</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>Blood transfusion</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>More than one option applies</td>
<td>15</td>
<td>17</td>
</tr>
<tr>
<td>Don’t know</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Other(^b)</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Classification of illness(^c)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>HIV</td>
<td>60</td>
<td>87</td>
</tr>
<tr>
<td>AIDS</td>
<td>9</td>
<td>13</td>
</tr>
<tr>
<td>Current medical problems related to HIV/AIDS(^d)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>30</td>
<td>34</td>
</tr>
<tr>
<td>No</td>
<td>58</td>
<td>66</td>
</tr>
<tr>
<td>Subjective severity of illness(^d)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very sick</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Somewhat sick</td>
<td>30</td>
<td>34</td>
</tr>
<tr>
<td>Not sick at all</td>
<td>57</td>
<td>65</td>
</tr>
</tbody>
</table>

\(^a\) 1 case missing, \(^b\) work-related needle stick, \(^c\) 21 cases missing, \(^d\) 2 cases missing

Most parents (72%) reported that they had been infected with HIV via sexual contact. Only 13% reported an AIDS diagnosis, whereas the majority (87%) reported being HIV+. In terms of subjective assessment of illness (e.g., how sick parents felt from HIV/AIDS), most (65%) reported not feeling sick at all. Though parents were not without current HIV-related medical problems, the overall medical information provided reflects a sample that was relatively healthy and well-functioning. HIV-related medical problems that were reported included side effects from medications and general fatigue.
Children.

Collectively, the parents in this sample cared for 317 children with an average of three children per family. The smallest family had one child and the largest had nine children. Parents reported a total of 155 adolescents between the ages of 10 and 18. Of the 155 adolescents, there were slightly more females (54%) than males (46%). The average age of adolescents was 14.6 years. Most parents (80%) reported daily contact with at least one adolescent in the age range of the study. Other parents reported contact ranging from multiple times per week to once or twice per month, representing a range of complex family structures and living situations. For example, some parents had contact with their adolescent(s) on weekends or certain weekdays, whereas others had monthly contact by phone or internet, but their adolescent only lived with them for summer and winters breaks. Table 8 summarizes some of the characteristics of adolescents obtained from participants’ family trees.
Table 8

**Characteristics of Adolescents**

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>No. of Participants</th>
<th>% of N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>84</td>
<td>54</td>
</tr>
<tr>
<td>Male</td>
<td>71</td>
<td>46</td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10-12</td>
<td>40</td>
<td>26</td>
</tr>
<tr>
<td>13-15</td>
<td>47</td>
<td>30</td>
</tr>
<tr>
<td>16-18</td>
<td>68</td>
<td>44</td>
</tr>
<tr>
<td>Freq. Contact w/ Parent</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Daily</td>
<td>72</td>
<td>80</td>
</tr>
<tr>
<td>Bi-weekly</td>
<td>9</td>
<td>10</td>
</tr>
<tr>
<td>Weekly</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>Bi-monthly</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Monthly</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Lives with parent full-time</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>63</td>
<td>70</td>
</tr>
<tr>
<td>No</td>
<td>27</td>
<td>30</td>
</tr>
</tbody>
</table>

**Contextual Variables**

A number of factors were discussed during the interview sessions, though they were not explicitly asked for in either the interview or questionnaire. These characteristics are provided to add context, but the frequencies should be interpreted cautiously, as they were not consistently discussed in every interview and are likely underestimates. If parents volunteered the information it was discussed; otherwise, it was not included as a topic of conversation in the interview. This allowed parents to discuss potentially sensitive topics at their discretion.

Contextual variables for parents included whether or not the parent reported: (1) being separated from their adolescent(s) at some point in time, (2) current or previous substance abuse, (3) having ever been sexually abused, (4) ever being diagnosed with an STI other than HIV, (5)
ever having been in jail or prison, (6) ever having been homeless, or (7) being homosexual or bisexual. The frequencies for these characteristics are reported in Table 9.

Table 9

*Contextual Variables from Interviews - Parents*

<table>
<thead>
<tr>
<th>Variable</th>
<th>No. of Participants</th>
<th>% of N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Separated from adolescent(s)</td>
<td>50</td>
<td>55.6</td>
</tr>
<tr>
<td>Substance abuse</td>
<td>60</td>
<td>66.7</td>
</tr>
<tr>
<td>Sexual abuse</td>
<td>16</td>
<td>17.8</td>
</tr>
<tr>
<td>STI other than HIV</td>
<td>9</td>
<td>10.0</td>
</tr>
<tr>
<td>Jail or prison</td>
<td>18</td>
<td>20.0</td>
</tr>
<tr>
<td>Homeless</td>
<td>14</td>
<td>15.6</td>
</tr>
<tr>
<td>Homosexual or bisexual</td>
<td>9</td>
<td>10.0</td>
</tr>
</tbody>
</table>

Of particular interest, over half of the parents in this sample (56%) reported being separated from one or more of their adolescent(s) at some point in time. This included parents who may have had their children temporarily placed in foster care due to unsafe living conditions, parents who enrolled in live-in drug or alcohol rehabilitation programs, parents who were too ill to care for their children or had spent extended amounts of time in the hospital, and parents who had been to jail or prison, etc. Parents in this sample also reported high levels of substance abuse (67%). These were parents who mentioned they had been in rehabilitation programs for drug and/or alcohol use, to support groups to try to stop using drugs and/or alcohol, were previous or current drug dealers, or had used drugs and/or alcohol to the extent that their addiction had negatively impacted their relationships with family and friends. Thus, parents in this sample had a number of situations that may have affected their relationships with their children, both positively and negatively.
A number of parents also commented on various characteristics or behaviors of their children during the interviews. Frequencies were calculated for parents who reported that one or more of their children had: (1) tried drugs, (2) engaged in unsafe sex, (3) been involved in an incident of sexual abuse, (4) been diagnosed with HIV, (5) been diagnosed with an STI other than HIV, (6) passed away, (7) been to jail or prison, or (8) come out as homosexual or bisexual. The frequencies for these contextual variables are provided in Table 10.

Table 10

*Contextual Variables from Interviews - Children*

<table>
<thead>
<tr>
<th>Variable</th>
<th>No. of Participants</th>
<th>% of N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Drug use</td>
<td>31</td>
<td>34</td>
</tr>
<tr>
<td>Unsafe sex</td>
<td>39</td>
<td>43</td>
</tr>
<tr>
<td>Sexual abuse</td>
<td>12</td>
<td>13</td>
</tr>
<tr>
<td>HIV+ child</td>
<td>7</td>
<td>8</td>
</tr>
<tr>
<td>STI other than HIV</td>
<td>13</td>
<td>14</td>
</tr>
<tr>
<td>Death of a child</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>Jail or prison</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>Homosexual or bisexual</td>
<td>5</td>
<td>6</td>
</tr>
</tbody>
</table>

As evidenced by the table, reports of children engaging in drug use or unsafe sexual behavior were moderate, with 34% of parents reporting they were aware that one or more of their children had tried drugs, and 43% reporting their awareness that one or more of their children had engaged in unsafe sexual behavior as an adolescent.

Of special relevance to the topic of this study, 8% (n = 7) of participants reported having one or more children who had been diagnosed with HIV. Of these seven HIV+ children, five had contracted HIV from their mother during childbirth and the other two had contracted HIV as
a result of unsafe sexual behavior. Neither of the adolescents who had contracted HIV from unsafe sex had been aware of their parent’s HIV status prior to becoming infected themselves. As one of the core tenets of the NMIC focuses on examining the meaning of conversations in particular samples and contexts, the following section focuses on the meaning of HIV prevention communication to parents in this study.

**Definition of HIV Prevention Communication**

HIV prevention communication is sometimes narrowly construed as direct talk about unsafe sex or intravenous (IV) drug use. For purposes of this study, HIV prevention was not explicitly defined for parents during the course of their interview. Parents were asked if they had ever discussed “ways to prevent HIV” with their adolescent(s) and, if applicable, to provide relevant examples. This allowed parents to define HIV prevention in their own terms and discuss the topics they perceived to be important.

Parents in this sample revealed a wide array of topics they discussed with their children in relation to HIV prevention. As expected, most of these topics overlapped with those traditionally detailed in prevention studies, such discussing abstinence, safe sex, condoms, and dirty needles. Other topics, however, seemed to have special relevance for families affected by HIV/AIDS, including household safety measures, issues of trust and vulnerability, and the focus on acceptance of people living with HIV or AIDS. The topics that may have been especially pertinent to HIV+ parents are summarized briefly in the paragraphs below.

Parents spoke of the importance of household safety measures and of making sure their children did not accidentally become infected with HIV at home. Many were extra cautious with their personal belongings. This included teaching children not to use their toothbrushes, razors, nail clippers, and not touch dirty laundry, medical equipment (e.g., diabetic finger prickers), or
anything else that might have remnants of blood or body fluids on it. One mother recounted an episode where her daughter had scared her by shaving with her razor:

She (my daughter) is getting to that age where they’ve just got to be curious. She was in the bathroom a long time and I said “Theresa, what are you doing?” She says, “Oh, I’m shaving my legs.” The first thing that went through my mind was “She’s using my shaver!” When she got out I said “Let me tell you something sweetheart. NEVER do that. Do not use my brush, do not use my (razor), do not use my other stuff.” Don’t get me wrong, it does give you a little bit of a scare. Because when I told her about HIV and AIDS and how it was transmitted, I never told her other precautions like toothbrushes and razors. I said, “Sweetheart, why did you use my razor?” But she didn’t know. I said “Sweetheart, you can’t use my razor.” She said “Why?” Then, “Oh! Yes, mother, you have HIV.” I said “Yes! And you should not be using it anyway. I hid it up in the cabinet. You are not supposed to be using it. Never use it. Never use my toothbrush.” So everything in our house is pretty much a precaution. There are certain things she knows she can’t do. (1063, Mother)

This mother had since re-arranged many of their household items to make them less available to her daughter. Some parents taught their children where the bleach and gloves were in the household and how to properly clean up wounds in case someone was hurt. A couple of parents reported avoiding kissing their children if they had open sores they were worried about, or if they had recently brushed their teeth and their gums were prone to bleeding. Stories such as these revealed that, when parents spoke of prevention, they also highlighted issues of how to stay safe from HIV infection at home. Even though the chance of HIV transmission in many of these instances was infinitely small, it was the fear that transmission might be possible that remained in parents’ minds.

Another issue raised multiple times by parents was that of lack of trust in romantic partners and increased vulnerability to HIV infection. Since many parents had been shocked by their initial diagnosis and had not felt they were at risk for HIV infection, their notions of perceived risk became substantially different than they might have been had they not been diagnosed HIV+. As one mother revealed:
In my case, my son’s father knew (he had AIDS), the 10 year old’s father, he knew and never said anything and we were just together like thick as thieves, and one day he got real sick. I knew he had this medicine but you know, I wasn’t paying attention to it because he always stayed with colds and he had chronic bronchitis or something like that. I just didn’t pay attention. We just went on and went on and one day he got sick. In reality, his kidneys had failed. So he was in the hospital for a long time, he went in the hospital one year right before Thanksgiving, so he was gone Thanksgiving, Christmas, and New Year’s -- he was in the hospital all that time. His sister used to come by and hang out with me and whatever, and one day we left and went to the hospital to go see him. Finally I guess some of his other siblings showed up or whatever and the sister was like “Who is that and does she know he has so and so and so and so?” And I was looking around the corner like “Oh, I could kill you.” Because now I’m scared as hell. (1007)

Oftentimes, these were parents who had thought they had been in monogamous relationships, only to find out their significant other had been unfaithful. Thus, talking to their child about HIV and prevention may have come at a time when they were considerably angry, upset, and frustrated with their romantic partners. Sometimes this translated into messages to adolescents that emphasized no one could be trusted and that everyone was vulnerable to HIV infection. Many parents steered away from traditional notions of “risky” behavior as having multiple sexual partners and instead emphasized that one sexual act, one time, with one person could result in HIV infection. For these parents, it seemed imperative to let their children know that even partners who seemed trustworthy may ultimately let them down.

Finally, a number of parents in this sample incorporated how to act towards individuals living with HIV or AIDS as a part of their conversations about HIV prevention. They spoke of being understanding, nonjudgmental, and having compassion towards those infected with the virus, as well as towards people of different backgrounds and lifestyles. As one father reflected:

I guess by having it (HIV), now when I talk to them...I have a different perspective on it. I was more homophobic (before) and now I run into a lot of gay guys that are good people. And I talk to them (my kids) about them. I work with a few gay guys also. I have clients that are gay. And I tell my kids about respecting them, because my youngest son, he’s more of a “thug” than my oldest son. So he wants to be this macho tough guy. And I was riding with him one day, we were riding and there was a gay guy standing at the bus stop. And he was like “Look at that faggot” (condescendingly). And I said
(disappointed), “Why are you calling him that, man? You don’t even know that man!” And he said, “Aww, well he’s a faggot.” I said, “Well you know what? A lot of “them” people helped save my life. Because they taught me about the ins and outs of HIV.” I said “Until you know them, man, don’t criticize them.” So talking to them (my kids) from that perspective was the big change. (1072, Father)

For some parents, being diagnosed had led to interactions with other positive individuals of different races, cultures, ethnicities, lifestyles, or sexual orientations, and to the realization that they were more tolerant and compassionate than they initially thought. These messages of tolerance and acceptance were oftentimes passed along to their children. Thus, when they spoke about how HIV was transmitted and how it could be prevented, they were careful not to foster stereotypes or negative attitudes towards those already infected.

Altogether, issues of household safety, trust and vulnerability, and acceptance remained salient in some parents’ minds and, as such, became incorporated into conversations about prevention with adolescents. For the remainder of the chapter, the term “HIV prevention communication” will be used to summarize any instance where a parent perceived him or herself to be communicating to adolescents about ways to avoid being infected with the HIV virus. Though the majority of examples used refer to conversations about sexual or drug activity, readers should keep in mind the large umbrella of topics and complex discussions that are often captured by this term and or that might be unique to parents living with HIV/AIDS.

**Facilitators & Barriers**

In response to the first specific aim of the study, this section identifies what helped and/or hindered parents from engaging in discussions about HIV prevention with adolescents. The following four questions dealing with facilitators and barriers were included in the interview guide:

1. Some parents think it is really hard to talk about ways to prevent HIV with their adolescent(s). What do you think?
2. Why do you think it might be hard to talk about ways to prevent HIV with adolescent(s)?

3. What do you think might make it easier to talk about ways to prevent HIV with your adolescent(s)?

4. Can you give an example?

Parental responses to these questions were compiled, as well as any other place in the interview where parents explicitly mentioned something that made it “easier” or “harder” to talk about HIV prevention.

Overall, parents reported a range of responses when asked if they considered it difficult to talk about HIV prevention with adolescents. Approximately one fourth of parents reported that it was relatively easy to talk to their children about ways to protect themselves from HIV and other STIs. For example, one mother explained “As far as finding it hard, no…Back in the day, maybe I would've, you know (found it hard). But nowadays, you have to be very upfront with these kids.” Similarly, Dexter, a single father with full custody of his teenage daughter noted that “It wasn’t hard for us, for me, because it was pretty much thrown at me. My daughter was 11 when her mom died (of AIDS-related complications). That was about the time she was starting her period and all that stuff.” Whereas some of these parents reported that conversations about prevention weren’t hard for them personally, they still acknowledged that topics like sex and drugs could be difficult for parents to talk about in general. Other parents in this group didn’t understand why it would be difficult for any parent to discuss things that were pertinent to their child’s future health and well-being.

Another one fourth of parents reported that they did find it challenging to talk about prevention with adolescents. As one mother noted “I don’t know…it shouldn’t be hard…but it is.” Gwendolyn, a mother of four and grandmother of 12, added that “It was kind of hard at first
for me to educate them about the prevention part. It was kind of hard, but they caught on.” The remaining half of parents didn’t explicitly state whether they considered conversations about HIV prevention to be “easy” or “hard.” Most of them fell somewhere in the middle of the spectrum, noting that certain topics of conversation may be easier to discuss than others, or that the difficulty level could depend on the child, on the parent, on their relationship, and/or on finding the right time to talk. This section categorizes the responses from the 84 parents who provided facilitators or barriers specific enough to be coded.

Facilitators of Conversation

As anticipated, parents revealed a variety of factors that helped them engage in conversations about sex, drugs, and general facts about HIV transmission. Nine major categories emerged after coding examples related to facilitating conversation. Some of these categories had subcategories that demonstrated the range and variation of participant responses, whereas others were more uniform in nature. A summary of the facilitator categories that will be detailed in this section is found in Table 11.
Table 11

**Summary Table of Facilitators to Conversation**

<table>
<thead>
<tr>
<th>Facilitator Category</th>
<th>N</th>
<th>%</th>
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</thead>
<tbody>
<tr>
<td>1. Utilizing support</td>
<td>40</td>
<td>48</td>
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<tr>
<td>➢ Supportive others</td>
<td></td>
<td></td>
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<tr>
<td>➢ Supportive resources</td>
<td></td>
<td></td>
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<tr>
<td>2. Focusing on benefits of communication</td>
<td>38</td>
<td>45</td>
</tr>
<tr>
<td>➢ Protecting child</td>
<td></td>
<td></td>
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<tr>
<td>➢ Fulfilling parental duty</td>
<td></td>
<td></td>
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<tr>
<td>3. Being HIV+</td>
<td>24</td>
<td>29</td>
</tr>
<tr>
<td>➢ Heightened risk awareness</td>
<td></td>
<td></td>
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<tr>
<td>➢ Better knowledge</td>
<td></td>
<td></td>
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<tr>
<td>➢ Visibility of Illness</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Having prior relationship with child</td>
<td>22</td>
<td>26</td>
</tr>
<tr>
<td>5. Employing adaptive talking style</td>
<td>21</td>
<td>25</td>
</tr>
<tr>
<td>➢ Open &amp; honest</td>
<td></td>
<td></td>
</tr>
<tr>
<td>➢ Supportive &amp; understanding</td>
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<tr>
<td>➢ Humor &amp; joking</td>
<td></td>
<td></td>
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<tr>
<td>6. Being knowledgeable</td>
<td>17</td>
<td>20</td>
</tr>
<tr>
<td>➢ Getting educated</td>
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<td></td>
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<tr>
<td>➢ Using child’s experiences</td>
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<tr>
<td>➢ Using parent’s experiences</td>
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<td></td>
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<tr>
<td>7. Recognizing child is ready</td>
<td>14</td>
<td>17</td>
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<tr>
<td>➢ Gender perceptions</td>
<td></td>
<td></td>
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<tr>
<td>➢ Child showing interest</td>
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<tr>
<td>➢ Child maturity level</td>
<td></td>
<td></td>
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<tr>
<td>8. Impact of upbringing</td>
<td>11</td>
<td>13</td>
</tr>
<tr>
<td>➢ Mirroring communicative patterns</td>
<td></td>
<td></td>
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<tr>
<td>➢ Determining to communicate differently</td>
<td></td>
<td></td>
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<tr>
<td>➢ Starting young</td>
<td></td>
<td></td>
</tr>
<tr>
<td>➢ Recurring conversations</td>
<td></td>
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</tbody>
</table>

*Note.* N=84.
1. Utilizing support.

The first major category that emerged was that of utilizing support. Forty parents (48%) mentioned the impact that friends, family members, health care providers, the media, and other supportive resources had on their ability to speak to their children about ways to prevent HIV. Some parents spoke of utilizing support prior to engaging in conversation, whereas others spoke of using support during the actual conversation(s) with their children. Parents generally referred to support provided by people (i.e., a human being or educational program offering support) or by informational resources (such as brochures, pamphlets, and media). These differences were captured by two subcategories within the broader category of utilizing support: supportive others (person-oriented support) and supportive resources (using tangible materials to facilitate conversations).

Supportive others.

Parents often spoke of engaging other people to help make communicative interactions more manageable. Social support was provided by family members, friends, neighbors, therapists, health care providers, health educators, schools, and churches. Examples of utilizing other people as support ranged from completely relying on others to merely having another person present during conversation for moral support. Jocelyn, a mother of five including a 17 year old daughter and 15 year old son, often talked to her children about HIV when her sister was present because it made conversations more comfortable.

*I talk to them (my kids). At first I wouldn’t talk to them, until me and my sister...It comes much easier when I’m with my sister, because when I was coming up she was always there for me and she told me a lot. When I’m with her and we talk to my kids, it just comes out – I’m comfortable. I don’t sugar-coat nothing. I just tell them...I’ve always had my family’s (support). (1037)*
Along these lines, a mother of a 13 year old girl noted that her friends who were also parents proved to be invaluable resources for her daughter, both when she was physically present and when she wasn’t.

(It’s easier if) you find the people that they kind of feel comfortable with. You know, I call them my eyes and ears, my second set. I have other friends that, their children will respond to me and sometimes my daughter responds to them. So, we kind of get together as parents and... find their comfort zones. Because our kids -- they’re not gonna always want to come to us about everything. (1051)

Aside from family members and other parents, participants also used professionals who were knowledgeable about HIV to help conversations go more smoothly. A number of parents were involved with HIV support groups and would bring their children with them to the group. Though the children and adults were usually in separate rooms or separate areas of the same room, it was not uncommon for children to overhear what the adults were talking about. This led to various opportunities to discuss HIV and prevention. For example, Eyana’s daughter asked a question during support group and a social worker was able to field the question so that Eyana didn’t have to leave the group.

She (my daughter) asked us what sex was. (Laughs). And when I had told her that you can catch HIV through sex, I guess I just assumed that she knew (what sex was)!...And she was like “Why does everybody keep talking about sex? What is sex?” And I’m like “Oooohh. Ok.” So luckily one of the workers there pulled her out into the room that sometimes they have the kids go over to and do projects or ask questions and talk to the workers. Like a younger environment. And she brought her over there and told her about sex. I was like “I’m glad you did that because I wouldn’t even have known where to begin!” (1074)

Another mother had been informed by her daughter’s doctor that it might be an appropriate time to talk about sexual activity, as well as informed by the school system that her daughter was having trouble coping with her mother being ill.

So I felt better when the pediatrician told medically (that my daughter was having sex), and the school board counseling (told me my daughter was worried about my HIV status). They were two good pieces that led me to talk to my child about STDs and HIV and AIDS. (1005).
Lastly, a few parents didn’t appear to already have clear support in place, but indicated that groups where teens and HIV+ parents got together to talk about prevention would be helpful to them, as it would give their children a chance to ask questions and learn from other teens and parents in a supportive atmosphere.

**Supportive resources.**

Aside from being supported by other people, parents were also supported by a variety of informational resources, such as books, pamphlets, brochures, television, radio, and the internet. Sometimes resources were used to help the parent better explain HIV to the child, whereas other times parents used books, pamphlets, or movies themselves, to increase their own knowledge in preparation for talking with their child. Quotes where parents indicated books, pamphlets, or brochures had been helpful to them included:

Well, you know, *I educated myself a little bit more on it (HIV) before I actually sat down to talk to her (my daughter). I read pamphlets. See, because I didn’t really understand it myself until I got it. You know, you see people with HIV on these (medical) units and stuff, but like I said, I’d never met a lot of women with it. (Mother, 1077)*

*I would get that book right there, Juvenile Delinquency, and have them read it. “Read this book,” I said, “Because that’s where you’re gonna end up.” And it talks about sex. It talks about drugs. It talks about crimes, stealing, murdering, and it also talks about diseases for juveniles. I said “That’s where you’re gonna go if you don’t get your act together.” And I told them. (Mother, 1049)*

*When I went to my group one day they actually had some good coloring books that had the different ways you could get it (HIV). I told them they actually needed to pass them out to some of the adults! Because the coloring books had a whole lot of information saying that, basically, you should be nice to people (with HIV), and that you can’t get it from this and that. So that helped her (my daughter) out a lot. She carries the coloring books and all her stuff from camp around with her like daily! (Laughs). I mean really, like daily. She carries it all around with her! (Mother, 1074)*
Movies, television shows, the news, and the radio were also popular sources of informational support. Media sometimes provided spontaneous opportunities for parents to discuss HIV and prevention with their children. As Janeka, mother of a 14 year old boy, shared:

*One day we were in the car. We were coming from church and we were listening to the radio and there was something on about it (HIV), so I just went on and told ’em…My son asked “How do you get HIV?” I said, “Through sharing needles with drug users and through sex.” And I just told him that I was HIV positive. It was already on the subject, so I just told him.* (1009)

Also grateful for being able to take advantage of technology, Wanda (sons ages 14 and 10) explained:

*It’s going to be challenging, and it’s going to be hard but…I think the thing that makes it so much easier than in the past is that everything is networked…When I say networked it’s like you have video and audiotapes of everything. And television shows are starting to deal with a lot more things that go on in the world today than they did back when I was their age.* (1007)

Whereas some parents noted conversations “happened to come up” when kids were viewing certain programs, other parents purposefully included movies and television as facilitators to prevention talks:

*Well, you know, you can watch documentaries. You can get a DVD at the HIV clinic. They have them for free. And they tell you how it (HIV) goes with the immune system, the fighter cells, the helper cells. They give you a whole big diagram of how it goes. My daughter – she loved that! She got a lot out of that I remember.* (Father, 1033)

Regardless of whether or not parents utilized other people as support or informational support in the form of media (and many parents utilized both), having support appeared to help parents both increase their knowledge and their skill level when it came to talking about prevention with adolescents. In many cases, these sources of support also made parents more aware of the benefits of talking to their adolescents. Focusing on the benefits or advantages of conversation was identified as another major facilitator in this study.
2. Focusing on the benefits of talking.

Thirty-eight parents (45%) referenced that it was easy (or easier) for them to talk to their children about HIV because they focused on the benefits that could result from having prevention conversations. Two specific benefits of conversation were especially salient in this category. The first was the desire to protect one’s child (from harm and/or from misinformation) and the second was being able to fulfill one’s parental duty by having conversations that could protect adolescent well-being. Each subcategory is summarized below.

**Protecting child.**

Parents expressed a deep desire to protect their children from harm and faulty information, along with the hope that things would be “different” for their children than it had been for them. Most parents wanted their children to be armed with as much information about HIV as possible, in hopes that their children would (a) feel prepared when they encountered situations that could lead to risky sexual and drug activity, and (b) be able to use this information to make safe and healthy behavioral decisions. As one mother noted, “I don’t find it hard (to talk) because when I look at it like ‘well I might have to be the person to save this person’s life,’ in one way or another it makes it a whole lot easier.” (1013)

Some parents who focused on the benefits of having prevention conversations acknowledged that they were difficult conversations to have (at least initially), but that the potential benefits to their children made the conversations worthwhile. The quotes that follow demonstrate two mothers’ desires to provide their children with guidance and reliable information, even when it meant having a difficult or awkward conversation.
HIV is never gonna be an easy subject, it just never will. But I think if parents keep in mind that, even if they have been affected by this, they need to realize their child hasn't yet. And they need to guide them down the right path so that they can avoid making the same mistakes as their parent or parents, which is all parents want for kids anyway. We want them to do right, not do what we did, and yeah sometimes they do anyway, but you know -- it's times like this where you really don't want them going down that path. (1048)

(I said to her) “Your friends are gonna give you the wrong information.” You know, because I would ask her, “What are they talking about? What are they saying? What are they saying sex is?” And her answer showed that they didn’t have a clue! So I said “If you really want to know, just ask me and I’ll tell you.” You know and I kind of tried to open up that dialogue with her sometimes….I may not like it, but I know I have to because there’s so much going on out here. So it’s like I can’t worry about my fear, I have to make sure she’s prepared for the worse. (1051)

Fulfilling parental duty.

To impart a lot of the knowledge that I have on my child, I feel that is my duty. (Father, 1028)

Another benefit that parents focused on to help them get through conversations was that of fulfilling their own role or duty as parents. Parents in this subcategory expressed specific ideas about what it meant to be a parent – someone who guides, loves, protects, and provides for their children. They viewed having prevention conversations as their parental responsibility, a concrete way that they could demonstrate their love for their children. Marcus, a father of two girls (ages 15 and 16) emphasized the importance of a parent’s role in the following quote:

I don’t think it’s hard because that’s your child! You know, you are taking care of that person, him or her. It shouldn’t be any problem to let them know what’s going on out there, that this is a deadly disease, but that it’s deadly only if you don’t take your medication. (1099)

Similarly, Dolores highlighted the permanency of a parent’s love and desire to protect his/her children, noting that her responsibility to provide for her children was among her highest priorities.
I think it would be easier – because the love of a parent is something different. I even had to have that conversation with my husband a couple of times because if I have something, to an extent, I will give it to each one of them (my kids). You know what I am saying? I had to let him (my husband) know “The love I’ve got for you ain’t got nothing to do with their love (the love I have for my kids). That’s an unconditional love. They will always be my children. I can divorce your ass in a minute and you will not be my husband. Or we’ll separate or whatever.” You know what I am saying? But a mother’s love, or a parent’s love, is so strong that you only want the best for them. You don’t want them to get hurt. Just like I told my daughter, the one that (just went to college)…I told her “I’ll be down there in a Chicago minute if somebody messes with you.” She said “Oh my God, you’re so ghetto Mom!” I said “I know! But you’re gonna be glad to have a ghetto Momma before it’s all over with.” (Laughs) (1064)

Though parents in this subcategory viewed it as their duty to love, protect, and share information with their children, they also acknowledged some of the limitations of their role as parents. Most felt it was their responsibility and obligation to provide relevant information about puberty, about relationships, about sex, and about drugs, but recognized that the ultimate decision-making came down to their child. In other words, they could provide guidance, but they could not ensure healthy choices.


The majority of parents who discussed how their HIV status had affected communication with their child viewed being HIV+ as a facilitator to conversation. Twenty-four parents (29%) indicated that their HIV status made it easier for them to talk about HIV prevention with their children. A couple of these parents stated that being HIV+ helped conversations, but couldn’t verbalize how it had helped, whereas most gave specific ways in which their experiences with HIV had enhanced their ability to discuss prevention with adolescents. The reasons they detailed are captured by the four subcategories below.

**Heightened risk awareness.**

Parents reported that living with HIV had increased their awareness of (a) their own vulnerability to infection, (b) the potential vulnerability of their children, and (c) the long-term
consequences of living with the disease. For many parents, being diagnosed with HIV led to the heightened awareness that HIV could “hit home” and therefore a greater sense of urgency to talk to their children about prevention. The following quotes illustrate parents’ reflections on how their HIV status may have impacted their communication with their children:

You’re always thinking as a parent, you know, “my child ain’t gonna be caught up in this type of ordeal because I wasn’t.” (Or), “I didn’t go through this, so I ain’t gotta worry about my child going through it.” So it’s easier for the parents that are (HIV+) -- I think, in my opinion. (1001, Mother)

The possibility of your kids having sex unprotected is devastating to those of us who really know what could happen. A lot of parents just think “Oh my God, I don’t want her to get pregnant! How bad would that be!” There’s just so much more than that at stake….So, I think we don’t have a choice but to talk to our kids and offer them options. You know, the parents who are screaming “don’t give my child a condom at school,” they are just not educated enough yet. They don’t have a clue what could happen...what a life sentence it is...It’s not that you’re dead anymore just because you’re positive, but your life changes. (1018, Father)

I don’t know if I would have talked to them about the disease if I had not been positive. But becoming positive made me be conscious of the danger of it, because even though we all know about the disease, knowing about it is different than living with it. So that made me be more cautious...I would talk to them because I became very aware. (1075, Mother)

Parents in this subcategory who had disclosed their HIV status to their children also felt that their status made their children more aware of their own susceptibility to STIs, and that this awareness had many times translated into stronger intentions to remain safe.

**Better knowledge.**

Aside from an increased awareness of the importance of discussing HIV prevention, parents felt their experiences with HIV had given them (a) more knowledge and (b) better quality knowledge to share with their children. Knowledge was referred to as both factual (e.g., modes of transmission, ways to remain safe) and experiential (e.g., what HIV does to the body, what it is like living with it on a day-to-day basis) in nature.
The following parents noted how being diagnosed with HIV increased their understanding of the disease and, ultimately, facilitated parent-adolescent discussions:

*It’s easier (talking about HIV with your kids if you are HIV+) because you have more knowledge. Well, at least you should, because you’re trying to understand what’s going on with you and your body. So you should have a little bit more knowledge. Therefore I could hold a conversation with my son and talk about it without revealing to him that I have it. If I didn’t have it I don’t know if I could do that.* (Mother, 1007)

*(It’s easier)…because me being HIV positive, I know the steps to prevent it. I know what to tell my child, you know, ‘I’d rather for you not to have sex, but if you’re gonna have sex, use a condom.’* (Mother, 1009)

Other parents focused more specifically on the knowledge they’d gained from personally living with the disease: dealing with unpredictable illness, side effects from medications, and the time it had taken them to cope with being diagnosed.

*I think it makes a difference because if the person is living with the HIV disease, I think that they have more knowledge. They can have more… They’re coping with it so they know how it feels to live everyday with the disease. And I feel that they can share their experience, what they know about it. You know, symptoms, the different things that you go through. So I think it does create room (to talk).* (1015, Mother)

*(It’s easier because…) when we are talking about illness that we have to live with for the rest of our lives, who wants to take medication all their life? And knowing that with that medicine-- if it helps you in one certain place of your body, it (causes) dysfunction in other parts…and you die regardless. We know we’re not promised tomorrow…*(1023, Mother)

*It’s easier for a parent who is more aware of their own body, who is in touch with their own body, who is in touch with their own disease, it is easier for them to explain to their children about HIV and AIDS.* (1046, Mother)

**Visibility of illness.**

Sometimes parents felt that being HIV+ resulted in easier prevention conversations simply because living with HIV meant that the subject came up more often. From doctor’s appointments and daily medications to support groups and special camps, HIV was arguably more visible in some families than in others. The degree to which a parents’ illness was visible
to their children depended on a number of factors, including (a) how long the parent had been infected and whether or not they had disclosed their status, (b) how involved the parent was in HIV-related support organizations, (c) how sick the parent felt, (d) the efforts taken by the family to shield the child from HIV, (e) family roles and responsibilities (e.g., “parentification,” or children stepping in to take on parental responsibilities), and (f) spontaneous events (e.g., death of a parent, sudden onset of illness, unanticipated disclosure).

Briana, who had been diagnosed with HIV while she was pregnant with her daughter, noted her initial surprise when her daughter (now 10 years old) first found out about her status. The discovery that her mother was HIV+ had been unintentionally facilitated by being “surrounded” by HIV from an early age:

> Every year she’s at that camp. At age 7, they said, “Well Ms. Dansin, we’re going to start disclosure talking about HIV/AIDS. Not disclosing about your status, but to let them know (what it is) and are you okay.” I had no problems with that. I signed the sheet. Theresa comes home November of 2007, I believe. She says, “Mother, guess what I learned about HIV and AIDS today?” I said, “Well what did you learn sweetheart?” She said, “Well, we learned how it’s transmitted and”…so forth – she told me every detail. I’m like, “Oh, that’s nice.” I said, “Well Theresa, do you know anyone who has HIV or AIDS?” She said, “Yes.” I said, “Who?” She says, “You.” My whole world just dropped to my foot. Because the first thing that went through my mind was “How dare my family tell her about me!” That’s what went through my mind. So I had to keep a straight face (for her). I didn’t know whether to cry or go (out of the room). I said, “Now Theresa, why would you say that?” She said, “Well, mother, we’ve been going to HIV support group since I was 3.” I fell out laughing. At that time, that was the time to open up to her. She knew that we were going to HIV support group. She knew everything. And then I figured “Well, sure. How do we go on these free camping trips? How do we do all these free things? Everything is surrounded by HIV and AIDS.” I never even thought (that she would know)! (1063)

Similarly, Kate (mother of three adolescents ages 14, 16, and 18) noted the toll AIDS had taken on her family and how the visibility of their step-father’s illness made the subject both necessary and easier to talk about in their household:
(It’s easier) because they’ve seen it first-hand... They’ve seen Timmy (their stepdad who passed away from AIDS complications 1 year ago), being (sick). You couldn’t tell with me and you couldn’t tell with Timmy at first until he got really sick, when the medicine wasn’t working with him. So they could kind of see. It was all there for them to see. They could see the different mood swings and everything like that and then all these doctor visits. (They’d ask) “Why do you have to get all that blood drawn?” You know they saw me go through that. So yeah, it made it easier to talk about. (1092)

Other parents had HIV medications come in the mail and needed their child to sign for them while they were at work, or a health care provider had left a message about HIV on the answering machine that their child overheard. Some parents would share their lab results (e.g., T cell count, viral load) with their adolescents, as a concrete way of discussing how HIV affects the body. Various situations like these stimulated conversations about HIV and HIV prevention.

Regardless of how HIV became visible, the more central a role HIV played in participants’ lives, the easier it appeared to establish HIV-related conversations. At the same time, however, parents also expressed a desire to not “overburden” their children with their illness. They wanted their adolescents to be able to do normal adolescent things and recognized the importance of maintaining healthy and balanced parent-child relationships.

4. **Having a prior relationship with one’s child.**

The third major facilitator that arose during parent interviews was that of having a prior relationship with one’s child. Twenty-two parents (26%) mentioned the importance of establishing a close and involved relationship with their adolescent before talking about HIV prevention. Close and supportive parent-child relationships were thought to build trust, earn respect, and make the atmosphere more comfortable during sensitive conversations. As one grandfather noted:

*If you’ve got a loving relationship with your kids, and I’m not talking about a love/hate relationship, but if you respect your kids and they respect you, and there’s a basic bond of love there, then it makes everything easier. If that’s not there, it makes everything more difficult, and I think that’s the best advice I can give.* (2000)
The emphasis on building healthy relationships may have been especially salient for parents in this sample who had been separated from their children for various amounts of time, or had substance abuse issues that led to strained and untrusting relationships. These parents often emphasized the need to re-establish themselves in their child’s life in general before they could begin to talk or “advise” their children on behaviors they were guilty of themselves. Jared, a single father who had been in and out of recovery for portions of his 16 year old son’s life, emphasized the importance of building and maintaining supportive relationships:

*At that age (early adolescence), they got to be well disciplined. Parents in their life. I’m talking about IN their life, in all their business….It is parents that are in their kid’s life, whatever they are doing, the parents are doing it with them. That makes a difference. Those kind of kids coming up like that are the ones that are going to get the education. They ain’t gonna be negative… The people that I’m talking about that are in their kids’ lives have a better chance of them not getting this virus. Because they’re gonna tell them about it. They’re gonna take them places. You know, they’re gonna do things with them. You got like me, a parent using drugs, not around their kids. Kids are doing what they want to do.* (1038)

When parents spoke of building supportive relationships, they spoke of spending quality time together, having regular family time, eating meals together, “bonding” with their kids, and taking time to listen to what went on at school.

*You’ve just gotta have a bond with your kids…Once a week we have girls’ day. (We) go to the movies, go out to eat. Just me and her and an atmosphere outside of the house. Sometimes we go bowling. Most of the time we go to the movies or go bowling or go out to eat, because that’s what she likes to do. And we just sit. I’ll be like “Do you want to talk about anything?” She’ll be like “No.” But we’ll just be together.* (1006, Mother)

Once these general communication patterns were established, specific conversations about sex, drug use, and HIV became less difficult. As some parents emphasized:

*(I) think it’s got to be the relationship you have with your child in the first place. Like with me and the oldest one, we talk about everything anyway so, you know, it’s like (clap) “Lindsey, are you having sex?” I just asked her like that. So for me, it’s just a normal conversation. So I don’t know, it wasn’t really difficult for me because of my method in the whole thing.* (1011, Mother)
The biggest thing is being able to -- if you hold conversations with your kids period, about anything, then eventually it’s going to come a time where you can ease in a question about sex. So once you establish where you can talk to your kids about anything, then you can talk to them about sex. And once you start talking to them about sex and just a normal STD and trying to keep them from getting that, then this right here (talking about HIV), that’s not a (difficult) conversation. (1007, Mother)

Parents also spoke of how establishing prior relationships provided children with necessary structure and guidance. Kallyn, a mother of two, had recently taken in her four nieces and nephews while her sister entered a drug recovery program. While she already sought to provide her own children with a loving yet structured environment, she now attempted to do the same for her sister’s children.

There’s nothing like having that child being able to talk to you and ask you about everything and anything. You know, because if a lot of parents would listen to their kids, then I think a lot less kids would turn to the streets. And that’s all their looking for, is love and attention and discipline. And (even) the gangs, they give them discipline. And I ask them, for example, my nephews. You know, they’ve been through so much and I asked them, "What do you prefer? Why do you like being here? Cause all I do is fuss at ya’ll! I give you a curfew. You can't do this, you can't do that!" And they're like, "We want this thing. We want someone to show us that they love us." (1049)

Finally, parents established and maintained relationships by being involved in their adolescents’ schools, extracurricular activities, and by getting to know their children’s friends.

In some cases, parents held conversations privately with their adolescent(s), whereas in other cases parents took advantage of opportunities to discuss HIV prevention in group settings with their child’s friends or relatives of a similar age. These differences in atmosphere as well as in parental talking style will be considered in the next category.

5. Employing adaptive talking style.

A number of participants mentioned that a parent’s affect, tone of voice, or general talking style or environment could affect the ease with which HIV prevention conversations occurred. The fifth facilitator category, employing an adaptive talking style, was created to
capture these examples. Specifically, 21 parents (25%) mentioned that utilizing a positive or adaptive talking style helped them broach conversations about HIV and prevention with adolescents.

While parents generally shared the aim of creating a positive talking environment for their adolescent(s), they did so in a number of different ways. The three most common talking styles discussed were being open, supportive, and using humor.

**Being open and honest.**

Parents in this subcategory felt that creating an open and honest atmosphere facilitated conversations about prevention. They spoke of the importance of being blunt, “real,” direct, not “sugar-coating” conversations, and giving information “in the raw.”

*I tell them….I just….say “Look let me tell you something, that little boy talking to you, don’t let him slip your little panties off and then you be doing this and doing that. Don’t let him grind up on you because it’s going to start feeling good and then you’re gonna have sex with him.” I tell her, I don’t be trying to hide nothing, I tell her! I said “He gets to kissing on you and feeling on your titties and all that, no! That’s not a young man because if he was he wouldn’t try that. I don’t mind if you go out with him to McDonalds or to the show or to bowling and come home, but talking about going to his house? No.” I tell her, I don’t hide anything. (1037, Mother)*

Some parents noted that being “open” also meant being receptive, approachable, and willing to listen. If adolescents were aware of parents’ willingness to discuss certain topics (or at least not to shoot them down), they were more likely to initiate and participate in discussions.

*A lot of times they (the kids) will bring it up themselves too…if they know that you’re open to talking to them…Like if you’re the driver taking everybody to the movies or taking everybody to the park to play football or whatever if you’re the driver, just keep your ears open and keep your mouth shut….And then sometimes somebody will say something that is just way off and totally not true and you can just pop up and say “where in the world did you hear that at?” And then they realize you’re listening but they also realize that you were listening but keeping your mouth shut until something untrue was said. So a lot of times that’s an easy way to bring it up. (1079, Mother)*
Being supportive and understanding.

Along the lines of being open, some parents reported that communicative interactions were easier when they were conducted in a supportive atmosphere. Creating a supportive atmosphere meant being non-judgmental, flexible, understanding, and ready to help. Being supportive sometimes meant being open, but other times represented going one step further and verbalizing a parent’s willingness to back their children, regardless of their behavioral decisions. One mother emphasized the importance of preparing her children for decisions they may face ahead, but also letting them know that she was there to help them if and when they did make mistakes.

(Well), sometimes it’s taking the shame (away) and letting them know that they’re going to go through some things, some decisions that they’re going to have to make. Whatever decision that you make I’ll be supportive of you but these are the options. And you have to make these decisions (1013, Mother)

Similarly, Delroy, who was raised by his grandmother in a strict religious environment, noted the importance of letting his children know that (a) he understood what it was like to be a teenager and (b) he would actively be “on their side” when navigating difficult decisions.

Respect them and be honest with them. Don’t try to talk over their heads. Always try to remember where you were at when you were their age, instead of being so rigid in your belief system that there ain’t no flexibility. Because that was one of the hardest aspects I found about (me) growing up. That I couldn’t talk to the adults that were in my world at that time about anything that was happening (with me). So (with my kids) I always try to keep the grounds of communication to where they know that “No matter what I am on your side. Regardless of whatever happens...I am still on your side. But we have to be honest with each other and respect each other before we can see how to move forward with the situation. (1073, Father)

Being supportive and understanding in conversations may have been particularly significant for parents in this sample, as many of them felt that they had been judged by family members for previous life choices. Aware of the shame, guilt, and stigma that often came with contracting
HIV, being supportive of various belief systems, choices, and lifestyles was seen as facilitating parent-child dialogue because it helped create a positive talking environment.

**Using humor and joking.**

While some parents indicated their conversations with their children about HIV prevention were “as serious as a heart attack,” others strove to create a fun and humorous learning environment. Humor was often used as a gateway to conversation, a way to get children to relax and open up.

As one father noted:

> I had to joke with them to ease it in...because if you get a child to laugh they feel comfortable. They let their guard down and they know it. So that way you've gotta put something tempting (for them to feel at ease). So a lot of jokes eases the tension in the air so we won’t have gaps. (1068)

Conversations that began humorous either remained light-hearted or parents adapted their tone to be more serious for parts of the conversation. Either way, humor was viewed as a good “starting point” for conversation.

> (So it’s easier if you) first start out joking with it and then work your way up to being serious about it. You know, so they will open up to you. (2001, Mother)

Overall, employing a positive and adaptive talking style served the purpose of creating a comfortable (or as comfortable as possible) environment for parents and adolescents to talk.

6. **Being knowledgeable.**

> It was a lot easier for me, because I already know about age 12 females anyway – they in heat. I was twelve years old in heat. So I said, you know what? I’m gonna stop this cycle. (1001, Mother)

The sixth facilitator identified had to do with having and using knowledge. This category included parents who referenced that “getting educated” and/or using knowledge of (a) their own experiences or (b) their child’s experiences made it easier to talk about abstinence, safe sex, drug
use, and HIV prevention. Seventeen parents (20%) mentioned examples that were classified into this category.

**Getting educated.**

Parents emphasized that, before they could share information with others, they needed to both attain and understand HIV-related information themselves. For some this was easy, as they were diagnosed in an era when knowledge of HIV transmission was well-documented. For others, getting educated and relaying their knowledge was more difficult, as they were among those who contracted HIV when panic was high and knowledge of transmission was low.

“Getting educated” not only meant learning about HIV transmission, however, it also meant keeping current on HIV-related knowledge. Sometimes the sheer amount of knowledge available about T cells, viral loads, antiretroviral regimens, and AIDS-related complications was overwhelming. Parents felt they had to be able to distill the pertinent information and translate that information to where it could be understood by an adolescent mind. As Dell, father of sons ages 15 and 17, relayed:

(It’s easier if parents) get educated themselves first…they have to know what they are talking about…to tell other people. I think before you tell your kids, or start talking to your kids about your disease, you need to know your disease. No matter what it is. (1095)

As a couple of parents pointed out, however, “knowing one’s disease” didn’t necessarily mean that parents would always have the answers. Sometimes “getting educated” meant admitting what parents didn’t know and being able to seek out resources where they and their adolescent(s) could learn together. As one parent noted:

She would ask me a question...(and I would say) “I don’t know, but you know what? I will find out.” And that’s really how I approached parenting with her. (1018, Father)
Using child’s experiences.

In some cases HIV prevention conversations were accelerated because parents learned their adolescent was engaging in risky behavior. One father discussed spending his daughter’s 16th birthday with her in an abortion clinic. Similarly, a few mothers relayed their hurt and frustration when their child had sex without protection, contracted an STI, or became pregnant as a teenager. Whereas no parents mentioned knowledge of their children injecting intravenous drugs, some were aware of their adolescent’s involvement with marijuana and/or alcohol. These situations often became “teachable moments.” Whether parents felt ready to talk or not, they were confronted with situations that hastened the need for communication. The following quotes illustrate how two participants used knowledge of their child’s sexual experiences to facilitate prevention conversations.

*I had an incident where she tried to have sex, my 12 year old…so I constantly try to tell her about these different types of diseases, especially AIDS.* (1008, Mother)

*Well…after I found out that they were having sex, yea it’s always easier to talk, and it was also easier for me to confront maybe some of their behaviors, as well as for them to come to me and just open up about things that they were secretly doing* (1013, Mother)

Using parental experiences.

The personal backgrounds and experiences of parents in this sample also facilitated discussions. Children who grew up with substance-abusing parents were usually aware of their parents’ previous habits and the havoc it had wreaked on their lives. Whether they had been told by a family member, their parent, or had figured it out themselves, children’s awareness of previous substance abuse situations seemed to make conversations about prevention easier to broach.

*Well, my experience has been that it’s not hard for me to talk about sex and drugs. Because they know a little of my history. For a long time I was going in and out of jail.*
And I was gang-banging in the city, using drugs, I’d been battling with a heroin addiction. So they are aware of those things (1073, Father)

Well (it was easier) because basically my kids were around my drug use, so they saw the effects of it. And now it’s like, I can easily talk to them about it now that I’m clean. It’s real easy. Because I don’t want them to go down that path. (1096, Mother)

7. Recognizing child is ready

The seventh facilitator identified had to do with a parent recognizing their child was ready to discuss prevention information. Some parents detailed that conversations became easier when they recognized their child was both ready and able to handle the topics being discussed. Fourteen parents (17%) mentioned examples that were placed into this category. The readiness of the child was often gauged by one of three main factors: gender, interest level, and maturity level.

*Gender perceptions.*

Sometimes parents indicated that prevention conversations were easier with one gender than the other because they “worried more” about one gender than the other. Mothers were often concerned about their sons, whereas fathers expressed greater worry about their daughters.

*I did that (always talked to my kids about prevention) because I have more boys than I have girls, you know. I got 3 girls and all the rest of them are boys. And you know how men are. Ok? That’s what my grandbabies come from! (1056, Mother)*

*When you have a girl it’s more (to worry about) than a boy. A boy, well it’s just as much, but for some reason you think it’s more with a girl. Because she’s the one who’s going to have to take care of it (a baby). (1059, Father)*

*Well I had other kids under my responsibility, back in my country, so I had to talk to them about that. It was all boys, there was only one girl but the majority was boys. So boys take sex more freely, they don’t have to worry about getting pregnant, that is the idea that boys have back in my country. So I would tell them (about protecting themselves)...(1075, Mother)*
Child showing interest.

Other parents conveyed that it was their child’s interest level that encouraged them to initiate discussions, or in some cases, to share more than they had initially intended.

Of course at school they also teach about sex, they kind of start showing it a little bit. But she (my daughter) wanted to know more about her female anatomy, and about what certain parts do and how they function. Of course I sat down with her and read the book, and we went over certain parts of the body and how they feel at a certain point in your life. And she was really just kind of amazed…She’s a quick learner and she loves to learn. So that was one of the things that made the conversations so smooth, that she was so open to the information. (1024, Mother)

You’ve really got to get into their world, into their way of thinking and think how they think. And their interest is really what helps you know. We have to go with what they like…(1051, Mother)

I think the easiest way so far to bring it up was when I took her to the AIDS walk, because she grew more curious about it. She saw that it wasn’t all stereotypes of just gay people. She’s seen that it’s a big diversity of people. (1089, Father)

Child maturity level.

Still other parents based their decisions to engage in conversations about prevention on their child’s mental maturity level.

Everybody’s got attitude [Laughs] but it’s a lot easier with my 10 year old. He’s cool. He’s different, he’s small, in stature of size, but his mind is way beyond what normal 10 year olds really talk about or expound on. (1007, Mother)

(It was easier because) she is very old – she’s very wise for her age. (Mother, 1077)

Regardless of what cued parents in to the readiness of their children to talk, the recognition that their children were ready (or at least potentially ready) was a large motivating factor to communicate.

8. Impact of parent’s upbringing

The eighth facilitator identified by parents was the impact of parental upbringing. Parents frequently cited examples of how their own family background (family culture, parental role modeling) had impacted the ease with which they could now talk to their adolescent(s) about
sex, drugs, and HIV. This category was created to capture those parents whose upbringing had a positive effect on their communication with adolescents—it had encouraged and facilitated conversations. Altogether, eleven parents (13%) gave examples relevant to this category. This included parents who mentioned (a) that they had a communicative role model in their life when they were growing up, and that this influence had enabled them to speak more easily with their own child, and (b) that they were raised without a strong communicative role model when it came to talking about sex, drugs, or STIs, but that this experience gave them the extra motivation to learn how to talk to their own children. These differences in how a participant’s upbringing encouraged them to talk are detailed by the subcategories below.

**Mirroring communicative patterns.**

*Well, I think it all starts from your upbringing. Because if your parents were open with you and talked to you, then you would know how to address your children in different situations.* (1031, Mother)

A few parents recalled an individual when they were growing up who had talked to them about puberty, sex, drug use, and/or protecting themselves from STIs. Parents who were fortunate enough to have a positive role model in their lives (a parent, older sibling, grandparent, godparent, or aunt/uncle) noted that these conversations had given them a solid framework to draw from when they went to discuss risk behavior with their own children. Nancy, who had been infected with HIV after receiving a blood transfusion, remembered her mother talking to her at the age of 12 about the consequences of STIs.

*She contracted an STD when she was a teenager, you know, from not using protection.... And she told me that, I think it was Chlamydia. She said, “Don’t never do this, you know, harmful stuff...It can harm your body.” That’s what she explained to me. And she had to take medication, a whole bunch of medication, you know, to cure it. Antibiotics, maximum strength antibiotics. She said she’ll never do that again. She learned from her mistakes so she talked to me about it. She said, “Make sure that the guys, they’re clean, you know, don’t have any type of disease, STDs, and just make sure he uses, you know (a*
condom). But that’s basically what she said to me. And I just took her advice, I did. I followed her advice. (1015)

Nancy’s mother’s willingness to openly discuss sensitive information had set the tone for conversations with her own daughter. As she further explained:

I wasn’t ashamed and my mom wasn’t ashamed, you know. It’s better to talk it out, she said, than to be ashamed…I had a good example. (1015, Mother)

Similarly, Joshua noted that topics like sex and drugs were “constantly” discussed in his home growing up, both from a prevention standpoint (“be careful about…”) and from a purely educational standpoint (“this is what happens to a male’s body when…”). His parents’ approachability when it came to sexual topics and their willingness to answer his questions translated into a desire for him to provide his daughter with an open atmosphere for discussing sexual topics.

So, we have an open speech pattern, and my mother pretty much raised me that way, and my daughter’s been around my family enough at family functions and so forth to know that nothing is off limits to talk about so the sexual portion of talking, like I said, that has been going on since between (the ages) of 5 and 7. (1028, Father)

Determining to communicate differently.

In some cases, it was being raised without a parental (or other) communicative role model that convinced parents of the importance of communication about risky behavior. Parents in this subcategory had been resilient. They remembered the confusion, anxiety, and loneliness they felt from not having someone to provide them with quality information and they expressed strong desires not to have their children feel as “lost” as they once felt when it came to sexual and developmental matters. The following quotes demonstrate how participants’ family backgrounds sometimes affected their determination to change communication patterns with their own children.
I mean it’s just like...I don’t know, from the way I was raised...it was hard for me to tell my mom I was having sex. I mean I denied it all the way to the point I got pregnant with my first kid. Because I didn’t know how to sit down with her and tell her, you know, I’m having sex and yaddy-yaddy-yada. But going through that experience has made me a little different from the way my mom was...Because maybe if I do talk to them, I can prevent it from happening, or I can at least get them some guidance when they are out there making those decisions on how to protect themselves. (1001, Mother)

I said to myself, since my mom never opened up with me, I am trying to be open with my kids. (1003, Mother)

So I always said that I would not raise my kids like my mother did me. Me and my sister always say that we want to be open with our kids. (1085, Mother)

Overall, family influences facilitated communication both directly (having a positive role model enhanced communication skills) and indirectly (lack of communication in one’s upbringing led to determination to acquire certain communication skills).

9. Timing & Recurring conversations

The final facilitator identified had to do with the timing of parent-child communication. Eleven parents (13%) expressed the general sentiment that risk communication got easier over time (i.e., with practice). Initial conversations may have been difficult, but those that followed were oftentimes less awkward, less emotional, and evoked substantially less anxiety from both the parent and the child. Parents in this category focused on two dimensions of timing: starting young and having recurring conversations.

Starting young.

Whereas parents in the facilitator #7 category (recognizing child is ready) often looked for signs that their children were ready for conversation, parents in this category expressed the importance of communicating about sex, health, and the dangers of destructive behavior starting from an early age. These parents viewed risk communication as a process that evolved as children grew up. By communicating age-appropriate risk information when a child was
younger, a general communication standard was set that sensitive topics were “okay” to discuss in the household. For example, one parent noted:

Start the dialogue with them younger so that it’s not like a, you know, (big surprise)…So if you start young I think it makes it just so much easier when they’re older. But if you wait till their older than it’s like (they) really don’t want to talk to you, you don’t hardly have that dialogue....I think that’s the trick, just talking to them young. (1011, Mother)

Parents varied in their opinions of what “early” meant. For some it meant a year or two prior to puberty, whereas for others it meant discussing certain topics from the time their child could talk. Early sexual talk often began with general assertions, such as “No one, male or female, can touch you,” “you have boundaries right here (below the belt),” or the notion that doing “certain things” to one’s body could make a person “sick.” As the child progressed in age, the parent was able to build upon the information previously given.

Recurring conversations.

This subcategory captured the notion that repeating messages was important because it (a) made subsequent conversations easier, and (b) provided reinforcement of what children had already learned. Supporting quotes from parents included:

They were nervous (at first). But after having quite a few discussions, it just became more and more easier for them to, (for us to) just to sit down and talk...about different things. (1001, Mother)

The very first conversation I had was very hard...Since then it hasn’t been so hard. (Mother, 1041)

Having recurring conversations appeared to increase parents’ confidence in their abilities to carry out future communications with their adolescent(s). The feelings of accomplishment or merely the perception that the conversation “wasn’t as bad as they thought” often led to resolutions to try to integrate more prevention communication into their normal activities with their child.

As noted previously, however, conversations weren’t always comfortable or easy. Along with identifying a number of influences that made conversations go more smoothly, parents also
detailed factors that made conversations difficult to broach. These factors are detailed in the section below.

**Barriers to Conversation**

Eight major categories emerged after coding examples of barriers to conversation. Some of these concepts simply provided the opposite end of the spectrum for a category already discussed (i.e., the presence of a conversational role model could facilitate conversation, whereas the absence of a role model generally made conversations more difficult). Other concepts, such as community norms, ignorance, and misunderstanding, were categories uniquely reported as barriers. A summary of the categories in this section can be found in Table 12.
### Table 12

**Summary Table of Barriers to Conversation**

<table>
<thead>
<tr>
<th>Barrier Category</th>
<th>N</th>
<th>%</th>
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</thead>
<tbody>
<tr>
<td>1. Fear &amp; focusing on disadvantages</td>
<td>27</td>
<td>32</td>
</tr>
<tr>
<td>➢ Concern for welfare of child</td>
<td></td>
<td></td>
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<tr>
<td>➢ Changed relationships</td>
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<tr>
<td>➢ Damaged self-image</td>
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<tr>
<td>➢ Awkward conversations</td>
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<tr>
<td>2. Living in denial</td>
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<td>30</td>
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<tr>
<td>➢ About HIV status</td>
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<tr>
<td>➢ About child’s behavior</td>
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<tr>
<td>3. Lacking role model</td>
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<td>25</td>
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<tr>
<td>4. Characteristics or reactions of child</td>
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<td>➢ Lack of interest</td>
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<tr>
<td>➢ Personality</td>
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<tr>
<td>5. Community norms, ignorance, or misunderstanding</td>
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<td>18</td>
</tr>
<tr>
<td>6. Competing opinions &amp; priorities</td>
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</tr>
<tr>
<td>7. Uncertainty about how to discuss</td>
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<td>15</td>
</tr>
<tr>
<td>8. Being HIV+</td>
<td>6</td>
<td>7</td>
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*Note. N=84*

1. **Fear & focusing on disadvantages.**

   *So, I’m scared of her. I don’t even want to talk to her. I ain’t ready to come down to that conversation with her yet...We’ve got so many parents that are scared to (talk to their) kids. (2001, Mother)*

Some parents expressed concern that talking to their children about HIV and HIV prevention could have negative consequences, and that focusing on these potential consequences either prevented them from talking altogether or made it more difficult for them to engage in conversation. Comments from 27 parents (32%) were included in this category. Most
dimensions of this category revealed some aspect of fear, though the source of fear depended on the parent. Major sources of fear included (a) concern for the welfare of their child, (b) fear of changed relationships or of unknown reactions, (c) fear of damaged self-image, and (d) fear of uncomfortable or awkward conversations. These different, yet overlapping dimensions of fear are detailed by the subcategories below.

**Concern for welfare of child.**

A number of parents were concerned that talking to their child about HIV and HIV prevention would make their child scared of HIV in general, or that it may jar stereotypical notions of HIV as a “death sentence” or “skull and bones” disease. These parents often saw conversations about prevention as being intricately linked with discussions about their own HIV status. As two mothers relayed:

*(It’s hard) because it’s scary. I remember before I was HIV positive...The first time I ever heard the word AIDS, and it wasn’t HIV – it was just flat out AIDS, when someone even said that to me, I get to trembling. I’m scared. AIDS – and all you think about is death...So when parents sit there and have to even have that word come out of their mouth, to a child, it’s like telling them you gonna die one day. They don’t understand it. Parents don’t understand, so they try to find ways to tell it to their kids in such a way that they’re not so much afraid. So what do we do? We try to avoid the conversation all at once. (1001, Mother)*

*Well my fear is that I don’t want to worry them...You know kids are good like that...I don’t care how horrible of a parent you are, they still have this inability to just forgive and just love, especially my children. So it’s hard for me to deal with just scaring the mess out them. And I know this is an issue that people who are educated in HIV and AIDS still fear. You know, and just imagine a little kid who knows from the stigma with the skull and bones that it’s something bad, dark, and dirty, you know, dangerous, and dirty. So just to put that on your kids with all the extra things that they go through: peer pressure, things like that. It’s just unbearable to think of. It’s just one added thing that I have to have them go through. And I wouldn’t wish that on any kid. (1017, Mother)*

Others parents were concerned that talking about sex and HIV may cause children to “grow up too fast,” or may encourage adolescents to engage in risky behavior. Selena, who was raising her 13 year old niece, noted:
It’s a spiritual thing I guess…People believe if they start telling their kids about sex that’s gonna give them the initiative to start. And you know the mind is a very powerful thing, so you never know what the mind does to different peoples children and what it’s telling them. So it’s just a risk. It’s something that’s a part of life that a person has to believe and trust that their kids are gonna be alright. (1081)

Still others were worried that conversations about anything HIV-related would be a reminder of the parent’s illness or a recent family death and may cause their child undue anxiety.

His father is deceased. He died of, well, he didn’t die of the virus - it was from complications. But he always asked how his father died and I would tell him, “Well, he was doing things to his body that he shouldn’t have been doing. And, you know, stuff happened.”...So with that, I don’t tell him...(about HIV and his father’s drug use)...I don’t think that should be... I don’t think he’s strong enough for that. (1004, Mother)

**Fear of changed relationships.**

Sometimes parents’ fears were rooted in the uncertainty of the unknown. They feared the topics that might arise during prevention conversations -- the questions their children might ask and the reactions they might give. On a deeper level, they feared that information shared during these conversations, including disclosing their HIV status, might permanently alter their relationship with their child. Such fears included the child having a negative reaction towards HIV in general and the child acting “differently” towards the parent as a result of learning about his or her status. Comments from parents who expressed these concerns included:

You want to tell people but you know when you tell people, your relationship ain’t never gonna be the same with that person. It’s not, and I’ve learned this first hand...just...holding conversations with them and you talking about this situation and I’m the only one at the table that actually has it, it makes it difficult. And then when you’re one on one you kind of want to say it, but every time you tell it, the whole relationship changes. It changes. (1007,Mother)

Once I came to grips with it I don’t really care about what other people think, but I think it’s more the reaction their children are going to give. So I think that’s why it’s hard, but that’s why I always stress with them about drugs and practicing safe sex, because I shared with them how I contracted it through not having safe sex due to my drug addiction. I’m a recovering person, and I’ve been clean...about 11 years. (1047, Father)
I think (it’s hard) because they (are) not open with their children. The reason I say that is because some parents may think their kid may shun them. So they don’t want to be ostracized by their kid. (1050, Father)

**Fear of damaged self-image.**

Similar to being scared of changed relationships, parents explained the tension between wanting to discuss their personal experiences with adolescents as a learning tool, and knowing that discussing such information could portray them in an unfavorable light. Thus, fear of damaged self-image was prominent in some parents’ minds:

*I think one of the reasons (that it’s hard) is because parents want to do a good job. And then kids might question what parents are telling them. They’ll say “Well, if you’re positive, how did you get to be positive?”... So they (parents) might be embarrassed to talk about their lifestyle.* (1046, Mother)

Conversations about parents’ past experiences not only brought up isolated instances of risk behavior, they also brought up deeper family issues like sexual abuse, extramarital affairs, and sexual orientation. One father had learned to avert this potential difficulty by setting firm conversational boundaries when discussing HIV-related information:

*One of my kids actually asked me, just the other night at the dinner table, “Well if, if you’re with HIM, how could you have been with HER?” I’m like, “I’m not getting into that because that goes back to parents and what happens in the bedroom between Mommy and Daddy. You don’t need to know about that.” Now, what happens between “Dick and Jane,” yeah we can talk about that. But what happens in THIS bedroom, we don’t talk about that. That’s more or less (why it’s hard), I think most parents are afraid of “let me tell you what happens in our bedroom rather than what’s happening in Dick and Jane’s.”* (1083, Father)

Setting up conversational boundaries appeared to be harder for some parents than others, however, and seemed to be related to gender roles, cultural values, how old the participant was when he/she became a parent, and personal life experiences. Parents whose own boundaries had been violated (e.g., sexual abuse), as well as those who’d had limited opportunities to be assertive in their own lives (e.g., teenage moms), may have had more difficulty with this than others.
Fear of uncomfortable or awkward conversations.

Lastly, participants highlighted the tendency of parents to be afraid of uncomfortable or awkward conversations. Fear of dealing with difficult issues like sexual activity and HIV was noted as a barrier to communication by the following parents:

(It’s hard because) they’re not ready or they’re probably scared, thinking, “Oh, they’re coming to me about sex. They want to have sex! Uh-uh (no). Go on, get out of here. I ain’t telling you nothing.” You know, which they should be glad for that. Sit down and discuss whatever they want to know. (1029, Mother)

I guess it’s just uncomfortable dealing with the issue of sex with your own children. At least that’s the biggest part for me...But I think it’s just uncomfortable for a lot of parents to talk to their kids about sex, they don’t want to talk to them. (1089, Father)

Maybe it was the way I was raised. I was an only child too...I was a loner, so I think that plays a lot in it and then I was shy so that subject was like “ahh” (awkward) [Laughs] (1092, Mother)

Whereas some parents were able to overcome or navigate their fears and engage in conversation, others had become so focused on these potential disadvantages that they chose to either suspend conversation temporarily or forgo communication altogether. Parents who spoke of coping with their fears spoke of two main coping mechanisms: (a) learning to accept their HIV status and move beyond their previous behavioral decisions, or (b) continuing to live in denial.

2. Living in denial.

A number of parents viewed living in denial as a barrier to having productive HIV-related conversations with adolescents. Living in denial had to do with a parent’s inability or difficulty accepting reality, usually in terms of HIV status or HIV risk behavior. Twenty-five parents (30%) discussed how living in denial could impede conversational progress. Parents spoke of their own denial as well as about denial of their childrens’ sexual and drug activity.
About own HIV status.

The information is out there, but they (parents) are not looking for it because a lot of them are still at the point where they don’t think it could ever happen to them, which is part of the problem. It’ll never happen to me. I suppose I’ve said the same thing, “it’ll never happen to me.” But the information is out. I think it’s definitely out there -- we’re just not looking for it. A lot of us still just don’t want to deal with the reality that it’s here. (Mother, 1016)

Some parents verbalized that living in denial (or the lack of acceptance of one’s HIV status) can impede the ability to talk about HIV. Parents in this subcategory noted that one of the first barriers to overcome in being able to talk about HIV was learning to accept that they were infected. Acceptance was difficult, in part, because parents were often shocked and expressed disbelief upon receiving news of their HIV diagnosis. The general sentiment expressed by participants was that they needed time to process the situation themselves before they could worry about talking to and dealing with other people. As one mother thoughtfully reflected:

Well first of all the parents have to be comfortable with themselves. They need to not be in denial...So I think a support group and you feeling comfortable with yourself and your illness. Because see in the beginning I wasn’t like that. I couldn’t stand the fact that the illness was running through my veins and I hated it. I was ashamed of it - I thought it was dirty. I thought people were gonna reject me. But once I learned about the illness and once I was going to support groups and just learning more and more about it and taking care of myself I didn’t care what people thought, you know? I just knew I needed to take care of myself. I think you have to get there before you can go any farther. (1012)

Similarly, one father noted that conversations with his family and with his children were difficult initially because he had neither accepted nor disclosed his status. Holding this information inside caused him great anxiety, but he felt that discussing his “secrets” with his children had improved his physical and emotional well-being:

Being very honest (about my status made it easier) because I had to be honest. I just had to. My secrets kept me sick. And I still live by that, secrets keep me sick. And I want to be well; I want all of my family (to be) well. (1082)
Finally, one mother emphasized the adaptive function of denial. For her, avoiding HIV-related topics was a coping mechanism, protecting her from facing a still overwhelming reality. As she explained:

*I really never like to talk about it because you know I live as if nothing happened. I try to forget about it even though I know it’s there but that’s the only way you live. I try not to stress myself because the depression and all that stuff gets to you and it just makes it worse.* (1023)

Parents who expressed similar sentiments felt that living in denial may have been protective, particularly early on in their diagnosis, but that it also had the potential to allow them to become comfortable ignoring the impact of HIV on their lives. Sometimes this came at the cost of avoiding HIV-related topics with their children.

*About child’s behavior.*

Other participants noted the general inclination of parents to live in denial when it came to their children’s potential sexual and drug activity. Parents noted that sometimes the tendency for parents to think their child “wasn’t ready” for conversation came from a reluctance to admit that *they* (the parents) weren’t ready to converse themselves. Parents generally felt that they were knowledgeable about what went on in teenager’s lives – they had been “out there” themselves. It was “other parents” they spoke of (presumably those not infected or affected by HIV) when relaying how living in denial prevented HIV prevention communication. As two parents indicated:

*My belief is that sometimes the parent’s know, but deep down inside they don’t actually know how things are going today. All they have is what they went through. And so many things, as you well know, have changed. It doesn’t take much for a youngster to fall in love or want to do the wrong things. Sex is one of them. And I want mine (my daughter) to be educated about using protection and some things like that, likeSTDs. You know, because she might love a guy but she doesn’t know where he’s been. That’s how it starts. (So sometimes it’s hard because parents think) “My daughter’s not doing it” or “My son is perfect.” They’re not!* (1033, Father)
I think they find it hard to talk about it because they're afraid. You know, a lot of people live in denial. And they only want to talk about what they think is true. So, to them, their child might have one opinion and they might have another. And to avoid all that, they think, "Oh let's not bring it up. The best thing for you is to stay a virgin forever." Ok, that's the best thing to be wanting for everybody, but 'HELLO', it's not gonna happen! (1049, Mother)

Regardless of what parents were refusing to accept (their own reality or the potential reality of their children), living in denial was viewed as a barrier to productive communication. Parents in the sample were often frustrated by their friends, relatives, neighbors, or general acquaintances who refused to talk about sex and protection with their children. Parents who were also HIV educators or case managers recounted stories of clients who didn’t want to acknowledge to themselves or to their families that they were infected, only to later find out that another one of their family member’s had been diagnosed HIV+. Briana, who had run an HIV support group for a number of years, expressed her frustration at the mothers in her group who would not discuss HIV or disclose their status to their children, despite their children engaging in unprotected sex and HIV running rampant in their community.

There are very few real mothers out there, but real mothers tell the truth. Those who want to be in denial stay there. And then those children are spreading this and they are dying. And killing other people! It’s like genocide...We’ve got some who have been living 10, 12, 20 years with this disease and won’t share with their (kids). “I ain’t got there yet.” Well, when are you going to get there sister? Girl, you know your kids are out there! I see them every weekend. People say “I know so and so is out there.”...It hurts in my heart when I see those parents, and unfortunately, I see it all the time. Some have gotten to where I am at today, and feel the same way that I feel. Some have not gotten there (yet) and that’s what they tell me. They say, “Well Briana, not everyone has gotten where you’ve got.” Whatever,” I say. “That sounds like an excuse. And we hold an excuse when we don’t want to accept things.” (1063, Mother)

As Briana highlights, some parents felt a sense of hurt and desperation that other parents weren’t sharing their HIV status or prevention information with their children, particularly since the rates of HIV infection appeared to be increasing among young people in their communities.
3. Lacking role model.

When asked whether or not they remembered one or both of their parents/guardians talking to them about sex or about sexually transmitted infections, 78% (66/85) of participants reported they did not have a parent who talked to them about such topics. Of the 22% (19/85) who did recall some sort of parental discussion about sex or STIs, most conversations either happened after the fact (e.g., after sex, pregnancy, or contracting an STI) or consisted of very brief comments like “don’t drop your drawers,” “keep your legs closed,” or “here’s a pamphlet – it will tell you everything you need to know.” The four participants who contracted HIV under unusual or external circumstances (e.g., rape, blood transfusion, and work-related needle stick) all recalled a parent who had talked to them about sex or sexually transmitted infections.

Whereas some parents who lacked communicative role models used their experiences as motivation to communicate differently (see facilitator #8), the majority of those lacking parental role models viewed this as a barrier to prevention conversations. Twenty-one parents (25%) expressed the sentiment that family influences, or lacking a role model, contributed to their difficulty conversing with adolescents about sexual and drug activity. One grandmother, whose 13 year old granddaughter currently lived with her, relayed her sentiments about generational differences in the following quote:

Well to tell you the truth, the way I was raised and the way I raised my kids, you were told “this is bad, this is good, this you don’t do” So it’s never any reason to have to talk about it because I’ve explained to you “this is a no-no.” And I’m accepting better now with this grandbaby with all her questions. If (only) my parents had been able to talk with me and express with me about it before...because the questions that baby asks me we would get popped in the mouth for. And it’s really hard to communicate when you got everything set up as “this is bad.” But this is like, I’m grown in my 30s when I wasn’t ashamed to have sex, it’s just something you didn’t do. Each time I get pregnant it was shameful for me because birth was a bad thing to do as I was coming up.. So it’s just more open now, and if you got any of those old fashion ideals instilled in you still, it’s hard to let go. (1027)
A number of fathers expressed similar ideas, highlighting the various ways they learned about sex and sexuality when they were growing up (none of which involved a parental figure):

I don’t know really (why it’s hard). In our community, most children learn from their peers about sex. That’s the way I learned. All I didn’t find out on television, I listened to the older guys (I hung out with) about what they were experiencing and what they were going through. That’s kind of how I learned. I guess I was kind of old-fashioned because that’s the way I learned it. I figured that was the way my children were going to learn it too. (1069)

I just think it’s kind of like that whole terrible...we don’t talk about religion often. Sexuality, well, at least that wasn’t talked about in my home. We don’t talk about...sexuality or drugs until the blister bursts and we’re ready to discuss everything about it -- or go into denial. But I think maybe parents just want to give you a book to read, or let society teach you. It’s not a societal issue though...In my own home we didn’t discuss a lot of things, especially my sexuality being bisexual...it was like “We’re just going to ignore that.” (1082)

Still, there’s a generation gap, there’s almost twenty years difference, I’ll say "this is the way this is supposed to be" and their generation (will be like), "what are you talking about?"...When we were brought up, my mother never said the word sex. (1083)

I guess it’s just uncomfortable dealing with the issue of sex with your own children. At least that’s the biggest part for me. I don’t ever recall my parents having any type of talk with me about sex or STDs or anything like that. Things are different now. I grew up in the 70s and kind of the 80s and things started to change I think in the 80s. (1089)

Lacking a sexual communicator in their families had left some parents, and particularly fathers, both unsure about the appropriateness of sexual talk in the home and inexperienced when it came to how to conduct conversations with their children about topics like sex and drugs.

4. Characteristics or reactions of child.

Just as certain personality or psychosocial characteristics of adolescents helped parents to recognize they were “ready” to talk about prevention (e.g., child showing interest, maturity level), other characteristics were viewed as inhibiting factors. For example, parents noted it was harder to talk to children who they thought were too young, too sensitive, not interested, or wanting to be too independent. These assertions are captured by the subcategories below.
Altogether, 19 parents (23%) mentioned that one or more of these factors made it difficult have conversations about HIV prevention.

**Age or maturity level.**

Sometimes it was a child’s age or mental maturity level that made parents hesitant to discuss prevention information. One mother gave the following rationale for not discussing sex, protection, HIV, or STIs with her 13 year old son.

> In my circumstances it’s still – you would think that would be the green light to say, “ok we need to start talking about this,” and it just hasn’t happened. And it’s not even a matter of; for me, to think that you’re going to give them too much information or you’re going to make them think about it. I think you have to know your child. And he’s kind of baby-fied. I don’t want to say baby-fied, but you know I don’t think he’s even there. But I know he’s there at the same time. I know his mind has gone there. Physically I suppose, but mentally I don’t think he’s prepared. But I don’t want to be one of those people that actually want to say, “Oh no he’s not thinking about it at all.” But it’s difficult to bring up the subject...and we really haven’t talked about it (1016)

**Gender perceptions.**

Whereas some parents noticed that they had more motivation to talk to children of the opposite gender (see facilitator #7), other parents noted that opposite gender conversations were substantially more difficult. As one mother noted:

> The boys, nobody wanted to talk to the boys. (Mothers think)“Aw he’s a boy, he’ll be ok.” No he won’t! Because if he come home with shit other than just getting a girl pregnant then what you gon’a do? (1011)

Similarly, Martin felt he was more protective of his daughters than his sons when it came to sexual matters, but still couldn’t bring himself to discuss prevention information with his girls.

> For me, it’s harder to talk to girls about it, see it ain’t no thing talking to my son about it, and when I’m talking to my daughter it just don’t seem appropriate you know, that’s, I guess I always considered that to be a ladies job. Talking to the girl...I don’t know if it’s the way I came up, but you know I feel more comfortable talking to the boy you know, I can open up about sex with him. But with girls it’s a bit more (difficult)...I love them and we talk about a whole lot of things but sex, when it comes to that, it’s kind of a touchy subject. (2002, Father)
While bringing up certain HIV-related topics were admittedly difficult, these barriers didn’t always discourage parents from talking. Raul, a single father who had discussed both his status and prevention information with his 18 year old daughter, was glad that he had talked to his daughter, but noted that both he and his daughter felt the conversation was uncomfortable.

*It was like she felt a little uncomfortable because I’m her father talking to her about it. I think because it’s a man I guess. I think she would feel more comfortable talking to my mother about it.* (1065, Father)

**Lack of interest.**

Some parents seemed willing to discuss prevention information with their children, but either (a) didn’t think their adolescent would be interested, (b) had been previously shut down when they attempted communication, or (c) had been discouraged by their children failing to listen to information they had given them previously. Examples of adolescents being uninterested or not listening included:

*(It’s hard) because they don’t want to listen. You see these teens, they don’t know what love is. They tend to think that because a guy likes you and you like the guy, that’s it. That’s all they care about -- and then comes the rest. So they really don’t listen, they don’t want to listen until it hits home. But I don’t know, some of them just don’t care.* (1023, Mother)

*It’s like everything I want to say to them it’s, ”Momma, I’ll call you back. Momma, I’ve gotta go.” I feel like that (they don’t have time or aren’t interested) all the time.* (1039, Mother)

*You know from the experience I have, they feel I guess immortal. They don’t heed what you’re actually trying to get across to them.* (1050, Father)

*He (my son) is in that age like somebody needs to talk to him about a lot of things. The last time I talked to him about, you know, (about) when he has a girlfriend—I don’t know. He was like, “I know, please don’t start.” I’m like “Ok.”* (1058, Mother)

**Personality.**

Still other parents spoke about conversations with adolescents being difficult because of the personality of their child. Within this group, a few parents noted that their children were
overly sensitive, shy, or emotional. Others noted that they used to be able to talk to their adolescents more easily, but that conversations became harder as their kids developed “teenage-like” attitudes.

It’s a little hard. It’s a little complicated. It’s – how can I put it – especially when they get 17 or 18 years old. They are like a totally different person. They are into their own thing... My daughter, she’s a quiet person. She’s real quiet. And the difference I see in her now compared to when she was 13 or 14 is -- it’s like she’s a totally different person. She’s developing more, she’s looking more like a women now, and it’s harder for me to talk to her or say things that I really want to say to her. I talk to her off and on, but it’s not like I used to talk to her. It’s not like that no more. (1065, Father)

It was okay up until they got teenagers (laughs). (Then) oh my goodness they grow and they get...ehh...My middle child she’s more independent so it’s very hard to talk to her sometimes about anything. And then she’ll come back and say “oh mama can we talk?” (1092, Mother)

In sum, parents’ noted that specific psychosocial and/or personality traits of their children made conversations with certain adolescents more difficult than with others. Not surprisingly, parents appreciated and enjoyed talking to adolescents who were interested and engaged, whereas they found it more difficult to talk to those who “didn’t want to listen” or “didn’t want to worry” about HIV.

5. Community norms, ignorance, or misunderstanding.

There are parents who, stigma is still up (high) in their community, so they ain’t talking to their children about HIV period...So it’s like, some (don’t talk) because of stigma. (1046, Mother)

Fifteen parents (18%) provided examples where community-level factors impacted the ease with which they could conduct conversations about prevention. In particular, they discussed how experiences of stigma, stereotyping, lack of knowledge, and/or misinformation about HIV either made conversations more difficult or prevented communication altogether. Miguel, a father of two teenage boys, admitted that society’s views of HIV were the number one reason he had difficulties discussing his illness with his family.
It’s hard because right now people see this sickness as a bad thing... From what I have seen in other people when a comment is made (about HIV)... it’s bad. It’s a sickness that is not accepted. It is often associated with homosexuals... it’s bad... like supposedly the majority of the people who have this, a large percentage, are not good people. Once people know, they look at us in a weird way and a treat us with a certain precaution. They treat (us) with a little precaution because they are scared of touching and transmitting. I say this because that happened with my own sister....Not exactly scared to touch me, but scared when we use the same bathroom, or something like that. (1076)

Rather than starting from neutral territory and being able to discuss HIV in purely informational terms, what seemed to stand out in these parents’ minds was the battle they still face, 30 years into the epidemic, to “write over” what their children had learned from society and teach them that there is no one face or one profile of HIV and AIDS. For example:

I don’t think it’s ever gonna be any easier. I guess the way society views (HIV) will make it easier. Oprah actually had a show on about these women who all dated this one man, and they were saying that he knowingly gave them the disease...So you got these unsuspecting women who have no idea...Everybody’s not just on drugs or sex workers and it’s not just about being a homosexual...So I don’t think it’s gonna ever get any easier as long as society has these ‘rules’ for people because, just like they said, “We didn’t think we fit the profile.”...As long as we don’t have enough information for people to know about the real issues and don’t get rid of the stigma then it’s not gonna be any easier. (1051, Mother)

Despite relatively high perceived stigma in their communities, some parents took an active role in local schools and churches to try to raise awareness about HIV. Parents who had taken the time to talk and teach about HIV prevention (and in some cases about their own status) noted that there were times their experiences had been rewarding, but other times they had been challenging (due to the lack of general acceptance of HIV in the mainstream community).

(It’s hard because)...some of them you know, “you got AIDS,” you hear that. The ones (teenagers) that I’ve been around don’t have any compassion towards a person who has HIV. No compassion. You got that ‘package’ you know, that’s what people call it, you got that ‘package.’ (1050, Father)

Lastly, one case manager thoughtfully reflected on many of the barriers above, discussing how she believed community, cultural, and family norms among her clients had affected their outlook on health and general attitudes toward preventing illness:
It's like (Caucasian girls) do it because boys like it or they do it because they see their friends doing it, because of the peer pressure thing. So that's in all groups, all cultures. But African American women are more apt to do it because the boy has money, drugs, and a car. He has bling. He has pimp daddy status...And so they’ll sleep with him because he has the ride. They’ll sleep with him because they can get their hair and their nails done. As opposed to Caucasian women...they’re more into prevention. We’re more into intervention. Once it happens, we are going to intervene. ...That’s the difference though. That’s how we’re culturally different. Because we (African American women), we think of ways of surviving...They use preventive methods but we use intervention methods...We all had the same opportunities but because our lifestyles were so different, because we were raised differently, something happened. So that kind of stuff – those are the cultural barriers. (1046, Mother)

As indicated in this quote, this mother felt that conversations with adolescents in her culture were difficult because of the tendency of many African American families to focus on “survival” (e.g., intervening once illness has already occurred), rather than to focusing on preventing illness. Examples like this illustrate the complex myriad of societal, cultural, and familial influences parents must take into account when determining what messages to communicate with their children. In these cases, it was not the challenge of providing informational messages that was the major conversational hurdle. Rather, it was the work that was needed to alter an adolescent’s and/or parent’s perception of his/her community at large.

6. Competing opinions & priorities.

Some parents mentioned that conflicting opinions from others (about whether or not to talk), as well as competing life priorities made it challenging to talk about prevention. Fourteen parents (17%) identified this as an area of difficulty. In terms of competing opinions, parents noted that other family members sometimes influenced when, how, and what they discussed with adolescents. These adolescents included their own children, as well as adolescents in their extended families. Supporting quotes from this category included:

*I think the main reason I put it off was her dad is really like, “Why you got to have that talk with her?” (I was like) “Because she needs it!” so yea. (1011, Mother)*
Well I talked to him, we talk all the time you know but his mom keeps telling me to wait. She wanted to talk to him. I said I can talk to him but, neither one has got around to it yet, so we are still debating on that. (1022, Father)

Sometimes my stepdaughter, I am very hard on her. She’s very open to a certain degree. I didn’t give her any condoms because I know how Jeremy (her father) feels. I didn’t want him to feel like I was sending his daughter to go out and, you know (have sex). (1063, Mother)

I (also) have a 17 year old cousin and he’s sexually active. And my aunt got mad at me because she found out I was giving him condoms...So she was like, "Why are you giving him condoms?!” And I said, “Well, you can always take him to the doctor and the doctors tell you, 'You have AIDS'. Or I can continue to give him condoms.” (1093, Mother)

Other parents spoke of the competing priorities in their own lives – for example, the difficulty of trying to talk to adolescents while still actively involved in an addiction.

(It’s hard) because there’s a lot of them (parents) into themselves, because all of them trying to get themselves together...I’m out here seeing it. I see it every day...Drug use, they forget about the kids. The kids are out here selling drugs, the kids are out here trying to make money. The kids are out here doing everything. Kids are out here killing. I’ve seen kids seeing their mama doing drugs. (1043, Mother)

If the household is not stable, talking to them doesn’t do good a lot of times, it depends on what kind of household they’re in. If you’re using drugs they aren’t trying to listen to nothing you’re really saying. And a lot of times when the parent is using they’re not telling their kids nothing productive anyway and by the time they stop using, a lot of their kids are actively using already. (1047, Father)

I think that if you are an alcoholic and having HIV and not doing anything about it, I think it would be hard for you to try to explain to them or tell them to do anything different than what you are doing (if you are still doing it)...But by me educating myself, going to support groups – I stopped drinking, I stopped drugging. I don’t have no problem telling them “Don’t do that, don’t do this.” Because even though I have done it, I am not doing it today. And I am not doing it anymore. And you saw when I’d done it what had happened to me. So I suggest you not do it (either). Because the last thing you want to do is to end up the way I was. (1072, Father)

Whereas parents who were able to overcome their addictions could now divert more of their attention to their families and to matters like child-rearing and keeping their children safe, many of them also faced significant struggles. One struggle faced was how to re-connect with one’s
children, including how to suddenly invoke standards of discipline in a household that used to have substantial flexibility. For this, parents often had to build trust, earn respect, and learn new parenting skills.

7. **Uncertainty about how to discuss.**

Approximately 15% (13 parents) indicated that they were uncertain about how to go about discussing prevention information with adolescents. Participants in this category felt parents sometimes lacked the knowledge and/or skill necessary to have productive conversations. A couple of parents noted the difficulties and lack of information available for their special needs children when it came to matters of sexual development. One mother noted:

*So then (my son) keeps asking me about girlfriends and wanting to have sex and you know, in my mind, due to his age and his mental state...I keep saying to myself, “How will I let him have a girlfriend, you know?” I keep saying that to myself! Cause he’s special (needs)...he has a disability.* (1003)

Still other parents noted that they “didn’t know how” or were “unsure” of how to approach their children.

*Yeah it is (hard), because I don’t even be knowing what to say to them because my kids still don’t know so, and when I do get ready to tell them how can I tell them, or what am I supposed to say to make them not be scared but I want to tell them so they can know what they have to do to not catch it too.* (1006, Mother)

*I think sometimes it can be hard for parents because maybe they don’t know how to approach their kids.* (1015, Mother)

*But you don’t know how to prevent it, because like I said it’s not just a sex thing. So figure out the cause (and) you’ve got your solution...I don’t know, if they come to me I try to give as much as I can but I don’t know myself.* (1027, Grandmother)

*I’m thinking he knows about HIV and AIDS and everything, but I don’t know I just don’t know how I want to start talking to my son. I think I need help for that really bad.* (1058, Mother)

8. **Being HIV+.**
The last barrier parents spoke of was how their experiences being HIV+ had sometimes negatively affected their abilities to converse with adolescents about HIV and prevention. Whereas 29% of parents identified aspects of being HIV+ as facilitating conversations (see facilitator #3), only 7% (6 parents) thought it was more difficult for parents living with HIV/AIDS to discuss HIV and prevention with their children. One parent noted that there is pressure on parents to explain more about HIV if they are living with it, because their children will likely want to know detailed information about the virus.

*I think it's more hard (if you are living with HIV), because the child has to get to know everything and then the details they probably get (confused). Like I say, they might turn it to where if they go and touch somebody or somethin they'll think they'll get it. Or if they use the washroom, then they'll get it. It takes them, I think, more longer (to understand) because of their feelings and because of their emotions and dealing with their personals. And because they're thinking that person (with HIV) don't have long to live with them. So, I think for a person that's with it, it's more hard. (1008, Mother)*

Another parent expressed concern that her children didn’t take HIV as seriously as some children might, because she had never been sick or had complications from the virus. This mother worried that her children had become so used to thinking about HIV as a “normal” part of their lives that they viewed as “no big deal” and therefore they may not be as motivated to protect themselves.

*See HIV, I think...my status makes it harder for them to believe how serious it is because everybody keeps, “Oh, Auntie you so healthy. And you had it since you were 16.” At least I knew at 16, I probably had it before that, but anyway...Yea that doesn’t really help I think. Sometimes I think me being positive has the opposite effect of keeping them from understanding how serious HIV is because they’re like, “nothing’s ever been wrong with you.” (1011, Mother)*
Overall, a few parents believed that their experiences living with HIV made it more difficult for them to discuss HIV-related information with their children than it would have been had they not been affected by HIV/AIDS. Part of the difficulty came from devising messages that tried to balance multiple extremes. For example, parents had to find a way to stress that HIV was serious, that everyone was vulnerable, but that children shouldn’t be afraid of people living with the virus, should be compassionate, and should understand that there are various types of people affected. Some parents had more difficulty than others overcoming communicative barriers to conversations, but many were able to engage in what they believed to be productive and effective conversations with adolescents. Parental perceptions of what constituted effective versus less effective conversations are detailed in the following section.

**Effective & Ineffective Strategies**

In response to the second specific aim of the study, this section identifies what parents perceived as effective versus ineffective (or less effective) strategies for talking about ways to prevent HIV with adolescents. The following four questions dealing with effective and ineffective strategies were included in the interview guide:

1. Do you think that some ways of bringing up the topic of HIV and ways to prevent HIV work better than others?

2. Can you give an example of a way you think would work well?

3. Can you give an example of a way you think would not be a good way to talk about HIV or ways to prevent HIV with your adolescent(s)?

4. Do you have any advice to give to other parents living with HIV about ways to bring up the topic of HIV prevention?

Parental responses to these questions were compiled, as well as any other place in the interview where parents explicitly mentioned “good” or “bad” ways to talk about HIV prevention. Many
parents, however, seemed taken aback at the notion that some strategies might work “better” than others. The initial sentiment endorsed was that any parent-child communication strategy was effective -- so long as the parent was talking, the child was better off. 

After being given a couple of moments to reflect on different methods of talking, almost all parents were able to come up with examples of what they considered effective versus less effective communication. Only three parents were unable to verbalize strategies that worked well. These parents reported that “no way worked well” or that “kids should learn on their own.” Responses from the remaining 87 parents were classified into ten major categories. Many of these categories overlap with those detailed in the barriers and facilitators section. Not surprisingly, factors that were identified as facilitating conversation were generally viewed as effective, whereas factors that were reported to hinder conversation were usually viewed as ineffective. This section details the responses from the 87 parents who commented on what they believed to be effective and less effective strategies to communicate.

**Effective Strategies**

Overall, parents reported a number of different methods to communicate about staying safe from HIV infection. Most participants seemed of the opinion that parents should be the primary prevention communicators for their children. Whereas other sources of information (e.g., schools, health care providers, family members, and friends) were by and large welcomed and viewed as helpful, many parents voiced their preferences to avoid their children “learning from the streets.” As one mother shared:

*Some things you can’t push under the rug. This generation, this day and time, you gotta talk to your kids about everything. Everything. Make sure nobody else in the streets is telling them nothing. I don’t want nobody in the streets telling my kids. If they learn anything, I want them to learn it from me...You gotta sit them down and talk to them. (1009)*

122
Identifying parents as the primary risk communicators didn’t necessarily mean that parents had to be the first to discuss HIV prevention with adolescents, or that they had to be the ones to initiate the conversation. It did mean, however, that at some point the parent and child needed to have an explicit talk about risky behavior and ways to stay safe from HIV infection. The most effective way to have this talk varied by parent and by the parent’s perceptions of the child. A summary of the categories parents viewed as effective is presented in Table 13.
Table 13

Summary Table of Effective Strategies

<table>
<thead>
<tr>
<th>Effective Category</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Enlisting support</td>
<td>75</td>
<td>86</td>
</tr>
<tr>
<td>➢ Supportive others</td>
<td></td>
<td></td>
</tr>
<tr>
<td>➢ Supportive resources</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Effective parent talking style</td>
<td>74</td>
<td>85</td>
</tr>
<tr>
<td>➢ Open &amp; honest</td>
<td></td>
<td></td>
</tr>
<tr>
<td>➢ Friendly or humorous</td>
<td></td>
<td></td>
</tr>
<tr>
<td>➢ Serious</td>
<td></td>
<td></td>
</tr>
<tr>
<td>➢ Supportive</td>
<td></td>
<td></td>
</tr>
<tr>
<td>➢ Relaxed or “like normal”</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Instilling values &amp; expectations</td>
<td>64</td>
<td>74</td>
</tr>
<tr>
<td>➢ Allowable sex or drug activity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>➢ Parental monitoring</td>
<td></td>
<td></td>
</tr>
<tr>
<td>➢ Relationship dynamics</td>
<td></td>
<td></td>
</tr>
<tr>
<td>➢ Maintaining focus &amp; having goals</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Giving educational facts</td>
<td>54</td>
<td>62</td>
</tr>
<tr>
<td>5. Characteristics or reactions of child</td>
<td>49</td>
<td>56</td>
</tr>
<tr>
<td>➢ Gender perceptions</td>
<td></td>
<td></td>
</tr>
<tr>
<td>➢ Interest level</td>
<td></td>
<td></td>
</tr>
<tr>
<td>➢ Age or maturity level</td>
<td></td>
<td></td>
</tr>
<tr>
<td>➢ Personality</td>
<td></td>
<td></td>
</tr>
<tr>
<td>➢ Prior to risky behavior</td>
<td></td>
<td></td>
</tr>
<tr>
<td>➢ After risky behavior</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Using personalized experience</td>
<td>42</td>
<td>48</td>
</tr>
<tr>
<td>7. Having interactive conversations</td>
<td>40</td>
<td>46</td>
</tr>
<tr>
<td>➢ Simple back &amp; forth exchange</td>
<td></td>
<td></td>
</tr>
<tr>
<td>➢ Hands-on or visual examples</td>
<td></td>
<td></td>
</tr>
<tr>
<td>➢ Quizzing child</td>
<td></td>
<td></td>
</tr>
<tr>
<td>➢ Checking in with child</td>
<td></td>
<td></td>
</tr>
<tr>
<td>➢ Setting the stage for future conversations</td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. Establishing relationship</td>
<td>39</td>
<td>45</td>
</tr>
<tr>
<td>9. Repeated, reinforcing or progressive messages</td>
<td>17</td>
<td>20</td>
</tr>
<tr>
<td>10. Introducing fear or scare tactics</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

Note. N=87.
1. Enlisting support.

The first method of effective communication identified by parents was that of enlisting communicative support. Similar to identifying facilitators to conversation (see facilitator #1), many parents felt that supportive resources and/or supportive others were essential to productive conversations about HIV prevention. Seventy-five parents (86%) identified support as being beneficial to parent-adolescent communication. The need for support appeared to be especially salient for those parents who disclosed their own status at the same time or around the same time they relayed prevention information to their child(ren). As one mother, who chose to enlist a therapist to help with both disclosure and prevention information, discussed:

*I used a therapist...because I did not want to leave anything out. I didn’t want any room for error...What I didn’t talk to her about, my therapist picked right up. So we worked together as a team. Even if my daughter wouldn’t have showed any type of emotions or anything, she was a professional there to pick it right on up. Because see when I see my daughter cry I have a tendency of crying and then I break down. Well, she was there in case anything like that happened so that’s why I used therapy...So kind of educate yourself first and if you’re still not sure about anything I suggest you get someone in there with you. It could be just a friend for support, but for me I needed a therapist -- not my therapist, but I needed someone like I said if I froze she’d kick right on in (1012)*

In this mother’s mind, enlisting professional support served to (a) ensure her daughter received thorough and accurate information, and (b) calm her own worries as a parent (by having a skilled professional in the room). During the conversation, the therapist helped to elicit the daughter’s prior knowledge about HIV/AIDS and played a game to teach how HIV is transmitted. When describing her overall evaluation of how the conversation went, this mother commented “It was beautiful the way that, when it was all over, my daughter understood exactly what we were talking about.” Other parents echoed similar sentiments about using mental health therapists, health educators, and medical professionals to have effective disclosure and prevention conversations with adolescents, including:
At the clinic they talked to them about the sexually transmitted diseases, they showed them pictures, they showed them everything related to HIV, so then I explained to them why their dad was so sick, and that I also have the same thing and that I was going to begin treatment. (1075, Mother)

If you’ve got kids that you suspect is using drugs a lot, you should take him with you one day when you go see the doctor. Let your doctor talk to them while you talk to them. (1022, Father)

I think you have to work together with people. I think for me my case manager is going to be a great resource. If the questions get too tough for me, I’m going to take her (my daughter) to her. (1018, Father).

Still other parents leaned on friends or family members as supportive others. For families where both parents were still alive and on good terms, participants sometimes reported working in tandem with the other parent. As Amber, mother of a 15 year old son and 13 year old daughter, indicated:

His father reiterates a lot of it, that male-male bondage thing. Like I said I can only explain so much, but then dad will step in and do the rest. He will kind of fill in the blanks for me. So it works hand in hand for both (of us). (1024)

Examples of parents leaning on friends for encouragement or emotional and/or informational support included:

She (my daughter) said, “Well, I don’t know. I think I had my cherry busted”. I’m like, “HUH??!” She said, “Well, I tried sex.” And I was like, “Oh my God! She’s tried sex.”...She was 13!...I was like, “Oh Lord. What do I do now?” So I called up one my friends. She said, “Girl, go ahead on and tell that baby. Tell her the right way so she’ll know. She gonna be educated. Tell her!” So I said, “Ok.” (1005, Mother)

Well, my best friend. My girlfriend has been visiting me. We met 4 years ago and she is just a blessing! She’s been here a couple of months now and has just taken over. She doesn’t have any children, so I was like “Whatever that you want to help me with with her (my daughter) is great.” And she has a different (take on things). Just because she’s not her mother does not mean my daughter can’t learn from her. Parenting comes as a village. This is the only vein that God gives us that you have to learn as you go. So you coming into my home and helping me with Theresa and you doing it a different way – it doesn’t bother me. (1063, Mother)
Support groups also provided a way for parents to interact with other parents and trade advice on how to effectively communicate with adolescents. Bringing adolescents along to support group provided a way for some parents to both expand on and reinforce what they had already discussed with their children at home. As one grandmother noted:

_I would take them to my meetings. That’s what I would do. That would be my suggestion for anyone because you can say it only so much coming from you, sometimes it’s just hearing it from other people that makes the difference._ (2005)

Finally, parents enlisted a variety of educational materials to support them in their endeavors to communicate effectively. Books, brochures, pamphlets, the internet, radio, television, and HIV quizzes were all mentioned as ways to communicate more effectively. Examples of using these informational resources included:

_I got a little mock (HIV) test that comes from the Center for Disease Control. Or maybe the Department of Public Health. It’s one of the two. It’s a little true or false (test). _ (1064, Mother)

_Definitely have some handouts so you can share with them and then the internet stuff, of course there’s a lot of things you can look up and find. _ (1084, Mother)

_Always relate it to something that they are interested in at the time, that involves something of a sexual nature, and I’m saying you know, again, movies, video games, if you got readers, maybe if they’re reading books, you know they pick up a romance novel, that’s a good time to start talking about sex education, because they’re be confronted with it in the book and they’re not going to be confronted with it in a sex education type of arena. _ (2000, Grandfather)

Condoms were also mentioned as effective resources to include in conversations with adolescents. Some parents noted that they kept condoms in a designated location in the house where their children could access them easily (e.g., a drawer, a basket, etc.), whereas other parents physically showed their adolescent what a condom looked like and/or how to use one as a part of their conversation. For example, one father commented:

_Just tell them -- just bring the condom out and then say, “This is what you need right here. Put this on, it’s going to help save your life. If you find the woman you want to be_
with, you’ll go to the doctor, and then and only then you can take these and put them in the drawer. But until that day it is always good to keep these in your pocket.” (2003)

Overall, many of the resources that made conversations easier for parents were also deemed to be effective strategies for talking about HIV prevention. Parents appeared to to access these resources relatively easily and were appreciative of their positive influence on their communicative interactions with their children.

2. Employing effective parent talking style.

The second most commonly identified influence on effective parent-adolescent communication was parental talking style or environment. Seventy-four (85%) of parents mentioned that certain tones of voice, styles of talking, or learning environments were more effective than others for talking to adolescents about prevention. Similar to the adaptive talking styles parents identified as facilitators (see facilitator #5), parents reported that being open, friendly, supportive, respectful, serious, humorous, and comfortable were effective ways to communicate. Some parents preferred to speak to adolescents one-on-one or in a private environment about prevention, whereas others deemed group settings (with siblings, relatives, or close friends) to be just as effective. The subcategories below attempt to capture the variation of participant responses.

Being open & honest.

Parents commonly referenced that being open, honest, blunt, or straightforward was an effective way to communicate with adolescents. Some parents called this “telling them in the raw” or “keeping it real.” Examples of parents in this subcategory included:

I try to talk to my kids about everything. I try not to keep nothing from them. Like, “Yea such and such got locked up because they did this dumb thing.”...I try to let them see the real world. Like, “this is the real world. It’s a shitty place, but you can make the best of it or you can be one of them people who get beat down by everything that happens in this world.” And that’s just my philosophy. (1011, Mother)
I tell my kids all the time “There’s absolutely nothing in the world that you can do or think of doing that I haven’t probably experienced, seen, witnessed, heard of or done. So don’t think that you need to hide anything from me. I might not like what you’re saying, but when the smoke clears then I can better help you because I’ve probably gone through it too. I’m not angry because of what you’re doing -- I’m angry because I’m remembering the effects that maybe that behavior had on my life. So you know...It’s just giving them a safe place and a safe space to be honest with you. They need to have that safe space to be honest with you about certain issues. And sex is one of the hardest ones. (1013, Mother)

Ain’t no way to sugarcoat it. Just tell them about it. Whether they like it or don’t like it. (Whether they) want to change the subject (or not). You’ve gotta instill in their heads that “There is too much out here.” Back then in the day you used to go to the clinic and get a shot or get a pill. It ain’t like that no more. There’s stuff out here that you can’t get rid of. So I try to be honest with mine… I’m just blunt. I’m just straightforward. (2001, Mother)

To some parents, being open and honest meant using slang terms for sex and drugs, whereas to others it meant using proper anatomical terminology when referring to sex and sexual development. Parents viewed being open and honest as an effective conversational strategy for a variety of reasons. In some cases, being open drew attention to “real world” circumstances, giving adolescents advance warning of harsh and sometimes unjust relational and cultural situations they were likely to encounter. In other cases, being open created an atmosphere where adolescents could learn in a non-threatening or comfortable environment. Finally, other parents reported that being open and straightforward helped to overcome generational communication gaps (i.e., if parental messages were direct and to the point, there was less room for the unintended meaning or error).

**Being friendly or using humor.**

A number of parents also highlighted the effectiveness of being friendly during conversation. Being friendly encapsulated parents who spoke of being gentle, kind, warm, interested, or maintained a positive attitude during conversation. It included parents who talked to their child as a “friend” rather than an authoritative figure, as well as those joked or strove to
maintain a pleasurable learning environment. Examples of parents who perceived this style of conversation to be effective included:

You have to be gentle with them. You need to be gentle to them and explain it to them to where they will understand. Don’t try to explain it to them like a professor or rocket scientist, you know. Come down to their level. Like a school teacher. It works great...And the things they don’t understand, you put them on the back shelf. Deal with the things you know they will understand and that works fine. (1033, Father)

You have to, I hate to say this, be kind of like their friend, type of go back and forth friend type. Instead of, I’m the parent, I said so. I find that works the best. (1041, Mother)

When you talk to them about sex too seriously, they don’t pay attention. When you talk about sex in a joking but serious way, like going down to their age, and a bit more openly, they pay more attention to you and they respond. (1076, Father)

I’m like “You know if a boy kisses you he can give you a nasty little film around your mouth, right? “ And they start laughing and be like “You are silly!” I’ll be like “No, do you know how bad it is?” They’re like “Yeah, we’re like grown. We’re not kids.” I’m like “Oh, I’m just checking because, you know, we never had that (when I was growing up).” They was like “You just dumb! (playing around).” So I kind of start off with a little playful thing and then it kind of goes into more serious ways. (1078, Mother)

Some parents also pointed out, however, that there were appropriate times to use humor and times that humor was not as appropriate. While they acknowledged that employing a playful atmosphere had worked for them personally, they also admitted that the effective use of humor depended on the child, the situation, and the topics being discussed.

**Being serious.**

Another talking style parents reported to be effective was utilizing a serious or sober tone of voice. Being serious meant approaching conversations about prevention as an authoritative figure, someone to be respected and obeyed. As one mother explained to her daughter:

You’re going to treat me like (someone you respect). First of all I’m not your friend. That’s another thing with this (new) parenting. My mother was not my friend. You ain’t my friend – you are my daughter. You are going to be my daughter until you leave (this earth) and you are going to be my only child. But you are my daughter – I am not your friend; I am your parent. Unfortunately, I don’t play...We can’t play with them and let them think they are grown. (1063)
For this mother, being serious during conversation was effective because it set firm boundaries for her daughter, as well as set up the expectation that she would behave within those boundaries. Other parents also embraced this “tough love” approach to parenting, noting how their views on effective parenting had changed as they evolved as parents, particularly as they overcame previous addictions and destructive life behaviors. As Dedra, mother of two teenage sons and one teenage daughter, explained:

*When I realized they were kids and they would take it (freedom) to the extreme, (I knew) that I would have to buckle down and I had to be a parent. I can’t be your friend anymore. So I don’t allow cigarette smoking in my house. You can’t bring marijuana in my house, you can’t roll it up, you can’t smoke it. And please don’t come to my house if you’re under the influence of alcohol or drugs because I am a recovering drug addict and you don’t want me to go back. You know what I’m saying? So you are threatening my recovery when you come around me like that...No marijuana smoking in my house, you’re not coming in my house different times of night. You make choices, decisions, the choices and decisions that you make are on you. I’m not opening my door unless I see you deathly bleeding or whatever. But, if it’s a certain time of night, I got younger kids in here, I’m not getting up. I’m not opening my door. I have to set limits, boundaries, and rules. (1017)*

For Dedra, serious conversations were effective because they gave her children more structure, but also because they helped to protect her own health and well-being. Given that parents generally recognized the ill effects of substance use, poor nutrition, and stress on their immune system, it was not uncommon for them to emphasize to adolescents that certain behaviors or undue levels of stress could seriously jeopardize their health. It was also not uncommon for a parent’s tone of voice to change depending on the child, topic of conversation, and whether or not the adolescent had already been involved in risky behavior. When teens had already engaged in situations that could potentially impair their decision making, it was generally felt that conversations called for a more serious tone of voice. This meant that parents had to be both flexible and adaptive in how they approached certain conversational encounters.
**Being supportive.**

Similar to being friendly and positive during conversations, parents emphasized the effectiveness of demonstrating support during communicative endeavors. Being supportive meant showing concern, listening to the adolescent’s point of view, being patient, and demonstrating respect. It also meant calming adolescents’ fears rather than criticizing their attitudes or behaviors. One father noted that an effective way to discuss HIV prevention was to teach adolescents to be accepting of individuals living with the virus and help allay their fears about transmission.

*(A good way would be to ask them) “Do you know anybody – friends or cousins or anybody – that are HIV (positive)? Do you know anyone in your school that is HIV positive? Today we don’t make fun of them. We try to support them and be sympathizing with them instead of criticizing them. There is nothing to be scared of as far as them touching you, hugging you, or even kissing you. There is nothing to be afraid of.” (1072)*

Other parents expressed their support for their children by reminding them that they loved them regardless of the decisions they may or may not make in life. These parents demonstrate that being supportive did not necessarily mean going along with an adolescent’s wishes or excusing their behavior – sometimes it meant being able to deal with conflict in constructive ways.

*I just keep it in the open that I’m always here. I’m open-minded. I’m gonna be very supportive, you know whether you’re right or wrong. If you’re wrong, we’ll try to fix it, bring it into the positive way. (1031, Mother)*

*I sat and talked to her. I said, “We can talk about everything. We can swear, we can kick ourselves. We’ve got many years to fight because we’re just alike. We have too much in common. We’re gonna bump heads, but we’re gonna talk about it. And after that we’re gonna hug each other, kiss each other, and say ‘I love you, alright, bye bye.’ (1049, Mother)*

Parents in this subcategory also spoke of the effectiveness of “treating kids like small adults” during prevention conversations (and as a parenting technique in general). As two parents discussed:
(A good way would be) well, just saying, for example, my daughter were to come to me and tell me, you know, "I'm thinking about having sex with so-and-so." Alright, sit down and talk about it. You know, "What steps are you willing to take to protect yourself? What steps is he willing to take to protect himself? Have you asked him about his sexual history? Is he active? Has he been tested for anything? Has he tested positive for anything?"...Kids are basically small adults and they want to be treated as such. (1048, Mother)

I’ve always treated her (my daughter) kind of like an adult, and I said, I’m not going to break down my words, and you know, that whole thing. If you don’t understand something, you ask me and I’ll give you the definition. If I don’t quite know, we’ll go look it up... (1028, Father)

The notion of treating their children like adults was not necessarily related to the child’s age. Some parents stressed that they had “always” treated their children as young adults, capable of weighing consequences and making their own decisions.

**Being relaxed or “like normal.”**

What appeared to matter more to certain parents than the actual tone of voice or talking style used was their ability to create a relaxed or “like normal” environment where their child could learn. Thus, if a parent typically joked with their child during general conversations, it was important for them to maintain some of this humor when talking about sexual safety. Likewise, if a parent typically employed a gentle or quiet tone of voice during general conversations, it was helpful for them to be consistent when discussing HIV prevention. As one parent commented:

*Kids know. If you’re scared, they’re gonna know it. And if you’re afraid of something or afraid to talk about something, that’s going to be the one thing they really want to know. So I think you just have to be calm. Use a normal tone of voice that you would normally use. I talk quietly, some people are always loud. If that’s normal for your family, great, but that’s not mine* (1018, Father).

Similarly, another parent noted that being in a relaxed or “like normal” atmosphere when discussing HIV prevention was effective because it lessened children’s anxiety and improved their ability to listen and learn.
I would say the best way to tell them is to just tell them. Really just like have them in a situation where y’all are comfortable or whatever, maybe its eating dinner together...I don’t know, whatever it is that you do with your child already that’s when I told them...Just something that you normally do so that it’s not like, “Honey, I need to sit down and have a talk with you,” and then they all nervous like “what’s this about?” And then they got this anxiety...Where if you just make it a normal part of whatever it is you’re having a conversation with them about it (HIV), you just bring it up so they know. (1011, Mother)

Lastly, some parents noted that an effective talking atmosphere was a private environment (without the adolescent's significant other or without other siblings providing a distraction), whereas others felt their children “let their guards down” more when their friends were involved in the conversation and the pressure wasn’t only on their child to talk.

3. Instilling values & expectations.

Sixty-four participants (74%) reported that effective communication with adolescents included a parent expressing his or her personal beliefs about what a child should or should not do. Parents in this category spoke of instilling values and expectations -- inculcating the “right” and “wrong” ways to behave. Sometimes this included more general values and expectations to keep their children safe from HIV infection (e.g., knowing where a child is at all times, increasing a child’s self-esteem, taking responsibility for one’s body, focusing on school instead of dating). Other times, however, values and cautionary advice were more specifically related to HIV prevention (e.g., using condoms, getting tested for STIs regularly, avoiding dirty needles). Regardless of the moral, ethical, or social values taught, the ultimate purposes for communicating these values seemed to be to (a) keep their children safe, and (b) to encourage them to grow to be successful and productive adults.

Allowable sex or drug activity.

Parents often discussed the effectiveness of letting adolescents know what was appropriate and expected of them when it came to sexual and drug activity. When discussing
what she deemed a productive way to discuss prevention with her daughter, one mother gave the following example:

(I say) “This is your pride and joy. This is your temple. If you don’t respect it, nobody else will. I want you to wear that white dress. I want you to do it the right way. I want you to go to college. I want so much for you and your life.” And she’s basically living a life that I basically want her to have. You know, I want her to do better. I said, “The things I experienced – I want you to be way better than me. And you’re gonna be.”

Similarly, another mother discussed with her 12 year old daughter that, at her age, dating and sex were off limits.

I mean it’s just like when you talk to them about it, you just (talk)...when it comes up, I just say, “I don’t want ya’ll to talk to no boys, don’t have no sex.” “I mean, your time will come.” And that’s what I say to them. (2004)

Overall, “allowable” sexual activity for adolescents ranged from being encouraged to not even talk to boys (participant above) to being permitted to have sex without protection with a member of the same or opposite sex, so long as both partners had tested negative for STIs and were in a monogamous and trusting relationship. Allowable drug and alcohol activity also varied by parent. While all parents discouraged the use of “hard” substances or IV drugs, some were okay with the occasional or recreational use of alcohol and/or marijuana. What parents considered permissible activity appeared to depend on the age of their child, the parent’s own upbringing, and the sociocultural norms in their community.

**Parental monitoring.**

Another way that parents expressed what activities were off limits to their children was by monitoring their adolescent’s time, friends, clothing, speech, and extracurricular activities. As one mother noted, communicating these rules and boundaries early on was key to maintaining them during the adolescent years:
(With) my kids (I’m) in the back of their mind. Like my daughter, when all the teenagers (were) leaving last weekend and they walked out of the house, my daughter walked out of the house and she walked back in the house (She said), “I got to call my mama,” like, “I can’t even walk out the door.” Because she knows, “Nope, my mama is in the back of my head already.” You got to already be there though. If you’re not already there you can’t get yourself there when they’re teenagers. You got to be in the back of their mind when they’re younger. When they’re younger start letting them make choices about stuff, but talk to them about why it could be the right choice or the wrong choice. So at least when they make the choice they know already in the back of their mind, “Wait my mama said that if I do this, this could happen.” (1011, Mother)

Similarly, other mothers were very careful about where their children went alone, despite their children's protests that they were old enough to go certain places by themselves.

I say, “Theresa, unfortunately, I can’t let you go to school by yourself. That corner right there – they don’t have a crossing guard there. So at 2:45 I will be right at that corner waiting for you.” She knows she cannot cross it (alone). And she tells me “Mom, you don’t have to walk me all the way to school.” I said, “Well you know what Theresa? I’m the parent and you are the child. Don’t tell me what I have to do. I’m going to do it anyway. No male or pedophile around here will grab my daughter.” You just have to be protective, be the parent, and not let your child tell you what to do. I’m not gonna let a 10 year old tell me what to do. (1063, Mother)

Still other parents emphasized the need to monitor children’s use of technology, including cell phones and social networking and/or dating websites like Facebook (Facebook © 2011) or MySpace (MySpace Inc. © 2003-2011).

But technology, cell phones, texting, there’s a lot of crap going on in the world right now and parents need to quit spending all that money on their kids and letting them have too much freedom with their technology. They’re sexting, sex texting. Yea, I think parents should be a little bit more protective at those precious ages. (1057, Mother)

She (my daughter) just likes to kid...She put this (phone commercial) -- there’s a phone commercial on facebook. It says, “Mom, stop stalking me on my Facebook page.” That’s what she says! That I’m stalking her. I said, “If you try to X me out of your Facebook page, then you and me are going to have a problem!” (Laughs). “I’m watching what you are doing. And yeah I’m concerned – I’m your mother!” But she’s good so far. So that’s how you gotta be. (1064, Mother)

Parents also highlighted the need to oversee their adolescent’s physical appearance, including what was appropriate and inappropriate dress. Monitoring how their children presented themselves to their peers and to society at large was one way of preventing situations
that could lead to risky behavior. As one father noted:

> So I don’t play that look at all. I wear clothes like these here that fit me well, with a belt. So my son dresses similar. But I’m not the total norm either. I dress appropriately, I’m relatively conservative, but he has his own style, its teen appropriate. But pants sagging down means that you want somebody to do something to you, that’s what message you are giving. (1082, Father)

While parents reported that adolescents’ sometimes viewed these measures as being over-protective, they emphasized that, in the neighborhoods and communities they lived in, being strict was essential to protecting their children from harm.

Finally, parents reported monitoring how much time adolescents spent with the family. Parents expected adolescents to help out with household responsibilities, as well as to spend certain times of the week enjoying time together as a family. One participant emphasized that he instilled these expectation to teach his son that “real” fathers stay out of trouble, avoid jail, and do not abandoned their children (1047).

**Relationship dynamics.**

A number of participants relayed that communicating values was effective because values helped adolescents learn about healthy and productive relationship dynamics. Being in a healthy relationship often meant being honest and respectful to one’s self, friends, family, and significant others. Emphasis was placed on building children’s self-esteem and teaching them to resist peer pressure. Parents gave examples of trying to empower their children (particularly daughters) when it came to sexual decision making. As two parents noted:

> We basically get together and we’ll discuss certain things. Do’s and don’ts and don’t play follow the leader. You gotta stand up for your own self. Stand up on your own two feet, don’t do what everybody else is doing. If anything, see if they carry protection. If not, you’ve got some, give them some. (Then) leave them, leave them right there, give them some protection and come on home. Go find somebody else to hang out with you know? They’re your friends, but all friends ain’t good friends to have...so you have to be careful. (1022, Father)
What I want you guys to do as young women is to stand up and be strong, and not be pushed around or not be led or misled into anything that is going to put you in an awkward position or a dangerous and bad position because you have a choice and you have a voice. And you need to use it and you do not need to be in an abusive relationship. You’re too damn young for that - you really don’t (need that).” (1007, Mother)

To these parents, being in a healthy relationship meant having relationships where both parties’ opinions, actions, and feelings were respected. Other parents specifically tried to combat societal stereotypes of men as “players” and instill in their sons that a healthy relationship was one where women were respected.

I just told him, “It’s a good thing you tell these girls you’re dating that you’re not ready to settle down, but just don’t do the hit it and quit it thing.” Because I was like, “you wouldn’t want anybody treating you like that. You have to remember you have sisters, you do have a mother, you do have female family members in your family and you would hate for anybody to treat them like that.” ...Treat people the way you want them to treat you (1051, Mother)

Some parents highlighted that productive relationships were ones where a person was self-sufficient and maintained his or her independence. These parents had often been stuck in abusive relationships themselves, or had lost trust in significant others who claimed to be faithful, but infected them with HIV. One mother emphasized the dangers of relying too heavily on a romantic partner in the following conversation:

(I told her) “Ain’t nothing wrong with looking, but when you pick, you have to pick someone that’s going to be for a lifetime -- not just for a moment. You have to pray to God and ask him ‘Is this the right mate?’ And at ya’lls age it isn’t the time to look for a mate, because you need to first be able to take care of yourself...See the old days you could depend on a husband to take care of the family. Now, hell, the husband might see another family that he wants to take care of and he don’t want you no more. So what you gonna do?..In 2009 you must have an education, you must be able to get up and go (on your own). (1052)

What appeared to stand out in this mother’s mind was the necessity of being able to survive on one’s own, regardless of relationship circumstances or outcomes. As she also emphasized, the best chance of maintaining this independence was focusing on education.
Maintaining focus & having goals.

Most parents believed that, at this point in their children’s lives, school should be the number one priority. Parents often emphasized and communicated with their children about the importance of finishing school and of getting an education. Whether finishing school meant completing high school or completing college and beyond, parents were adamant that their children place more emphasis on academics and their future careers than they did on dating and sexual relationships. In many cases, parents encouraged their children to go beyond the education level they had obtained themselves. One parent noted that, though neither he nor his spouse had gone to college, they had always set high expectations for their daughters. As he explained:

*College was never an option. College was expected. And when she went to high school and started talking to her friends she said “I’m the only one thinking about colleges. None of them want to go to school. How can they think that way?” And I just thought it was so funny. We had trained her so much for so long that she’s very determined to have things her way. And I don’t think she would ever have unprotected sex, I don’t think she would ever do anything to jeopardize herself or her health.* (1018, Father)

Instilling values by communicating about the importance of education was seen to be effective for various reasons. On one hand, parents were hoping that adolescents would focus on academics and good grades rather than hanging out in the streets, where there was often inappropriate and dangerous behavior. If parents could keep their children busy enough with academics and sports, they reasoned that they would have less time to be “bored” and to experiment with sex, drugs, gangs, and violence. On the other hand, focusing on education was perceived as a way to equip children with survival skills – skills they must have to one day secure a job and achieve financial independence. Many parents had encountered financial trouble throughout their lifetimes and been dependent on others or on government support to survive. They desperately wished to avoid these harsh financial situations for their children.
Finally, parents emphasized that school and education were a privilege. Particularly salient in the minds of women and African American participants were the days when education was not an option for everyone. As such, parents wanted their children to appreciate the opportunities they were currently afforded and make good use of them. To engage in activities or behaviors that could jeopardize their health would be to squander the chances others had struggled to achieve.

In summary, parents expressed that communicating their values and expectations was an effective strategy for discussing HIV prevention with adolescents. Notably, however, some parents emphasized that communicating expectations was only as effective as a parent’s own modeling behavior. Thus, regardless of what a parent communicated to a child about HIV prevention, a parent’s own actions were viewed to be the ultimate determinant of whether or not the child adopted those values him or herself. This issue was particularly salient when parents discussed substance use and abuse. Parents generally viewed communication about prevention as being the most effective for parents who had never struggled with substance abuse, followed by those who had managed to overcome their addiction, followed by those who were still struggling but did not use illicit substances in their home. The least effective group of communicators reported were those who were still struggling with addiction issues and brought or allowed substances in their household. In these instances, value ambiguity (or the mismatch of spoken values to parental actions) was viewed as decreasing the effectiveness of communicative messages dealing with sex, drugs, or HIV prevention.

Finally, whereas instilling values and expectations is not a parenting practice unique to parents living with HIV/AIDS, what may hold special relevance for parents living with HIV/AIDS (or other parents with a potentially life-threatening illness) is an expedited need to
instill these principles. Some parents expressed the pressure they felt to prepare their children for a life where their presence would be diminished (while they were ill) or completely absent (should they die as a result of their illness). Thus, communicating their values and expectations became a way to build their legacy -- to leave their children something to remember them by. Already having communicated about values and expectations also gave parents a sense of relief, a way to allay their own concerns about whether or not their children were “ready” to continue on without them and thrive in new environments.

4. Giving educational facts.

*I pretty much keep it simple with her and give her the facts.* (1001, Mother)

Another strategy perceived to be effective for relaying HIV prevention messages to adolescents was giving them educational facts. When parents spoke of providing educational facts, they spoke of relaying HIV prevention material in a relatively objective or informational manner. Fifty-four parents (62%) discussed the effectiveness of this method. Facts parents relayed to their children included educational information about modes of HIV transmission, T cell counts, viral loads, how HIV affects the body (medically), and what it means “at risk” for HIV, to be abstinent, and/or to engage in safe sexual behavior. Some examples of giving educational facts included:

*I tell them that anyone who has sex and unprotected sex (is) at risk for catching HIV/ AIDS, or STDs. So you don’t have to be white, black, young, or old. If you’ve ever had sex and if you ever had unprotected sex you are at risk. So I broaden the base so to make them look at it in a more liberal sense that it could happen to anyone.* (Mother, 1017)

(I tell them) it is preventable if you take the right steps. If you use condoms and if you know how you can get it and how you know, not by touching someone...and I think saliva and tears, I think it’s a very, very slim chance. Open cut, you know. If you know how to get it and you know how you don’t get it, preventative measures are the best way for kids not to (get HIV). (1041, Mother)

Well the first thing is to start off with the sex talk, so that kind of brought that right into place as we talked about that. Then we moved right on to the topic of what can happen if
you’re not having protected sex. And then we got to talking about HIV and stuff. So that was one way of introducing it. I thought that was a good way. (1084, Mother)

Parents perceived educating adolescents with facts to be effective for different reasons. First, providing educational data had the obvious benefit of giving children information that could be used to keep them safe. Second, facts could help clear up stereotypes and misinformation about HIV, both for their own children and for other adolescents in their families and neighborhoods. Thus, educating children with facts was seen as an effective step towards combating HIV-related stigma. Third, using an informational or objective tone to discuss prevention could help manage emotions. In some cases, parents’ desired to regulate their own emotions, as they may have felt guilt, shame, sadness, or anxiety when talking about HIV. Being able to rely on objective information provided a concrete conversational focus, helped them to feel prepared, and allowed them to share important information without divulging their personal experiences and behaviors. Finally, in other cases, it was for the benefit of their children that parents relied primarily on educational facts. These parents may have (a) not been sure what information was appropriate for their child yet and wanted to begin with emotionally neutral information, or (b) hoped to avoid sounding critical or “preachy” when discussing sexual behavior.

5. Characteristics or reactions of child.

Much like the case for identifying facilitators (see facilitator #4), some parents based their evaluations of conversational effectiveness on child-related factors. Forty-nine parents (56%) mentioned that a child’s age, maturity level, gender, prior knowledge, sex or drug experience, and/or personality could enhance the quality of parent-adolescent conversations. Since these subcategories are similar to those given in previous sections, examples are detailed only briefly here.
Gender perceptions.

Boys you can’t just talk to them, you have to talk to them, you have to walk with them, you have to show them and you have to guide them and you have to say “See that’s not what you want to do, this is what you want to do.”...I remember teaching my daughter how to do chores. I showed her twice, she’s good; she’s going to do them. The boys, oh my God you have to run up behind them, you have to threaten to beat them and put them on punishment and take this away and take that away and then they get up and start working and as soon as you go out of the door they go back to doing what they were doing. (1007, Mother)

Interest level.

With my son I can just tell things...he makes statements about how a woman is beautiful or not....And the things he wants to watch, even Nickelodeon has Adult Swim which is crazy to me. But there are things that he’s watching and listening to. And he’ll say (make comments about) Beyonce’s behind! ....So I think once you start seeing any of those signs it’s time. (1016, Mother)

Age or maturity level.

I think it is important that parents have that conversation at the beginning of sexual peak or identification. And again it becomes younger and younger. There is not level or label that you can place on it as far as age goes. But I think to engage in conversation with those children at an early age predicts what their outcome will be long-term. (1025, Father)

Personality.

It depends on the personality and how that person speaks and talks...Because a lot of 18 year olds are getting it (HIV) out here. And a lot of 18 year olds aren’t. A lot of 11 year olds are kind of smart, and a lot of 11 year olds aren’t even aware – aren’t even thinking about stuff like that. (1004, Mother)

Prior to risky behavior.

Some parents don’t even tell their kids...they wait until the kids do it, and then they tell them after the fact. Tell them before anything happens. (1008, Mother)

My feeling is it’s never too early...I think my 10 year old is about the youngest that I’ve started harping about getting tested (for HIV). And (he's like) "I’m not doing anything!" (And I'm like) "I know -- great time to get tested!" [Laughs]. But you establish a baseline, you know? So I encourage (them), “The younger you start the better,” and I think that’s good. I don’t think there’s a minimum age, and I don’t think 10 years old is too young (2000, Grandfather)
After risky behavior.

I think it's a good idea to talk to them...but I think what I would do, I would just try to see if he's having sex first. And go about it that way. See if he's having sex first, and if he says that he's having sex, then I would talk to him about STDs and where to go to get tested and stuff like that. (1009, Mother)

Overall, parents seemed to agree that effective conversations took place “early.” As discussed previously, however, parents varied in their conceptualizations of what early conversation meant. Though many parents made reference to the efficacy of teaching children early on, they also admitted there were times when they had not talked to their children early enough (i.e., they began talking after they found out that their child was sexually active, involved with drugs, or had contracted an STI). Thus, even for parents who were knowledgeable about the risks of HIV and the tendency of adolescents to engage in HIV risk behaviors, it was sometimes difficult to map the possibility of those behaviors onto their own children or onto their own environment. One father discussed his surprise at finding out his 11 year old daughter and her friends were wearing friendship bracelets to school to indicate their level of sexual experience: “As much as I knew it was possible, I just never knew it was in my own yard” (1090).


Forty-two parents (48%) reported using “personalized” experience as an effective strategy for discussing HIV prevention with adolescents. The term “personalized” is used instead of “personal” to include parents who did not reference their own personal experience but still attempted to connect HIV prevention information to a concrete face, person, or name. Parents who used personalized experiences made reference to (a) their own HIV status or previous risk behaviors, (b) someone the adolescent knew personally who engaged in risky behavior, or (c) a specific person in a movie, television show, or book who told their story about
HIV or about risky behavior. Those who used personalized experience often did so a warning to adolescents, in efforts to convince them that there were some things in life that were not worth experiencing for themselves. As one mother emphasized:

*You gotta tell them. You gotta feed that knowledge to them. “I went through all the bad to bless you to where you wouldn’t have to.” And that’s what I tell my kids all the time. When I get into little ordeals with my daughter. You know, “You ain’t gotta do this. You ain’t gotta subject yourself to this. I went through all that bad. I went through the rapes, I went through the crying, the sexual abuse, the physical abuse, I went through all the bad relationships – I’m blessing you. You don’t have to go through this. I could tell you better than you experiencing it.”* (1001)

Parents also reported that using personalized experience was effective because it made or could make HIV “hit home,” increasing their child’s awareness that they or someone they know could become infected.

*Tell them how it is, you dealing with the situation, going through what you’re going through. I think that would wake a child up, because I know it’s hard. I don’t know about everybody else but I can just speak for me how hard it is to go through what I’m going through. I think if I told my kids that would wake them up and make them not want to go out there and make the same mistakes I made…just to have to wake up every morning and feel like everything is just all over with and the medicines you have to take six and seven medications, it makes you tired and sleepy, so I think that would wake a child up.* (1006, Mother)

*I told my 17 year old when she was probably maybe 15…I told her because of her behavior. I was trying to basically give her a wakeup call. You know, “You’re out here sleeping around and doing stuff.” And I just went into the conversation asking her “Do you know what a person with HIV looks like?” (She said), “Yeah, they’re skinny and they’re sick and they look all crazy.” I said, “Well does your brother look like that?” (She said) “No.” I said, “Do I look like that?” She said, “No.” And I was like “Well we are both HIV positive.” So that’s when I told her.* (1076, Mother)

Sometimes parents used personal examples from other family members, friends, or public TV figures (such as Magic Johnson) to accomplish these same goals in conversation. One mother shared the previous experience of her son’s father to encourage her son to avoid drugs:

*Tell them your experience, what you went through. And tell them the good part and the bad part and what can come out of it....I tell him “Look at your father. He was on drugs and he’s been sober for the past 12 years, so just imagine the things that he went*
through. Before he started getting to the hard core drugs he was using what you are using, but then he needed something to get him higher.” I said “You don’t want to go down that road.” And he (my son) was like “Right.” So I tell him that experience. I think any time you talk to your kids about anything, tell them if you experienced that or know somebody that been there...that should help them. (1085)

Much like the agreement on talking “early,” however, parents were sometimes hesitant to share their personal experiences until the adolescent had already engaged in sexual or drug activity. Thus, using personalized experience was sometimes used as a “last resort” strategy, one to heighten a child’s awareness and/or emotional response to information after other methods had been perceived as relatively ineffective.


Forty parents (46%) spoke of the effectiveness of having interactive conversations with adolescents about HIV prevention. Parents who used this strategy sought to actively involve adolescents in prevention dialogues, whether it was through simple back-and-forth exchanges, using hands-on or visual examples, quizzing the child, checking in on the child’s thoughts, feelings, or questions, or setting the stage for future prevention conversations. Each of these subcategories is described below.

Simple back & forth exchange.

Sometimes involving adolescents in dialogue was as simple as taking turns speaking during conversation. For example, when asked what conversations about HIV prevention she thought had gone well with her 16 year old granddaughter, Debbie responded:

*She used to say, “I go with him” (as in going out or dating). (I was like) “Go with him where?” I’ll be messing with her. [Laughs] “Where you going with him? Where ya’ll going?” (She’d be like)“Grandma, you know! We go together,” I’d say, “Where you all go? Where ya’ll be going?” She say, “Grandma, you know,” I say, “No I don’t, where ya’ll going? Whatcha’ all be doing when you go?”* (2006)
By gently making fun of and pretending not to understand her granddaughter’s terminology for dating, Debbie was able to engage her in the conversation and eventually move the dialogue to more direct talk about how to date safely. Not all back and forth exchanges used humor or joking, but all participants who did use this strategy allowed and even encouraged adolescents to participate in conversation.

**Hands-on or visual examples.**

Another interactive strategy parents deemed effective was using hands-on or visual examples. This included situations where parents used pictures, presentations, field trips, games, or condom demonstrations to help explain prevention information. As one father explained:

> What I did was look on the internet (and said), “Oh look, herpes, okay, look, a picture!” and syphilis, gonorrhea. I told them, “come here, you gotta see this!” I was actually sitting in the bedroom with the laptop (and said) “Come here, look! See what I’m gonna use at work.” They’re going, “Oh gross! What is that!?” I said, “That is herpes.”...They were going like, “Oh Dad that is so sick, what is that for, what’d you look that up for?” “I’m just showing you what it looks like,” I said, “So you’ll know.” I said “Put a hat (condom) on it, (unless) you want this. [Laughs] Look you want to see the other one I got? Do you know how to prevent it? Put a hat on it.” (1083, Father)

Similarly, Nancy had created games and flash cards to teach her daughter about how HIV was transmitted:

> I just use different techniques....Sometimes I use card games. Like, I might get flash cards and I like her sit down at the table and I just, we have popcorn, and I just go over, you know, I’ll put like “Dirty needles”, and on another card like “STD”, and like “Prevention”. Like (different) questions. We talk about it, like I put prevention up and she says “What’s prevention?” I say, “To prevent things from happening, like a situation”, and she’ll say “Ok, I understand now” and then you get her more involved. She likes those games though. (1015)

Kallyn, on the other hand, liked to follow up prevention conversations with field trips or activities where she could visually point out potential consequences of being involved with gangs, drugs, and sexual promiscuity.
Show them what can happen. Don't just talk and talk and talk. Show them reality because that's what they need to see. Find shelters that they can go and see kids their ages going through what they're going through. Take them places like adoption agencies so that they see what this is like. Take them to DCFS to see it. Ask questions. Take them to the jails and stuff so they can see. You know, you can tell them all day long, but they have to see it too. They have to see it and experience it. (1049, Mother)

Still other parents showed adolescents how to put condoms on and then had the adolescent demonstrate that he or she knew how to do so. Altogether, the parents who gave examples of using hands-or visual examples appeared to be highly knowledgeable, comfortable, and skilled in discussing HIV prevention. They were able to take the factual and/or experiential knowledge they wanted to teach and creatively engage adolescents in prevention-related material.

**Quizzing child.**

Along the lines of playing games to teach HIV prevention, some parents commented on the usefulness of calmly quizzing adolescents to encourage interaction. Parents generally quizzed their children for two separate purposes: 1) to elicit an adolescent’s knowledge of HIV or related material prior to engaging in conversation, or 2) to practice different sexual or drug-related scenarios with the adolescent.

When it came to eliciting prior knowledge from adolescents, parents would typically ask questions like “What have you heard about HIV or AIDS?,” or “Do you know anyone who is HIV positive?” Sometimes parents would withhold giving information to allow adolescents to think through the answers for themselves. For example, one mother had initial conversations with her two daughters and then allowed the older daughter to answer questions from the younger one. This was her way of testing what her children had retained from previous talking encounters. As she explained:

> She (my daughter) said, “Did you say that you can get a STD from oral sex if a person has a STD?” I said, “Yes, I said that.” At first I didn’t say anything. And then she went and asked my older daughter. She was like, “Mom, aren’t you going to answer her
question?” I said, “But you already knew! I taught you that! I taught you that!” So my daughter was like, “Yes. Yes, you can little sister. Yes, yes.” She said, “Mom, how come you didn’t tell her the answer to that?” I said, “I wanted to see whether there’s anyone in the household educating besides me.” She was like, “Ok. It was a test! Alright, we understand.” (1005, Mother)

By eliciting knowledge she had given her children previously, this mother was able to see how much her children remembered and encourage them to share information with one another. This strategy also helped her to gauge how well her children had mastered one topic before moving on to others.

Other examples of quizzing adolescents included going over examples of risky scenarios. Parents encouraged critical thinking about scenarios to (a) increase adolescent awareness of how risky situations might arise, and (b) get adolescents thinking about how to plan for and successfully navigate these difficult situations. Parents often initiated these conversations with questions like “What would you do if….”? As one mother noted:

(I say)...What are you going to do if you’re in the heat of the moment? You like this guy, he likes you. Yeah, you’re alone and you’re together and you guys decide this is what you’re going to do, and ‘oh’ nobody has a condom. What are you going to do? Think about it. You know, nobody knows, it’s just you and him in the heat of the moment. What are you going to do? Are you going to wait and go to the store and get a condom? Are you just going to say no? Are you going to continue to have sex? (1017, Mother)

After parents had detailed a given scenario and elicited the adolescent’s opinion on how to handle the situation, parents were able to offer suggestions that might be helpful when navigating similar situations. Parents who gave examples of this strategy used quizzing as a learning tool rather than a way criticize adolescents’ for faulty answers.

Checking in with child.

Other parents expressed the importance of checking in with adolescents during conversations or HIV-related events to see if they understood the information being discussed, how they felt about the topic, and/or if they had any questions that the parent could answer. As
one mother noted, it was important for her daughter to be able to express her thoughts and feelings about what was going on with her body, particularly during puberty and adolescence.

_I have her voice her opinion and keep talking because some things have got to stick. You don’t just have one-sided conversations about their body. They have to have some kind of input, you know? And I didn’t get that chance (with my mom), so I want her to have that opportunity to discuss how she feels about what’s going on with her body._ (1052, Mother)

A couple of parents even asked their children what sex was like for them and if they were enjoying it. This usually led to conversations about the different reasons that people have sex and how important it is to not feel pressured to engage in sexual activity or to have sex for someone else. As one mother explained to her daughter (1011): “Both of you guys have to want it, and both of you have to like it. If you both don’t like it, then don’t do it.” By using examples like the ones given above, parents were trying to express to their children that they understood adolescents faced difficult situations, that they cared about them enough to listen to their thoughts and feelings, and that it was productive to reflect on sexual experiences both prior to and after they occurred.

*Setting the stage for future conversations.*

Finally, parents who emphasized the effectiveness of interactive conversations sometimes spoke of setting the stage for future prevention conversations. One mother noted the importance of encouraging her son to come back and talk to her after giving him brochures and pamphlets on prevention and encouraging him to attend an educational class on HIV. As she explained:

_(A good way is to say) “Here is some literature I picked up. I want you to read about it and let me know what you think about it. If you want me to go to the class with you, I’ll go with you. If you feel more comfortable going with one of your friends, (that’s okay). But go and come back and talk to me and tell me what you think about it.”_ (1046, Mother)

This mother was allowing her son to process information she had given him without pressuring him to have an immediate face-to-face conversation. She was recognizing that there were
multiple effective modalities for her son to learn, but also communicating to him that she welcomed and expected conversations between the two of them in the future. Other parents set the stage for future conversations by acknowledging what they would talk about “next time,” or by letting their children know that it was okay to think about the information they learned and come back to them later with additional questions.

Overall, parents who used interactive strategies appeared to have a high comfort level discussing sex and HIV. Parents in this group were often health educators, case managers, or may have been involved in research, volunteer activities, or therapy where they received training relevant to communicating about HIV-related topics. The interactive strategies parents spoke of were not meant to be used in isolation, but rather in conjunction with one another. Thus, a parent could quiz a child to elicit prior knowledge, give a hands-on condom demonstration, and check in with the child for questions all within a given conversation or series of conversations.

8. Establishing a close & involved relationship.

Similar to facilitator #4, parents highlighted the effectiveness of establishing a close and involved relationship with adolescents prior to engaging in HIV prevention talks. In general, these close relationships established general communication patterns that could then be tailored to effective sexual or drug-related talk. Thirty-nine parents (45%) discussed how establishing close and involved relationships could augment the quality of discussions about HIV prevention. Examples of parents who emphasized the effectiveness of this strategy included:

(A good way to talk to them is)...just those times when I’m doing something with them, taking them somewhere. Not at a baseball game or something like that but (where it’s) just me and her...Maybe at a pajama party or something, or maybe it was pizza day and we wanted to take more kids with us. Go on a skating trip and get them all together and bring it up then. Not so much as being joyful and skating and eating pizza, but (let them know that) this is something that we want to discuss with you guys and it’s very important. I think they will remember it, it will always be there. (1081, Mother)
Sometimes they (parents) ... don't really connect. Sometimes the way they go about it, the way they rush and say things, they don't say it from their heart ... (but) ... a child might need you at any time and at any point. And when they need you, they need you. And some parents will say, "Well, I'll talk to you when I get home." You need to put all of that on hold and say, "Hold on a second." Take that minute out of your day to really talk to your child. Because that can change their whole entire life. They might make that mistake because you didn't stop and talk to them. (And) listen and be there when they really need you. (1008, Mother)

I wouldn't give this (my relationship with my daughter) up for nothing in the world. I'm able to tell her that “I'll be there tomorrow at 4pm.” I'm there tomorrow at 3pm. So my word is my bond today. And that makes me feel like more of a man than any other time (in my life) and growing up. Because your word is all you have today. People respect you for your word. So I cherish that...I am able to sit down and talk to her, to laugh and have a good time. So she has her Daddy now. Unfortunately it wasn’t all of her life, but it’s not too late now. And she appreciates that. (1072, Father)

After you have a good laugh, initiate more (with them). Find out (things that are going on in their lives) and question them. Take time. Say “You want an apple?” Take time. Cut it up, de-core it, and slice it up. And ask the questions while you are spending time with them. Then say, “Here, taste that.” Now they’re ‘Oh, ok. Well, there was a question I was wondering (about)... (1068, Father)

As these examples highlight, spending time building and maintaining close relationships with adolescents allowed for multiple opportunities to introduce and/or answer questions about HIV-related content. These relationships also gave adolescents reason to trust their parents in general, as well as when it came to personal and sensitive information.

9. **Repeated, reinforcing, or progressive messages.**

Similar to facilitator #9 (where parents reported that talking about HIV prevention got easier over time), seventeen parents (20%) emphasized that effective learning required repetition. Thus, repetition of messages was viewed as beneficial to both parents and adolescents. For parents, increased frequency of communication often led to “easier” conversations, ones where parents were progressively more comfortable and skilled in their communicative endeavors. For adolescents, repetition of dialogue served the purpose of reinforcing or building upon what they had previously learned, encouraging them to remember information that could prove vital to their
I’ll get a book like a little pamphlet and that’s how I start showing, because that’s what I did to Nicky. You know she looks at it and everything and freaks out on it and then she looks and she’s like ‘Wow!.’ But then she forgets, so that’s why you gotta keep on them all the time...(1023)

I’ll always, I tell them that constantly. Not just one time, all the time...I mean a lot of talking. I mean a lot! I mean like everyday. 365 (days per year)! [Laughs] (1029)

10. Introducing fear or scare tactics.

A very small number of parents (4 parents, 5%) reported that introducing fear or using scare tactics with adolescents was an effective strategy for discussing HIV prevention. Parents who gave examples of the effectiveness of scare tactics generally focused on trying to induce an emotionally negative reaction (fear, horror, anxiety), or on concentrating on the negative consequences associated with unprotected sexual activity. They hoped that if adolescents were fearful enough of the consequences of certain behaviors, they would avoid behaviors that could lead to HIV, STIs, or poor decision making altogether. Whereas parents in previous categories may have also used somewhat graphic images, they typically did so in a non-threatening or less threatening manner. Parents in this category generally sought a higher level or intensity of fear. One mother mentioned trying to “scare the hell” out her children with extremely graphic images of genitalia falling off as a complication of an untreated STI. Another parent tried to highlight the associations between HIV and death for her children, noting that parents should:

Put it in the raw...Get pictures and stuff of how a person looks with HIV and AIDS and stuff as they dying and carrying on. (Be like), "You wanna be like this?" You know what I’m saying? Yeah. Just put it out there. (1056, Mother)

Parents appeared to perceive fear as effective because a child’s emotionally heightened reaction might (a) make them more likely to remember the information, and/or (b) make them too scared to engage in such situations themselves.
Whereas the 10 strategies detailed above reflect parental perceptions of effective HIV prevention conversations, parents were also asked to give examples of ways to discuss HIV prevention they deemed to be less effective. Sometimes these ineffective strategies simply revealed the opposite end of the spectrum or new dimension to a category already discussed, but in other cases new factors emerged. The next section focused on the strategies parents perceived to be less effective for prevention-related talk.

**Ineffective Strategies**

Parents reported six main strategies that they perceived to be not effective (or less effective) for discussing prevention information with adolescents. Those six strategies included: 1) using an ineffective parent talking style, 2) avoiding talking, 3) giving inaccurate information, 4) characteristics or reactions of their child, 5) giving limited information, and 6) inducing fear. Each of these strategies is considered separately. Table 14 provides a summary of these strategies.
Table 14

Summary Table for Ineffective Strategies

<table>
<thead>
<tr>
<th>Ineffective Category</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Ineffective parent talking style</td>
<td>50</td>
<td>57</td>
</tr>
<tr>
<td>➢ Harsh</td>
<td></td>
<td></td>
</tr>
<tr>
<td>➢ Too blunt</td>
<td></td>
<td></td>
</tr>
<tr>
<td>➢ Sugar-coating reality</td>
<td></td>
<td></td>
</tr>
<tr>
<td>➢ Uncomfortable</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Avoiding or not talking</td>
<td>34</td>
<td>39</td>
</tr>
<tr>
<td>3. Giving inaccurate information</td>
<td>19</td>
<td>22</td>
</tr>
<tr>
<td>4. Giving limited information</td>
<td>15</td>
<td>17</td>
</tr>
<tr>
<td>5. Inducing fear</td>
<td>15</td>
<td>17</td>
</tr>
<tr>
<td>6. Child being dismissive</td>
<td>12</td>
<td>16</td>
</tr>
</tbody>
</table>

Note. N=87

1. Ineffective parent talking style.

Whereas participants generally considered an effective talking style to be one in which the parent was open, friendly, supportive, and relaxed, they reported that an ineffective talking style included being harsh, too blunt, uncomfortable, or sugar-coating reality. Fifty parents (57%) referenced the ineffectiveness of these talking styles as they pertained to conversations about HIV prevention.

*Being harsh.*

Parents in this subcategory expressed that using a harsh or abrasive talking style with adolescents during conversations was many times counterproductive. When parents referred to a harsh talking style they referred to being angry, frustrated, forceful, or critical. As some of the parents who deemed these styles ineffective articulated:

*I don’t yell. I explain to her why I don’t yell. I said, “It never really gets anything done.” However, for me, with HIV, it causes stress. Stress kills me, quickly. I don’t want...*
to be stressed, so I’m not going to be yelling at you and saying stuff over and over. (1028, Father)

I don’t think that if you are in the heat of the situation or the situation has occurred that you should confront it head on. So I think that that would be not as effective. Or, if they made a mistake, to go back over and say “I told you so.” That whole scenario or situation, I think that that would be controversial and not as effective as it could be. (1025, Father)

Where I come from, (they say), “You’re just a nasty little slut like your momma. You won’t ever be no good. You’re just nasty. You’re a ho!”... They scream, “I knew you weren’t gonna be nothing!” But guess what? The same person who is yelling at that child is the same person who got yelled at when they were younger by their parents. So they didn’t know how to train their kids. Those are the bad ways. That’s when they (the kids) run to it (sex, the streets, etc). I’ve seen it. (1046, Mother)

Well it’s not good to talk down to them. It’s more of talk to them like a person, out of concern as opposed to scolding or “I better not catch you having sex.”... Because now they’re not going to open up to you. And they want to shut down. (1097, Father)

Being harsh and critical was therefore deemed ineffective because it could (a) discourage the adolescent from opening up or being truthful, (b) make them less likely to engage in future conversations, and (c) upset or anger them enough where they might engage in rebellious activities.

**Being too blunt.**

Whereas being open and realistic was generally deemed effective, a couple of parents noted that it was possible to be too open or too blunt with adolescents, and that being too blunt should be avoided. This included using vulgar terms or slang when referring to body parts or to sexual activity. For example:

*I think parents mess up and talk about it the wrong way when they’re not using all the medical terms. Like they were saying ‘dick’ and ‘pussy’ and ‘fucking’ and all that. They be like, “Oh! Mom said that!”... (Instead of) saying ‘perform oral sex’ and ‘sexually active’. That, to me, would be a better way -- to say, “Are you sexually active?” In the place of a parent asking “Are you fucking?”—No, I don’t think that’s the proper way to go about asking. (1005, Mother)*
This mother was pointing out that, as an authority figure and someone setting an example for her children, she believed in using the proper medical terms to reference sexual activity.

**Uncomfortable atmosphere.**

Talking in an uncomfortable atmosphere included parents who acted ashamed, awkward, or embarrassed to talk to adolescents about sensitive topics like sex, drugs, HIV, and prevention. As two mothers noted:

_I think (a bad way is) when they act like they’re ashamed to talk about it. When they act like one topic is taboo to talk about. I think you have to have a really really open mind when it comes to talking to kids about sex because you never know where their mind is. I think that actually kids probably start thinking and experimenting about sex when they’re really little so you never know what they’ve seen, you never know what they’ve gone through, and so to stand in front of your child and he actually has more courage to hear it then you have to talk about it is the biggest mistake in the world._ (1013, Mother)

_(A bad way would be) to act like it’s a non-approachable subject. Like “we don’t about it in the house, like it’s not going to happen.” Because it’s everywhere. It’s all around. Sex sells. They are all interested in it and their hormones are kicking._ (1064, Mother)

Talking in an uncomfortable atmosphere also included parents who chose to discuss prevention information when they were under the influence of drugs or alcohol. This was generally seen to create an unstable atmosphere where adolescents either wouldn’t understand what the parent was talking about or they wouldn’t take the parent seriously. For example:

_Talking to them when you drunk, or you just, that’s not a good way you can’t, you have to have a sober heart and a sober mind to sit down and talk to your kids about that. Because they’ll blow you right off they won’t pay you no attention, they’ll think you are having fun with them._ (1022, Father)

Some parents recalled distinct conversations where their own parents or guardians had talked to them under the influence of alcohol or drugs when they were growing up. As one mother recounted:

_My auntie used to try to talk to me about sex and boys and not skipping school and stuff like that but she was always under the influence of alcohol and I couldn’t understand nothing that she said. So that was that way I couldn’t really get no information and I_
think that was really annoying at that particular time back at my age when I was younger. I didn’t understand and I wanted to understand--I just wanted to find out what was going on... (1081, Mother)

**Sugar-coating reality.**

Parents who spoke of the ineffectiveness of “sugar-coating” reality generally spoke of skirting or obscuring the truth. When asked to give an example of sugar-coating one mother responded:

*(By sugar-coating I mean) "I know you a good girl. I know you a good boy. And I know you’re not having sex.” Bullshit. Ok?...Don’t sugar coat it...Sugar-coating is just gonna go in one ear and come out the other. I mean you’re not around them 24 hours a day. So you have to put it out there to prevent it because they could have been having sex at 5 or 6 years old. For real. Pretending to have sex or whatever. And you don’t even know it. (So) don’t sugar coat it.* (1056)

Sugar-coating reality was deemed to be ineffective because it might lead adolescents to believe (a) that their parent was ill-informed or “in the dark” about the challenges teenagers face, or (b) that their parent was uncomfortable having the conversation because they couldn’t get straight to the point. If parents took too long to get information out, they risked losing the child’s interest altogether. As one father noted:

*It’s best to be straightforward with them. Beating around the bush, they ain’t going to listen to you, kids are hard headed.* (2003, Father)

Overall, ineffective parent talking styles included those that were harsh, too blunt, uncomfortable, or too indirect or unrealistic. Parents appeared to perceive these styles as ineffective because they created confusion, compromised the quality of information the child received, or made the conversational atmosphere awkward.
2. Avoiding or not talking.

Another ineffective strategy reported was avoidance. Thirty-four parents (39%) mentioned that a “bad” way to discuss HIV-related information was to avoid or not talk about it at all. Parents who expressed this sentiment included:

*I think...nowadays parents, they know what to say to the kid. It’s just that they don’t want to talk about it. They just want to push it under the rug.* (1009, Mother)

*They don’t talk. People don’t talk to their kids about none of these (issues). That’s how I feel. The biggest thing, the worst thing -- some don’t talk to their kids.* (1020, Father)

*(A bad way would be) ignoring it. Ignoring it, again acting like it doesn’t exist, or waiting for society to teach him or the streets to teach him.* (1082, Father)

One mother expressed a deep sense of regret for not talking to her children about the dangers of illicit drugs.

*Never ignore it...I say that if I had talked to my kids the first time they heard anything, that would have never happened to them. They would have never said yes to whatever they took. They would not have taken (drugs).* (1039)

Sometimes parents avoided conversations initially, but later ended up having discussions about sex, dating, puberty, birth control, drugs, or HIV. These were usually situations where a child directly requested information and caught the parent off guard. Not uncommonly, these encounters ended up with the parent (a) lying about the situation (particularly about his or her own HIV status), (b) ignoring or avoiding the topic, or (c) having an awkward and ill-prepared discussion. These situations were deemed ineffective because parents had to either keep track of multiple lies (if the parent had chosen not to answer the child’s question) or deal with the hurt and loss of trust that came from admitting he or she had not been truthful initially.

Other participants highlighted that by ignoring or avoiding HIV-related topics, parents were forcing their children to depend on other, often less reliable or less detailed sources of information.
(A bad way would be) closing your eyes to it. Because we know that happens. Some parents are so afraid because they are positive that they won’t tell their kids, so their kids aren’t going to know about HIV and AIDS unless somebody on the streets tell them, or the public school system tells them. And it’s a joke to me when they say the public school system can teach their kids, because they don’t tell them much. (1046, Mother)

Many parents also remembered they way they felt when their own parents ignored topics that were pertinent to their health and sexual development. Ignoring or not talking about key issues like sexual abuse, homosexuality, and HIV appeared to reinforce the stigma associated with these topics in parents’ minds.


Nineteen parents (22%) conveyed that giving children inaccurate or not completely accurate information about HIV and ways to prevent it was not an effective means to educate adolescents. Parents generally spoke of myths, half-truths, and false or “bogus” information when they spoke of inaccurate information. In many parents’ minds, misinformation about HIV was still relatively common. As the following parents emphasized:

*You know, if you’re a parent who’s never faced this you could be like my biological father was and say “Get away from me – don’t give this disease to my daughter!” That’s just a stupid attitude. And you know, if your kids go home with information, and Dad’s response is, “Oh, only the queers get that,” there’s going to be a problem! Because that’s not real information.* (1019, Mother)

*They (other parents) always say, “You better put her on some birth control pills.” The birth control pills ain’t gonna stop no STD! They not telling them right. You need condoms. If you using condoms you ain’t got to worry about no STDs or no baby. They, some of the parents, give them false information. “Yeah, I’m going straight and putting her on some birth control pills.” I wouldn’t even put all that mess on my child.* (1029, Mother)

*Don’t make them feel like they can’t come talk to you, because then who can they talk to? Because what they are going to tell them in the streets for sure ain’t right. Yours (your information) is going to be more right than anything they are going to learn on the street. But that (the street) is where they will look to if they can’t get the answers that they want at home.* (1064, Mother)
Some parents also spoke of the ineffectiveness of using ambiguous terms during conversations about prevention. These ambiguous terms were usually euphemisms for body parts that may have been passed down from their parents or guardians. For example, one mother had vivid memories of a “talk” with her parents about sex when she was younger.

*They (my parents) said “keep your pocket book closed.” That wasn’t the right word to say. Because to me, using what they told me, “keep that pocket book closed” (I didn’t know what that meant). So I told Theresa very early, I said “vagina.” Because pocket book means you want money for it. I don’t think my mother literally meant that but when she said “gotta keep that pocket book closed,” I was like “pocket book?” As I got older in my youth years I was like “She said pocket book!” One of my girlfriends said “Well Briana think about it. Your mother was from the south.” She (my mother) just believed in “legs closed, panties up.” But she was never open about sex. That was something we didn’t talk about. So unfortunately that didn’t work (for me).* (1063, Mother)

As this mother noted, using ambiguous terminology created the potential for confusion and misunderstanding. Whereas the mother in this example may have thought she was being polite, clear, and sparing her daughter embarrassment, what her daughter took away from the conversation was a vague (and partially inaccurate) notion of what the talk had been about.

Parents didn’t appear to think euphemisms were inherently ineffective, though some did express their personal preference for using medically correct terminology. Rather, what stood out in parents’ minds was the potential for miscommunication these terms created. It was using ambiguous terminology without at least one explicit discussion about what the term(s) meant that was deemed to be grossly ineffective.

4. **Giving limited information.**

The fourth ineffective conversational category identified was giving limited information. Fifteen parents (17%) highlighted the problems associated with giving limited prevention information to adolescents. Parents who spoke of giving limited information generally referred to discussing only isolated bits of prevention information, or discussing some prevention
methods but not others. For example, teaching about abstinence while leaving out any mention of condoms was often viewed as ineffective. As one mother commented:

_They (the schools, other parents) just want to preach abstinence and I understand that. But if you’re realistic, okay how many kids really are going to wait until they’re 21, 25, and 20? 16 even sometimes, so I think people just really want to act like it doesn’t exist, which isn’t a good thing._ (1079, Mother)

Other participants expressed that sometimes parents had planned and were willing to discuss prevention information, but were then unprepared and/or unwilling to discuss the topics that came up as a result of prevention talks. For example, a talk about abstinence could have led to a talk about controlling sexual desires, which could have then led adolescents to ask about masturbation. Being unwilling to discuss certain topics, particularly those adolescents explicitly asked about, was viewed as ineffective because (a) it was a missed opportunity to educate children and give them high quality information and (b) it could impair a child’s ability to make a fully informed decision. As some parents expressed:

_Be honest. Be upfront with them. Not telling them one thing and then leaving out other details of that one thing. You know, if you’re gonna talk to them about something, tell them all the aspects of that certain thing. That’s how I would and I have (done it)._ (1087, Mother)

_Remember when you put it on the table be willing to accept what else comes with that, you know, because you open the door now that has several other doors and a lot of parents don’t look at it that way. This is what we are discussing and that’s it. You can’t do that. You have to be willing to let those other doors be open as well. If you’re going to put it on the table, put it on the table._ (1090, Father)

Giving limited information also included examples where parents would give a broad or blanket statement like “don’t do it” or “protect yourself,” without following up to explain how to protect one’s self, why it is important to protect one’s self, or what can happen if one doesn’t protect him/herself.
5. Inducing fear.

Though 5% of parents noted that introducing fear was an effective strategy to discuss HIV prevention, a larger percentage (17%, 15 parents) reported the opposite. For these parents, scaring children into protecting themselves or making them afraid of HIV or STIs was not an effective way to engage in dialogue. As two parents expressed:

_Fear is never the best way to go at somebody. You have to give them an opportunity to try to understand what you’re saying._ (1016, Mother)

_I think the worst way that I know of is exactly the way I believe I was brought up, where we were afraid to talk about sex._ (1020, Father)

It is possible that parents in this group avoided focusing on fear tactics in part because of their experiences living with HIV/AIDS. Parents who had disclosed their HIV status to their children may have wanted to avoid damaging their self-image as well as avoid any implications that their children should be scared of them. Parents who knew their children may already be scared about HIV often tried to allay those fears, or at least not to intensify them. Finally, some parents had their own poignant memories of times when they had been scared or occasions when they had inadvertently scared others. As one mother explained:

_Don’t scare them. Because I was scared. I was scared and I don’t want my kids…my son is scared. He doesn’t talk to me and I think I scared him when I told him about all the different girls. (I’d say) “Don’t be bringing all them girls (home)”, or “I don’t want to see all them girls in my house,” instead of sitting down telling him the right way. And still telling him how I felt, but having his trust. He probably thought I was going to argue with him or be against him, so he suppressed a lot of his feelings. I don’t want that for my daughter._ (1012, Mother)

As this example highlights, fear was also related to a parent’s talking style. Conversations where parents were negative, angry, critical, or conversations where parents spoke too forcefully could cause a child to become afraid and less likely to listen or open up during future conversations.
6. Child being dismissive.

Similar to factors discussed in previous sections, some parents gauged the effectiveness of prevention conversations by the actual or anticipated reactions of adolescents. Twelve parents (14%) gave examples of how certain characteristics of or reactions from adolescents resulted in less effective conversations. Examples in this category generally centered on adolescents being dismissive. For example, parents noted that conversations were much more difficult to conduct and that they (the parent) got discouraged more easily when their child acted uninterested, critical, judgmental, or rebellious. As two mothers expressed:

Well the teenagers, sometimes they don’t want to listen. It’s hard to listen (for them). Me too. When I was a teenager, it was like that too. It’s not easy but you have to talk and keep talking to them. (1091, Mother)

Sometimes I might bring it up some and she’ll be like, “Ma, you ain’t got to say all that, I know!” (I’ll say) “Just listen. You ain’t got to respond like that! See you’re being hard-headed...and being sassy to me. Just listen!” (Mother, 1004)

When adolescents acted uninterested in the topics of conversation or voiced that they already knew the information their parent was trying to convey, parents often became frustrated, hurt, angry, or simply stopped talking. In general, these types of encounters were viewed as unproductive learning experiences.

Chapter Summary

Overall, parents identified a variety of factors that helped and/or prevented them from engaging in HIV prevention conversations with adolescents. Some of these categories dealt with parental factors (e.g., the impact of being HIV+, perceived advantages/disadvantages of conversation, parental knowledge level, and parent talking style). Other categories that emerged dealt with characteristics of the child (e.g., recognizing a child is ready to talk, talking at a specific time in the child’s life). Still others categories emphasized the social and relational
factors that facilitated or hindered conversations (e.g., utilizing support, the impact of family upbringing and role modeling, and the impact of parent-child relationships). Factors that were uniquely stressed as barriers included living in denial, uncertainty about how to discuss prevention information, the competing opinions of family members, and community norms and stigma surrounding HIV/AIDS.

Parents also expressed a variety of useful strategies for discussing HIV prevention with adolescents. Such strategies highlighted the role of social and informational support, the importance of parental talking style during conversation, and the effectiveness of instilling values and expectations and providing educational facts. The effectiveness of these strategies also depended upon certain characteristics of the child (e.g., maturity level, interest level, personality). Some parents highlighted the effectiveness of using personalized examples in their conversations with adolescents, of making conversations interactive, or of having a supportive parent-child relationship prior to engaging in HIV-related talk. Finally, other parents underscored the efficacy of repeated prevention conversations, with later conversations being used to both reinforce and progressively build upon information discussed in earlier talks.

When it came to discussing which strategies were ineffective, parents highlighted the unfavorable effects of avoiding conversation or being angry, blunt, or awkward while conversing. Low quality information, that which was inaccurate or limited in nature, was also regarded as ineffective. It should be noted that areas of mixed reporting (where some parents viewed a category as effective while others viewed it as ineffective) included the following: the effectiveness of being friends with one’s child, the role of fear in prevention conversations, the role of being HIV+, and when to initiate prevention conversations with kids.
Taken as a whole, the qualitative results illustrate the myriad of strategies parents used to discuss HIV prevention with adolescents, as well as the substantial overlap of these strategies with what has been deemed “effective” communication in the parent-adolescent literature (as discussed in Chapter 2). The following chapter will allow readers to place these contextualized qualitative results amidst quantitative measures of parent-adolescent communication.
CHAPTER 5: QUANTITATIVE RESULTS

Chapter Overview

The purpose of this chapter is to summarize the results for the quantitative portion of the study. The chapter is divided into three main sections. The first section provides information on the items in the questionnaire, scale reliability, and descriptive statistics for the scales of interest. The second section details the findings from hypothesis testing (corresponding to the hypotheses presented in the Chapter 2). Finally, the third section summarizes the results of linear and logistic regression models exploring variables that may contribute to predicting frequency of conversation, disclosure, parental communication strategies, and HIV-related stress.

Scale Items

Six main scales were included in the questionnaire (described previously in the methods chapter). The construct measured by the scale, the scale items, and the scale response options are summarized in Table 15.
**Table 15**

*Scale Items in Questionnaire*

<table>
<thead>
<tr>
<th><strong>HIV Disclosure:</strong></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>D1. My bosses/employers</td>
<td></td>
</tr>
<tr>
<td>D2. Close friends</td>
<td></td>
</tr>
<tr>
<td>D3. Casual friends</td>
<td></td>
</tr>
<tr>
<td>D4. My parents</td>
<td></td>
</tr>
<tr>
<td>D5. My brothers and sisters</td>
<td></td>
</tr>
<tr>
<td>D6. My children</td>
<td></td>
</tr>
<tr>
<td>D7. My significant other(s)</td>
<td></td>
</tr>
<tr>
<td>D8. People I am sexually active with</td>
<td></td>
</tr>
<tr>
<td>D9. My health care provider(s)</td>
<td></td>
</tr>
</tbody>
</table>

Response options: None (1), Some (2), All (3), Does not apply to me (4)

<table>
<thead>
<tr>
<th><strong>Frequency &amp; Content (Modified PACS):</strong></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>F1. Sex</td>
<td></td>
</tr>
<tr>
<td>F2. Drugs</td>
<td></td>
</tr>
<tr>
<td>F3. How to use condoms</td>
<td></td>
</tr>
<tr>
<td>F4. Protecting one’s self from sexually transmitted diseases (STDs)</td>
<td></td>
</tr>
<tr>
<td>F5. Protecting one’s self from the AIDS virus</td>
<td></td>
</tr>
<tr>
<td>F6. Protecting one’s self from becoming pregnant</td>
<td></td>
</tr>
<tr>
<td>F7. Getting tested for STDs</td>
<td></td>
</tr>
<tr>
<td>F8. Getting tested for the AIDS virus</td>
<td></td>
</tr>
<tr>
<td>F9. Your HIV or AIDS status</td>
<td></td>
</tr>
</tbody>
</table>

Response options: Never (1), Rarely (2), Sometimes (3), Often (4)
### Self-efficacy:

SE1. What you think about adolescents his/her age having sex  
SE2. What you think about adolescents his/her age using drugs  
SE3. How to use condoms  
SE4. How to protect one’s self from sexually transmitted diseases (STDs)  
SE5. How to protect one’s self from the AIDS virus  
SE6. How to protect one’s self from becoming pregnant  
SE7. The importance of getting tested for STDs  
SE8. The importance of getting tested for the AIDS virus  
SE9. Your HIV or AIDS status  

Response options: Not sure at all (1), Somewhat sure (2), Pretty sure (3), Completely sure (4)

### Importance of Communication:

IC1. How to have safe sex  
IC2. How to stay away from drugs  
IC3. How to use condoms  
IC4. Protecting one’s self from sexually transmitted diseases (STDs)  
IC5. Protecting one’s self from the AIDS virus  
IC6. Protecting one’s self from becoming pregnant  
IC7. The importance of getting tested for STDs  
IC8. The importance of getting tested for the AIDS virus  
IC9. Your HIV or AIDS status  

Response options: Not at all important (1), Somewhat important (2), Pretty important (3), Very important (4)
Strategies:

ST1. I wait until my adolescent brings the topic up.

ST2. I bring it up after my adolescent(s) have watched a movie, TV show, or commercial that deals with sex, HIV, or STDs.

ST3. I bring it up when we go to health care appointments.

ST4. I bring it up when I realize that my adolescent is interested in dating.

ST5. I bring it up when my adolescent hits puberty.

ST6. I rely on friends, relatives, or neighbors to teach my adolescent(s) about it.

ST7. I rely on the school system to teach my adolescent(s) about it.

ST8. I rely on health care providers to teach my adolescent(s) about it.

Response options: Never (1), Rarely (2), Sometimes (3), Often (4)

HIV-Related Stress (Avoidance):

A1. I avoided letting myself get upset when I thought about having HIV.

A2. I tried to remove HIV from my memory.

A3. I stayed away from reminders of having HIV.

A4. I felt as if it hadn’t happened or wasn’t real.

A5. I tried not to talk about having HIV.

A6. Other things kept making me think about having HIV.

A7. I was aware that I still had a lot of feelings about HIV, but didn’t deal with them.

A8. I tried not to think about having HIV.

A9. My feelings about having HIV were kind of numb.

Response options: Not at all (1), Rarely (2), Sometimes (3), Often (4)

Reliability of Scales

Some scales had previously published reliability and validity information, whereas others were created or adapted specifically for the purposes of this study. Cronbach’s alpha was run on
all scales to assess internal reliability. The scale was considered acceptable if Cronbach’s alpha was .70 or greater (Morgan, Gliner, & Harmon, 2006). See Table 16 for the internal reliability results.

Table 16

*Internal Reliability of Scales*

<table>
<thead>
<tr>
<th>Scale</th>
<th>Cronbach’s Alpha</th>
</tr>
</thead>
<tbody>
<tr>
<td>HIV Disclosure</td>
<td>.863&lt;sup&gt;a&lt;/sup&gt;</td>
</tr>
<tr>
<td>Frequency &amp; Content (PACS)</td>
<td>.935</td>
</tr>
<tr>
<td>Self-efficacy</td>
<td>.910</td>
</tr>
<tr>
<td>Importance of Communication</td>
<td>.917</td>
</tr>
<tr>
<td>Strategies</td>
<td>.637</td>
</tr>
<tr>
<td>HIV-related stress</td>
<td>.879</td>
</tr>
</tbody>
</table>

<sup>a</sup> N= 31

As seen in Table 16, the HIV disclosure scale had an acceptable Cronbach’s alpha, but was only based on the 31 participants who were able to answer all scale items. Those who answered “does not apply to me” for one or more scale items were coded as “system missing” and were excluded from analysis.

Another scale, the strategies scale, did not have an acceptable Cronbach’s alpha as a whole (<i>α</i> = .637). This scale was subjected to exploratory factor analysis to explore correlations between items and to ascertain the number of constructs being represented by each scale. It was suspected that half of the items on the scale represented active strategies parents used to communicate and that the other half represented passive strategies parents used to communicate. Indeed, factor analysis revealed two main factors corresponding to active and passive strategies. The results of the exploratory factor analysis are presented in Table 17. Each factor is listed,
along with its eigenvalue, each individual item’s loading value for that factor, and the Cronbach’s alpha for each factor. Principal Components Analysis with Orthogonal rotation (Varimax with Kaiser Normalization algorithm) was used in order to maximize the variance of factor loadings. Convergence of factors was reached in three iterations. Eigenvalues of greater than or equal to one were retained as separate factors. Items with factor loadings of .500 or above were retained within a given factor, so long as they did not also have a >.500 loading on the other factor.

Table 17

*Exploratory Factor Analysis for Strategies Scale*

<table>
<thead>
<tr>
<th>Factor/Items Loading on Factor</th>
<th>Eigenvalue</th>
<th>Item Loading</th>
<th>Cronbach’s alpha</th>
</tr>
</thead>
<tbody>
<tr>
<td>Active Strategies</td>
<td>2.72</td>
<td>.796</td>
<td>.824</td>
</tr>
<tr>
<td>ST2</td>
<td></td>
<td>.796</td>
<td></td>
</tr>
<tr>
<td>ST3</td>
<td></td>
<td>.825</td>
<td></td>
</tr>
<tr>
<td>ST4</td>
<td></td>
<td>.800</td>
<td></td>
</tr>
<tr>
<td>ST5</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Passive Strategies</td>
<td>1.92</td>
<td>.548</td>
<td>.691</td>
</tr>
<tr>
<td>ST6</td>
<td></td>
<td>.881</td>
<td></td>
</tr>
<tr>
<td>ST7</td>
<td></td>
<td>.868</td>
<td></td>
</tr>
<tr>
<td>ST8</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

It should be noted that one item (ST1) loaded only weakly on both factors (<.300) and was excluded from the scale. Overall, this resulted in a four item active strategies scale with a Cronbach’s alpha of .824 and a three item passive strategies scale with a Cronbach’s alpha of .691.

**Descriptive Summary of Scales**

Table 18 provides summary information for the main scales of interest for the study, including the full range of the scale, the range reported by participants, the mean of the scale, and
the scale’s standard deviation in this sample. A brief description of participant responses on each scale follows.

Table 18

*Parental Scores on Scales*

<table>
<thead>
<tr>
<th>Scale</th>
<th>Full Scale Range</th>
<th>Reported Range</th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Frequency &amp; Content (PACS)</td>
<td>9-36</td>
<td>9-36</td>
<td>27.24</td>
<td>7.85</td>
</tr>
<tr>
<td>Self-efficacy</td>
<td>9-36</td>
<td>9-36</td>
<td>31.38</td>
<td>5.79</td>
</tr>
<tr>
<td>Importance of Communication</td>
<td>9-36</td>
<td>12-36</td>
<td>34.88</td>
<td>3.13</td>
</tr>
<tr>
<td>Active Strategies</td>
<td>4-16</td>
<td>4-16</td>
<td>11.92</td>
<td>5.51</td>
</tr>
<tr>
<td>Passive Strategies</td>
<td>3-12</td>
<td>3-12</td>
<td>3.39</td>
<td>2.34</td>
</tr>
<tr>
<td>HIV-related stress</td>
<td>9-36</td>
<td>9-36</td>
<td>19.08</td>
<td>7.37</td>
</tr>
</tbody>
</table>

**HIV Disclosure Scale.**

Parents in this sample reported moderate to high levels of disclosure (mean 21.48; range 9-27). The mean and standard deviation for each item is reported in Table 19. Approximately 53% of participants reported that they had a current boss or employer. Of those reporting an employer, 45% had informed all or some of their employers about their HIV status. In terms of disclosing to friends, most participants (84%) had disclosed their HIV status to at least one close friend. Only 33% of participants had disclosed to all of their close friends, however, and an even lower number (14%) had disclosed to all of their casual friends. Disclosure to parents and siblings was moderate, with approximately 68% of participants reporting they had disclosed to all of their parents and 66% reporting they had disclosed to all of their brothers and sisters. When it came to disclosing to children, 63% of parents indicated that they told all of their
children about their HIV status. Twenty percent indicated that they told some of their children about their HIV status, and only 17% of parents indicated that none of their children knew about their HIV status. Parents reported slightly higher levels of disclosure for significant others. Of parents who were in relationships, almost 80% reported disclosing their HIV status to their significant other(s). Approximately 75% of participants reported being sexually active. Of those sexually active, the majority (74%) had disclosed their HIV status to all of their sexual partners.

Table 19

*Parental Scores on HIV Disclosure Scale*

<table>
<thead>
<tr>
<th>Items on Scale</th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>D1. My bosses/employers</td>
<td>2.76</td>
<td>1.31</td>
</tr>
<tr>
<td>D2. Close friends</td>
<td>2.17</td>
<td>.68</td>
</tr>
<tr>
<td>D3. Casual friends</td>
<td>1.76</td>
<td>.85</td>
</tr>
<tr>
<td>D4. My parents</td>
<td>2.75</td>
<td>.86</td>
</tr>
<tr>
<td>D5. My brothers and sisters</td>
<td>2.64</td>
<td>.78</td>
</tr>
<tr>
<td>D6. My children</td>
<td>2.47</td>
<td>.77</td>
</tr>
<tr>
<td>D7. My significant other(s)</td>
<td>2.90</td>
<td>.66</td>
</tr>
<tr>
<td>D8. People I am sexually active with</td>
<td>2.94</td>
<td>.82</td>
</tr>
<tr>
<td>D9. My health care provider(s)</td>
<td>2.91</td>
<td>.44</td>
</tr>
</tbody>
</table>

Response options: None (1), Some (2), All (3), Does not apply to me (4) – coded as missing

**Frequency & Content Scale (PACS).**

Parents reported moderate to high levels of communication with adolescents about HIV and HIV prevention (mean 27.24; range 9-36). The mean and standard deviation for each item is reported in Table 20. The majority of parents reported that they “sometimes” or “often” talked about sex, drugs, condoms, protection from STDs and AIDS, and protection from pregnancy.
When it came to talking about getting tested for STDs or AIDS, conversations were slightly less frequent. Still, however, over half of parents reported talking “sometimes” or “often” about getting tested for STDs or AIDS. In terms of talking about their own HIV or AIDS status, 63% reported the topic was “sometimes” or “often” discussed when talking with their adolescent(s).

Table 20

*Parental Scores on Frequency & Content Scale (PACS).*

<table>
<thead>
<tr>
<th>Items on Scale</th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>F1. Sex</td>
<td>3.19</td>
<td>.87</td>
</tr>
<tr>
<td>F2. Drugs</td>
<td>3.17</td>
<td>1.02</td>
</tr>
<tr>
<td>F3. How to use condoms</td>
<td>2.88</td>
<td>1.14</td>
</tr>
<tr>
<td>F4. Protecting one’s self from sexually transmitted diseases (STDs)</td>
<td>3.22</td>
<td>.99</td>
</tr>
<tr>
<td>F5. Protecting one’s self from the AIDS virus</td>
<td>3.23</td>
<td>1.01</td>
</tr>
<tr>
<td>F6. Protecting one’s self from becoming pregnant</td>
<td>3.17</td>
<td>1.07</td>
</tr>
<tr>
<td>F7. Getting tested for STDs</td>
<td>2.81</td>
<td>1.15</td>
</tr>
<tr>
<td>F8. Getting tested for the AIDS virus</td>
<td>2.76</td>
<td>1.19</td>
</tr>
<tr>
<td>F9. Your HIV or AIDS status</td>
<td>2.82</td>
<td>1.18</td>
</tr>
</tbody>
</table>

Response options: Never (1), Rarely (2), Sometimes (3), Often (4)

*Self-Efficacy Scale.*

Parents generally reported high levels of self-efficacy about discussing HIV and HIV prevention topics (mean 31.38 ; range 9-36). The mean and standard deviation for each item is reported in Table 21. The majority (approximately 80-90%) reported that they were “pretty sure” or “completely sure” they could talk about what they thought about their adolescent having sex, using drugs, how to use condoms, how to protect one’s self from STDs and AIDS, and the importance of getting tested for STDs and AIDS. Slightly less (approximately 75%) reported
that they were “pretty sure” or “completely sure” that they could talk about their own HIV or AIDS status with their adolescent.

Table 21

*Parental Scores on Self-Efficacy Scale*

<table>
<thead>
<tr>
<th>Items on Scale</th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>SE1. What you think about adolescents his/her age having sex</td>
<td>3.38</td>
<td>.87</td>
</tr>
<tr>
<td>SE2. What you think about adolescents his/her age using drugs</td>
<td>3.49</td>
<td>.85</td>
</tr>
<tr>
<td>SE3. How to use condoms</td>
<td>3.52</td>
<td>.80</td>
</tr>
<tr>
<td>SE4. How to protect one’s self from sexually transmitted diseases (STDs)</td>
<td>3.54</td>
<td>.78</td>
</tr>
<tr>
<td>SE5. How to protect one’s self from the AIDS virus</td>
<td>3.52</td>
<td>.81</td>
</tr>
<tr>
<td>SE6. How to protect one’s self from becoming pregnant</td>
<td>3.57</td>
<td>.85</td>
</tr>
<tr>
<td>SE7. The importance of getting tested for STDs</td>
<td>3.54</td>
<td>.77</td>
</tr>
<tr>
<td>SE8. The importance of getting tested for the AIDS virus</td>
<td>3.53</td>
<td>.78</td>
</tr>
<tr>
<td>SE9. Your HIV or AIDS status</td>
<td>3.28</td>
<td>1.05</td>
</tr>
</tbody>
</table>

Response options: Not sure at all (1), Somewhat sure (2), Pretty sure (3), Completely sure (4)

*Importance of Communication Scale.*

Parents also reported very high levels on the importance of HIV prevention communication (mean 34.88; range 12-36). The mean and standard deviation for each item is reported in Table 22. The overwhelming majority (90% and above) reported that it was “very important” to them that their adolescent(s) know about sex, drugs, how to use condoms, how to protect one’s self form STDs and AIDS, and the importance of getting tested for STDs and AIDS. When it came to the importance of their adolescent knowing about their HIV status, however, only 79% reported that it was “very important” that their adolescent know about their status.
Table 22

**Parental Scores on Importance of Communication Scale**

<table>
<thead>
<tr>
<th>Items on Scale</th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>IC1. How to have safe sex</td>
<td>3.92</td>
<td>.31</td>
</tr>
<tr>
<td>IC2. How to stay away from drugs</td>
<td>3.93</td>
<td>.25</td>
</tr>
<tr>
<td>IC3. How to use condoms</td>
<td>3.90</td>
<td>.43</td>
</tr>
<tr>
<td>IC4. Protecting one’s self from sexually transmitted diseases (STDs)</td>
<td>3.90</td>
<td>.43</td>
</tr>
<tr>
<td>IC5. Protecting one’s self from the AIDS virus</td>
<td>3.94</td>
<td>.35</td>
</tr>
<tr>
<td>IC6. Protecting one’s self from becoming pregnant</td>
<td>3.89</td>
<td>.41</td>
</tr>
<tr>
<td>IC7. The importance of getting tested for STDs</td>
<td>3.88</td>
<td>.42</td>
</tr>
<tr>
<td>IC8. The importance of getting tested for the AIDS virus</td>
<td>3.89</td>
<td>.44</td>
</tr>
<tr>
<td>IC9. Your HIV or AIDS status</td>
<td>3.63</td>
<td>.79</td>
</tr>
</tbody>
</table>

Response options: Not at all important (1), Somewhat important (2), Pretty important (3), Very important (4)

**Active Strategies Scale.**

Active strategies included the parent bringing up the conversational topics when adolescents watched media, when the parent and child were on their way to health care appointments, when the parent realized his/her adolescent was interested in sex or sexual relationships, and/or when the adolescent hit puberty. Scores on the active strategies scale were moderate to high (mean 11.92; range 4-16). The mean and standard deviation for each item is reported in Table 23. The most often used active strategy was bringing HIV-related information up when the parent realized the adolescent was interested in dating. Fifty-five percent of parents reported that they often used this method to discuss prevention information with their adolescent, whereas 44% of parents often brought the topic up when their adolescent hit puberty. Thirty-four percent of parents reported they often brought the topic up when they went to health care appointments.
appointments. Finally, 29% of parents indicated they often brought the topic up after their adolescent had watched media pertaining to sex, HIV, drugs, or STIs.

Table 23

Parental Scores on Active Strategies Scale

<table>
<thead>
<tr>
<th>Items on Scale</th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>ST2. I bring it up after my adolescent(s) have watched a movie, TV show, or commercial that deals with sex, HIV, or STDs.</td>
<td>2.88</td>
<td>.99</td>
</tr>
<tr>
<td>ST3. I bring it up when we go to health care appointments.</td>
<td>2.72</td>
<td>1.16</td>
</tr>
<tr>
<td>ST4. I bring it up when I realize that my adolescent is interested in dating.</td>
<td>3.29</td>
<td>.97</td>
</tr>
<tr>
<td>ST5. I bring it up when my adolescent hits puberty.</td>
<td>3.03</td>
<td>1.06</td>
</tr>
</tbody>
</table>

Response options: Never (1), Rarely (2), Sometimes (3), Often (4)

Passive Strategies Scale.

Passive strategies included the parent relying on others (friends, relatives, neighbors, the school, or health care providers) to teach their adolescent about HIV and HIV prevention. Scores on the passive strategies scale were relatively low (mean 5.51; range 3-12). The mean and standard deviation for each item is reported in Table 24. Seventy percent of parents reported never relying on friends, relatives, or neighbors to discuss HIV prevention with adolescents. This number decreased to 52% of parents reporting never relying on the school system and 37% reporting never relying upon health care providers to teach their adolescent HIV-related information. If parents did report relying upon others to discuss HIV prevention with adolescents, they most often utilized health care providers (16%), followed by the school system (10%), followed by friends, relatives, or neighbors (3%).
Table 24

**Parental Scores on Passive Strategies Scale**

<table>
<thead>
<tr>
<th>Items on Scale</th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>ST6. I rely on friends, relatives, or neighbors to teach my adolescent(s) about it.</td>
<td>1.46</td>
<td>.80</td>
</tr>
<tr>
<td>ST7. I rely on the school system to teach my adolescent(s) about it.</td>
<td>1.85</td>
<td>1.04</td>
</tr>
<tr>
<td>ST8. I rely on health care providers to teach my adolescent(s) about it.</td>
<td>2.19</td>
<td>1.11</td>
</tr>
</tbody>
</table>

Response options: Never (1), Rarely (2), Sometimes (3), Often (4)

HIV-Related Stress Scale.

HIV-related subjective stress was measured by the impact of event scale, specifically the avoidance subscale. Scores on this scale were moderate (mean 19.08; range 9-36). The mean and standard deviation for each item is reported in Table 25. Forty-two percent of participants reported “not at all” avoiding letting themselves get upset when they thought about having HIV. Approximately half of participants reported “not at all” for the following items: trying to remove HIV from their memory, staying away from reminders of having HIV, feeling as if having HIV hadn’t happened or wasn’t real, and/or trying to avoid talking about HIV. Closer to 40% of participants reported “not at all” for: letting themselves get upset when they thought about having HIV, having other thinks keep making them think about having HIV, being aware they still had a lot of feelings about having HIV but didn’t deal with them, trying not to think about HIV, and/or having feelings about HIV that were kind of numb.
Table 25

*Parental Scores on HIV-Related Stress Scale*

<table>
<thead>
<tr>
<th>Items on Scale</th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>A1. I avoided letting myself get upset when I thought about having HIV.</td>
<td>2.21</td>
<td>1.20</td>
</tr>
<tr>
<td>A2. I tried to remove HIV from my memory.</td>
<td>2.10</td>
<td>1.19</td>
</tr>
<tr>
<td>A3. I stayed away from reminders of having HIV.</td>
<td>1.88</td>
<td>1.10</td>
</tr>
<tr>
<td>A4. I felt as if it hadn’t happened or wasn’t real.</td>
<td>1.86</td>
<td>1.08</td>
</tr>
<tr>
<td>A5. I tried not to talk about having HIV.</td>
<td>2.12</td>
<td>1.20</td>
</tr>
<tr>
<td>A6. Other things kept making me think about having HIV.</td>
<td>2.20</td>
<td>1.11</td>
</tr>
<tr>
<td>A7. I was aware that I still had a lot of feelings about HIV, but didn’t deal with them.</td>
<td>2.20</td>
<td>1.11</td>
</tr>
<tr>
<td>A8. I tried not to think about having HIV.</td>
<td>2.29</td>
<td>1.17</td>
</tr>
<tr>
<td>A9. My feelings about having HIV were kind of numb.</td>
<td>2.22</td>
<td>1.12</td>
</tr>
</tbody>
</table>

Response options: Not at all (1), Rarely (2), Sometimes (3), Often (4)

**Correlations Between Scales**

The correlation matrix for the scales of interest is shown in Table 26. Scales that were significantly correlated at the $p \leq .01$ or $p \leq .05$ level are summarized below.
Table 26

Correlation Matrix

<table>
<thead>
<tr>
<th>HIV Disclosure</th>
<th>Frequency &amp; Content (PACS)</th>
<th>Self-efficacy</th>
<th>Importance of Communication</th>
<th>Active Strategies</th>
<th>Passive Strategies</th>
<th>HIV-related Stress</th>
</tr>
</thead>
<tbody>
<tr>
<td>HIV Disclosure Pearson Correlation 1</td>
<td>.201</td>
<td>.321</td>
<td>-.174</td>
<td>.086</td>
<td>-.203</td>
<td>-.116</td>
</tr>
<tr>
<td>Sig. (2-tailed) -----</td>
<td>.279</td>
<td>.078</td>
<td>.350</td>
<td>.646</td>
<td>.273</td>
<td>.535</td>
</tr>
<tr>
<td>N -----</td>
<td>31</td>
<td>31</td>
<td>31</td>
<td>31</td>
<td>31</td>
<td>31</td>
</tr>
<tr>
<td>Frequency &amp; Content (PACS) Pearson Correlation -----</td>
<td>1</td>
<td>.565(**)</td>
<td>.263(*)</td>
<td>.625(**)</td>
<td>-.045</td>
<td>-.007</td>
</tr>
<tr>
<td>Sig. (2-tailed) -----</td>
<td>-----</td>
<td>.000</td>
<td>.013</td>
<td>.000</td>
<td>.672</td>
<td>.950</td>
</tr>
<tr>
<td>N -----</td>
<td>-----</td>
<td>90</td>
<td>89</td>
<td>89</td>
<td>89</td>
<td>89</td>
</tr>
<tr>
<td>Self-efficacy Pearson Correlation -----</td>
<td>-----</td>
<td>1</td>
<td>.469(**)</td>
<td>.437(**)</td>
<td>.023</td>
<td>-.141</td>
</tr>
<tr>
<td>Sig. (2-tailed) -----</td>
<td>-----</td>
<td>-----</td>
<td>.000</td>
<td>.000</td>
<td>.832</td>
<td>.188</td>
</tr>
<tr>
<td>N -----</td>
<td>-----</td>
<td>-----</td>
<td>89</td>
<td>89</td>
<td>89</td>
<td>89</td>
</tr>
<tr>
<td>Import. of Commun. Pearson Correlation -----</td>
<td>-----</td>
<td>-----</td>
<td>1</td>
<td>.059</td>
<td>-.012</td>
<td>.047</td>
</tr>
<tr>
<td>Sig. (2-tailed) -----</td>
<td>-----</td>
<td>-----</td>
<td>-----</td>
<td>-----</td>
<td>.581</td>
<td>.914</td>
</tr>
<tr>
<td>N -----</td>
<td>-----</td>
<td>-----</td>
<td>-----</td>
<td>89</td>
<td>89</td>
<td>89</td>
</tr>
<tr>
<td>Active Strategies Pearson Correlation -----</td>
<td>-----</td>
<td>-----</td>
<td>-----</td>
<td>1</td>
<td>-.044</td>
<td>-.038</td>
</tr>
<tr>
<td>Sig. (2-tailed) -----</td>
<td>-----</td>
<td>-----</td>
<td>-----</td>
<td>-----</td>
<td>.684</td>
<td>.724</td>
</tr>
<tr>
<td>N -----</td>
<td>-----</td>
<td>-----</td>
<td>-----</td>
<td>89</td>
<td>89</td>
<td>89</td>
</tr>
<tr>
<td>Passive Strategies Pearson Correlation -----</td>
<td>-----</td>
<td>-----</td>
<td>-----</td>
<td>-----</td>
<td>1</td>
<td>.440(**)</td>
</tr>
<tr>
<td>Sig. (2-tailed) -----</td>
<td>-----</td>
<td>-----</td>
<td>-----</td>
<td>-----</td>
<td>-----</td>
<td>.000</td>
</tr>
<tr>
<td>N -----</td>
<td>-----</td>
<td>-----</td>
<td>-----</td>
<td>-----</td>
<td>89</td>
<td>89</td>
</tr>
<tr>
<td>HIV-related Stress Pearson Correlation -----</td>
<td>-----</td>
<td>-----</td>
<td>-----</td>
<td>-----</td>
<td>-----</td>
<td>1</td>
</tr>
<tr>
<td>Sig. (2-tailed) -----</td>
<td>-----</td>
<td>-----</td>
<td>-----</td>
<td>-----</td>
<td>-----</td>
<td>-----</td>
</tr>
<tr>
<td>N -----</td>
<td>-----</td>
<td>-----</td>
<td>-----</td>
<td>-----</td>
<td>-----</td>
<td>-----</td>
</tr>
</tbody>
</table>

** Correlation is significant at the 0.01 level (2-tailed).
* Correlation is significant at the 0.05 level (2-tailed).

As evidenced by the table, frequency of parent-adolescent communication was significantly
correlated with self-efficacy (Pearson’s r = .565, p = .000), importance (Pearson’s r = .263, p =
.013), and using active strategies (Pearson’s r = .625, p = .000). Thus, parents who reported more
frequent conversations were more likely to report greater confidence that they could discuss HIV-related topics with their adolescent(s), thinking communication was important, and using more active strategies when they did talk with adolescents. Similarly, self-efficacy was significantly correlated with importance of communication (Pearson’s r = .469, p = .000) and using active strategies (Pearson’s r = .437, p = .000). Finally, using passive strategies was significantly associated with HIV-related stress (Pearson’s r = .440, p = .000). Parents who had a higher score on the passive strategies scale were significantly more likely to report a higher level of HIV-related stress.

### Hypothesis Testing Results

Two main hypotheses were included in the quantitative portion of the study. The section below reviews these hypotheses and summarizes the hypothesis testing results.

**Hypothesis 1: Content Focus of Prevention Discussions**

**H1**: Parents will report focusing the content of HIV prevention discussions around how they believe they were personally infected.

**H1a**: Parents who think they were infected with HIV by sex will be more likely to report discussing sex frequently with adolescents.

**H1b**: Parents who think they were infected with HIV by drug use will be more likely to discuss drugs frequently with adolescents.

Conceptually, this hypothesis sought to assess whether or not the topics parents frequently talked about with adolescents were associated with how parents believed they were personally infected with HIV. Chi-square analysis was conducted to assess the degree to which mode of HIV infection and frequency of conversation were associated. It should be noted that this hypothesis was difficult to investigate in this sample because of the low number of participants reporting infection by drug use alone (6.7%, n = 6). Thus, mode of infection was divided into two dichotomous variables: (1) parents who reported being infected by sex (yes or no) and (2)
parents who reported being infected by drug use (yes or no). Parents who reported being infected by sex and drugs were counted once in the infected by sex variable and once in the infected by drugs variable. Dichotomous variables were also created for high versus low levels of communication about sex and drugs with adolescents. High levels of communication about sex included parents who reported they “sometimes or often” talked about sex with adolescents, whereas low levels of communication about sex included parents who reported they “rarely or never” talked about sex. Similarly, high levels of communication about drugs included parents who reported they “sometimes or often” talked about drugs with adolescents, whereas low levels of communication about drugs included parents who reported they “rarely or never” talked about drugs. Small cell counts prevented the use of Pearson’s Chi-Square test, however the cell counts and results of Fisher’s Exact test are reported in Table 27 (for sex) and Table 28 (for drugs).

Table 27

Parents Infected by Sex by Frequency of Communication About Sex

<table>
<thead>
<tr>
<th>Infected by sex</th>
<th>Frequency of communication about sex</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Low</td>
<td>High</td>
</tr>
<tr>
<td>No</td>
<td>1</td>
<td>9</td>
</tr>
<tr>
<td>Yes</td>
<td>12</td>
<td>67</td>
</tr>
<tr>
<td>Total</td>
<td>13</td>
<td>76</td>
</tr>
</tbody>
</table>

Fisher’s Exact Test (Exact Sig., 1-sided) p = .552
Table 28

Parents Infected by Drug Use by Frequency of Communication About Drug Use

<table>
<thead>
<tr>
<th>Infected by drugs</th>
<th>Frequency of communication about drugs</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Low</td>
<td>High</td>
</tr>
<tr>
<td>No</td>
<td>17</td>
<td>52</td>
</tr>
<tr>
<td>Yes</td>
<td>3</td>
<td>16</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>20</td>
<td>68</td>
</tr>
</tbody>
</table>

Fisher’s Exact Test (Exact Sig., 1-sided) p = .316

Overall, this hypothesis was not supported. Being infected by sexual contact was not significantly associated with frequently discussing sex with adolescents. Similarly, being infected by drug use was not significantly associated with frequently discussing drugs with adolescents.

**Hypothesis 2: Barriers to Prevention Discussions**

H2: Limited disclosure of HIV status and high HIV-related stress will be identified as barriers unique to parents living with HIV/AIDS.

H2a: Parents who report limited disclosure of their HIV status to their children (as measured by the HIV Disclosure scale) will report less frequent discussions about HIV prevention with their adolescent(s).

H2b: Parents who report a high degree of HIV-related stress and avoidance of HIV (as measured by the Impact of Event scale) will report less frequent discussions about HIV prevention with their adolescent(s).

Overall, this hypothesis sought to identify quantitative barriers to prevention conversations. For hypothesis 2a, a one-way ANOVA was run to assess any differences between extent of disclosure to children (all, some, or none) and parental score on the frequency of communication (PACS) scale. Results revealed a significant effect between extent of disclosure to children and parental mean sum on the frequency of communication scale ($F_{(2,87)} = 5.73$, $p = .005$). Post hoc comparisons using the Fisher LSD test indicated that the mean sum for the
parents who had disclosed to “all” of their children was significantly higher than the mean sum for parents who had disclosed to “some” of their children and the mean sum for parents who had disclosed to “none” of their children. However, the mean frequency sum for parents who had not disclosed their HIV status to any of their children (“none” category) did not significantly differ from parents in the “some” disclosure category. The results of the ANOVA are presented in Table 29, along with the means and standard deviations in Table 30.

Table 29

One-way ANOVA – Extent of Disclosure on Frequency of Communication

<table>
<thead>
<tr>
<th>Frequency Scale Sum</th>
<th>Sum of Squares</th>
<th>df</th>
<th>Mean Square</th>
<th>F</th>
<th>Significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Between Groups</td>
<td>638.03</td>
<td>2</td>
<td>319.01</td>
<td>5.73</td>
<td>.005</td>
</tr>
<tr>
<td>Within Groups</td>
<td>4848.07</td>
<td>87</td>
<td>55.73</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>5486.10</td>
<td>89</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Table 30

Means/Standard Deviations – Extent of Disclosure on Frequency of Communication

<table>
<thead>
<tr>
<th>Extent of Disclosure</th>
<th>N</th>
<th>Mean</th>
<th>Standard Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Frequency Scale Sum</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>All</td>
<td>57</td>
<td>29.25</td>
<td>7.13</td>
</tr>
<tr>
<td>Some</td>
<td>18</td>
<td>24.22</td>
<td>8.16</td>
</tr>
<tr>
<td>None</td>
<td>15</td>
<td>23.30</td>
<td>7.90</td>
</tr>
</tbody>
</table>

Correlations between the sums of the HIV disclosure scale and frequency of communication scale were also conducted, in order to assess if the extent of disclosure in general (and not specifically to children) was associated with talking about HIV prevention more frequently. These scales were not significantly correlated, indicating that disclosure as a whole
(to employers, friends, family members, etc.) was not associated with frequency of prevention communication with adolescents. Taken together, these results demonstrate that parents who disclosed their HIV status to all of their children were more likely to report frequently discussing HIV prevention information with adolescents. This bivariate analysis supports hypothesis 2a, suggesting that limited disclosure to children can function as a barrier to HIV prevention communication.

Analysis for hypothesis 2b consisted of correlations between the HIV-related stress scale and the frequency of communication scale. This analysis was conducted to see if parents reporting high levels of HIV-related stress reported less frequent discussions about HIV prevention than parents with lower levels of HIV-related stress. No significant association was found between HIV-related stress and frequency of prevention communication. Further analyses were conducted to examine HIV-related stress scale in relation to other scales (self-efficacy, importance, active strategies, and passive strategies). As reported previously in the correlation matrix (Table 26), HIV-related stress was only significantly correlated with one other scale: using passive strategies to discuss HIV prevention (Pearson’s r = .440, p=.000).

Overall, these results suggest that HIV-related stress levels did not significantly affect frequency of prevention discussions. Hypothesis 2b was not supported. However, the significant association between HIV-related stress and using passive strategies suggests that, while reported frequency of conversations may not differ by stress level, the specific communication strategies used by parents reporting high stress may differ from those used by parents reporting lower levels of stress.
Regression Analyses

Six regression analyses of interest emerged as a result of the previously presented hypotheses and quantitative results. These models focused on identifying predictors of the following dependent variables: (1) frequency of communication, (2) disclosure to children, (3) HIV-related stress, (4) parental use of active strategies, (5) parental use of passive strategies, and (6) parental use of effective versus ineffective strategies. Separate linear or logistic regression analyses were run (as appropriate) to determine the relative contributions of the predictor variables to the variance in each of the six dependent variables. The number of predictor variables was limited to 18 for each model, following the general rule of thumb that the number of predictor variables should not exceed the total sample size divided by five (Brace, Kemp, & Snelgar, 2009). Categorical variables with more than two options were recoded into dummy variables to comply with regression restrictions. Assumptions for linear and logistic regression were assessed and no marked violations were found. For linear regression, assumptions checked included normality of residuals for the dependent variable (via a histogram and normal probability plot), homoscedasticity (via a scatterplot of standardized residuals against the standardized predicted values of the dependent variable), and the absence of multicollinearity (via VIF and tolerance statistics). For logistic regression, which is less strict in its assumptions (Peng, Lee, & Ingersoll, 2002), the absence of multicollinearity was checked.

Independent variables included background variables (e.g., demographic, family-related, and health-related variables) and communication variables. The majority of the regression analyses were exploratory and not based on a previous theoretical framework. Thus, backward stepwise variable entry was used in efforts to produce parsimonious models from a relatively large number of independent variables. The backward stepwise method enters all independent
variables at once and then removes non-significant variables sequentially, so that only useful
predictors remain in the final model. Predictors were removed from the model if their
significance level was >.1 (removal criterion) and allowed to enter back into the model if their
significance level was <.05 (re-entry criterion). Table 31 details the variables included in the
regression models. All variables were included in each model unless otherwise specified. For a
complete list of which variables were included in each model please reference Appendix K. For
any significant correlation values between these variables please reference Appendix L.
Table 31

Variables for Regression Models

<table>
<thead>
<tr>
<th>Variable Type</th>
<th>Variables</th>
<th>Variable Levels</th>
</tr>
</thead>
<tbody>
<tr>
<td>Demographic</td>
<td>Age</td>
<td>Continuous (27-65)</td>
</tr>
<tr>
<td></td>
<td>Gender</td>
<td>Female (1), Male (0)</td>
</tr>
<tr>
<td></td>
<td>Ethnicity</td>
<td>African American (1), All other (0)</td>
</tr>
<tr>
<td></td>
<td>Education Level</td>
<td>High school and up (1)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Less than high school (0)</td>
</tr>
<tr>
<td></td>
<td>Employment status</td>
<td>Employed (1), Unemployed (0)</td>
</tr>
<tr>
<td>Family</td>
<td>Number of children 10-18</td>
<td>Continuous (1-5)</td>
</tr>
<tr>
<td></td>
<td>Live with child 10-18</td>
<td>Yes (1), No (0)</td>
</tr>
<tr>
<td></td>
<td>Ever separated from child</td>
<td>Yes (1), No (0)</td>
</tr>
<tr>
<td></td>
<td>Relationship status</td>
<td>Long-term/Married (1)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Single/Dating (0)</td>
</tr>
<tr>
<td>Health</td>
<td>Previous substance abuse</td>
<td>Yes (1), No (0)</td>
</tr>
<tr>
<td></td>
<td>Previous sexual abuse</td>
<td>Yes (1), No (0)</td>
</tr>
<tr>
<td></td>
<td>Years living with HIV</td>
<td>Continuous (2-30)</td>
</tr>
<tr>
<td></td>
<td>Feel sick or not from HIV</td>
<td>Very/Somewhat sick (1)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Not at all sick (0)</td>
</tr>
<tr>
<td></td>
<td>Current HIV-related medical problems</td>
<td>Yes (1), No (0)</td>
</tr>
<tr>
<td>Communication</td>
<td>Disclosed to children (1st recode)</td>
<td>All or some (1), None (0)</td>
</tr>
<tr>
<td></td>
<td>Frequency scale sum</td>
<td>Continuous (9-36)</td>
</tr>
<tr>
<td></td>
<td>Self-efficacy scale sum</td>
<td>Continuous (9-36)</td>
</tr>
<tr>
<td></td>
<td>Importance scale sum</td>
<td>Continuous (12-36)</td>
</tr>
<tr>
<td></td>
<td>Active strategies scale sum</td>
<td>Continuous (4-16)</td>
</tr>
<tr>
<td></td>
<td>Passive strategies scale sum</td>
<td>Continuous (3-12)</td>
</tr>
<tr>
<td></td>
<td>HIV-related stress scale sum</td>
<td>Continuous (9-32)</td>
</tr>
</tbody>
</table>

Note. Table contains 21 variables.

Model #1: Frequency of communication

All independent variables listed in Table 31 were included as predictors in the model for frequency of communication, with the exception of using passive strategies and HIV-related
stress. These variables were not included since they were not found to be significantly correlated with frequency of communication in the correlation matrix (previously presented in Table 26).

Results of the final multiple linear regression model are detailed in Table 32.

Table 32

*Final Model for Frequency of Communication*

<table>
<thead>
<tr>
<th>Variable</th>
<th>Unstandardized Coefficients</th>
<th>Standardized Coefficients</th>
<th>t</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Constant</td>
<td>-2.134</td>
<td>-----</td>
<td>-.643</td>
<td>.522</td>
</tr>
<tr>
<td>Employed</td>
<td>-2.153</td>
<td>-.139</td>
<td>-1.687</td>
<td>.095</td>
</tr>
<tr>
<td>No. children 10-18</td>
<td>1.111</td>
<td>.129</td>
<td>1.691</td>
<td>.095</td>
</tr>
<tr>
<td>Current HIV-related medical problems</td>
<td>2.530</td>
<td>.156</td>
<td>2.042</td>
<td>.044*</td>
</tr>
<tr>
<td>Self-efficacy</td>
<td>.474</td>
<td>.358</td>
<td>4.254</td>
<td>.000*</td>
</tr>
<tr>
<td>Active strategies</td>
<td>1.095</td>
<td>.481</td>
<td>5.426</td>
<td>.000*</td>
</tr>
</tbody>
</table>

*Note.* Analysis based on 85 cases. Adjusted \( R^2 = .534 \). *= \( p < .05 \). The final model was significant (\( F(5,79) = 20.271, \ p < .0001 \)). Altogether, the predictor variables accounted for 53.4\% of the variance in frequency of communication scores for parents in this sample. Only three predictors were statistically significant at the \( \alpha < .05 \) level. These included having current HIV-related medical problems, self-efficacy, and using active strategies. Two other variables, being employed and the number of children between ages 10 and 18, remained in the final model but were not statistically significant.

Overall, this model indicates that parents who reported having current HIV-related medical problems, high self-efficacy, and reported using active strategies to talk about prevention were more likely to report communicating frequently with adolescents about HIV and HIV prevention.
For example, having current HIV-related medical problems predicted an average increase of 2.53 points in parental frequency score.

**Model #2: Disclosure of HIV Status to Children**

Logistic regression was used to investigate variables that might be associated with the extent to which parents disclosed their HIV status to their children. Two dummy variables were created to serve as dependent variables. One of these variables separated parents into those who had disclosed to “all or some” of their children versus “none” of their children (1st recode). The other separated parents into those who had disclosed to “all” of their children versus “some or none” of their children (2nd recode). All predictors except for using passive strategies and HIV-related stress were included in the models. Results of the final multiple logistic regression models are detailed in Table 33 and Table 34.

Table 33

*Final Model for Disclosure to All/Some versus None of Children (1st Recode)*

<table>
<thead>
<tr>
<th>Variable</th>
<th>B</th>
<th>SE</th>
<th>Wald $\chi^2$</th>
<th>P value</th>
<th>Odds Ratio</th>
<th>95% C.I. for Odds Ratio</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>.132</td>
<td>.054</td>
<td>5.967</td>
<td>.015</td>
<td>1.142</td>
<td>1.027 - 1.270</td>
</tr>
<tr>
<td>Separated from child</td>
<td>-1.708</td>
<td>.835</td>
<td>4.188</td>
<td>.041</td>
<td>.181</td>
<td>.035 - .930</td>
</tr>
<tr>
<td>Self-efficacy</td>
<td>.172</td>
<td>.059</td>
<td>8.391</td>
<td>.004</td>
<td>1.187</td>
<td>1.057 - 1.333</td>
</tr>
<tr>
<td>Constant</td>
<td>-8.294</td>
<td>3.055</td>
<td>7.370</td>
<td>.007</td>
<td>.000</td>
<td></td>
</tr>
</tbody>
</table>

*Note.* Analysis based on 85 cases.

The final model was significant ($\chi^2=17.910$, df=3, p <.0001). Altogether, the predictor variables accounted for between 19.0% (Cox and Snell R squared) and 32.1% (Nagelkerke R squared) of the variance in disclosure for parents in this sample and classified 83.5% of cases correctly. Only three predictors were statistically significant in this model. These included age, separated from child, and self-efficacy. The strongest predictor of disclosing to children was
self-efficacy, with an odds ratio of 1.19. A one point increase in self-efficacy predicted a 1.19 increase in the odds of parents disclosing to “all or some” versus “none” of their children. This indicates that parents who disclosed to “all or some” of their children were more likely to have high self-efficacy compared to parents who disclosed to “none” of their children, controlling for all other factors in the model. The odds ratio for being separated from child was less than one, indicating that parents who reported having been separated from their children at some point in time were less likely to report disclosing their status to “all or some” of their children.

Overall, this model indicates that parents who were older and had higher self-efficacy were more likely to report disclosing their HIV status to their children. In contrast, parents who reported being separated from their child were less likely to report disclosing their HIV status.

The above analysis was repeated for the second disclosure variable (2nd recode), which compared parents who had disclosed to “all” of their children against those who had disclosed to “some or none” of their children. The final model is reported in Table 34.

Table 34

<table>
<thead>
<tr>
<th>Variable</th>
<th>B</th>
<th>SE</th>
<th>Wald χ²</th>
<th>P value</th>
<th>Odds Ratio</th>
<th>95% C.I. for Odds Ratio</th>
<th>Lower</th>
<th>Upper</th>
</tr>
</thead>
<tbody>
<tr>
<td>Employment status</td>
<td>-1.151</td>
<td>.600</td>
<td>3.684</td>
<td>.055</td>
<td>.316</td>
<td>.098</td>
<td>1.025</td>
<td></td>
</tr>
<tr>
<td>Yrs. living with HIV</td>
<td>.120</td>
<td>.053</td>
<td>5.138</td>
<td>.023</td>
<td>1.128</td>
<td>1.016</td>
<td>1.251</td>
<td></td>
</tr>
<tr>
<td>Self-efficacy</td>
<td>.087</td>
<td>.050</td>
<td>3.063</td>
<td>.080</td>
<td>1.091</td>
<td>.990</td>
<td>1.202</td>
<td></td>
</tr>
<tr>
<td>Active strategies</td>
<td>.201</td>
<td>.092</td>
<td>4.785</td>
<td>.029</td>
<td>1.222</td>
<td>1.021</td>
<td>1.463</td>
<td></td>
</tr>
<tr>
<td>Constant</td>
<td>-5.352</td>
<td>1.709</td>
<td>9.805</td>
<td>.002</td>
<td>.005</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Note. Analysis based on 85 cases.

The final model was significant ($\chi^2 = 19.624$, df=4, p=.001). Altogether, the predictor variables accounted for between 20.6% (Cox and Snell R squared) and 28.1% (Nagelkerke R
squared) of the variance in disclosure for parents in this sample and classified 69.4% of cases correctly. Only two predictors were statistically significant in this model. These included years living with HIV and active strategies. Two other variables, employment status and self-efficacy, remained in the final model but were not significant at the α<.05 level. The strongest significant predictor of disclosing to children was using active strategies, with an odds ratio of 1.22. This indicates that each point increase on the active strategies scale predicted a 1.22 increase in the odds of disclosing to “all” versus “some or none” of their children, controlling for all other factors in the model. Similarly, the odds ratio for years living with HIV was 1.13, indicating that each point increase in using active strategies predicted a 1.13 increase in the odds of parents disclosing their status to “all” of their children. Overall, this model indicates that parents who used more active strategies and had been living with HIV for longer were more likely to report disclosing their HIV status to all of their children.

**Model #3: HIV-Related Stress**

All independent variables listed in Table 31 were included as predictors in the model for HIV-related stress except for frequency, self-efficacy, importance, and active strategies. These variables were not included since they were not found to be significantly correlated with HIV-related stress in the correlation matrix (previously presented in Table 26). Results of the final multiple linear regression model are detailed in Table 35.
Table 35

Final Model for HIV-Related Stress

<table>
<thead>
<tr>
<th>Variable</th>
<th>Unstandardized Coefficients</th>
<th>Standardized Coefficients</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>B</td>
<td>SE</td>
</tr>
<tr>
<td>Constant</td>
<td>16.541</td>
<td>2.384</td>
</tr>
<tr>
<td>Education level</td>
<td>4.302</td>
<td>1.507</td>
</tr>
<tr>
<td>Yrs. living with HIV</td>
<td>-.382</td>
<td>.123</td>
</tr>
<tr>
<td>Passive strategies</td>
<td>1.132</td>
<td>.295</td>
</tr>
</tbody>
</table>

*Note. Analysis based on 85 cases. Adjusted $R^2 = .309$. *= p<.05.*

The final model was significant ($F_{(3,81)}=13.517$, $p = .000$). Altogether, the predictor variables accounted for 30.9% of the variance in HIV-related stress scores for parents in this sample. Only three predictors were statistically significant at the $\alpha <.05$ level. These included education level, number of years living with HIV, and using passive strategies.

Overall, this model indicates that parents who reported having a high school education or above and using passive strategies were more likely to report higher levels of HIV-related stress. For example, having a high school education or above predicted an average increase of 4.302 points in parental HIV-related stress score. Conversely, parents who had been living with HIV for longer reported less HIV-related stress. Each additional year living with HIV predicted an average decrease of .348 points in HIV-related stress.

Model #4: Active Strategies

All independent variables listed in Table 31 were included as predictors in the model for using active strategies except for importance, passive strategies, and HIV-related stress. These variables were not included since they were not found to be significantly correlated with using
active strategies in the correlation matrix (previously presented in Table 26). Results of the final multiple linear regression model are detailed in Table 36.

Table 36

**Final Model for Active Strategies**

<table>
<thead>
<tr>
<th>Variable</th>
<th>Unstandardized Coefficients</th>
<th>Standardized Coefficients</th>
<th>t</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Constant</td>
<td>3.838</td>
<td>-----</td>
<td>3.806</td>
<td>.000*</td>
</tr>
<tr>
<td>Employment status</td>
<td>2.058</td>
<td>.301</td>
<td>3.722</td>
<td>.000*</td>
</tr>
<tr>
<td>Frequency</td>
<td>.253</td>
<td>.575</td>
<td>7.106</td>
<td>.000*</td>
</tr>
</tbody>
</table>

*Note. Analysis based on 85 cases. Adjusted R² = .464. *= p<.05.*

The final model was significant (F(2,82) = 37.356, p = .000). Altogether, the predictor variables accounted for 46.4% of the variance in active strategies scores for parents in this sample. Only two predictors were statistically significant at the α <.05 level. These included employment status and frequency of HIV prevention communication.

Overall, this model indicates that parents who reported currently having an employer and who reported more frequently discussing HIV and HIV prevention were more likely to report using active strategies when talking to adolescents. For example, having a current employer predicted an average increase of 2.058 points in parental active strategies score. Frequency had a lesser effect, with each additional point on the frequency scale predicting an average increase of .253 points on the active strategies scale.

**Model #5: Passive Strategies**

All independent variables listed in Table 31 were included as predictors in the model for using passive strategies except for frequency, self-efficacy, importance, and active strategies. These variables were not included since they were not found to be significantly correlated with
using passive strategies in the correlation matrix (previously presented in Table 26). Results of the final multiple linear regression model are detailed in Table 37.

Table 37

*Final Model for Passive Strategies*

<table>
<thead>
<tr>
<th>Variable</th>
<th>Unstandardized Coefficients</th>
<th>Standardized Coefficients</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>B</td>
<td>SE</td>
</tr>
<tr>
<td>Constant</td>
<td>-.191</td>
<td>1.510</td>
</tr>
<tr>
<td>Age</td>
<td>.068</td>
<td>.029</td>
</tr>
<tr>
<td>Previous sexual abuse</td>
<td>1.407</td>
<td>.613</td>
</tr>
<tr>
<td>Feel sick from HIV</td>
<td>-.844</td>
<td>.484</td>
</tr>
<tr>
<td>HIV-related stress</td>
<td>.156</td>
<td>.034</td>
</tr>
</tbody>
</table>

*Note.* Analysis based on 85 cases. Adjusted $R^2 = .252$. *= p<.05.*

The final model was significant ($F_{(4,80)}=8.058$, $p = .000$). Altogether, the predictor variables accounted for 25.2% of the variance in passive strategies scores for parents in this sample. Only three predictors were statistically significant at the $\alpha <.05$ level. These included parental age, previous sexual abuse, and HIV-related stress. One other predictor, feeling sick from HIV, was included in the final model but was not statistically significant in this sample. Overall, these results indicate that parents who were older, reported previous sexual abuse during their interview, and had higher HIV-related stress scores were more likely to report using passive strategies when talking to adolescents. For example, previous sexual abuse predicted an average increase of 1.407 points in parental passive strategies score.

**Model #6: Effective versus Ineffective Strategies**

Logistic regression was used to investigate variables that might be associated with parental use of effective versus ineffective communication strategies. Based upon the literature review
(see Chapter 2), high use of active strategies was considered to be effective. A median split on the active strategies scale was conducted to divide parents into those who had high versus low use of active strategies. Parents who fell at the median of the scale were included in the low strategies group. A similar variable was created for parents who used passive strategies, dividing them into high versus low passive strategy users. A variable for effective versus ineffective communication was then created based on parents who had a high use of active strategies (regardless of their level of passive strategies). Thus, parents who had high use of active strategies and high use of passive strategies, as well as parents who had high use of active strategies and low use of passive strategies, were counted as using effective strategies. Parents who had low use of active strategies and low use of passive strategies, or parents who had low levels of active but high levels of passive strategies, were counted as using ineffective strategies. All predictors were included in the model except for using active strategies, using passive strategies, and the perceived importance scale. Results of the final multiple logistic regression model is presented in Table 38.

Table 38

<table>
<thead>
<tr>
<th>Variable</th>
<th>B</th>
<th>SE</th>
<th>Wald $\chi^2$</th>
<th>P value</th>
<th>Odds Ratio</th>
<th>95% C.I. for Odds Ratio</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Lower</td>
</tr>
<tr>
<td>Age</td>
<td>.077</td>
<td>.042</td>
<td>3.395</td>
<td>.065</td>
<td>1.080</td>
<td>.995</td>
</tr>
<tr>
<td>Employment status</td>
<td>1.289</td>
<td>.624</td>
<td>4.269</td>
<td>.039</td>
<td>3.630</td>
<td>1.069</td>
</tr>
<tr>
<td>Frequency</td>
<td>.189</td>
<td>.059</td>
<td>10.449</td>
<td>.001</td>
<td>1.208</td>
<td>1.077</td>
</tr>
<tr>
<td>Self-efficacy</td>
<td>.134</td>
<td>.083</td>
<td>2.607</td>
<td>.106</td>
<td>1.143</td>
<td>.972</td>
</tr>
<tr>
<td>Constant</td>
<td>4.734</td>
<td>3.856</td>
<td>14.601</td>
<td>.000</td>
<td>.000</td>
<td>.000</td>
</tr>
</tbody>
</table>

*Note.* Analysis based on 85 cases.
The final model was significant ($\chi^2 = 38.984$, df=4, $p = .000$). Altogether, the predictor variables accounted for between 36.8 (Cox and Snell R squared) and 50.3% (Nagelkerke R squared) of the variance in effective strategies for parents in this sample and classified 81.2% of cases correctly. Two predictors were statistically significant at the $\alpha<.05$ level in this model. These included employment status and frequency of communication. Two other variables, age and self-efficacy, remained in the final model but were not significant at the $\alpha<.05$ level. The strongest significant predictor of using effective strategies was employment status, with an odds ratio of 3.63. Thus, parents who reported a current employer were almost four times more likely to use effective strategies when compared to parents who did not report a current employer. Overall, this model indicates that parents who were employed and reported frequent HIV prevention conversations were more likely to report using effective strategies to discuss HIV prevention.

**Chapter Summary**

The results presented above detailed the quantitative findings of the study. Descriptive statistics were provided for scales examining HIV disclosure, frequency, self-efficacy, parental perceived importance of communication, parental use of active and passive strategies, and HIV-related stress. Hypothesis testing identified limited disclosure as a barrier to HIV prevention conversations, but failed to find any significant association between frequency of communication and HIV-related stress. Hypothesis testing also failed to find any significant association between parental mode of infection (sex or drugs) and frequency of conversation about sex or drugs. Finally, linear and logistic regression models provided exploratory analyses on possible demographic, family, and health-related predictors of frequency, disclosure, active versus
passive strategies, effective versus ineffective strategies, and HIV-related stress. The following chapter (Chapter 6) will discuss the broader implications of these findings.
CHAPTER 6: DISCUSSION

Chapter Overview

As Antle et al. (2001) assert, “parenting when living with HIV/AIDS requires attention from clinicians and researchers in a range of settings” (p.167). Consistent with Antle et al.’s emphasis on the multidisciplinary nature of HIV care, the findings of this study may be relevant to HIV/AIDS researchers, case managers, social workers, psychologists, physicians, or any health-related professional who is part of an HIV care team. The purpose of this chapter is to interpret key findings of the study as a whole (both the qualitative and quantitative components) and discuss the implications of these findings for future research and behavioral interventions. As such, the chapter is broken into the following six sections: 1) summary of the study, 2) comparison to previous research, 3) theoretical implications, 4) practical implications, 5) study limitations and strengths, and 6) future research directions.

Summary of Study

The main goal of this study was to investigate the strategies parents living with HIV/AIDS use to communicate with adolescents about HIV prevention, as well as explore facilitators and barriers to having prevention conversations. The study consisted of both qualitative and quantitative components. Parents living with HIV/AIDS who had adolescents between the ages of 10 and 18 were interviewed and filled out a brief questionnaire. Guided by theories of health behavior (the UTB) and health communication (the NMIC), interview findings summarized what parents perceived to help and/or hinder conversation, what strategies they used to talk about HIV and HIV prevention with adolescents, and which strategies they perceived to be effective. Similarly, questionnaire findings summarized parents’ self-reports of how frequently they discussed prevention information with their children, which topics were
commonly discussed, parental strategies for bringing up prevention information (including active versus passive strategies), and parental reports of current HIV-related stress.

**Qualitative Results**

Qualitatively, parents reported a number of factors that helped or hindered their communicative encounters with adolescents, as well as many strategies they had either personally used or believed would be effective for talking about HIV prevention. The three most frequently reported facilitators included utilizing support, focusing on the benefits of communication, and the role of being HIV+ in encouraging prevention conversations. The three most frequently cited barriers included fear, living in denial, and lack of a communicative role model. Parents’ beliefs about what constituted effective communication overlapped considerably with what they identified as facilitating factors. Thus, most factors that made it easier to communicate were perceived to be effective, whereas most factors that made it more difficult to communicate were viewed as less effective communication strategies.

Frequently cited successful communication practices included enlisting support, using an effective talking style (i.e., being open, “like normal,” and supportive), and instilling family values and expectations during conversations. Similarly, top ineffective communication practices included using an ineffective talking style (i.e., being too harsh, blunt, awkward, or unrealistic), avoiding the conversation altogether, and giving low quality information (inaccurate or limited in nature). Overall, the interviews reflected parents who had discussed a variety of prevention-related topics with adolescents, often finding age-appropriate and creative ways to engage in conversation.

**Quantitative Results**

Quantitatively, parents also reported frequently (sometimes or often) talking to adolescents about a multitude of prevention-related topics (sex, drugs, condoms, protection from
STDs, pregnancy, and AIDS). Topics talked about less often included STD or HIV testing and discussions surrounding a parent’s own HIV status. As a whole, parents thought it was important to talk about prevention topics and had high levels of confidence they could explain these topics to their children. Again, parents’ confidence levels dropped slightly when it came to discussing their own HIV status, emphasizing the complex nature of living and coping with HIV infection and the continued need for programs that assist with HIV disclosure. Finally, parents reported on the strategies they used to discuss prevention information, indicating a moderate use of active strategies (the parent initiating conversation) and low use of passive strategies (the parent relying on others to initiate conversation).

In terms of quantitative barriers to conversation, both limited disclosure and HIV-related stress were hypothesized to negatively impact the frequency of HIV prevention communication. These barriers were examined two separate ways: (1) initial statistical hypothesis testing and (2) subsequent exploratory regression modeling. Hypothesis testing results confirmed limited disclosure as barrier to prevention communication in this sample. When entered into a linear regression model among other variables, however, limited disclosure to children did not significantly predict frequency of conversations (see Table 3). This indicates that, even though disclosure had a statistically significant impact on communication about prevention, other variables played a stronger role in determining frequency of communication in this sample. The second hypothesized barrier, HIV-related stress, was not identified as a barrier to conversation in hypothesis testing or in regression models. Thus, even though some parents reported avoiding HIV-related thoughts, this did not preclude them from discussing prevention information with adolescents.
Finally, a variety of variables were investigated as potential predictors of disclosure, HIV-related stress, active and passive strategies, and effective versus ineffective conversation. For example, parents who were older, reported previous sexual abuse, and had higher HIV-related stress scores were more likely to report using passive strategies when talking to adolescents. Although HIV-related stress was not related to frequency of conversation, it was associated with using passive communication strategies.

**Comparison with Previous Research**

As detailed in the literature review (see Chapter 2), prevention efforts for parents living with HIV/AIDS have been relatively uncommon. Previous research has questioned the effect of a parent’s HIV status on parent-adolescent communication and, ultimately, on adolescent risk for HIV infection (Chabon & Futterman, 1999; Chabon et al., 2001; O’Sullivan et al., 2005). To the researchers’ knowledge, only two previous studies have investigated parents’ motivation and reluctance to communicate about HIV prevention in families already affected by HIV/AIDS (Cederbaum, 2009; O’Sullivan et al., 2005). One of these studies (Cederbaum, 2009) focused on mothers who had already disclosed their HIV status to their daughters and therefore did not examine the impact of disclosure on communication about HIV prevention. The other (O’Sullivan et al., 2005) reported that moms of kids who knew their mother’s HIV status were more likely to report discussing HIV. This study builds upon these previous studies in the following ways: (1) it includes parents who had disclosed their HIV status to “none,” “some,” or “all” of their children, (2) it examines parental communication strategies from both a public health and communication perspective, and (3) it includes both mothers and fathers living with HIV/AIDS.
The Role of Being HIV+

O’Sullivan et al. (2005) suggest that parents living with HIV/AIDS discuss prevention topics with adolescents often and this study supports such findings. Overall, parents in this sample believed their HIV status enhanced communication about prevention with their children. Parenting while living with HIV provided a heightened sense of HIV risk, increased HIV-related knowledge, and additional opportunities to discuss HIV-related topics. Many parents were able to take advantage of HIV-related resources and programs to provide their children and families with what they perceived to be high quality information about HIV prevention. Similar to findings from Hutchinson & Cederbaum (2004), these data suggest that HIV status can be used to create additional “teachable moments” for children in HIV-affected families.

Whereas parents in this study reported high levels of prevention communication, it should be noted that frequent communication does not always translate into adolescent intentions or behaviors. Indeed, Cederbaum (2009), who examined sexual communication in mother-daughter dyads of both HIV+ and HIV- families, found that maternal HIV status was not a significant predictor of parent teen sexual risk communication. Maternal HIV status did significantly predict daughters’ intentions to abstain from sex, as well as their beliefs about the negative consequences of sex and their perceptions of condom use. Even though daughters in the study had positive intentions of abstaining from sex, they were more likely than daughters of HIV- mothers to report ever having had sex.

Studies such as the one above do not negate the influence of parent-adolescent communication, but do indicate a need for increased attention to structural and community-level factors when examining parent-adolescent communication. It may be that parental communication is still protective in families affected by HIV/AIDS, but that these families are more likely to be dealing with environmental and social factors that increase their risk for early
onset of sexual activity, drug use, and HIV infection. Such factors could counteract the positive influence of parent-adolescent communication. According to Cederbaum (2009), HIV+ mothers were more likely to report sexual abuse, substance abuse, and a younger age at first sex than HIV- mothers. The complex family histories and living situations of parents living with HIV/AIDS places increasing attention on the role of clinical providers in understanding client backgrounds and helping infected parents to accept and cope with past behaviors, stressors, and adverse life events.

It may also be that HIV+ and HIV- parents report similar frequencies of communication, but differ in the types of strategies and messages they use with adolescents. One of the exploratory regression models in this study indicated that HIV+ parents who used active strategies, had current HIV-related medical problems, and high self-efficacy were more likely to report frequent conversations. This model complements what is currently known in the broader parent-adolescent communication literature, mainly that interactive strategies are considered effective (DiIorio et al., 2008) and that self-efficacy is known to be a powerful predictor of the frequency of health behaviors (Guilamo-Ramos et al., 2008). In addition, research on HIV-infected parents indicates that those with poorer health disclose more information about their HIV status (Lee & Rotheram-Borus, 2002; Vallerand, Hough, Pittiglio, & Marvicsin, 2005). The following section addresses the results discussed above as per their implications for public health and health communication theory.

**Theoretical Implications**

**Implications for the UTB**

The UTB outlined five factors thought to be immediate determinants of whether or not a parent intends to discuss HIV prevention with adolescents. Those five factors were (1) parental perceived advantages versus disadvantages, (2) social norms, (3) maintaining self-image,
(4) positive emotional reaction, and (5) high degree of self-efficacy. Proponents of the UTB also advocated exploratory research to discern how the general theory could be applied to specific communities of interest. This study affirmed the importance of all of these factors in parental decisions to engage in conversation, as well as identified the relevance of these factors to parents living with HIV/AIDS. The implications for each factor and how it might be adapted for parents living with HIV/AIDS will be considered in turn.

**Parental advantages versus disadvantages.**

One of the top three factors that made it easier for parents to talk about prevention was focusing on the benefits of conversation. Specific benefits of conversation that encouraged parents to talk included the desire to protect their children from harm and to fulfill their parental duty. This suggests that interventions highlighting the role of parents as protectors and central providers of adolescent health information would have great appeal for parents in this sample. Interestingly, this finding applied to mothers as well as fathers. Though mothers are often regarded as the primary source of sexual information for adolescents (Miller, Kotchick et al., 1998), mothers and fathers were equally likely to report frequent communication about prevention with adolescents in this study.

This may in part be attributed to the unique structure of many families affected by HIV/AIDS. A few of the fathers in this study had significant others or spouses who died of AIDS-related complications. As a result, they had sole custody of their children and were the primary sexual communicator in the family. In several other cases, fathers were homosexual or bisexual and wanted to be able to openly discuss topics they had not felt comfortable discussing in their families growing up. Still other fathers were employed as social workers, HIV case managers, or peer mentors and may have had HIV-related training that increased their
confidence and motivation for discussing prevention information with others. Regardless of the reason that fathers in this sample were active in providing adolescent health information, the results indicate a need to design future programs that encourage fathers to communicate with adolescents and provide them with guidance on how to talk to adolescents about potentially sensitive topics.

While many parents identified general benefits of parent-adolescent communication (e.g., protecting their children from harm) and had the confidence to carry out a conversation, some parents still seemed uncertain about the effectiveness of parent-child communication in influencing their child’s beliefs and/or behaviors. Programs that emphasize specific, research-based benefits of parent-adolescent communication (e.g., delaying the onset of sexual activity, decreasing risky behavior, and promoting safer sex) may help parents realize the influence they can have on adolescent intentions and behaviors and encourage them to keep communicating. Many of these suggestions are already utilized in existing parent-adolescent communication programs and could be tailored to families affected by HIV/AIDS with relatively little effort.

The most frequent barrier identified by parents was fear about the potential negative outcomes of prevention conversations. When asked to identify specific fears and disadvantages, parents spoke of four main fears: (1) concern about the welfare of their child, (2) fear of changed relationships (3) fear of a damaged self-image, and (4) fear of an awkward or uncomfortable conversation. These barriers are strikingly similar to parental fears about disclosure one’s HIV status to children (Murphy, 2008), indicating the close association that exists between disclosure conversations and prevention conversations in many parents’ minds.

Taken together, these data suggest that programs addressing disclosure could be an important step toward encouraging parent-child communication about HIV and HIV prevention.
For example, parents who have disclosed their status may feel more comfortable bringing up HIV-related topics with their children and may be likely to do so frequently. However, it is also important to emphasize that prevention conversations and disclosure conversations can occur as separate entities -- a parent does not need to wait to disclose his/her status in order to bring up general HIV prevention information. Many parents in this sample successfully used conversations about what HIV was and how it was transmitted to set the groundwork for a later conversation where they disclosed their status to their children. This lends evidence to the view of disclosure as a process rather than a one-time isolated conversation (Murphy, 2008).

**Social norms.**

In their integrated model, Guilamo-Ramos et al. (2008) found that four of the five UTB factors were significantly correlated with parent-adolescent sexual communication. The only factor not significantly correlated was social norms. The concept of social norms included perceptions about how many other parents had talked with their children about sex and how much important others would approve of parents talking to their child(ren) about sex. Interestingly, only 6 parents (7%) in this sample mentioned that conflicting opinions of family members or friends made it difficult to talk with adolescents about prevention. What seemed to stand out more in parents’ minds was the community stigma related surrounding HIV/AIDS.

Close to 20% of parents provided examples where community-level norms such as stigma, stereotyping, and lack of knowledge about HIV had impacted the ease with which they could conduct conversations about prevention. This suggests that the influence of community stigma (or perceived community stigma) could be an important area for future study, particularly for families already affected by HIV/AIDS. Whereas parents not personally affected by HIV may not be deterred by HIV-related stereotypes or feel the need to address stigma when
discussing HIV, parents in this sample specifically avoided HIV-related topics of conversation with their children because their communities portrayed HIV+ individuals in a negative light. These findings reiterate the need for interventions that identify strategies for parents and adolescents to manage and cope with HIV-related stigmatizing experiences. They also indicate a larger, community-level need to raise awareness of the changing epidemiology of HIV infection and to continue to raise awareness of HIV transmission.

**Maintaining self-image.**

As discussed under perceived advantages and disadvantages of communication, one of the four major fears of parents in this sample was fear of a damaged self-image. Maintaining a positive self-image may be particularly difficult for individuals living with HIV/AIDS, as many suffer from low self-esteem, depression, are trying to overcome past addictions, have experienced HIV-related stigma, and/or may still be adjusting to their identity as an individual living with HIV (Antle, Wells, Goldie, DeMatteo, & King, 2001; Lawless, Kippax, & Crawford, 1996; Moneyham et al., 1996; Murphy et al., 2002). On the one hand, parents wanted to protect their children from harm and felt it was their responsibility to talk openly with them about HIV prevention. On the other hand, some were concerned that conversations about HIV prevention may lead to a discussion about their own HIV status, as well as questions about how they were infected. These parents feared that, if they shared their personal histories with their children, they risked being thought of as dirty, promiscuous, a drug addict, and/or an irresponsible parent – all of which could be severely damaging to their self-image and how their children viewed them. In addition, parents who were prostitutes, drug users, and/or homosexual or bisexual may have faced a layering effect, whereby revealing their HIV status also revealed other potentially damaging aspects of their identity (Herek, 1999). These findings suggest that communication
Interventions for parents living with HIV/AIDS need to be sensitive to all of these concerns. Interventions that build upon parental strengths and include measures to increase parental self-image and self-esteem may be especially beneficial in fostering family communication in these families.

**Emotional reaction.**

Approximately 25% of parents mentioned that employing an adaptive or effective talking style facilitated prevention conversations with adolescents. These parents spoke of the effectiveness of being open and honest, supportive and understanding, and using humor and joking. They also spoke of the importance of being able to appropriately match one’s emotional tone and talking style to the nature of the conversation. For example, parents who were bringing up prevention information for the first time seemed more likely to use humor and joking to initiate conversation, whereas those who were confronting their children about engaging in a potentially risky behavior seemed more likely to use a direct but honest tone. While parents generally strove to create a comfortable and positive atmosphere for discussing prevention information, some families also acknowledged the reality that topics like sex, drug use, and HIV were never going to be easy topics to discuss with adolescents. Altogether, these results suggest the need for communication skills training programs that allow parents to practice communication techniques in response to increasing levels of emotional stimuli. For example, parents could be given prompts where they practiced discussing risk behavior in an emotionally neutral situation and work up to addressing risk behavior in a potentially confrontational or more emotional context. For parents living with HIV/AIDS, these highly emotional contexts might include issues surrounding HIV disclosure, HIV-related stigma, their children engaging in HIV risk behavior, and/or figuring out what to reveal about how they were personally infected.
Self-efficacy.

Data from the questionnaire identified self-efficacy as the most influential predictor of frequent conversations in this study. In general, parents in this sample had high levels of self-efficacy and may have taken this characteristic for granted. Consistent with this assertion, only 15% of parents identified uncertainty about how to discuss HIV prevention as a barrier to communication in their interview. Instead, parents focused on components that might help build self-efficacy, such as being knowledgeable about HIV and having recurring conversations. In addition, they noted the importance of family upbringing and communicative role models in making conversations easier to broach. Finally, they discussed the tremendous impact of having support had on their ability to communicate. Results here indicate that, though parents did not identify self-efficacy as a concept, they listed a variety of factors that are likely associated with increased self-efficacy (knowledge, practicing the skill of interest over time, role modeling, and having support) as being beneficial to prevention communication.

Implications for the NMIC

In addition to the UTB’s focus on what might predict whether or not parents engaged in conversation, the NMIC was included as a way to analyze and organize prevention conversations that had already occurred between parents and adolescents. The three main tenets of the NMIC included (1) examining the meaning of HIV prevention conversations to parents in this sample, (2) evaluating what conversations parents believed to work in what contexts, and (3) explaining why some conversations were perceived as being effective versus ineffective or less effective. This section explores the relevance of study results to the main tenets of the NMIC.

Meanings of HIV Prevention Communication.

The NMIC acknowledges that meanings are socially constructed and can vary by context and population. In line with the NMIC, this study investigated the meanings parents living with
HIV/AIDS ascribed to HIV prevention communication or “what it meant” to these parents to talk about ways to prevent HIV. As detailed in the qualitative results chapter (see Chapter 4), parents in this sample expanded the sometimes narrowly construed definition of HIV prevention to include topics that may have special relevance for families affected by HIV/AIDS. These topics included household safety precautions, issues of trust and vulnerability, and the focus on acceptance of people living with HIV or AIDS. Findings from this study indicate the need to work with an expansive and multi-faceted definition of HIV prevention communication when designing programs for families affected by HIV/AIDS. While prevention topics like safe sex and avoiding drug use are important to include, content about how to clean up blood and body fluids in the household, how to use universal precautions, and reminders about which household items could feasibly transmit the virus should also be incorporated. In addition, parents should be provided with constructive ways to talk about trust in relationships. This might include messages that address the risks of being too trusting of others, but don’t cause adolescents to fear relationships or avoid trusting romantic partners altogether. Since many parents in this sample were separated from their child(ren) at some point in time, issues of building or re-building family trust would also be highly relevant. Finally, parents could benefit from practical advice on how to address the most common stereotypes about HIV in their community with their children. For many parents, the realization that HIV affected a wide variety of people came from attending HIV-related support groups, camps, or public awareness events. Thus, parents who were ready could be encouraged to take their adolescents along to HIV-related events as a means of fostering acceptance of individuals affected HIV/AIDS.
Evaluating what strategies work.

The final specific aim of the study (RQ#3) was to compare parents’ perceived effectiveness of various communication strategies to what current health communication/health behavior research deems effective parent-adolescent communication. As mentioned in the literature review (Chapter 2), most current evidence suggests that effective parent-adolescent conversations share the following characteristics:

- frequent
- timely (before the onset of sexual activity)
- comprehensive in nature (various topics discussed)
- good quality
- occur within supportive parent-child relationships
- high parental knowledge
- high parental confidence (self-efficacy)
- high parental comfort level
- open and direct conversations
- interactive conversations (adolescent and parent participate)

Parents in this sample echoed all of these sentiments, but also emphasized the importance of enlisting support, instilling values and expectations, and using personalized experience to highlight prevention within the context of a child’s own family, neighborhood, or community. Given that the most frequently identified means of effective conversation was enlisting support, researchers and clinicians should be encouraged to create and distribute resources to parents that offer suggestions on how to bring up topics like HIV transmission, HIV prevention, safe sex,
drug use, and homosexuality. Members of HIV care teams would be in an ideal position to distribute such resources, particularly HIV/AIDS case managers. These materials should include sample conversations from parents who have already had such talks. They should also encourage parents to think through what types of personal information they are willing to share with their adolescent, what family and cultural values they would like to include, and specific stories or examples they could use to illustrate those expectations or values. This strategic thinking should be done prior to initiating conversation. For parents who need additional help, public health programs, role playing with a mental health professional, or having a conversation with a mental health professional present could also be effective. Parents in this sample who used such strategies felt that they created a supportive and high quality conversational atmosphere.

It is important to note that, though parents emphasized that effective conversations were timely, there was no consistent age or time when parents thought talking should commence. A few parents incorporated age-appropriate prevention information from the time their children were four or five years old, whereas others thought “early” meant talking when adolescents were fifteen or sixteen years of age. Still others emphasized the importance of talking early only after one of their older children became pregnant or contracted an STI. This illustrates that even parents who are well aware of the risks of HIV infection can have difficulty identifying when to initiate conversation. Clinicians could play a critical role in encouraging parents to begin communication about sexual health prior to adolescent interest in sexual activity. In addition, future prevention programs could emphasize specific times or ages that might be appropriate to begin communicating about HIV risk and highlight for parents the average ages when youth in their community express interest in experimenting with sexual or drug activity. A couple of
parents suggested it might be useful for the school system to hold a meeting with parents before they began discussing HIV-related information with children in the classroom. This would allow parents to reinforce the content learned in the classroom, as well as tailor the information to their family, their belief systems, and their child’s personality.

Finally, parents gave explicit advice on how to be interactive during high quality prevention conversations. They indicated that an interactive conversation might begin with a simple back and forth exchange (in which the parent encouraged the adolescent to participate in conversation) and then include hands-on or visual examples such as pamphlets, brochures, media, or condom demonstrations. They also indicated that a quiz or check of how much information the child knew and/or was retaining was useful (either verbal, written, or as a game), as was checking in with the child about their thoughts and feelings about the discussion. Finally, they emphasized the importance of setting the stage for future conversations before the conversation ended. These five steps or guidelines for interactive conversation (back and forth exchange, using hands-on examples, quizzing child, checking in with child, and setting the stage for future conversations) could be incorporated into programs that aim to promote effective communication between parents and adolescents.

**Why some strategies are better.**

In general, parents favored strategies where they felt well-prepared and well-supported, could talk in an open or “like normal” atmosphere, and could tailor the conversation to a) their own beliefs and family values and b) their child’s age, interests, and personality. Parents also expressed a variety of sentiments and rationales for why certain strategies and atmospheres were better for communicating than others. For example, using support was seen as effective because it allowed parents to feel prepared and confident when talking about HIV with adolescents. This
may have been especially relevant for parents who lacked a communicative role model when they were growing up or who still had difficulty accepting their HIV status. Most parents derived a sense of comfort and reassurance from knowing they had the physical, social, and emotional resources necessary to deal with potentially sensitive topics of conversation. As one mother noted, using a therapist to disclose her status and discuss HIV prevention with her daughter lessened some of the pressure associated with the conversation, because she knew her therapist would cover any topics she forgot to bring up.

Similarly, parents appeared to prefer relaxed, friendly, or “like normal” conversational atmospheres because this allowed their adolescents to be more comfortable discussing HIV-related information. If children were comfortable, parents reasoned that they would a) pay more attention, b) be more likely to participate, and c) be more likely to share their thoughts and concerns, as well as be open to future conversations on similar topics. Though conversations were rarely perfect or completely comfortable, parents were able to use humor, “ease topics in,” and/or change their tone of voice when they deemed necessary to make the environment more relaxed. Conversations were also thought to be more effective over time (with repetition), as this allowed parents to reinforce their messages in new contexts and add new information to keep their adolescents interested.

Finally, parents emphasized the importance of tailoring conversations to their own family, cultural, and community values, as well as to their child’s age, interests, and personality. Tailoring communication to one’s values was seen as effective because it gave children much needed structure and guidelines and let them know what was expected of them within the context of their family, as opposed to some of the information they might get from their peer groups or within their communities. For example, parents were able to emphasize what constituted
allowable sexual activity in their family, what healthy romantic relationships might look like, the
importance of education and having future family and career goals, and the necessity of knowing
where their child was and who they were with at all times.

Tailoring communication to their child’s age, interests, and personality was viewed as
effective because it allowed parents to provide developmentally appropriate information in ways
that engaged their children in conversation. Overall, this highlights the importance of teaching
parents to use multiple strategies when discussing HIV risk with adolescents, to be flexible and
creative in their communication style, and to be able to move between different strategies within
the contexts of different situations. Many parents felt that general communication patterns
needed to be established before moving on to potentially uncomfortable topics like sexual
activity and drug use. Thus, they advocated that communication programs begin by encouraging
parents to experiment with conversational techniques on general topics and then move to
specialized sessions where parents learned to discuss potentially sensitive topics like HIV risk
and HIV disclosure.

**Practical Implications**

While the above sections highlight the relevance of study findings to the guiding
theoretical perspectives, attention will now be turned to implications for how members of HIV
care teams might intervene or adapt their current practices to better address the concerns of
families affected by HIV/AIDS.

**The Role of HIV Disclosure**

One finding especially relevant to members of HIV care teams is the potential role of
limited disclosure in hindering prevention communication. The bivariate evidence in this study
revealed that parents who had disclosed their HIV status to all of their children were more likely
to discuss HIV prevention than parents who had disclosed to some or none of their children.
Clinicians oftentimes advocate that HIV+ parents disclose their status to their children, for the benefit of the parent and the child (Armistead & Forehand, 1995; Zayas & Romano, 1994). Studies have found that mothers who disclose their status are less depressed and report greater family cohesion (Wiener, Battles, & Heilman, 1998). In addition, recent research suggests that parental disclosure of HIV status may have a protective effect on adolescent intention to abstain from sex (Cederbaum, 2009). Given the mounting evidence that disclosure of HIV status is beneficial to parents and children, along with the preliminary finding that limited disclosure can serve as a barrier to prevention conversations, HIV care teams should be reminded of their important work in helping parents to prepare for disclosure discussions with their families. Many HIV care teams are already familiar with helping clients through disclosure-related concerns and could be given additional materials that emphasize how to effectively incorporate prevention information into disclosure conversations, as well as how to use prevention conversations to set the tone for future disclosure conversations.

For parents who have not yet had prevention talks, it may be helpful for HIV care professionals to emphasize the ways other parents have been able to successfully use their HIV status to strengthen their parenting and communication skills. Whereas parenting while living with HIV/AIDS presented of host of stressors and challenges for parents in this sample, it also provided opportunities for increased communication and strengthened parent-child relationships.

The Need for Support

Another clinically relevant finding of this study is that parents indicated a great need and desire for support when talking about HIV and HIV prevention with their children. From providing educational resources to social and emotional support, HIV care teams are in an ideal position to address these parental needs and concerns. The large majority of the parents in this sample did not have a parent who talked to them about preventing STIs when they were growing
up, suggesting that clinicians and/or communication programs may especially useful for simulating conversations with clients to increase their confidence and communicative abilities. Given that parents in this study who reported high levels of HIV-related stress were also more likely to report using passive communication strategies, clinicians could teach parents techniques to manage their stress levels productively and focus on encouraging active and interactive communication strategies among these parents. It is worth noting that all of the major facilitators and barriers parents reported in this study are considered modifiable factors. As such, they are in an ideal position to be addressed by HIV support programs and care teams.

Finally, a number of parents in this sample reported previous adverse life events, such as sexual abuse, physical abuse, incarceration, periods of homelessness, and experiences of discrimination. Studies are steadily documenting the tremendous health consequences that events like these can have over the lifespan of individuals who experience them. For example, the Adverse Childhood Experiences (ACE) study is one of the largest studies to measure the impact of childhood stress (as measured by various forms of abuse, neglect, and household dysfunction) on health and social functioning. Results of the ACE study indicate that, the more childhood adverse events experienced, the more individuals are at risk for early onset of sex, multiple sexual partners, adolescent pregnancy, intimate partner violence, depression, alcohol abuse, and suicide attempts, among other factors (CDC, 2010b). Since these events are relatively common in families affected by HIV/AIDS, one way HIV care teams can be supportive of parents living with HIV/AIDS is to be sensitive to these past experiences. This includes providing a comfortable and non-stigmatizing atmosphere for discussing the past, being aware of the impact previous life events can have on health and social functioning, and providing HIV+
individuals with evidence-based strategies for managing their stress and anxiety surrounding these experiences.

**Study Limitations and Strengths**

**Limitations**

Though this study adds to a small but growing body of literature on how families with HIV communicate about HIV-related topics, a few main limitations must be kept in mind. First, the method for recruitment (non-probability sampling) limits the generalizability or external validity of the findings (Babbie, 2001). The sample size of 90, though small for quantitative studies and large for qualitative ones, was viewed as a compromise between both methodologies. Because this project aimed to conduct an in-depth exploration of sexual discussion strategies using multiple methods (interviews and questionnaires), larger numbers of participants would have been impractical. Furthermore, the goal of an exploratory and predominantly qualitative study of this nature is not to generalize across all parents living with HIV/AIDS, but instead to provide a variety of detailed and interesting avenues for further study. Similarly, since the majority of participants were African American, had been living with HIV for more than five years, and were relatively healthy, these results must be taken in context. Findings may not be applicable to other races/ethnicities, parents who have recently been diagnosed, or parents who have substantially more health-related problems than the ones who participated in this study.

Second, the study relied on self-report. It is possible that social desirability and/or recall bias may have come into play and that parents may not have accurately reported the strategies they use to discussion HIV prevention. To address concerns about social desirability, instrument questions were designed to be neutral in content and tone. Feedback was sought during the expert review and the preliminary focus group to make sure that potential participants felt comfortable completing the interview and questionnaire. Additionally, no names were attached
to the interview or the questionnaire and it was emphasized in the instrument instructions that participants should feel free to answer truthfully. To minimize recall bias, items on the questionnaire were limited to specific time periods (e.g., in the past six months, how often have you and your adolescent talked about sex?).

Finally, the study only assessed parental reports of HIV prevention discussions. Parental ratings, while important for elucidating parenting behaviors, are not always consistent with child ratings of similar phenomena (Paikoff & Collins, 1991). Many parents choose not to disclose their HIV status to their children (Green & Smith, 2004), however, and may have been hesitant to participate in studies where their children would also be asked about HIV and HIV prevention. To be sensitive to these concerns, only parents were included in this study. Nonetheless, in-depth information about parents’ motivations and potential difficulties discussing HIV prevention provide some of the first known data about how parents living with HIV broach prevention discussions with their adolescent children.

**Strengths**

Despite the above limitations, this study offered the following strengths: (1) substantive knowledge on a largely unexplored topic (strategies used for discussing HIV prevention with adolescents in HIV-affected families); (2) the expertise and commitment of a multidisciplinary research team (medical experts, behavioral experts, communication experts, mixed methods expert) and the ability of the researcher to integrate multiple disciplines and perspectives; (3) mixed methods nature of the study, which sought to both maintain consistency with measures previously used, while also complementing and elaborating on previous measures; (4) support from various clinical workers and HIV/AIDS organizations, such as social workers, case managers, and physicians (among others) with close ties to families affected by HIV/AIDS.
Overall, it is hoped that the findings of this study provide an important step towards forming effective communication interventions for parents living with HIV/AIDS and their children.

**Future Directions**

Keeping this study’s strengths and limitations in mind, there are a number of avenues for further study that arise as a result of study findings.

1. Future studies could use the qualitative information presented here to design and validate scales to measure the types of strategies that parents use to discuss HIV prevention. These scales could be compared in HIV+ and HIV- parent-child dyads.

2. Studies that examine the effectiveness of these conversational strategies in changing adolescent beliefs, intentions, or behaviors relating to adolescent sex and/or drug activity are also sorely needed.

3. Future studies could identify parental characteristics that may be associated with using passive versus active communication strategies, as well as develop evidence-based programs to encourage parents to focus on using active and interactive communication strategies with their children.

4. Measuring additional dimensions of HIV-related stress will also be important. Since this study measured only one aspect of HIV-related stress (i.e., subjective stress related to avoidance of HIV-related topics), future studies could investigate the role of other dimensions of HIV-related stress on HIV disclosure and HIV prevention communication. For example, some parents may have stress related to their physical functioning, perceived discrimination, or their stress may manifest as intrusive thoughts rather than avoidant thoughts about HIV and AIDS.
5. Future studies could explore the relationship between parental report of acceptance of HIV status, HIV-related stress, and extent of parental HIV disclosure/prevention conversations. It would be interesting to note whether or not stress and frequency of conversations decrease when acceptance levels increase.

6. The quantitative findings in this study (e.g., the association found between frequency of HIV prevention conversations and extent of parental HIV disclosure to children) should be examined in larger samples. Future studies could further investigate these preliminary associations by exploring potential covariates (including mediating, moderating, or confounding factors). Variables such as child gender, child age, and whether or not the family also has an HIV+ child could be included in these models.

7. Finally, additional studies could be used to create and validate more specific HIV disclosure scales. These scales might take into account which children are aware of the parent’s HIV status, when and how the child(ren) found out (e.g., from the parent, from another family member, from a health care professional, etc.), as well as the specifics of what the child knows about the parent’s status (e.g., “Mom is sick” versus “Mom has HIV”).

Chapter Summary

Overall, the findings of this study have implications for health behavior theory, communication theory, and for clinical and public health practice. Results indicate that parents living with HIV/AIDS report frequent discussions with adolescents about HIV-related topics, but also face a variety of barriers when contemplating whether or not to discuss and what to discuss with adolescents about HIV prevention. One previously unexplored barrier that warrants further
exploration is the role of limited HIV disclosure on the frequency of parent-adolescent prevention communication. HIV care teams and HIV support programs are in an ideal position to help parents overcome communication barriers by providing them with informational, social, and emotional support. Communication strategies that employed an open and supportive talking environment, focused on instilling family values, and gave high-quality HIV-related education were deemed especially effective by parents in this sample. Future behavioral interventions should focus on helping parents maximize their use of effective communication strategies.
REFERENCES


Leland, N. L., & Barth, R. P. (1993). Characteristics of adolescents who have attempted to avoid HIV and who have communicated with their parents about sex. *Journal of Adolescent Research, 8*, 58-76.


ATTENTION PARENTS

Are you a parent living with HIV/AIDS with a child ages 10-18?

We would like to learn how parents talk to kids about HIV prevention.

Your interview will be confidential.

Interested in participating - want more information?

Please contact:
Laura Hickman (lhickm2@uiuc.edu), Department of Communication
Phone: 1-877-892-5189 (Toll-free)
or 217-244-0015
APPENDIX B: LETTER TO RECRUITMENT ORGANIZATIONS

Dear HIV/AIDS Service Provider:

My name is Laura Hickman and I am an MD/PhD student at the University of Illinois. I am currently conducting a research study on families affected by HIV/AIDS. It is my hope that the information gained from this study will help form educational and support programs for parents living with HIV/AIDS and their kids.

Your organization was recently recommended to me as one that provides an array of services for people living with HIV/AIDS. I have enclosed some study fliers for clients who might be interested in participating in this study. To participate, parents would undergo a confidential interview and fill out a brief questionnaire. Parents will receive $30 for participating. The study has already been approved by the University of Illinois Urbana-Champaign Institutional Review Board (IRB). The IRB can be contacted at 217-333-2670 for questions about the approval (or for a copy of the IRB approval letter).

I am currently conducting interviews throughout Illinois and Indiana. I also am happy to send you an electronic version of the flier, or to come speak about the study in person if you would prefer. Feel free to contact me should you have additional questions or concerns. Thank you in advance for your help with this important project!

Sincerely,

Laura L. Hickman
MD/PhD Student
Department of Community Health
University of Illinois Urbana-Champaign
Lhickm2@illinois.edu
1-877-892-5189 (Toll-free)
APPENDIX C: TELEPHONE RECRUITMENT SCRIPT

Discussion of Study
Hello. Thank you for calling about the study on parent-adolescent communication. Can I answer any specific questions about the study for you? In this study we are hoping to learn how parents talk to kids about ways to prevent HIV. We’d also like to know things that might make it hard for parents to talk about ways to prevent HIV with kids.

Assessment of Inclusion Criteria
You do not need to have talked to your child about HIV to participate in this study. We will only be focusing on parents (and not children) in this study, so you your child does not need to know about your HIV status for you to participate.

You are eligible to participate in the study if you meet all of the following criteria:

(a) you are currently living with HIV or AIDS
(b) you are the parent or guardian of at least one child ages 10-17 who is not infected with HIV
(c) you are 21 years of age or older
(d) you have had regular (at least monthly) contact with your adolescent child for the past year.

If you meet these criteria and are interested in participating, I can schedule a study session for you. The session will take approximately 1.5 hours. You will be meeting with me for a 1 hour interview and filling out a questionnaire for approximately 15 minutes. To make sure we capture your comments accurately, the interview will be tape-recorded (voice only). Every effort will be made to keep your interview confidential. You may also choose to bring someone you know with you to the interview if you would like (as long as this person is 21 years of age or older). This person could be a significant other, family member, friend, or anyone you think of who might know about your experiences communicating with your child(ren). This person can either come with you for moral support, or they can choose to participate in the study too. We will only be able to offer $30 total, regardless of who you bring.

Do you have any questions?

Would you like me to schedule a time for you to participate?

- If yes, the researcher will schedule a date, time, and location with the potential participant and give them an overview of what to expect when they arrive at the study session. The researcher will also ask the participant to provide basic information about his/her family (i.e., how many children he/she has, their genders, and how old they are).
- If no, the researcher will thank the parent for his/her time.
APPENDIX D: INFORMED CONSENT FORM

INFORMED CONSENT FORM: PARENT-ADOLESCENT COMMUNICATION

Purpose and Procedures: This project is being conducted by Dr. Janet Reis, Department of Family Medicine, Dr. Dale Brashers, Department of Communication, and Ms. Laura Hickman, Department of Community Health at the University of Illinois. The purpose of this study is to explore parent-adolescent communication about HIV prevention. You will be asked to participate in an interview and fill out a questionnaire. The interview will last approximately 1 hour and the questionnaire will take approximately 15 minutes to complete. The interview portion will be audio-recorded (voice only). It is hoped that information gained during this study will help inform educational programs for parents and adolescents.

You are eligible to participate in this study if you are 21 years of age or older and received a study flyer from an HIV/AIDS-related organization.

Voluntariness: Your participation in the research study is completely voluntary. You may refuse to participate, discontinue participation, or skip any questions you do not want to answer at any time. Your decision to participate or not participate will have no affect on any future relations with the University of Illinois, with your health care provider, or with the HIV/AIDS related organization where you received your flyer.

Risks and Benefits: You may experience some embarrassment or discomfort when answering questions about HIV prevention. Although you may not receive direct benefit from participating in this study, the study may provide the community with information about parents’ views of discussing HIV prevention information with adolescents.

Confidentiality: Every effort will be made to keep all information about your responses confidential. Your comments in the interview will have no personally identifying information and will be analyzed in aggregate along with other participants. The researchers will share the overall results of the analysis with the public health community in the form of academic papers and/or conference presentations, but names or any other personally identifying information will not be used. Direct quotes from the interviews may be used in publications, but names or any other personally identifying information will not be used. You should be aware that, though the researchers will keep your responses confidential, your responses may not be completely confidential if you have elected to bring someone with you to the interview. Though each person in the interview session will be asked to keep the conversation private, the researchers cannot guarantee that participants will keep what was said private.

Compensation: Each family or group will receive $25 for participating in this study. This amount will be given to you at the end of your scheduled study session. You will receive the full $25 regardless of the total length of the interview and questionnaire session. The full amount will be given to you even if you decide to withdraw from the study early. You will also receive compensation for transportation in the form of bus tokens or money for gas (up to $5 in value).

Who to Contact with Questions: Questions about this research study should be directed to the primary investigator, Dr. Janet Reis, or Laura Hickman. Dr. Reis can be reached by telephone at 217-383-5007 or by e-mail at jreis@uic.edu. Laura can be reached by e-mail at lhickm2@uic.edu. Questions about your rights as a research participant should be directed to the UIUC Institutional Review Board Office at 217-333-2670 or irb@uic.edu, or to the Carle Institutional Review Board Office at (217) 383-4366 or IRB@Carle.com. You will be given a copy of this informed consent form to keep for your personal records.

I have read and understand the above consent form and voluntarily agree to participate in this study. By signing below, I also agree to have my voice audio-recorded during the interview portion of this study.

Participant Signature

Date

Carle IRB approved Consent Form
Do not use this version after:
11/16/2010

v. 6.14.09

DECEMBER 1, 2010
Family Tree

Please draw your family tree below. You may include anyone you consider to be in your immediate family. Be sure to include each person's role (e.g., mom, son, daughter), age, and gender.
APPENDIX F: INTERVIEW SCRIPT

Parent-Adolescent Communication Interview Script

Approximate time: 1 hour

Before we get started with the interview there are a couple of logistical questions I’d like to go through.

Verbal Discussion of Informed Consent
- Do you have any questions about the form or about the study in general?
- (Verbally review the informed consent form with potential participant)
- Do you understand that you may choose not to answer any question?
- Do you also understand that you may end this interview at any time?

Great. If there are no further questions, I’ll go ahead and collect the informed consent form from you. Remember to keep one copy for your records.

Opening Statements:
Thank you so much for agreeing to participate in this study and being willing to talk about some of your experiences as a parent. I am going to give you a series of topics to discuss, but ultimately this should be a conversation. There are no right or wrong answers. You are the expert here and I am interested in learning about your experiences and opinions. Your feedback will help inform future research efforts for parents living with HIV or AIDS. Specific examples are usually helpful, but feel free to give as much or as little information as you want to give. Also, if you think that something we don’t cover is important, feel free to bring it up. You are more than welcome to ask any questions as we go along. Do you have any questions before we begin?

Please keep in mind that we will be focusing on adolescents ages 10-18. Some parents choose to talk to their children about sexual behavior and ways to prevent sexually transmitted diseases (STDs) and some do not. Some may not talk to their children directly but have other ways of letting their children know about their values and what they expect of them. We are interested in responses from parents who have talked with their children about sex and HIV and those who have not, so do not worry if you have not talked with your child about HIV or about HIV prevention. Please answer honestly.

Warm-up question
1. Can you tell me a little bit about your family? For example, how many children do you have? Boys or girls? (Fill in family tree with participant).

If it’s okay with you we’ll go ahead and get started with the interview questions.
**Barriers to Discussing HIV Prevention**

First I’d like to talk generally about things that might make it hard for a parent to talk about HIV prevention with their child.

1. Some parents think it is really hard to talk about ways to prevent HIV with their adolescent(s). What do you think?
2. Why do you think it might be hard to talk about ways to prevent HIV with adolescent(s)?
3. Do you think living with HIV or AIDS makes a difference in how parents might talk to their adolescents about ways to prevent HIV?
   a. If so, how?
   b. If not, why not?
4. Do you remember if your parents ever talked to you about ways to prevent sexually transmitted infections? About drug use?

**Effectiveness of Strategies for Discussing HIV Prevention**

We’re now going to talk a little bit about ways to bring up the topic of HIV prevention.

5. Do you think that some ways of bringing up the topic of HIV and ways to prevent HIV work better than others?
6. Can you give an example of a way you think would work well?
7. Can you give an example of a way you think would not be a good way to talk about HIV or ways to prevent HIV with your adolescent(s)?

**Strategies for discussing HIV Prevention Information**

This next section hits a little closer to home. We’re going to discuss any ways that you personally may have used to discuss HIV prevention with your adolescent child.

1. Have you ever talked to your adolescent(s) about ways to prevent HIV?
   a. Have you ever talked to your adolescent(s) about sex?
   b. Have you ever talked to your adolescent(s) about drug use?
2. If so, how did those conversations go?
   a. Can you tell me about the time you are thinking of? (specific example)
   b. Where were you?
   c. Who was there?
   d. How did your son or daughter respond?
   e. What is your overall assessment of how the conversation went?
3. Have you ever talked to your adolescent(s) about being tested for STDs or HIV?
Facilitating HIV Prevention communication

I’d like to finish by getting your advice on what you think might make it easier to talk about HIV with adolescents.

1. What do you think might make it easier to talk about ways to prevent HIV with your adolescent(s)?
2. Do you have any advice to give to other parents living with HIV about ways to bring up the topic of HIV prevention?

Wrap up
Well, those are all the interview questions I have for you. I’ve asked you a lot of questions today and I really appreciate everything that you have told me. Is there anything else you would like to add or anything that I may have missed?

If not, there is one more thing. I have a questionnaire to give you. It should take about 15 minutes to complete. This questionnaire contains research information that I would like your opinion on. Some of the questions might overlap with what we discussed in the interview, but we really need to have a lot more information from parents like you. It is our hopes that the information you provide here (both in the interview and in the questionnaire) will help inform research in this field and help inform educational efforts for parents and for children.

Here is the questionnaire. I will stay in the room while you fill it out. Feel free to ask me if you have any questions. When you are finished, please bring it back to me and I have a list of resources to give to you.
Communication Questionnaire

Approximate time: 15 minutes

BACKGROUND QUESTIONS

Please answer the questions below to the best of your ability.

1. What year were you born?  ____________

2. What is your gender?
   a. Male
   b. Female
   c. Transgender

3. What is your current relationship status? (Please choose only one option).
   a. Single
   b. Dating
   c. Long-term relationship
   d. Married
   e. Other: ________________________

4. Do you currently live with your significant other?
   a. Yes
   b. No
   c. I am not in a relationship.

5. What is the highest level of education you have completed?
   a. Less than high school
   b. High school graduate (or GED)
   c. 4 year college degree (e.g. BA, BS)
   d. Advanced degree (e.g. PhD, MBA, MD, MSW)

6. Into what ethnic category would you place yourself?
   a. African American or Black
   b. Caucasian or White
   c. Asian
   d. Hispanic
   e. Latino
   f. Other: ________________________
7. What year did you find out that you had HIV? ______________
   (If you cannot remember the exact year, please give your best guess).

8. How do you think you got infected with HIV? Circle all that may apply.
   a. Sex
   b. Drug use
   c. Blood transfusion
   d. During childbirth
   e. Don’t know
   f. Other: ______________________

9. What were your most recent CD4 count and viral load?
   a. CD4 count: ___________
   b. Viral load: ____________

10. Are you currently having ongoing medical problems related directly to having HIV/AIDS?
    a. Yes
    b. No

11. Are you currently having ongoing side effects from medications you are taking for HIV/AIDS?
    a. Yes
    b. No

12. How sick do you feel from HIV/AIDS?
    a. Very sick
    b. Somewhat sick
    c. Not sick at all
COMMUNICATION QUESTIONS

*Please answer the questions below to the best of your ability. There are no right or wrong answers, so please answer honestly. You may skip questions you do not wish to answer or questions that do not apply to you. While we may have gone over similar questions in your interview, we probably did not have time to talk about all of the options below. Your answers to these items will be very important in helping us form a fuller picture of parent-adolescent communication about HIV and STD prevention.*

13. Please indicate how many of the following people you have told about your HIV status. If you have not told anyone about your HIV status, please circle option ‘j’ below.

<table>
<thead>
<tr>
<th></th>
<th>None</th>
<th>Some</th>
<th>All</th>
<th>Does not apply to me</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. My bosses/employers</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>b. Close friends</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>c. Casual friends</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>d. My parents</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>e. My brothers and sisters</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>f. My children.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>g. My significant other(s).</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>h. People I am sexually active with.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>i. My health care provider(s).</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>j. I have not told anyone about my HIV status.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
14. In the past 6 months, how *often* have you and your adolescent(s) talked about the following things:

<table>
<thead>
<tr>
<th></th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Often</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Sex</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>b. Drugs</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>c. How to use condoms</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>d. Protecting one’s self from sexually transmitted diseases (STDs)</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>e. Protecting one’s self from the AIDS virus</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>f. Protecting one’s self from becoming pregnant</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>g. Getting tested for STDs</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>h. Getting tested for the AIDS virus</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>i. Your HIV or AIDS status</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>
15. How **sure** are you that you can explain the following things to your adolescent(s)?

<table>
<thead>
<tr>
<th></th>
<th>Not sure at all</th>
<th>Somewhat sure</th>
<th>Pretty sure</th>
<th>Completely sure</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. What you think about adolescents</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>his/her age having sex</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>b. What you think about adolescents</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>his/her age using drugs</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>c. How to use condoms</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>d. How to protect one’s self from</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>sexually transmitted diseases (STDs)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>e. How to protect one’s self from the</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>AIDS virus</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>f. How to protect one’s self from</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>becoming pregnant</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>g. The importance of getting tested for</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>STDs</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>h. The importance of getting tested for</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>the AIDS virus</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>i. Your HIV or AIDS status</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>
16. How *important* is it to you that your adolescent(s) know about the following things?

<table>
<thead>
<tr>
<th></th>
<th>Not at all important</th>
<th>Somewhat important</th>
<th>Pretty important</th>
<th>Very important</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. How to have safe sex</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>b. How to stay away from drugs</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>c. How to use condoms</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>d. Protecting one’s self from sexually transmitted diseases (STDs)</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>e. Protecting one’s self from the AIDS virus</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>f. Protecting one’s self from becoming pregnant</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>g. The importance of getting tested for STDs</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>h. The importance of getting tested for the AIDS virus</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>i. Your HIV or AIDS status</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>
17. Below is a list ways of parents might bring up protection from HIV and STDs with their adolescent(s). Please indicate how often you have used these methods to discuss how to prevent HIV or other STDs with your adolescent(s).

<table>
<thead>
<tr>
<th>Method</th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Often</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. I wait until my adolescent(s) bring the topic up.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>b. I bring it up after my adolescent(s) have watched a movie, TV show, or commercial that deals with sex, HIV, or STDs.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>c. I bring it up when we go to health care appointments.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>d. I bring it up when I realize that my adolescent is interested in sex or sexual relationships.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>e. I bring it up when my adolescent hits puberty.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>f. I rely on friends, relatives, or neighbors to teach my adolescent(s) about it.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>g. I rely on the school system to teach my adolescent(s) about it.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>h. I rely on health care providers to teach my adolescent(s) about it.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>
18. Below is a list of comments made by people after they experience life events that can be stressful. Please circle each item, indicating how frequently these comments were true for you during the past 7 days. If they did not occur during the past 7 days, please mark the “not at all” column.

<table>
<thead>
<tr>
<th>Comment</th>
<th>Not at all</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Often</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. I avoided letting myself get upset when I thought about having HIV.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>b. I tried to remove HIV from my memory.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>c. I stayed away from reminders of having HIV.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>d. I felt as if it hadn’t happened or wasn’t real.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>e. I tried not to talk about having HIV.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>f. Other things kept making me think about having HIV.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>g. I was aware that I still had a lot of feelings about having HIV, but didn’t deal with them.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>h. I tried not to think about having HIV.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>i. My feelings about having HIV were kind of numb.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>
If you would like to comment on this questionnaire or your experience filling it out, please use the space below, or you may talk to a member of the research team before you leave here today.

*Thank you for your time and help with this project.*
APPENDIX H: TRANSCRIPTION TEMPLATE

Participant#: 1026
Interviewer: LH
Transcribed by: LH
Date Transcribed: 9.23.09

Pseudonym Name: Ebony

Interview Date: 9/18/09

Interview Location: private room in library, Illinois

Notes:
- Ebony had a bad (productive) cough and had been very ill the week before, but put “not sick at all” on the questionnaire when asked how sick she had been in the past week.
- Unclear sections on page 4:
  - boy getting them now (**unclear 4:04**) p.4

Interview Summary:
- Ebony had a very complicated relationship with her mother. She was bitter towards her Mom for telling the children she had HIV (“busting her out”). She was also bitter towards her Mom because her mother was very involved in HIV/AIDS activities even though she wasn’t infected. Ebony saw this as her mother taking all of her AIDS benefits.
- Ebony also had a complicated relationship with her children. The kids live with her mother but she visits everyday and sometimes spends the night. It seems the kids live with her mother because Ebony has problems with “getting into trouble.”
- Ebony gave various compliments to her children but also stated that her daughter talks too much and she ignores her, and that her children lie a lot.
- Ebony rarely talked with her children about sex or HIV. In her words, “it just doesn’t come up.” She also seemed to indicate that they learn all of the material at school and wouldn’t want to talk to her about it.

Family Tree:
- Ebony (not in a relationship)
  - 4 kids
  - 22 yo boy
    - Has a 1yo son
    - 2 babies on the way (different mothers)
  - 15yo boy
  - 13yo girl
  - 6 yo girl
- Each child has a different father and most of the fathers are not involved in the kids’ lives.
- Grandmother (the children live with Ebony’s mother)

INTERVIEWER: I usually like to start by just getting an idea of who is in your family.

APPENDIX I: CODEBOOK EXCERPT

Linked Item
Tree Nodes\Prevention Conversations\Facilitators of & barriers to talking\Barriers\Being HIV +

Name: Being HIV+ - barrier

Pneumonic: HIV-

Definition: Parents who think that their HIV status has made it difficult for them to have conversations about safe sex and HIV prevention with adolescents.

Inclusion criteria: Include examples (or hypothetical conversations) where parents talk about how their HIV status has made it difficult to have prevention conversations.

Exclusion criteria: Exclude examples that focus on parents who think that their HIV status has made it easier for them to talk to adolescents about prevention (these examples will be coded under facilitators).

Supporting examples:

1008, Reference 1

NORA: I think it's more hard (if you are living with HIV), because the child has to get to know everything and then the details they probably get (confused). Like I say, they might turn it to where if they go and touch somebody or somethin they'll think they'll get it. Or if they use the washroom, then they'll get it. It takes them, I think, more longer (to understand) because of their feelings and because of their emotions and dealin with their personals. And because they're thinkin that person (with HIV) don't have long to live with them. So, I think for a person that's with it, it's more hard.

1011, Reference 1

TONYA: see HIV I think on the other hand, my status makes it harder for them to believe how serious it is because everybody keeps, “Oh, auntie you so healthy. And you had it since you were 16.” At least I knew at 16, I probably had it before that, but anyway so. Yea that doesn’t really I think help my cause sometimes I think me being positive has the opposite effect of keeping them from understanding how serious HIV is cuz they’re like, “nothing’s ever been wrong with you.” But that’s because I bike and I eat right.

1017, Reference 1

DEDRA: And you know what, I’m ashamed of myself cuz now I seem to think about it now as we speak that… I’m scared to tell them because it makes it more of a reality for me. And to them I’m like this strong person. And to tell them that makes me feel very vulnerable to in a sense. You know maybe that has something to do with it (why it’s hard to talk to them).
SHERYL: The kids think you’re crazy when you start talking about “Oh that’s, they gon think you the biggest slut in town. How you gon tell me about protection, you wasn’t using it you got it.” Every statement you make in cases like this, it’s a question mark at the end of it, it’s no period ever, just a question mark.

NATHAN: It's kinda hard because I don't use myself as an example (I don't tell them that I have HIV)...I just tell them to be careful.

SELENA: Well as I said, after I said it (told my kids about HIV and that I was living with the virus)…I kinda felt inferior. I had an inferior complex about me. I don’t know why. I just felt less than. And I know they’re growing up and what have I done lately? But anyway I just need to do something for myself and I probably won’t, I mean it was a feeling that passed.

Notes about relationships between nodes:
- A handful of parents conveyed that their HIV status actually made it more difficult to talk to their children about HIV and HIV prevention. This was due to a variety of factors including:
  - If kids see their parents healthy they may not take HIV as seriously
  - Bringing up HIV (when the parent is positive) may make the child emotional
  - Kids of positive parents will want to know lots of details about the virus and may be scared about contracting it themselves
  - The conversation may bring up personally embarrassing topics (how the parent became infected)
  - Having to monitor what information parents revealed to their children (having to actively think during conversation about what their children know about them v. what they don’t).
  - Telling others might make it more of a reality for the parent
- May want to go back to Bertrisa (1046) for the “four sides” of how being HIV+ affects how parents talk to their kids. She gave a very sophisticated and nuanced picture of the various conflicting thoughts parents face when deciding whether or not to discuss HIV and prevention with kids.
APPENDIX J: CODING AGREEMENT SHEET

Coding Round #1
  • Categorizing examples into general domains (facilitator/barrier v. effective/ineffective)

<table>
<thead>
<tr>
<th>Coding Category</th>
<th>% Participants Checked</th>
<th>% References Checked</th>
<th>% Inter-rater Agreement</th>
</tr>
</thead>
<tbody>
<tr>
<td>Facilitators/Barriers</td>
<td>23.8</td>
<td>33.0</td>
<td>95.2</td>
</tr>
<tr>
<td>Effective/Ineffective</td>
<td>48.3</td>
<td>51.4</td>
<td>95.6</td>
</tr>
</tbody>
</table>

Coding Round #2
  • Categorizing examples into specific categories (e.g., “utilizing support”) within each general domain (e.g., “facilitators”)

<table>
<thead>
<tr>
<th>Coding Category</th>
<th>% Participants Checked</th>
<th>% References Checked</th>
<th>% Inter-rater Agreement</th>
</tr>
</thead>
<tbody>
<tr>
<td>Facilitators</td>
<td>36.4</td>
<td>16.2</td>
<td>95.0</td>
</tr>
<tr>
<td>Barriers</td>
<td>31.7</td>
<td>14.1</td>
<td>95.8</td>
</tr>
<tr>
<td>Effective</td>
<td>57.1</td>
<td>20.2</td>
<td>100.0</td>
</tr>
<tr>
<td>Ineffective</td>
<td>27.9</td>
<td>15.5</td>
<td>100.0</td>
</tr>
</tbody>
</table>
APPENDIX K: OUTLINE OF ANALYSIS FOR REGRESSION MODELS

Model #1: Frequency of communication

**Dependent Variable for Regression Model**

<table>
<thead>
<tr>
<th>Variable Type</th>
<th>Variable Description</th>
<th>Variable Name</th>
<th>Variable Levels</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dependent</td>
<td>Frequency scale sum</td>
<td>freq_scale_sum</td>
<td>Continuous (9-36)</td>
</tr>
</tbody>
</table>

**Independent Variables for Regression Model**

<table>
<thead>
<tr>
<th>Variable Type</th>
<th>Variable Description</th>
<th>Variable Name</th>
<th>Variable Levels</th>
</tr>
</thead>
<tbody>
<tr>
<td>Demographic</td>
<td>1. Age</td>
<td>age</td>
<td>Continuous (27-65)</td>
</tr>
<tr>
<td></td>
<td>2. Gender</td>
<td>female</td>
<td>Female (1), Male (0)</td>
</tr>
<tr>
<td></td>
<td>3. Ethnicity</td>
<td>ethnicity_rec2</td>
<td>African American (1), All other (0)</td>
</tr>
<tr>
<td></td>
<td>4. Education Level</td>
<td>education_rec2</td>
<td>High school and up (1), Less than high school (0)</td>
</tr>
<tr>
<td></td>
<td>5. Employment status</td>
<td>disclose_a_rec</td>
<td>Employed (1), Unemployed (0)</td>
</tr>
<tr>
<td>Family</td>
<td>6. Number of kids 10-18</td>
<td>num_child_10to18</td>
<td>Continuous (1-5)</td>
</tr>
<tr>
<td></td>
<td>7. Live with child 10-18</td>
<td>live_with_10-18</td>
<td>Yes (1), No (0)</td>
</tr>
<tr>
<td></td>
<td>8. Relationship status</td>
<td>relat_status_rec2</td>
<td>Long-term/Married (1), Single/Dating (0)</td>
</tr>
<tr>
<td>Health</td>
<td>9. Separated from child</td>
<td>sep_from_child</td>
<td>Yes (1), No (0)</td>
</tr>
<tr>
<td></td>
<td>10. Previous substance abuse</td>
<td>subst_abuse</td>
<td>Yes (1), No (0)</td>
</tr>
<tr>
<td></td>
<td>11. Previous sexual abuse</td>
<td>sex_abuse</td>
<td>Yes (1), No (0)</td>
</tr>
<tr>
<td></td>
<td>12. Years living with HIV</td>
<td>yrs_live_HIV</td>
<td>Continuous (2-30)</td>
</tr>
<tr>
<td></td>
<td>13. Feel sick from HIV</td>
<td>sick_2</td>
<td>Very/Somewhat sick (1), Not at all sick (0)</td>
</tr>
<tr>
<td></td>
<td>14. Current HIV-related medical problems</td>
<td>problems</td>
<td>Yes (1), No (0)</td>
</tr>
<tr>
<td>Communication</td>
<td>15. Disclosed to children</td>
<td>disclose_f_rec2</td>
<td>All (1), Some/None (0)</td>
</tr>
<tr>
<td></td>
<td>16. Self-efficacy scale sum</td>
<td>self_eff_scale_sum</td>
<td>Continuous (9-36)</td>
</tr>
<tr>
<td></td>
<td>17. Importance scale sum</td>
<td>import_scale_sum</td>
<td>Continuous (12-36)</td>
</tr>
<tr>
<td></td>
<td>18. Active strategies scale sum</td>
<td>active_strat_sum</td>
<td>Continuous (4-16)</td>
</tr>
</tbody>
</table>
**Model #2A: Disclosure of HIV status to children**

*Dependent Variable for Regression Model*

<table>
<thead>
<tr>
<th>Variable Type</th>
<th>Variable Description</th>
<th>Variable Name</th>
<th>Variable Levels</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dependent</td>
<td>Extent of disclosure (# kids disclosed to)</td>
<td>disclose_f_rec1</td>
<td>All/Some (1), None (0)</td>
</tr>
</tbody>
</table>

*Independent Variables for Regression Model*

<table>
<thead>
<tr>
<th>Variable Type</th>
<th>Variable Description</th>
<th>Variable Name</th>
<th>Variable Levels</th>
</tr>
</thead>
<tbody>
<tr>
<td>Demographic</td>
<td>1. Age</td>
<td>age</td>
<td>Continuous (27-65)</td>
</tr>
<tr>
<td></td>
<td>2. Gender</td>
<td>female</td>
<td>Female (1), Male (0)</td>
</tr>
<tr>
<td></td>
<td>3. Ethnicity</td>
<td>ethnicity_rec2</td>
<td>African American (1), All other (0)</td>
</tr>
<tr>
<td></td>
<td>4. Education Level</td>
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<td>live_with_10-18</td>
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<td>8. Relationship status</td>
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<td>Health</td>
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<td>10. Previous substance abuse</td>
<td>subst_abuse</td>
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<td>11. Previous sexual abuse</td>
<td>sex_abuse</td>
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<tr>
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<td>12. Years living with HIV</td>
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<td>14. Current HIV-related medical problems</td>
<td>problems</td>
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<td>Communication</td>
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<td>16. Frequency scale sum</td>
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<td>17. Importance scale sum</td>
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**Model #2B: Disclosure of HIV status to children**

*Dependent Variable for Regression Model*

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*Independent Variables for Regression Model*

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<td>2. Gender</td>
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<td>3. Ethnicity</td>
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<td>4. Education Level</td>
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<td>5. Employment status</td>
<td>disclose_a_rec</td>
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<td>Family</td>
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<td>7. Live with child 10-18</td>
<td>live_with_10-18</td>
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<tr>
<td></td>
<td>8. Relationship status</td>
<td>relat_status_rec2</td>
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<td>Health</td>
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<td>sep_from_child</td>
<td>Yes (1), No (0)</td>
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<td></td>
<td>10. Previous substance abuse</td>
<td>subst_abuse</td>
<td>Yes (1), No (0)</td>
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<tr>
<td></td>
<td>11. Previous sexual abuse</td>
<td>sex_abuse</td>
<td>Yes (1), No (0)</td>
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<tr>
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<td>12. Years living with HIV</td>
<td>yrs_live_HIV</td>
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<td>sick_2</td>
<td>Very/Somewhat sick (1), Not at all sick (0)</td>
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<td>14. Current HIV-related medical problems</td>
<td>problems</td>
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<td>15. Self-efficacy scale sum</td>
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<td>16. Frequency scale sum</td>
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<td>17. Importance scale sum</td>
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### Model #3: HIV-Related Stress

**Dependent Variable for Regression Model**

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**Independent Variables for Regression Model**

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<th>Variable Name</th>
<th>Variable Levels</th>
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<td></td>
<td>2. Gender</td>
<td>female</td>
<td>Female (1), Male (0)</td>
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<td>3. Ethnicity</td>
<td>ethnicity_rec2</td>
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<tr>
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<td>4. Education Level</td>
<td>education_rec2</td>
<td>High school and up (1), Less than high school (0)</td>
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<td>5. Employment status</td>
<td>disclose_a_rec</td>
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<td>6. Number of kids 10-18</td>
<td>num_child_10to18</td>
<td>Continuous (1-5)</td>
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<tr>
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<td>7. Live with child 10-18</td>
<td>live_with_10-18</td>
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<tr>
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<td>8. Relationship status</td>
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<td>Long-term/Married (1), Single/Dating (0)</td>
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<td>9. Separated from child</td>
<td>sep_from_child</td>
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<td>10. Previous substance abuse</td>
<td>subst_abuse</td>
<td>Yes (1), No (0)</td>
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<tr>
<td></td>
<td>11. Previous sexual abuse</td>
<td>sex_abuse</td>
<td>Yes (1), No (0)</td>
</tr>
<tr>
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<td>12. Years living with HIV</td>
<td>yrs_live_HIV</td>
<td>Continuous (2-30)</td>
</tr>
<tr>
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<td>13. Feel sick from HIV</td>
<td>sick_2</td>
<td>Very/Somewhat sick (1), Not at all sick (0)</td>
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<tr>
<td></td>
<td>14. Current HIV-related medical problems</td>
<td>problems</td>
<td>Yes (1), No (0)</td>
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<td>15. Disclosed to children</td>
<td>disclose_f_rec2</td>
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**Model #4: Active Strategies**

**Dependent Variable for Regression Model**

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**Independent Variables for Regression Model**

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<td>2. Gender</td>
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<td>3. Ethnicity</td>
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<td></td>
<td>4. Education Level</td>
<td>education_rec2</td>
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<td>5. Employment status</td>
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<td>Employed (1), Unemployed (0)</td>
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<td>Family</td>
<td>6. Number of kids 10-18</td>
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<td>7. Live with child 10-18</td>
<td>live_with_10-18</td>
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<td></td>
<td>8. Relationship status</td>
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<td>10. Previous substance abuse</td>
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<td></td>
<td>11. Previous sexual abuse</td>
<td>sex_abuse</td>
<td>Yes (1), No (0)</td>
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<td>12. Years living with HIV</td>
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<td>13. Feel sick from HIV</td>
<td>sick_2</td>
<td>Very/Somewhat sick (1), Not at all sick (0)</td>
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<td>14. Current HIV-related medical problems</td>
<td>problems</td>
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<tr>
<td>Communication</td>
<td>15. Disclosure</td>
<td>disclose_f_rec2</td>
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<td>16. Self-efficacy scale sum</td>
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**Model #5: Passive Strategies**

*Dependent Variable for Regression Model*

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*Independent Variables for Regression Model*

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<td>2. Gender</td>
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<td>10. Previous substance abuse</td>
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<td>11. Previous sexual abuse</td>
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<td>14. Current HIV-related medical problems</td>
<td>problems</td>
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**Model #6: Effective v Ineffective Strategies**

*Dependent Variable for Regression Model*

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*Independent Variables for Regression Model*

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<td>3. Ethnicity</td>
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<td>5. Employment status</td>
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<td>Employed (1) Unemployed (0)</td>
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<td>8. Relationship status</td>
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<td>11. Previous sexual abuse</td>
<td>sex_abuse</td>
<td>Yes (1), No (0)</td>
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<tr>
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<td>12. Years living with HIV</td>
<td>yrs_live_HIV</td>
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<td>Very/Somewhat sick (1) Not at all sick (0)</td>
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<td>problems</td>
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<td>16. Frequency scale sum</td>
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<td>17. Self efficacy scale sum</td>
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<td>18. Stress scale sum</td>
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**APPENDIX L: SIGNIFICANT CORRELATION VALUES FOR PREDICTORS**

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<td>.023</td>
<td>89</td>
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<td>Substance abuse</td>
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<td>89</td>
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