

**INVESTIGATION OF EXISTING EDUCATIONAL CONTENT REGARDING HIV-  
POSITIVE PREGNANT WOMEN IN GENETIC COUNSELING PROGRAMS**

by

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**Objectives/Research Questions:** The purpose of this study was to assess existing curricula regarding HIV positive pregnant women in genetic counseling graduate programs.

**Methods:** Genetic counseling programs were surveyed to assess existing curricula regarding prevention and treatment issues for HIV positive pregnant women. Programs were asked to identify their need for HIV-related educational materials, specifically issues and content needed to provide effective education for students and types of materials that would most benefit programs.

**Results:** Of the 32 graduate genetic counseling programs, 26 (81.3%) responded to the survey. The data show that 65.4% currently offer HIV education in their curriculum. With regard to development of educational materials to address HIV in pregnancy, 64.3% (9/14) of programs that provide HIV education and 88.9% (8/9) of programs that provide no HIV education indicated they would benefit from development of these materials. The most commonly requested materials were webinars, PowerPoint presentations, and clinical case examples.

**Conclusions:** The results of this study indicate a need for the development of additional educational materials addressing issues specific to HIV positive pregnant women and reduction of perinatal transmission. Through the Pennsylvania/MidAtlantic AIDS Education and Training

Center, web-based seminars and other educational materials were developed for distribution to genetic counseling programs.

**Implications for Public Health:** HIV is a major public health issue for all health-care providers who work with women of child-bearing age. Improving knowledge of HIV prevention and treatment in pregnant women is important for genetic counselors who may encounter HIV-positive pregnant women in their clinical practice.

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## **PREFACE**

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## **1.0 INTRODUCTION**

### **1.1 DESCRIPTION OF THE PROBLEM AND SPECIFIC AIMS**

HIV has been described as the most significant public health problem of our time<sup>1</sup>. In 1984 when the epidemic began, HIV/AIDS was primarily characterized as a disease of homosexual males. Since then, however, the numbers of women being diagnosed with AIDS has increased from 8% of all cases in 1985 to 26% in 2008<sup>2, 3</sup>. In 2009, the Centers for Disease Control and Prevention (CDC) reported that nearly a quarter of the people living in the United States who have HIV were women<sup>2, 3</sup>. The number of affected women is reported as being approximately 280,000 with 80% of these women becoming infected due to high risk heterosexual contact<sup>3</sup>. For women of all races and ethnicities, the rates of new diagnoses were highest between the ages of 15 and 39<sup>3</sup>. This indicates that the majority of women becoming infected with HIV are of reproductive age.

Due to advances in management and treatment for HIV, individuals with HIV have been living longer<sup>4-8</sup>. A study conducted by Emory University indicated that the average lifespan of a person following diagnosis with HIV has jumped from 7 years in 1993 to 24 years in 2006<sup>6</sup>. Because of this, an HIV diagnosis is now largely becoming a chronic disease which requires lifelong management. More women with HIV are having children due to increased life expectancy and increased quality of life. The CDC estimates that approximately 6000 to 7000

women living with HIV will choose to become pregnant each year.<sup>9</sup> Perinatal transmission of HIV is the leading cause of HIV in children in the United States. Nearly all children infected with HIV in the United States have become infected following exposure during pregnancy, childbirth, or breastfeeding<sup>2, 3, 9, 10</sup>. In 1994, studies first found that antiretroviral medications taken during pregnancy reduced the risk of perinatal transmission. Since then, the rates of perinatal transmission have decreased dramatically and only 73 children were diagnosed with HIV in 2007<sup>10</sup>. Today, the majority of perinatal transmission is due to mothers not knowing that they were HIV-positive during the pregnancy. It is estimated that if left untreated, HIV-positive pregnant women will have a 30-45% chance of infecting their child with the virus. If infected mothers take one antiretroviral during pregnancy, the risk of transmission drops to 8%, and if three antiretroviral drugs are taken, the risk declines to lower than 2%<sup>9, 11</sup>. These findings have prompted the CDC to recommend that all pregnant women be given an HIV test during the first trimester and again prior to labor and delivery<sup>12</sup>. In addition to screening of pregnant women, ten states have initiated HIV testing of newborns as part of their newborn screening programs. The majority of states only perform newborn testing if the HIV status of the mother is unknown or is not clear. The only state to include HIV on their standard newborn screen is New York.<sup>13</sup>

Because of the increasing numbers of HIV-positive women who are living longer and deciding to have families as well as the decision of states to initiate HIV testing of newborns, the needs of HIV-positive women may become relevant in the field of genetic counseling. According to the 2006 definition of genetic counseling released by the National Society of Genetic Counselors (NSGC), genetic counseling is “the process of helping people understand and adapt to the medical, psychological and familial implications of genetic contributions to disease. This process integrates interpretation of family and medical histories to assess the



chance of disease occurrence or recurrence, education about inheritance, testing, management, prevention, resources, and research, and counseling to promote informed decisions and adaptation to the risk or condition”<sup>14</sup>. HIV is not a genetic condition that would be the object of focus during a counseling session; however women with HIV have unique psychosocial needs and medical issues that should be taken into consideration during a counseling session<sup>15-17</sup>. HIV is part of a woman’s medical history, and this diagnosis can have implications for treatment, management, and recommendations during pregnancy<sup>11</sup>. Women with HIV are not just women with HIV, they are women who are being referred for counseling due to advanced maternal age, genetic risk, medication exposure, or any other reason that a woman without HIV would be referred for genetic counseling.

In order to investigate the role of genetic counseling in the care of HIV-positive pregnant women, I propose to assess the current educational content addressing HIV utilized by genetic counseling programs in the United States and Canada. Using this information, I will develop educational materials for genetic counseling programs to facilitate the incorporation of the special needs of an HIV-positive woman receiving prenatal counseling into their existing curricula.

### **1.1.1 Specific Aim 1**

Survey current genetic counseling programs in the United States and Canada and determine what current HIV content exists in higher education programs for genetic counseling students.

### **1.1.2 Specific Aim 2**

Survey current genetic counseling programs in the United States and Canada and identify types of educational materials that would be useful to genetic counseling program directors in providing education to their students.

### **1.1.3 Specific Aim 3**

Analyze data collected from Aims 1 and 2 and develop educational product for genetic counseling programs to address the needs of HIV-positive pregnant women.

## **1.2 HUMAN IMMUNODEFICIENCY VIRUS**

### **1.2.1 Disease Basics**

In the early 1980's, homosexual men in San Francisco starting presenting with a condition characterized by opportunistic infections resulting from a severely compromised immune system<sup>18</sup>. The condition that affected these men would eventually be referred to as acquired immune deficiency syndrome (AIDS). At the time of the initial outbreak, the cause of AIDS was unknown, and it was diagnosed almost primarily in men who were having sex with men (MSM). In 1983, a virus was isolated from affected individuals and found to be the responsible for AIDS<sup>19</sup>. The newly discovered virus was named human immunodeficiency virus (HIV)<sup>19</sup>. Following initial HIV infection, the virus infects the cells of the body's immune system,

specifically macrophages and CD4+ T-cells. These cells are integral in the recognition of foreign pathogens, initiation of immune responses, and prevention of infection<sup>20</sup>. As HIV infection progresses, the number of circulating CD4+ cells is depleted, which eventually leads to AIDS.

HIV is spread by three primary routes: sexual, parenteral (blood borne), and perinatal.<sup>20</sup> Sexual transmission of the HIV virus can occur following unprotected male to male, male to female, female to male, or female to female sexual contact<sup>20</sup>. The risks of infection are the highest following unprotected anal and vaginal intercourse, although there is a risk of infection following unprotected oral sex<sup>19,20</sup>. Some of the sexual risk factors that put an individual at risk for becoming infected with HIV are having multiple sex partners and being infected with other sexually transmitted infections (STIs).

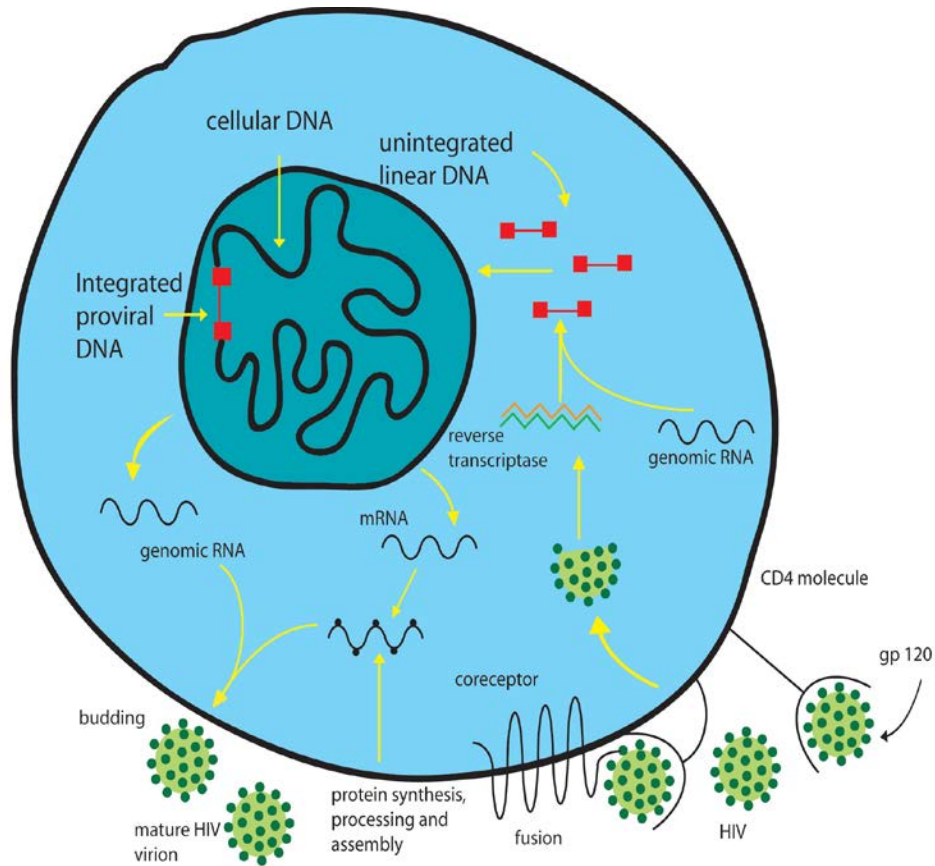
Parenteral (blood borne) infection is characterized by infection following contact with contaminated blood products. This can occur following a blood transfusion or occupational exposure to HIV-positive blood or intravenous drug use with contaminated needles<sup>20</sup>. Infection following intravenous or injection drug use can be caused by exposure to HIV-positive blood from syringes, rinse water, or other equipment that is used in the preparation of injection drugs.<sup>19</sup>

The third most common route of HIV infection is perinatal infection – the passing of HIV from a mother to child during pregnancy, labor and delivery, or breast feeding<sup>19, 20</sup>. It is estimated that 91% of pediatric HIV cases in the United States are due to perinatal transmission<sup>20</sup>. Perinatal transmission risks will be discussed in more detail later in this introduction.

### 1.2.2 HIV Viral Life Cycle

HIV is classified as a lentivirus belonging to the retrovirus family. The lifecycle of HIV is complicated and is reliant upon both viral and host cell proteins<sup>18</sup>. HIV targets cells that have CD4+ receptors on their surface, namely macrophages and CD4+ T-cells. By using two additional co-receptors, HIV is able to differentiate between these two cell types. HIV is an enveloped virus that has two glycoproteins on its surface, gp41 and gp120, which aid in the initial binding and entry into host cells. Once the virus enters a cell, the envelope is dissolved and the viral RNA is released into the cytoplasm.<sup>18</sup>

In the cytoplasm, reverse transcriptase transcribes the RNA into DNA, which is then integrated into the host cell's cellular DNA. This ensures that each time the host cell replicates, a copy of the HIV DNA will also be copied. Integration of the HIV genome into host cells also allows the HIV virus to use the host cell's machinery for transcription and translation, which results in the production of new virus particles. The RNA transcript serves not only as a template for protein production but also as the genome for newly forming virus particles. The lifecycle of HIV is complete once a new virus buds from the surface of the host cell, taking part of the host cell's membrane along with it.<sup>18</sup> A summary of the HIV lifecycle can be seen in Figure 1.



**Figure 1: Schematic of the HIV Lifecycle<sup>18</sup>**  
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### 1.2.3 Natural History of HIV Infection

Untreated HIV is a chronic illness that progresses through stages based on the clinical manifestations of the disease and CD4+ T-cell counts<sup>20</sup>. Clinical conditions associated with HIV tend to cluster around CD4+ T-cell counts, with more severe infections manifesting as CD4+ T-cell counts drop. Staging of HIV infection is important for clinicians to make treatment and management decisions for the patient<sup>20</sup>.

Five to thirty days following exposure to HIV, some individuals may develop flu-like symptoms, but others will have no signs of illness. This stage is called the infection stage and

during this stage, the HIV virus begins to replicate at high rates (as many as several million copies of HIV RNA per mm<sup>3</sup> of plasma) and integrate itself into CD4+ cells.<sup>20, 21</sup>

During the next stage of HIV infection, the response stage, the body's immune system recognizes and combats the virus. The virus load is decreased in the plasma, and by this point the virus is already integrated into CD4+ cells and can remain latent or can produce new virus particles. This is the point where an individual becomes positive for HIV antibodies, meaning they have antibodies against the HIV virus<sup>19</sup>. The HIV-infected cells continue to replicate and divide, increasing the number of latent HIV viruses<sup>20</sup>. Within the plasma, the amount of viruses reaches an equilibrium between those that are produced from infected cells and those that are cleared by the immune system. This equilibrium is referred to as the "viral set point"<sup>20</sup>. The amount of virus present in the "viral set point" varies by individual, and is highly predictive of the rate of disease progression in HIV<sup>20</sup>.

A relatively stable stage follows the response stage, and during this time period an individual infected with HIV may not experience any symptoms or know that they are infected. Symptoms of HIV can take several years to develop, and are triggered by the body's CD4+ T-cell count dropping too low<sup>19</sup>. As the CD4+ T-cells count decrease, symptoms such as persistent fever or diarrhea or recurrent yeast infections can begin to develop. AIDS is the final stage of HIV infection, and is classified by plasma CD4+ T-cell count <200 cells/mm<sup>3</sup>. AIDS is characterized by a series of opportunistic infections, or infections that are typically not seen in individuals with healthy immune systems. These infections include, but are not limited to cytomegalovirus, Kaposi's sarcoma, *pneumocystis carinii* pneumonia (PCP), and histoplasmosis<sup>5</sup>. Currently, there is no cure for HIV, and all individuals who are diagnosed with

HIV will eventually develop AIDS and die as a result of infections caused by a severely compromised immune system.

#### **1.2.4 Antiretroviral Therapy and HIV**

Following the initial cases of HIV, a need quickly emerged for medications to help suppress HIV infection and delay or prevent the onset of AIDS. Prior to the introduction of HIV-specific medications, AIDS was treated by managing the symptoms and complications associated with the various opportunistic infections. In 1985 zidovudine (ZDV), originally developed in 1964 as a drug to help treat cancer caused by viruses, was first described to have antiretroviral activity against HIV<sup>22</sup>. A randomized clinical trial of ZDV found that the drug was able to prolong the life of patients with AIDS and in 1987 the drug was approved for clinical use<sup>23</sup>. This breakthrough was the first step in a long history of developing new drugs to target HIV and treat AIDS.

In 1996, a new approach was taken to treating HIV by combining multiple antiretroviral medications. Called highly active antiretroviral therapy (HAART), this method typically uses three different antiretroviral medications, sometimes referred to as a 'cocktail'.<sup>24</sup> Today, some drug combinations of several antiretroviral agents are considered the standard of care for individuals with HIV<sup>22</sup>. Since its introduction, HAART has had many successes but has also created some unique issues for individuals with HIV.

As a result of the successful integration of combination therapy as the standard of care for individuals with HIV, there has been a disappearance of the majority of the signs and symptoms of HIV, and the incidence of many AIDS related opportunistic infections has also decreased. An individual taking HAART has a reduced risk of transmitting the virus to others, which can

increase quality of life and improve relationships. One of the major successes of HAART therapy has been the transition of HIV from an acute disease to a chronic disease that requires lifelong management.

Prior to the introduction of antiretroviral therapy, the average lifespan following diagnosis was only 7 years<sup>6</sup>. In a study done looking at the records of over 7,000 HIV-positive patients treated in 18 different centers across the United States, the average life expectancy in 2006 was more than 20 years<sup>6</sup>. It is now thought that an individual with HIV who is treated with HAART therapy will have a lifespan that is close to an individual in the general population.

In spite of these achievements, there have also been some drawbacks associated with HAART. Many individuals still suffer from anxiety and depression following their HIV diagnosis, regardless of how successful HAART is in managing their disease. HAART has also been associated with long-term physical side effects, such as increased blood pressure, elevated cholesterol levels, redistributions of fatty tissue, increased risk for insulin resistant diabetes, and peripheral neuropathy. These adverse effects can have a negative impact on a person's self image and relationships with others.<sup>5</sup> Finally, the demanding medication schedule, adverse drug reactions, and unpleasant side effects can lead to difficulties in adhering to HAART<sup>18</sup>. Strict adherence is important to help avoid the development of viral resistance to a particular medication or class of medications. If resistance develops, one option is to replace the medication with another anti-HIV compound<sup>24</sup>.

In 2008, there were 25 anti-HIV compounds licensed for the treatment of AIDS<sup>18, 22</sup>. These compounds can be classified into categories depending on what part of the HIV life cycle they target. A table summarizing the different types of HIV medications can be seen in Table 1.



**Table 1: Classes of HIV Medications<sup>22</sup>**

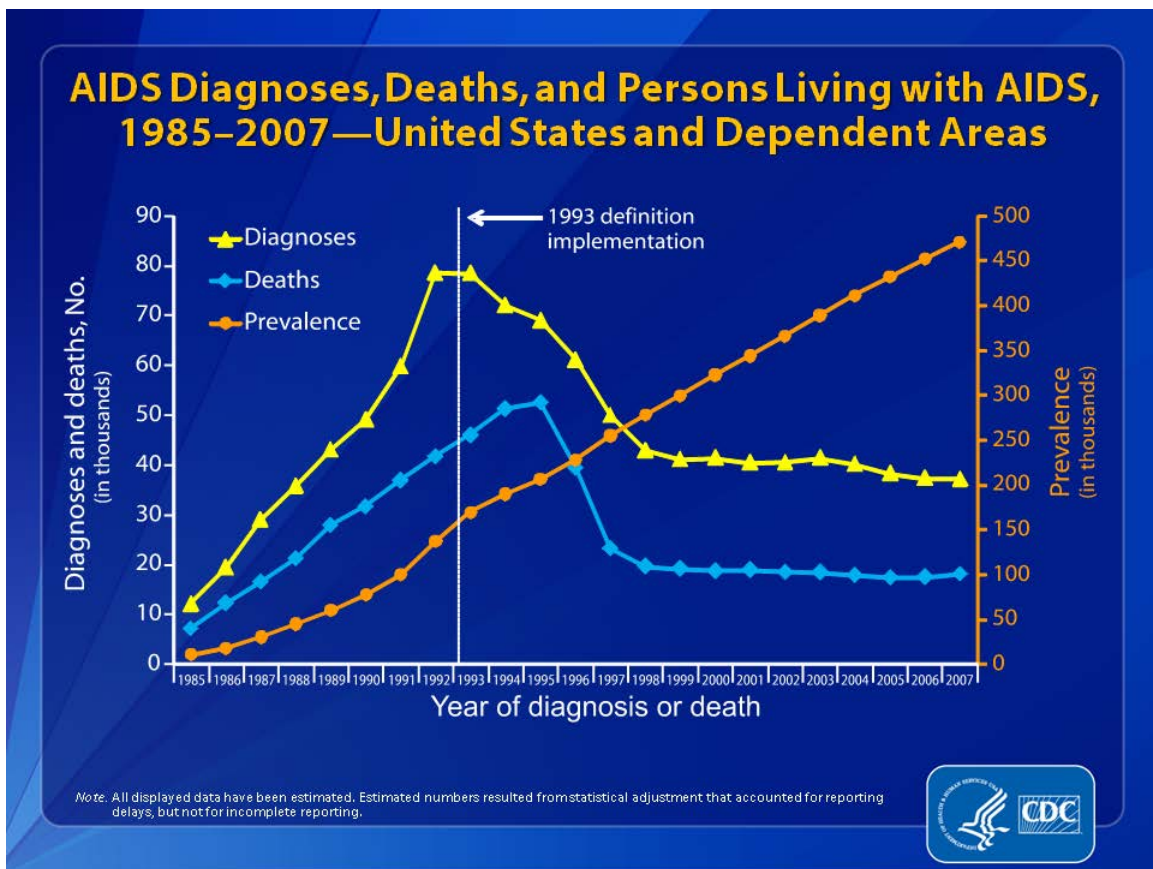
<b>Class of Drug</b>	<b>Method of Action</b>
<b>Nucleoside reverse transcriptase inhibitors (NRTIs)</b>	Inhibit Reverse Transcriptase
<b>Nucleotide reverse transcriptase inhibitors (NtRTIs)</b>	Inhibit Reverse Transcriptase
<b>Non-nucleoside reverse transcriptase inhibitors (NNRTIs)</b>	Inhibit Reverse Transcriptase
<b>Protease inhibitors</b>	Inhibit HIV Protease
<b>Integrase Inhibitors</b>	Inhibit HIV Integrase
<b>Entry inhibitors (fusion inhibitors)</b>	Prevent virus from fusing and entering target cells.
<b>CCR5 Receptor antagonists</b>	Bind to CCR5 receptors on T-cells and block viral attachment
<b>Maturation inhibitors</b>	Prevent processing of viral proteins

### **1.2.5 The Shifting Epidemiology of HIV in the United States – Impact on Women**

During the first decade of the HIV epidemic, steady and sharp increases were observed in the incidence of HIV/AIDS<sup>25</sup>. The disease during this time was characterized as an illness in Caucasian MSM, the group in which the AIDS was first recognized. Other at risk groups, including intravenous drug users, heterosexual males, and women accounted for approximately 33% of the total incident cases of HIV infection. The HIV Epidemic peaked in 1993 when 80,000 new infections were reported. In 1995, the death rate due to AIDS reached its peak, accounting for 2% of all deaths in the United States. During this time, AIDS was the leading cause of death in men and women 25 to 44 years of age and was the 8<sup>th</sup> leading cause of death overall.<sup>25, 26</sup>

Following 1993, the incidence rates of HIV/AIDS began to decrease, likely due to the introduction and successful use of antiretroviral drug therapy and prophylactic treatment with Bactrim to prevent PCP. Other factors, such as increased use of primary protection and

prophylactic medications for opportunistic infections also likely contributed to the lower incidence rates of HIV. From 1998 to 2007, the rates of HIV infection stabilized, with 40,000 new infections being reported every year<sup>25, 26</sup>. Despite falling incidence rates, prevalence rates have steadily increased as a result of decreased morbidity and mortality associated with HIV. Figure 2 summarizes the trends for AIDS from 1985 to 2007. In 2007, it was estimated that 1.2 million people were living with HIV and 450,000 people were living with AIDS in the United States<sup>25, 26</sup>. In 2009, the CDC estimated that an additional 35,000 were diagnosed with AIDS<sup>26</sup>.

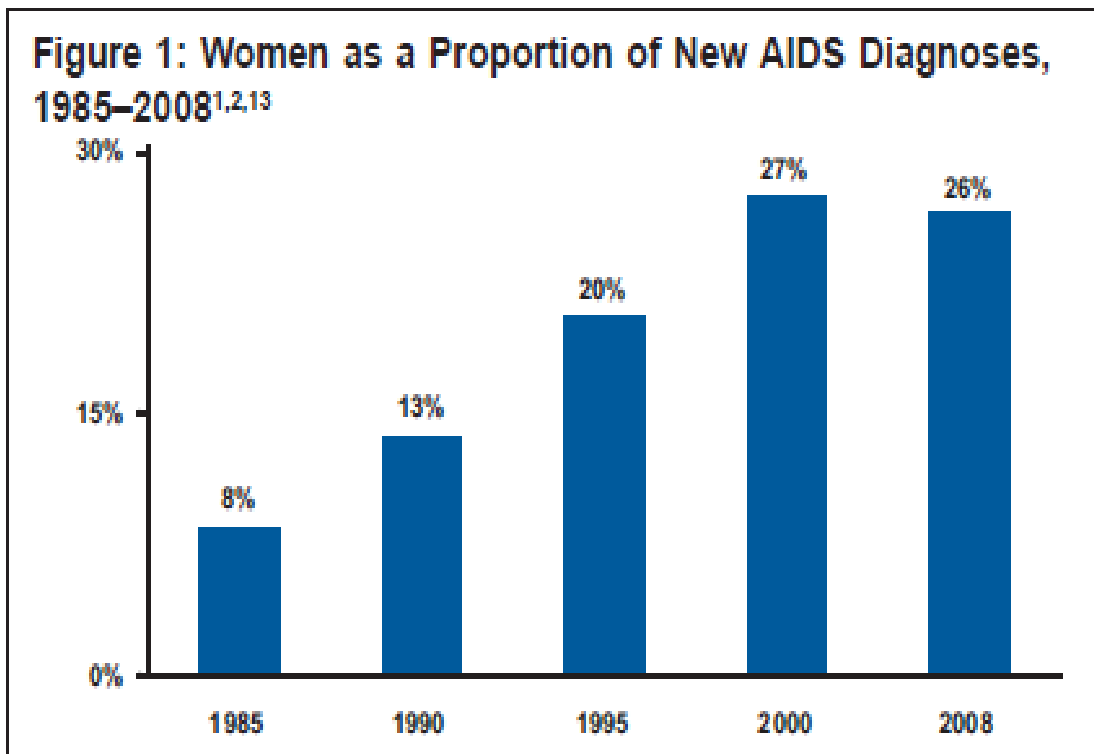


**Figure 2: Characteristics of the AIDS Epidemic in the United States: 1985-2007<sup>26</sup>**

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In addition to shifting rates of infection, the epidemic has also changed in terms of groups at risk. As the epidemic continued, the rates of infection increased for heterosexual men, minorities, and women<sup>27</sup>. Because the focus of this thesis is HIV infection in pregnant women, the growing epidemic in women will be the primary focus of the following discussion.

In 1985, women accounted for 8% of the total number of individuals diagnosed with AIDS. Over time, the proportion of the total epidemic represented by women has increased dramatically. In 2008, it was estimated that 26% of new AIDS diagnoses were in women<sup>2</sup>. The progression of women in relation to the total AIDS disease burden can be seen in Figure 3.



**Figure 3: The Proportion of Women in the AIDS Epidemic: 1985-2008<sup>2</sup>**  
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Using extended back calculation methods, Hall *et al.* estimated the incidence rate of HIV infection for men and women in the United States from 1980-2006. The rates of infection in women began to increase in the late 1980s and have remained constant, whereas the rate of infection in men decreased dramatically and stabilized over the same time period<sup>27</sup>.

In 2006, it was estimated that 15,000 new cases of HIV were diagnosed in women in the United States and 280,000 women were living with HIV/AIDS<sup>2, 27</sup>. Eighty percent of these cases are due to high-risk heterosexual contact, whereas the remaining 20% are due to intravenous drug use, a combination of high-risk heterosexual contact and intravenous drug use, or other factors<sup>3</sup>.

HIV-positive minority women represent the majority of the incident AIDS disease burden<sup>2</sup>. When comparing the percentages of minority women belonging to minority groups being diagnosed with AIDS to the total percentages in the general population, there are dramatic differences. African-American women make up the majority of diagnoses of AIDS, 65%, but only 12% of the total population of women in the United States. This is in comparison to Caucasian women, who make up 16% of new AIDS diagnoses, but account for 68% of the total population of women in the United States. The proportion of AIDS diagnoses and percentages of the total population for Latina women and all other ethnic groups are more comparable, at 17% and 13% for Latinas and 3% and 7% for other ethnic groups, respectively.

The majority of women living with HIV/AIDS are of reproductive age. For women of all races and ethnicities, the largest number of HIV/AIDS diagnoses during recent years were in women of childbearing age, between the ages of 15 and 39<sup>3</sup>. Because the majority of newly diagnosed women are within their childbearing years, the decision to bear children is an issue that many HIV-positive women consider. Increases in lifespan and successful medication

regimens that reduce the risk of perinatal transmission have impacted the pregnancy rates among HIV-positive women in the United States<sup>28</sup>.

In 1994, prior to the introduction of antiretroviral therapy for HIV-positive pregnant women, 14% of women who were HIV-positive were becoming pregnant annually.<sup>28</sup> A study by Blair *et al.* in 2004 examined the pregnancy rates among HIV-positive women following the introduction of ZDV and HAART. The results of this study can be seen in Figure 4.

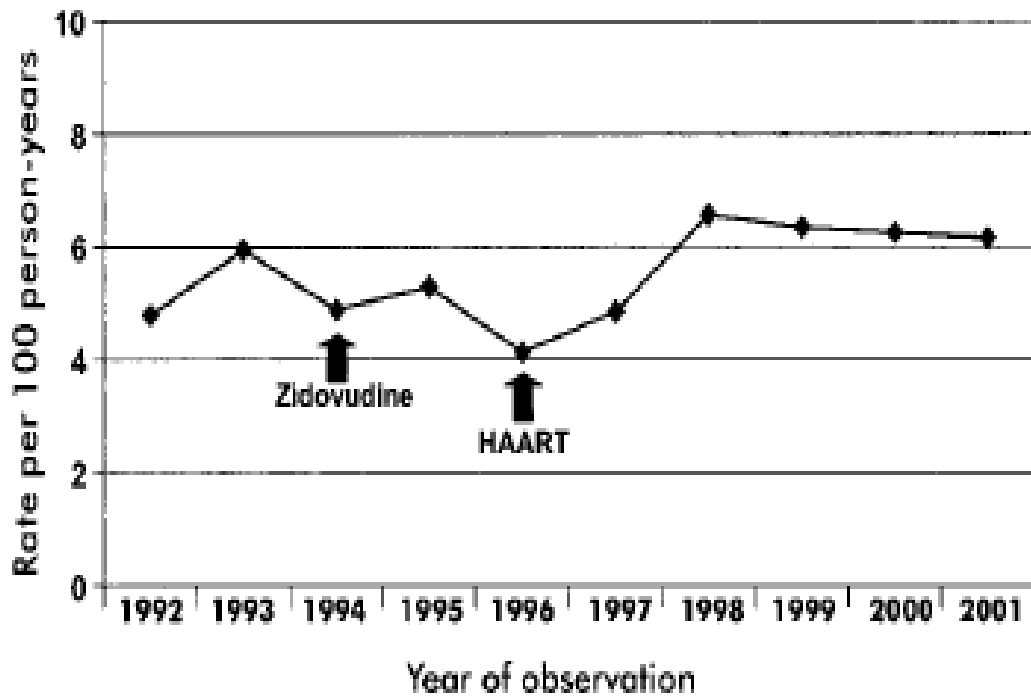


Figure 4: Pregnancy Rates in HIV-positive Women: 1992-2001<sup>28</sup>

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Following the introduction of HAART in 1996, the rates of pregnancy increased in HIV-positive pregnant women from 4 pregnancies per 100 person-years to 6 per 100 person years<sup>28, 29</sup>. Consistent with this study, a study by Sharma *et al.* showed that the live birth rate was 150% higher among HIV-positive women following the introduction of HAART as compared to birth

rates in the pre-HAART era<sup>30</sup>. The rates were higher among women of all age groups, but the largest differences were seen in women older than 35<sup>30</sup>. Studies have also shown that in addition to an increase in the number of women who are choosing to become pregnant, these same women are more likely to carry their pregnancy to term rather than choosing an elective termination<sup>29</sup>. The CDC estimates that every year, between 6,000 and 7,000 HIV-positive women will become pregnant<sup>3,9,31</sup>.

As the numbers of women living with HIV/AIDS in the United States continue to increase, the number of HIV-positive pregnant women can also expect to increase. As more HIV positive women become pregnant, it becomes more likely that these same women will be referred to prenatal genetic counseling for matters unrelated to their HIV infection.

## **1.3 GENETIC COUNSELING**

### **1.3.1 What is Genetic Counseling?**

Genetic counseling is the process of helping people understand and adapt to the medical, psychological, and familial implications of genetic contributions of disease<sup>32</sup>. The process of genetic counseling integrates “interpretation of family and medical histories to assess the chance of disease occurrence or recurrence, education about inheritance, testing, management, prevention, resources, and research, and counseling to promote informed choices and adaptation to the risk or condition”.<sup>32</sup> Genetic counselors work with physicians, nurses, social workers, and other members of the health care team to help provide quality care to patients.

### **1.3.1.1 Principles and Goals of Genetic Counseling**

Genetic counselors practice under a number of assumptions or principles which are important to the profession. Some of these tenets are voluntary utilization of services, equal access, client education, complete disclosure of information, nondirective counseling, attention to psychosocial and affective dimensions in counseling, and confidentiality and protection of privacy.<sup>32</sup>

Genetic counselors believe that the utilization of genetic services is a choice that should be made by the patient. Patients are not forced to meet with genetic counselors and should not feel as though they are being irresponsible if they decline the services provided by such professionals. At the same time, however, it is important that all individuals have the option of pursuing genetic counseling. Equal access to services provided by genetic counselors is the ideal. However, it is documented that people who live in urban settings, people with health insurance, and people with higher education are more likely to seek genetic counseling compared to other individuals. Measures have been taken to reduce this discrepancy by expanding genetic counseling services to rural areas, lower-income populations, and to individuals who might otherwise not be aware, or identify the need for services.

One of the most important parts of a genetic counseling session is client education and disclosure of information. A genetic counselor's role is to provide patients with the most accurate and detailed information necessary to allow the patient to make an informed decision. The education provided within a session is usually extensive, and typically covers the features, natural history, and range of variability of the condition in question, the genetic (or nongenetic) basis, how it is diagnosed, the clinical management, the risk of occurrence or recurrence in family members, economic, social, and psychological impact, challenges it presents, prevention

strategies, and relevant research to increase the understanding of the disorder.<sup>32</sup> Genetic counselors are responsible for providing the most accurate and relevant information possible to patients. “Being selective in what one tells a client is viewed as paternalistic – and disrespectful of the person’s autonomy and competence”.<sup>32</sup> Providing a client with information should not be confused with an attempt to influence a client’s decision, because this conflicts with genetic counselors’ approach that counseling should be non-directive.

It has been discussed in the literature that adherence to nondirective counseling is the most defining feature of genetic counseling<sup>32</sup>. Information provided by a genetic counselor should be presented in a nonbiased and fair manner without an attempt to influence an individual towards a particular decision. Nondirective counseling can be difficult in some situations, however it is the genetic counselor’s role to help guide an individual through the decision process that is most appropriate for them.<sup>32</sup>

Delivery of information does not necessarily promote an informed decision-making process. Each individual has a combination of social, cultural, educational, economic, emotional and environmental circumstances that influence the decision-making process. Learning about genetic or reproductive risks can create strong emotional reactions. A crucial part of genetic counseling is recognizing the possible occurrences of these reactions, and helping patients anticipate and make plans for how to deal with these emotions.<sup>32</sup> A skilled genetic counselor will be able to listen effectively and identify key issues which are important to a patient while exploring a patient’s personal interpretation of the information and risks presented to them.<sup>32</sup> Information which may be discussed in a genetic counseling session may be highly personal or private, and patients should be assured that all information will be kept strictly confidential.



Although patient confidentiality has always been an important part of genetic counseling, the passage of The Health Insurance Privacy and Accountability Act (HIPAA) in 1996 formalized a patient's rights to privacy. Genetic information is a highly sensitive and personal subject, and patients should be assured that unless direct permission is given, genetic counselors cannot share information with anyone, even other family members. Additional information shared in sessions is also kept confidential, regardless of its genetic relevancy or not.

In order to gain competency in these principles, genetic counselors must successfully complete training which is outlined by the American Society of Genetic Counselors (ABGC).

### **1.3.1.2 Training Programs for Genetic Counselors**

Currently, genetic counseling training requires the completion of an undergraduate degree followed by a two-year master's degree program. Prior to the establishment of formal training programs, genetic counseling was completed by nurses, social workers, physicians, or individuals who had undergraduate degrees in genetics<sup>32</sup>. Today, the majority of genetic counselors have masters of science degrees, although some counselors choose to pursue additional degrees in nursing, social work, public health, and business<sup>33</sup>.

The first genetic counseling program was started in 1969 at Sarah Lawrence College. Since then, over 30 programs have been established in the United States and Canada. There are currently 32 accredited genetic counseling programs recognized by the American Board of Genetic Counselors in the United States and Canada. These programs vary in number of students taken, affiliation with other institutions (graduate schools, medical schools, schools of public health, etc.), and curriculum. A list of the current genetic counseling programs in the United States and Canada can be found at [www.abgc.net](http://www.abgc.net).

Genetic counseling training programs use a combination of traditional classroom learning and clinical internships to educate their students regarding the different roles of genetic counselors.

### **1.3.1.3 Prenatal Genetic Counseling**

The practical scope of genetic counseling has grown since its introduction. Genetic counselors practice in a variety of settings and serve a diverse patient population. According to the National Board of Genetic Counselors, 83% of genetic counselors work in a clinical setting, meaning that they interact with patients on a regular basis. As the field of genetic counseling has grown, the areas of practice for genetic counselors have also expanded. There are currently over two dozen specialty areas for genetic counseling, but the majority of counselors still identify prenatal genetic counseling as their primary area of focus.<sup>33</sup>

Prenatal genetic counseling focuses on providing services for pregnant women, their partners, and their families. Women who seek prenatal genetic counseling may be referred for a variety of reasons, some of which are not truly genetic indications. Table 2 provides examples of some reasons why women would be referred to prenatal genetic counseling.

**Table 2: Common Reasons for Referral to Prenatal Genetic Counseling<sup>34-36</sup>**

<b>Reason for Referral</b>	<b>Comment</b>
<b>Advanced Maternal Age (&gt;35)</b>	<b>Increased risk for chromosome conditions like Down syndrome, Trisomy 18, or Trisomy 13</b>
<b>Personal/family history of a genetic condition</b>	<b>Increased risk of passing on genetic condition</b>
<b>Previous child with genetic condition or birth defect</b>	<b>Increased risk of recurrence for genetic condition/birth defect</b>
<b>High-risk ethnic background</b>	<b>Increased carrier risk for conditions specific to ethnic backgrounds</b> <ul style="list-style-type: none"> <li>• Cystic Fibrosis in the Caucasian population</li> <li>• Sickle Cell Anemia in the African-American population</li> <li>• Tay-Sachs in the Ashkenazi Jewish population</li> </ul>
<b>Multiple Miscarriages (&gt;3)</b>	<b>Increased risk of a genetic cause for recurrent miscarriages</b>
<b>Consanguinity (pregnancy between two individuals more closely related than 2<sup>nd</sup> cousins)</b>	<b>Increased risk for birth defects or recessive conditions</b>
<b>Women with ‘high risk’ medical conditions</b>	<b>Examples: Diabetes, hypothyroidism, phenylketonuria</b>
<b>Exposure to drugs or alcohol during the pregnancy</b>	<b>Increased risk for pregnancy complications, birth defects, withdrawal following delivery, and long-term adverse effects to the child</b>
<b>Exposure to medications during pregnancy known to be associated with birth defects or adverse fetal outcomes</b>	<b>Increased risk for miscarriage/stillbirth, birth defects, or complications following delivery</b>
<b>Maternal viral, bacterial, or protozoal infections during pregnancy</b>	<b>Increased risk for miscarriage/stillbirth, birth defects, complications following delivery, and fetal infection.</b>

During a prenatal genetic counseling session, counselors will collect a family history, perform a risk assessment, and discuss different testing options available for the parents and the fetus to help clarify specific risks. Maternal serum screening tests are one option that use a combination of ultrasound and maternal blood work generate personalized risk estimates for Down syndrome and Trisomy 18. These tests are not diagnostic, however. Diagnostic options for couples with risks for birth defects or chromosome conditions include diagnostic ultrasound and early invasive diagnostic procedures. Diagnostic ultrasound is done during the second trimester and uses ultrasound to look for physical signs birth defects which may be associated

with genetic conditions or chromosome abnormalities. These detailed anatomical ultrasounds are able to detect about 50% of cases of Down syndrome, 90% of cases of Trisomy 13 and 18, and 95% of cases of spina bifida. In addition to looking for these conditions, diagnostic ultrasounds can also detect structural birth defects such as congenital heart defects or brain malformations. Diagnostic tests include the early invasive procedures such as chorionic villus sampling and amniocentesis. These tests collect fetal tissue or cells to allow for direct testing for conditions of interest. These procedures are able to confirm the presence of a chromosome abnormality with greater than 99% accuracy and can also be used for genetic testing for specific conditions of interest if parental mutations are known. Because chorionic villus sampling and amniocentesis are invasive procedures, they carry a 1 in 1000 risk of complications that could result in miscarriage. It sometimes may be necessary to do genetic testing on one or both parents check for underlying chromosome changes or genetic conditions which might put the pregnancy at risk. Prenatal genetic counselors describe the different options available to women/couples to help understand and personalize risks, discuss the benefits and limitations of each option, and help women and their partners work through the decision-making process to choose the option that works best for them.<sup>34</sup>

If a genetic condition or birth defect is identified in a pregnancy, genetic counselors work with families to help them make decisions about the outcome of the pregnancy. Potential options include continuing the pregnancy with intention to keep the baby, giving the baby up for adoption following delivery, or elective termination of the pregnancy. If a chromosome change is identified or an underlying genetic condition is identified in a parent, couples can be counseled regarding fertility options, including chorionic villus sampling/amniocentesis, preconception genetic diagnosis, adoption, or the use of a donor sperm/egg to help reduce the risks of having a

child with an unbalanced chromosome abnormality.<sup>34</sup> Counselors are also useful in these situations to provide psychosocial counseling for issues that can arise from diagnosing and managing an at-risk pregnancy<sup>37</sup>.

As discussed, there are many reasons a woman might be referred for prenatal genetic counseling. It is not uncommon for many women to fall into more than one of these categories. Although HIV is not a true genetic condition which would warrant genetic counseling, it is a relevant part of a woman's medical history and can have implications on management during pregnancy. Women with HIV are not just women with HIV, they are women who are being referred for counseling due to advanced maternal age, genetic risks, medication exposures, and any other of reasons that a women without HIV would be referred to genetic counseling. HIV-positive pregnant women have unique medical and psychosocial issues which may be relevant topics of discussion during a prenatal genetic counseling session. The next section of this thesis examines these issues in more detail.

## **1.4 HIV AND PREGNANCY AND GENETIC COUNSELING: TOPICS OF CONCERN**

### **1.4.1 HIV Perinatal Transmission Risks**

HIV infection during pregnancy has not been found to have detrimental effects on the health of the mother and has not been associated with an increased risk for miscarriage<sup>29, 31</sup>. The major risks for infants born to mothers with HIV are the risks associated with perinatal infection.

Perinatal transmission is the most common way for children to become infected with HIV<sup>9</sup>. HIV varies from other vertically transmitted pathogens because it is able to be transmitted to infants during pregnancy (in utero exposure), labor and delivery (intrapartum exposure), and breastfeeding<sup>38</sup>.

The majority of in utero transmission of HIV occurs during the third trimester of pregnancy, although fetal infection has been reported during the first two trimesters<sup>38</sup>. The most likely mode of transmission is due to HIV crossing the placenta from microtransfusion of maternal blood across the placenta<sup>39</sup>. In the absence of intervention, the risk of transmission for in utero exposure is 5-10%<sup>39</sup>. HIV-related risk factors associated with in utero transmission are the mother's HIV plasma viral load and CD4+ T-cell count. The risk of transmission during pregnancy is greater in women with higher HIV plasma loads and studies have shown that a low maternal CD4+ T-cell count (<500cells/mm<sup>3</sup>) is also associated with increased rates of transmission<sup>39</sup>. Additional risk factors include infections during pregnancy such as common bacterial infections or sexually transmitted infections (STIs).<sup>38</sup> To date, no links have been established between in utero transmission risks and maternal age, race or ethnicity, or history of a previously-infected child<sup>40</sup>.

HIV transmission from mother-to-child is also possible during labor and delivery following exposure of the infant to contaminated maternal blood and genital secretions<sup>38</sup>. Among non-breast fed infants, the risk of infection during labor and delivery in untreated mothers is 10-20% and represents 66% of all perinatal infections. Similar to the transmission risks in utero, the higher the maternal plasma viral load, the higher the risk of infection for the infant. Additional risk factors include prolonged duration of ruptured membranes (>4 hours) and vaginal lacerations that may occur during childbirth<sup>39</sup>. In a study examining risks during labor

and delivery, the risk of infection increased by 2% for every hour the membranes remained ruptured.<sup>38, 39</sup>

A final method of transmission from mother-to-child is from exposure to HIV through breastfeeding. It is difficult to determine the exact transmission risks associated with breastfeeding because it is hard to separate these risks from exposures late in utero or during labor and delivery. Despite these limitations, it is thought that 10-20% of infants who are breastfed from HIV-positive mothers will become infected. Risk factors for transmission include duration of breastfeeding and maternal plasma viral load. Viral load in breast milk is decreased approximately 2-3 log<sub>10</sub> as compared to plasma and each 10-fold increase of viral RNA in breast milk is associated with a 2 fold increase in transmission.<sup>38</sup>

Combining the risks associated with in utero, intrapartum, and breastfeeding exposures, the risk of an exposed infant to become infected with HIV is approximately 30-45% in the absence of interventions. Successful intervention strategies include successful treatment with antiretroviral medications, obstetric interventions, and alternatives to breastfeeding<sup>38</sup>.

## **1.4.2 Management During Pregnancy**

### **1.4.2.1 Recommended medications and risks associated with medications**

Successful use and adherence to antiretroviral medications has been shown to reduce the risks associated with mother-to-child transmission of HIV. In 1994 it was shown that short-course regimens of ZDV were able to reduce the incidence of vertical transmission of HIV by 15-20%. ZDV is able to cross the placenta and is thought to reduce the maternal HIV viral load and provide prophylactic protection to the fetus during birth. ZDV is not able to suppress the levels of virus in breast milk following birth, so treatment with ZDV alone does not lower the

transmission risks associated with breast feeding. In the United States, ZDV is still a commonly used antiretroviral medication in HAART regimens for HIV-positive pregnant women<sup>41</sup>. The current standard of care for HIV-positive women is to use a combination of three antiretroviral drugs from two or three different classes<sup>39</sup>. The introduction of additional antiretrovirals in combination with ZDV has lowered the rate of perinatal transmission to <2%<sup>39</sup>. When to initiate therapy and what type of therapy to begin depends on several factors specific to the woman, including her overall health, prior antiretroviral regimens, and the gestational age of the fetus at the first evaluation. Table 3 discusses the recommendations for antiretroviral therapy for HIV-positive pregnant women in a variety of clinical situations.



**Table 3: Recommendations for Antiretroviral Drug Use for HIV-Positive Pregnant Women<sup>42</sup>**

Clinical Situation	Recommendation
<p><b>HIV-infected woman who is receiving HAART and becomes pregnant</b></p>	<p>Continue current HAART regimen if successfully suppressing viremia, except avoid use of efavirenz or other potentially teratogenic drugs in the first trimester and drugs with adverse potential for mother.</p> <p>In general, if the woman requires treatment, antiretroviral drugs should not be stopped during the 1<sup>st</sup> trimester.</p> <p>Continue HAART regimen during intrapartum period (ZDV given as continuous infusion during labor while other antiretroviral drugs are continued orally) and postpartum.</p>
<p><b>HIV-infected woman on combination antiretroviral drug therapy who becomes pregnant</b></p>	<p>In general, if the woman requires treatment, antiretroviral drugs should not be stopped during the first trimester or during pregnancy.</p> <p>Continue current combination antiretroviral therapy regimen if successfully suppressing viremia, however, avoid use of efavirenz or other potentially teratogenic drugs in the first trimester and drugs with known adverse potential for the mother.</p> <p>Perform HIV antiretroviral drug resistance testing if the woman has detectable viremia on therapy.</p> <p>Continue combination antiretroviral therapy regimen during intrapartum period (ZDV given as continuous infusion during labor while other antiretroviral agents are continued orally) and postpartum.</p>
<p><b>HIV-infected pregnant woman who is antiretrovirals naïve and has indications for antiretroviral therapy</b></p>	<p>Initiate HAART regimen.</p> <ul style="list-style-type: none"> <li>• Avoid use of Efavirenz or other potentially teratogenic drugs in the first trimester and drugs with known adverse potential for mother</li> <li>• Use of ZDV as a component of the antiretroviral regimen is recommended when feasible</li> <li>• Nevirapine can be used as a component of HAART for women with CD4+ count &lt;250 cells/mm<sup>3</sup> if the benefit clearly outweighs the risk due to an increased risk of severe hepatic toxicity</li> </ul> <p>For women who require immediate initiation of therapy for their own health, treatment should be initiated as soon as possible, including in the first trimester.</p> <p>Continue HAART regimen during intrapartum period (ZDV given as continuous infusion during labor while other antiretroviral agents are continued orally) and postpartum.</p>

**Table 3 Continued**

<p><b>HIV-infected pregnant woman is antiretroviral naïve and does not require treatment for her own health</b></p>	<p>HAART is recommended for prophylaxis of perinatal transmission in women who do not require treatment for their own health.</p> <ul style="list-style-type: none"> <li>• Consider delaying HAART initiation until after first trimester is completed</li> <li>• Avoid use of efavirenz or other potentially teratogenic drugs in the first trimester and drugs with known adverse potential for the mother</li> <li>• Use of ZDV as a component of the antiretroviral regimen is recommended when feasible</li> <li>• Nevirapine should only be used as a component of therapy in women with CD4+ counts &lt;250 cells/mm<sup>3</sup> if the benefit clearly outweighs the risk due to an increased risk of severe hepatic toxicity</li> </ul> <p>Use of ZDV prophylaxis alone is controversial but may be considered for those women with plasma HIV RNA levels &lt;1000 copies/mL on no therapy.</p> <p>Continue HAART regimen during intrapartum period (ZDV given as continuous infusion during labor while other antiretroviral agents are continued orally).</p> <p>Evaluate need for continued therapy postpartum; discontinue HAART unless has indications for continued therapy.</p>
<p><b>HIV-infected pregnant woman who is antiretroviral experienced but not currently receiving antiretroviral drugs</b></p>	<p>Obtain full antiretroviral treatment history and evaluate need for antiretroviral treatment for own health.</p> <p>Initiate HAART, with regimen chosen based on resistance testing and prior history</p> <ul style="list-style-type: none"> <li>• Avoid use of efavirenz or other potentially teratogenic drugs in the first trimester and drugs with known adverse potential for the mother</li> <li>• Use of ZDV as a component of the antiretroviral regimen is recommended when feasible</li> <li>• Nevirapine should only be used as a component of therapy in women with CD4+ counts &lt;250 cells/mm<sup>3</sup> if the benefit clearly outweighs the risk due to an increased risk of severe hepatic toxicity</li> </ul> <p>Continue HAART regimen during intrapartum period (ZDV given as continuous infusion during labor while other antiretroviral agents are continued orally).</p> <p>Evaluate need for continued therapy postpartum; discontinue HAART unless has indications for continued therapy.</p>
<p><b>HIV-infected woman who has received no antiretroviral therapy prior to labor</b></p>	<p>ZDV given as continuous infusion during labor</p> <p><i>OR</i></p> <p>ZDV given as continuous infusion during labor, plus single dose nevirapine at onset of labor. Consideration should be given to adding lamivudine during labor and maternal ZDV/lamivudine for 7 days postpartum, which may reduce development of nevirapine resistance.</p>

For women undergoing Caesarian sections, it is recommended that intravenous ZDV therapy begin 3 hours before the scheduled delivery<sup>41</sup>. For women delivering vaginally, intravenous ZDV should begin throughout labor and delivery<sup>42</sup>.

A registry has been established to examine the risks for birth defects and negative pregnancy outcomes in women with HIV who are taking antiretroviral medications. The purpose of this registry is to “collect observational, nonexperimental data on the antiretroviral exposure during pregnancy for the purpose of assessing the potential teratogenicity” of antiretroviral medications<sup>43</sup>. The Antiretroviral Pregnancy Registry has found that the risk for birth defects is 5.8% for all women taking antiretrovirals during the first trimester, which is higher than observed in the general population. Women taking antiretrovirals later in pregnancy have not had an increased risk for birth defects, and the risks are similar to those seen in the general population<sup>42</sup>. When counseling HIV-positive pregnant women, it is important to keep these risks in mind and also to help weigh the risks versus the benefits of initiating or continuing antiretroviral use during the first trimester.<sup>39, 42</sup>

When deciding which medications should be used in a HAART regimen for an HIV-positive pregnant woman, the FDA pregnancy categories for medications should be taken into consideration. The majority of HIV medications are FDA category B or C, meaning that they can be considered for use during pregnancy without clear risks of associated birth defects<sup>11, 42</sup>. Some medications should not be used during pregnancy because of possible risks to the fetus or to the health of the mother.

Efavirenz, a non-nucleoside reverse transcriptase inhibitor, is categorized by the FDA as a category D medication<sup>42</sup>. Use of Efavirenz during the first trimester has been associated with

an increased risk for open neural tube defects, facial cleft defects, hydrocephalus, and anophthalmia (the congenital absence of one or both eyes). Because there are alternative medications that HIV-positive pregnant women can consider for use during pregnancy in replacement of Efavirenz, it is recommended that its use be discontinued as soon as possible during the pregnancy<sup>42</sup>.

Some additional antiretroviral medications are not recommended for use during pregnancy because of risks to the fetus. Zalcitabine has been associated with a high risk of hydrocephalus in rodents and Delavirdine has been associated with an increased risk for ventricular septal defects in rodents. Although no human studies have been done to characterize the risk of birth defects, it is recommended that these medications be avoided. Finally, tenofovir has been associated with bone abnormalities in multiple species of lab animals. Data from the antiretroviral pregnancy registry has shown a 2.66% risk of birth defects in women taking tenofovir during the first trimester similar to those seen in the general population. Despite these results, it is recommended that tenofovir should be used as a component of HAART only after alternatives have been ruled out.<sup>42</sup>

Higher rates of preterm birth and low birth weight have been described in infants born to mothers who have taken antiretrovirals during pregnancy<sup>44</sup>. In particular, it is thought that the use of protease inhibitors during pregnancy can lead to pregnancy complications. Results of studies examining pregnancy outcomes for women using antiretroviral therapy vary, and it is currently thought that some of the relationship between complications and antiretroviral exposure can be explained by the presence of additional risk factors. In particular, low birth weight and preterm delivery have been associated with race/ethnicity, substance abuse, parity, prior preterm birth, hypertension, maternal diabetes, low maternal weight, and poor prenatal

care<sup>44</sup>. Women with HIV should be supervised appropriately during pregnancy according to risk factors and indications from prenatal ultrasound to help manage the risks for complications such as low birth weight and preterm delivery.

One medication, nevirapine, was initially used in combination with ZDV to treat women with HIV during pregnancy. It is now known that nevirapine may not be recommended in women with CD4+ T-cell counts  $>250$  cells/mm<sup>3</sup> because of adverse effects for the mother, specifically hepatotoxicity<sup>39,41</sup>.

For more information on the safety of the use of antiretroviral medications during pregnancy and the current antiretroviral combination recommendations, the Public Health Service Task Force guide, “Recommendations for use of antiretroviral drugs in pregnant HIV-infected women for Maternal Health and Interventions to Reduce Perinatal transmission in the United States” is useful. Information regarding the Antiretroviral Pregnancy Registry can be found at <http://www.APRegistry.com>.

#### **1.4.2.2 Obstetric Management for HIV-positive Pregnant Women**

Women with HIV should undergo traditional prenatal health care as well as some additional assessments to help characterize the status of their infection and to determine what treatment methods should be utilized<sup>42</sup>. In addition to the standard antenatal assessments for all pregnant women, the initial evaluation should include evaluation of CD4+ T-cell count, plasma viral load, complete blood count, and renal and liver function tests. It is also important to get an accurate medical history for the mother including history of prior and current antiretroviral treatment, history of prior antiretroviral drug use to prevent perinatal transmission in a prior pregnancy, results of prior and current antiretroviral drug resistance testing, and an assessment of additional supportive care needs<sup>42</sup>. Continual monitoring of the mother’s viral load and CD4+ T-

cell count is an important component of maternal care and should be measured every 3 months following the initial visit. Viral load should be checked 2-6 weeks following initiation or alteration of antiretroviral therapy and then monthly until undetectable. If viral load becomes undetectable, it should still be monitored at least every 2 months during pregnancy.<sup>11, 42</sup>

Just as important as initiating antiretroviral therapy is the monitoring of the mother for adverse side effects which may impact her ability to continue therapy. Monitoring for complications from therapy should be done throughout pregnancy and changes should be made as necessary. In addition, it is recommended that both first trimester and second trimester ultrasound be done to identify any birth defects or pregnancy complications that could be a result of antiretroviral therapy.<sup>42</sup>

HIV-positive pregnant women who choose to undergo maternal serum screening tests should be aware that their HIV infection may impact the results of the testing. Maternal serum screening tests for Down Syndrome and Trisomy 18 are available during the first and second trimester. The first trimester test uses a combination of maternal serum testing for two chemicals produced by the pregnancy (human chorionic gonadotrophin and pregnancy-associated plasma protein) as well as ultrasound measurement of the nuchal translucency to generate a risk estimate for both Down syndrome and Trisomy 18<sup>45</sup>. A study examining first trimester screening outcomes found that a woman's HIV status decreases the values of both chemicals analyzed, but does not impact the overall risk estimate generated for these women<sup>45</sup>.

Second trimester maternal serum screening is called the quad screen, and uses a combination of four chemicals produced by the pregnancy (alpha-fetoprotein, human chorionic gonadotropin, estriol, and inhibin-A) to estimate the risks for Down syndrome, Trisomy 18, and spina bifida<sup>46</sup>. The quad screen has been found to have a false positive rate of 5% in the general

population. Studies examining the results of the quad screen in HIV-positive women have shown that the screen-positive rate is as high as 33% compared to 5% in the general population<sup>46</sup>. Specifically, maternal serum levels of human chorionic gonadotrophin have been found to be significantly increased in women with HIV, which may explain the higher rate of false positives<sup>46</sup>. An explanation for this increased false positive rate has not yet been determined, although some studies have suggested that certain types of antiretroviral therapy and CD4+ T-cell counts may impact the measurement of these chemicals during pregnancy<sup>46</sup>. Because the results of the quad screen may be difficult to interpret for HIV-positive women, it is recommended that they undergo the first trimester screen or detailed second trimester ultrasound to assess for fetal abnormalities associated with chromosome conditions<sup>46</sup>. In the case where a woman's risk is elevated for a chromosome condition these women may consider the option of early invasive diagnostic testing.

HIV-positive pregnant women may consider the option of early invasive diagnostic techniques like chorionic villus sampling or amniocentesis because of advanced maternal age, elevated maternal serum screening test results, clarification of the cause of birth defects detected on ultrasound, or because of a risk of a genetic condition<sup>47</sup>. Prior to the introduction of antiretroviral therapy, early invasive procedures were associated with high risks of vertical infection. Two independent studies done in the 1990s found that the risk for mother-to-child transmission following early invasive procedures was greater than 36%<sup>47</sup>. It is important to note that these studies were done prior to the widespread use of HAART during pregnancy. In 2005, a study examined the pregnancy outcomes of 63 women who underwent early invasive diagnostic techniques. They found that 3.3% of infants born to these women were infected with HIV upon delivery, which was not statistically different from infants born to mothers who did

not have invasive diagnostic procedures done during pregnancy<sup>47</sup>. This is reassuring for HIV-positive pregnant women, although it is recommended that women with HIV consider these procedures only if they have undetectable viral loads and are receiving antiretroviral therapy.

### **1.4.2.3 Delivery Options for HIV-positive Pregnant Women**

One of the major management decisions that must be made for women with HIV is whether to deliver the baby through vaginal delivery or by Caesarian section. Elective cesarean section delivery prior to the onset of labor has been shown to reduce the risk of HIV transmission by 50% when compared to women who delivered vaginally<sup>41</sup>. An important consideration is that the Caesarian section must be elective – meaning that the membranes have not ruptured prior to the initiation of the procedure. The rates of transmission have been found to be similar in women who deliver vaginally and in women who deliver via Caesarian section following the onset of labor. Although it is difficult to prove conclusively, it is thought that the labor process is responsible for a considerable amount of intrapartum infections<sup>41</sup>. The majority of studies looking at transmission rates when comparing modes of delivery were done prior to the introduction of combination therapy as the standard of care for HIV-positive pregnant women. Recent studies show that the risk to transmit HIV following a Caesarian section or vaginal delivery in a mother who has been managed with HAART is not significantly different, approximately 1.8% and 2.0% respectively<sup>41</sup>. In the United States it is recommended that a viral load test be done at 34-36 weeks of pregnancy to help guide decisions regarding the mode of delivery. The American College of Obstetricians and Gynecologists Committee on Obstetric Practice recommend that women with viral loads  $>1000$  copies/mm<sup>3</sup> be offered a Caesarian section<sup>39</sup>. If the viral load is  $<1000$  copies/mm<sup>3</sup>, however, the mother can decide whether or not she prefers vaginal delivery or Caesarian section<sup>39,41</sup>.



#### **1.4.2.4 Alternatives to Breastfeeding**

Because of the risks associated with breastfeeding and transmission of HIV, it is recommended that all HIV-positive women avoid breastfeeding whenever possible<sup>41</sup>. Even for HIV-positive women are receiving antiretroviral therapy, breastfeeding is not considered safe and alternative methods should be identified<sup>39</sup>. In the United States and other developed countries, safe and sustainable alternatives to breastfeeding are available because of the accessibility to formula foods and clean water supplies<sup>48</sup>.

An important consideration when discussing alternatives to breastfeeding may be the cultural implications of its absence. In some cultures, it is expected that women will breastfeed, and this may pose difficulties for women with HIV. Expectations from family members, friends, and larger social groups may make the decision to use alternative methods to breastfeeding difficult. Health care providers should provide support and resources to aid these women in explaining why it is important to consider alternatives to breastfeeding.<sup>49</sup>

#### **1.4.2.5 Management for Children Following Birth**

Infants born to HIV-positive women also require specialized management during their first weeks of life. Continuation of antiretroviral medications is important and it is recommended that all HIV-exposed infants receive ZDV for 6 weeks following delivery<sup>42, 50</sup>. Ideally, the first dose should be given within the first 12 hours of life<sup>42</sup>. Infants taking ZDV may be at a higher risk to develop anemia compared to other infants, and close monitoring for signs of anemia should be done while the infant is taking ZDV<sup>42</sup>. Long-term effects of antiretroviral medications on infants born to HIV-positive mothers following in utero exposure are not well characterized. Conflicting reports have shown that some infants may suffer some degree of mitochondrial dysfunction following exposure, but these risks have not been confirmed<sup>42</sup>.

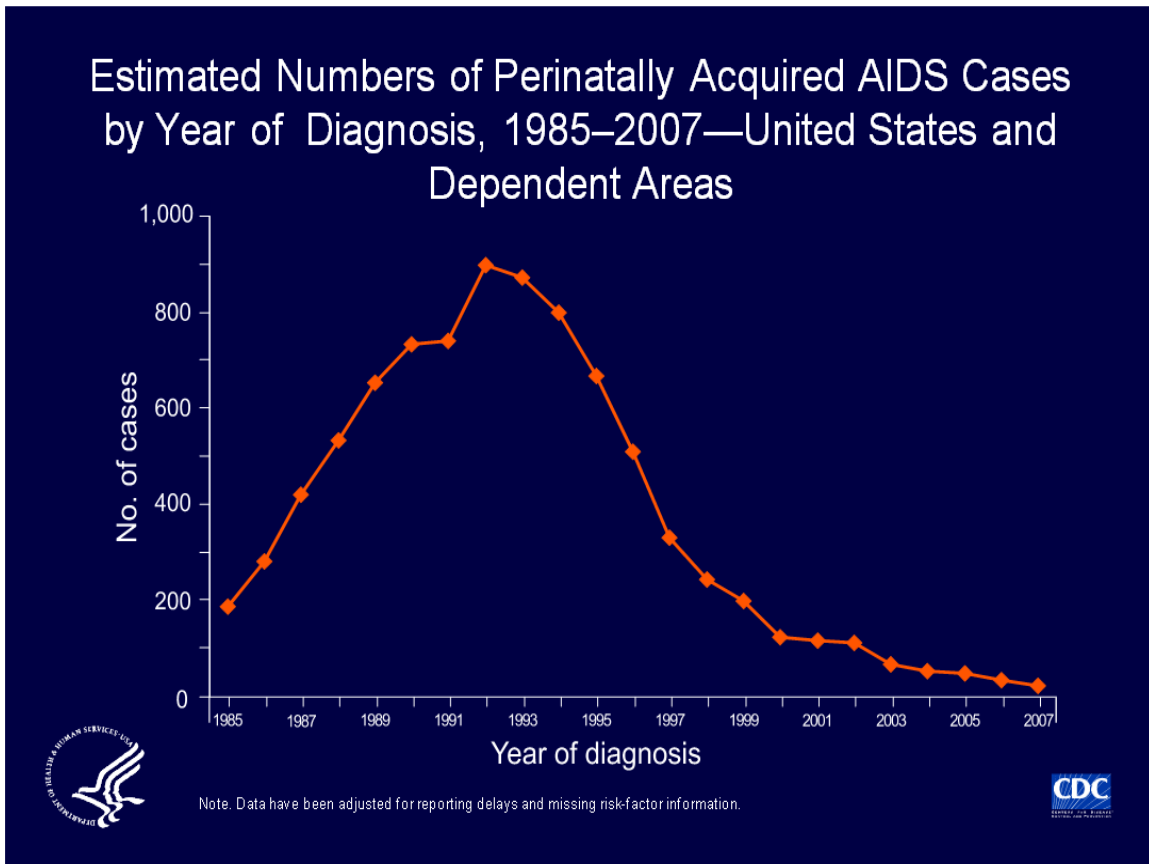
Another important component in the care for infants born to HIV-positive women is testing for HIV following delivery. Because maternal antibodies for HIV are able to cross the placenta during pregnancy, antibody-based tests are not appropriate to diagnose HIV infection until after 18 months of age<sup>42</sup>. In children younger than 18 months, diagnosis is based on virological tests at 2-3 weeks, 1-2 months, and 4-6 months of age. A positive test requires follow-up with a second test to confirm positive status. Two positive HIV tests confirm the diagnosis. Negative results are definitive in infants who have two negative tests done after 1 month and after 4 months of age respectively<sup>42</sup>. Finally, all infants, regardless of their initial test results, should have antibody titers drawn for HIV at age 18 months for confirmatory diagnosis.<sup>50</sup>

Following birth, all HIV exposed infants should have a detailed physical examination<sup>42</sup>. Because infection cannot be ruled out completely in infants until the age of 18 months, some prophylactic medications, like Bactrim, are also recommended to help prevent AIDS-related infections such as PCP. Infants will often begin taking antibiotics between 4 and 6 weeks of age and continue taking them until an HIV diagnosis can be definitively ruled out or confirmed at 18 months.<sup>50</sup>

Finally, vaccination is an important part of care for all infants. HIV exposed or infected infants that are asymptomatic should receive all recommended vaccinations on a regular schedule. For symptomatic infants with or those with documented immune suppression, a limited schedule of vaccinations should be given. Varicella and oral polio vaccine should be avoided, but all other standard vaccines can be given without concern. All children exposed to HIV, regardless of immune function or symptoms, should consider having Haemophilus Influenzae Type B and pneumococcal vaccines.<sup>50</sup>

### **1.4.3 The Impact on Transmission Risks following initiation of HAART and other Interventions**

As discussed, there are now several methods which can reduce the risks associated with perinatal transmission of HIV infection. Rates of perinatal infection peaked in 1992, when it was estimated that 1650 children born to HIV-positive mothers became infected with HIV in the United States<sup>9, 48</sup>. After the introduction of antiretroviral therapy and HAART, these numbers have decreased, and in 2007 it was estimated that less than 200 children were diagnosed with HIV following perinatal exposure<sup>9, 10</sup>. The rates of AIDS diagnosis have also decreased, and these trends can be seen in Figure 5.



**Figure 5: Estimation of Perinatally Acquired AIDS Cases in the United States: 1985-2007<sup>9</sup>**  
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The rates of AIDS diagnoses also peaked in 1992, when approximately 855 children were diagnosed<sup>9, 10</sup>. In 2005, 68 children were diagnosed with AIDS and 67 of them had been infected with HIV following perinatal exposure<sup>10</sup>. Despite the decreases in both HIV and AIDA diagnoses from maternal to child transmission, children are still being infected following perinatal exposure. The majority of these children are born to mothers who did not know they are HIV-positive<sup>48</sup>. It is estimated that 25% of people who have HIV are not aware of their infection<sup>12</sup>. Routine screening for HIV during pregnancy can help reduce the number of children perinatally infected with HIV each year.

## **1.4.4 CDC Testing Recommendations for Pregnant Women**

### **1.4.4.1 Previous Testing Guidelines**

In 1995, the CDC first recommended HIV testing for all pregnant women. The release of these guidelines coincided with the first reports that use of ZDV during pregnancy could decrease the risk of perinatal infection<sup>51</sup>. The guidelines were developed to provide guidance for health-care workers when educating women about risks of perinatal HIV infection<sup>51</sup>.

The 1995 guidelines recommended that health care providers counsel and encourage all pregnant women to undergo HIV testing as early in the pregnancy as possible. The guidelines recommended that full pre-test counseling be conducted prior to testing and should include “information regarding the risk for HIV infection associated with sexual activity and injecting-drug use, the risk for transmission to the woman’s infant if she is infected, and the availability of therapy to reduce this risk”.<sup>51</sup> The recommendations stressed that testing should be voluntary, and consent should be obtained in writing. Re-testing in the third trimester was recommended for women who practiced high-risk behaviors during the pregnancy.

For women who presented during labor and delivery without prior prenatal care, the 1995 recommendations suggested that these women undergo assessment for prior HIV testing, the results of these tests, and risk history. The guidelines stressed that pre-test HIV counseling for these women be completed before testing. If a child was born to a mother whose HIV status was unknown or to a mother who refused testing during pregnancy, the child should be tested as soon as possible following birth for HIV (with consent from the mother). The recommendations note that mothers should be warned that such testing may implicate her HIV infection status, regardless of her decision to decline HIV testing.<sup>51</sup>

Following the release of the 1995 guidelines regarding testing and treatment for HIV during pregnancy, the rates of perinatal infection in the United States declined rapidly. By 1999, the rates of perinatal infection had decreased by 83%<sup>40</sup>. Despite the successes of these guidelines, they were not perfect, and infants were still being born to HIV-positive mothers who were not aware of their status. A study conducted by the Institute of Medicine (IOM) in 1998 found that “continued perinatal transmission was mainly caused by a lack of awareness of HIV status among some pregnant women.”<sup>40</sup> Many women were declining testing because they thought their health-care providers did not strongly recommend it. In addition, some providers did not offer testing because they perceived their patients at low risk, thought that the pre-test counseling process was too burdensome and time consuming, or misunderstood the requirements of counseling to obtain informed consent<sup>40</sup>. The IOM recommended that HIV testing during pregnancy become universal, meaning that it should be offered to all women as part of the standard battery of prenatal tests, regardless of risk factors or the prevalence rate of HIV in the population<sup>40</sup>. The IOM believed that such a transition to universal testing would avoid some of the stereotyping and stigma of socioeconomic or ethnic groups which might be perceived as high-risk by health care providers<sup>40</sup>.

These recommendations led to the replacement of the 1995 guidelines in 2001. The 2001 guidelines published by the CDC emphasized universal HIV testing as a standard component of routine prenatal care. These new guidelines also simplified the pre-test counseling and informed consent processes. Health-care providers were encouraged to recommend HIV testing to all pregnant patients as early in the pregnancy as possible, while providing the ‘minimum information’ necessary to obtain informed consent. Required topics that should be covered included:

- HIV is the virus that causes AIDS. HIV is spread through unprotected sexual contact and injection-drug use. Approximately 25% of HIV-infected pregnant women who are not treated during pregnancy can transmit HIV to their infants during pregnancy, during labor and delivery, or through breast-feeding.
- A woman might be at risk for HIV infection and not know it, even if she has had only one sex partner.
- Effective interventions for HIV-infected pregnant women can protect their infants from acquiring HIV and can prolong the survival and improve the health of these mothers and their children.
- For these reasons, HIV testing is recommended for all pregnant women.
- Services are available to help women reduce their risk for HIV and to provide medical care and other assistance to those who are infected.
- Women who decline testing will not be denied care for themselves or their infants.<sup>40</sup>

Under the 2001 recommendations, HIV testing was still a voluntary test and women had to ‘opt-in’ in order to have testing performed by obtaining documented informed consent. The new guidelines stressed that if a woman were to decline testing, health-care providers should address the reasons for declining, to build trust and rapport with the patient so they may choose to undergo testing at a later date<sup>40</sup>.

Re-testing before 36 weeks of gestation was recommended for women known to be at high-risk for acquiring HIV, including women who “have a history of sexually transmitted diseases, exchange sex for money or drugs, have multiple sex partners during pregnancy, use illicit drugs, have sex partners(s) known to be HIV-positive or at high risk, and have signs or symptoms of seroconversion”<sup>40</sup>. Health care facilities with high rates of HIV among women of childbearing age were also recommended to do repeat HIV testing in the third trimester.

For women who presented at labor and delivery with an unknown HIV status, the 2001 guidelines recommended that rapid testing be done to determine her status so antiretroviral therapy could be initiated if required. Informed consent of HIV testing during labor and delivery

was required and women had to ‘opt-in’ to allow testing to be done.<sup>40</sup> The recommendations for babies born to mothers with unknown HIV statuses did not change – the 2001 guidelines recommended that these infants be tested (with the mother’s approval), although implications of test results should be explained to the mother with regard to her own HIV status.<sup>40</sup>

These improvements from the 1995 guidelines made the testing process easier for many health care providers and resulted in an increased number of pregnant women being screened<sup>12</sup>. Despite these successes, certain populations of women were not being screened. Reasons for these women being missed were “language barriers, late entry into prenatal care, health care providers’ perceptions that their patients were at low risk for HIV, lack of time for counseling and testing (particularly for rapid testing during labor and delivery), and state regulations that required counseling and separate informed consent”<sup>12</sup>. To help address some of these issues, the CDC released updated recommendations for HIV testing in 2006.

#### **1.4.4.2 The 2006 CDC Testing Guidelines**

In September 2006, the CDC released “Revised Recommendations for HIV testing of Adults, Adolescents, and Pregnant Women in Health-Care Settings.” These guidelines updated the 2001 recommendations for HIV screening during pregnancy and reiterated the suggestion that HIV screening be included universally as part of standard prenatal care. It is important to recognize that the guidelines to vary depending on existing state regulations.

The changes from the 2001-2006 guidelines are subtle, but further streamline the process of HIV screening during pregnancy. The 2006 guidelines continue to recommend that all pregnant women be offered HIV screening as part of their standard prenatal care as early in the pregnancy in possible. HIV is now included in the standard battery of blood tests pregnant women receive at their first prenatal appointment. Notification of HIV testing is still required,



however unless women actively decline testing, or “opt-out”, it will be performed.<sup>12</sup> This is different from the 2001 guidelines that required an “opt-in” consent process. It is still recommended that if a woman chooses to “opt-out” of HIV testing, her health care provider discuss the reasons for declining the test and address them to build trust and rapport so that in the future she may choose to consent to HIV testing.<sup>12</sup> The 2006 guidelines recommend that rapid testing should be performed for all women in labor who have an undocumented HIV status. In this setting, women should be notified that HIV testing is recommended for all pregnant women and that unless the patient actively declines, the testing will be done. This again varies from the 2001 guidelines which required an “opt-in” policy during labor and delivery.<sup>12</sup> . In some states, however, testing cannot be done without written consent of the mother. Similar to the 2001 guidelines, the 2006 recommendations support that women at high-risk should undergo a second HIV test during the third trimester. An additional group of women that should be tested are women who live in “jurisdictions with elevated HIV or AIDS incidence and for women receiving health care in facilities with at least one diagnosed HIV case per 1,000 pregnant women each year”.<sup>12</sup>

The 2006 guidelines are still in use today for all pregnant women. To help reinforce these recommendations, the CDC launched the “One Test, Two Lives Campaign” in 2008<sup>48</sup>. This campaign strives to limit maternal transmission of HIV to their children and promote the health of mothers. To help meet the goals of this campaign, educational materials have been developed for both pregnant women and healthcare providers addressing the importance of HIV testing during pregnancy. With the release of these recommendations and programs like those discussed above, the numbers of healthcare providers routinely offering HIV testing to their patients during pregnancy is increasing.

A study conducted in 2006 found that 95-99% of providers reported routinely offering HIV testing to their patients who were pregnant with 64-89% of patients accepting testing<sup>52</sup>. To further support these findings, a survey of women's opinions on routine HIV testing during pregnancy found that 90% of women agreed that HIV testing should be part of routine prenatal care<sup>52</sup>. Despite these accomplishments, infants are still being born to women who do not know their HIV status. To help identify infants who may have been exposed to HIV during pregnancy, some states are choosing to include HIV testing as part of newborn screening panels.

#### **1.4.5 Newborn Screening**

Every infant in the United States is screened for a variety of congenital conditions shortly following birth<sup>53</sup>. The first newborn screen was developed in the 1960s to identify infants born with phenylketonuria, an inherited metabolic disorder. Since then, newborn screening tests have been developed for dozens of conditions, the majority of which are genetic. To qualify as a condition that is included in the newborn screening panel, the condition must be able to be accurately screened for (have a low rate of false positives and false negatives), must have a treatment which can change the course of the disease, and must be cost-effective<sup>53</sup>.

Newborn screening is a public health initiative that involves a coordinated process of testing, follow-up, diagnosis, disease management, and evaluation<sup>53</sup>. Conditions screened for vary within states, the District of Columbia, and Puerto Rico. Currently, 21 conditions are required by law to be included in newborn screening panels<sup>53</sup>. Additional conditions can be added to panels by the discretion of individual states. Efforts are being made, however, to increase the number of required conditions screened for using newborn screening to help standardize the test for all infants born within the United States<sup>53</sup>.

Some states have also begun to incorporate HIV testing into their newborn screening panels. As of January 2011, ten states currently offer HIV testing for infants. Nevada, Mississippi, South Carolina, North Carolina, New Jersey, South Dakota, Wisconsin, Connecticut and Illinois offer HIV testing for all infants born to mothers without a documented HIV test result that was done during pregnancy.<sup>13</sup> Rhode Island is also in the process of initiating a newborn screening program to test for HIV in infants born to mothers without a documented HIV test. New York is the only state that routinely screens for HIV in all infants.<sup>54</sup>

In 1987, New York State began screening all babies born within the state for HIV<sup>55</sup>. The newborn screening tests check the infant's blood for antibodies against HIV<sup>56</sup>. If the child's blood tests positive, this is proof that the child was exposed to HIV during pregnancy. Infants with a positive HIV screening test should be started on ZDV as soon as possible to prevent infection. Mothers of infants with positive HIV screening tests should be counseled about the results. A positive test result in an infant indicates that the mother has HIV and for all intents and purposes involuntarily tests the mother. If the HIV status was previously unknown, she should be evaluated to determine if she requires treatment to manage her condition and counseled to consider alternatives to breastfeeding.<sup>56</sup> All infants with positive newborn screening HIV tests should be monitored according to accepted guidelines to confirm or rule out HIV infection.

The CDC's recommendations that testing be done in infants born to mothers who have an undocumented HIV status may cause more states to include HIV on their newborn screening panel for either a subset or all infants. Mandatory newborn screening will identify all infants exposed to HIV in pregnancy and allow for early treatment and decrease the odds of infection<sup>57</sup>.

In addition, routine newborn screening for HIV has been found to be cost-effective, even in areas where the prevalence of HIV is low<sup>57</sup>.

#### **1.4.6 Psychosocial Issues**

Women with HIV deal with unique psychosocial issues that are a result of their HIV infection. “When a woman contracts HIV infection, it does not occur in a vacuum; it occurs in the psychosocial context of a life with preexisting stresses within the woman’s social construct.”<sup>49</sup> Distrust, stigmatization, trauma, mental illness, and substance abuse are all psychosocial issues that have been associated with the diagnosis of HIV in women<sup>58</sup>. For the HIV-positive pregnant woman, the impact of her HIV diagnosis as well as the pregnancy can lead to additional stresses and concerns that can exacerbate these psychosocial issues and create distinctive concerns for this demographic.<sup>58</sup>

A distrust of medical services and health-care providers can be a major barrier to treatment for individuals living with HIV, especially women who are pregnant<sup>59</sup>. Studies have shown that minority populations in general may have a greater distrust and are less likely to participate in clinical studies and treatment programs<sup>59</sup>. When working with HIV-positive patients, health care providers must work to build trust to make the patient feel as comfortable as possible to increase compliance with treatment and management recommendations. Health-care providers should treat every patient with respect and should not be condescending, patronizing, or judgmental. In addition, a patient’s personal beliefs and cultural values should be respected and non-traditional treatment modalities should be complimented with traditional medical treatment, not replaced.<sup>20</sup> Sensitivity when speaking with these patients is also crucial. “Responding to a patient’s fear, anxiety, denial, or anger is inevitably part of the health

provider's role and requires consideration of more than a disease process, but of a whole person and the entire context of her life."<sup>20</sup> Finally, the patient should be reassured that the details of the visits are confidential and the information shared will not be discussed with anyone unless the patient grants permission. Patients should be encouraged and assisted in disclosing their HIV status to important individuals like sexual partners and other health care providers. Some states require that HIV diagnoses be reported, and such regulations should be discussed with every patient.<sup>20</sup> Confidentiality is important for individuals living with HIV because of the fear of discrimination and stigma that can result from an HIV diagnosis.

Since the beginning of the outbreak, individuals with HIV have faced stigma regarding their diagnosis. Much of this stigma revolves around society's negative views that a person's behaviors led to their becoming infected with HIV.<sup>49</sup> This is particularly true for women because of the connotations with HIV infection, promiscuity, and prostitution<sup>20</sup>. Stigma may be either experienced directly or perceived, but has been associated with negative impacts regarding antiretroviral adherence and increased risks for depression and risky sexual behavior<sup>59</sup>. HIV-positive women choosing to become pregnant may face additional stigmatization resulting in their decisions to have children.<sup>58</sup> Family members and others within the community may view an HIV-positive woman's decision to have a child as "reckless" or "self-serving"<sup>49</sup>. For women who have not disclosed their status to family members or loved ones, the decision to disclose may be a difficult one. Women may fear abandonment, judgment, or violence following disclosure of their HIV status<sup>20</sup>.

Trauma is relatively common among individuals with HIV and women with HIV are at an increased risk above men<sup>17</sup>. Data from the HIV Costs and Service Utilization Study (HCSUS) found that 20.5% of women reported a physical assault by a partner or someone important to

them after becoming diagnosed with HIV<sup>59</sup>. HIV-positive pregnant women may be at an increased risk for violence resulting from the disclosure of the infection status. A study done in 2009 indicated that 8.9% of pregnant women experienced recent violence. Adjusting that to the rates of HIV-positive pregnant women, it was concluded that between 528 and 616 HIV-positive pregnant women are victims of violence while they are pregnant<sup>17</sup>. Trauma and abuse have been associated with higher levels of mental illness and substance abuse in women with HIV.<sup>59</sup>

Mental illness is a common finding in people living with HIV. The HCSUS indicated that as many as 48% of people surveyed had probable psychiatric disorders<sup>59</sup>. Depression is one of the most common mental illnesses present among people living with HIV. Studies suggest that the rate of major depressive disorder is 10 times higher in HIV-positive persons than in persons who are not HIV infected. For women specifically, it is thought that 40% of women living with HIV suffer from symptoms of depression and 50.3% of HIV-positive women who are pregnant are depressed.<sup>20, 58</sup>

Depression is associated with adverse outcomes in pregnancy, including low birth weight, preterm labor, and an increased risk for post-partum depression. For women living with HIV, depression is “the most robust predictor of non-adherence” for antiretroviral regimens. As discussed previously, antiretroviral therapy during pregnancy is a crucial part of prevention of maternal to child transmission as well as prevention of resistant strains of HIV.<sup>58</sup> In addition to non-adherence, depression has been reported by HIV-positive pregnant women as a reason why some choose to postpone or not receive prenatal care. Careful assessment and consideration of treatment for depression during pregnancy is important for HIV-positive women. Because women with HIV are already exposing their infants to a variety of medications during

pregnancy, it has been recommended that HIV-positive pregnant women consider counseling or psychotherapy to help manage their symptoms of depression before medications are prescribed.

Substance abuse represents a co-morbidity related to HIV<sup>58</sup>. In 2002, it was estimated that 26% of women were infected with HIV following injection drug use. Non-injection drug use was also a risk factor for HIV, likely because of its association with risky sexual behavior.<sup>20</sup> Individuals who struggle with substance abuse issues may avoid seeking treatment because of fear of stigma or persecution because of their dependencies. For HIV-positive pregnant women, this is especially true because of fear of criminal prosecution resulting from substance abuse during pregnancy. Substance abuse, like many of the other psychosocial issues discussed, can negatively impact a women's adherence to antiretroviral treatment<sup>20</sup>. In addition to adherence issues, care providers must consider the possible interactions between street drugs, antiretroviral therapies, and therapies for substance abuse. Decisions on how to initiate antiretroviral therapy for HIV-positive women struggling with substance abuse must be determined on a case-by-case basis<sup>20</sup>.

#### **1.4.7 Resource Identification**

The needs of HIV-positive pregnant women extend beyond the clinical setting. These women may need assistance in identifying programs that aid in obtaining low-cost medications, knowledgeable HIV case managers or social workers, child care services, HIV support groups, HIV counseling services, legal services, and other resources available to the HIV/AIDS community. Understanding what resources are available as health care providers and knowing where to refer patients can help manage the various care needs of an HIV-positive patient.

Resources for HIV-positive persons vary based on geographical location, urban or rural setting, and prevalence of HIV within an area. Because resources can vary so greatly, national services which can aid in resource identification for both providers and patients are described in Table 4 and Table 5, respectively.



**Table 4: Selected National Resources for Health Care Providers<sup>20</sup>**

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Resource	Description	Contact information
<b>AIDS Education and Training Centers (AETC)</b>	Regional centers that provide HIV training and education, including preceptorships for health care providers; national and international centers that provide technical assistance in evaluation and specific areas of clinical care, such as hepatitis and palliative care; the resource center that provides resource materials on a wide range of HIV-related topics and links to other centers.	<a href="http://www.aidsetc.org">http://www.aidsetc.org</a>
<b>AIDS info</b>	Website of the U.S. Public Health Service treatment guidelines, continually updated (living documents), clinical trials, and drug and vaccine information.	<a href="http://www.aidsinfo.nih.gov">http://www.aidsinfo.nih.gov</a> 1-800-HIV-0440
<b>American Psychological Association Office on AIDS</b>	Organization that provides information, training, and technical assistance on HIV/AIDS related topics associated with coping, mental health services, prevention, community collaboration, and ethics.	<a href="http://www.apa.org/pi/aids">http://www.apa.org/pi/aids</a>
<b>The Body Pro</b>	Website with medical treatment information, comprehensive care and prevention information, interactive question and answers, and access to written information.	<a href="http://www.thebodypro.com">http://www.thebodypro.com</a>
<b>CDC National Prevention Information Network</b>	Comprehensive reference, referral, and distribution service for information on HIV/AIDS, sexually transmitted diseases, and tuberculosis, with information specialists who can assist in identifying appropriate resource materials.	<a href="http://www.cdcnpin.org">http://www.cdcnpin.org</a> 1-800-458-5231
<b>HIVdent</b>	Website with information on the dental manifestations of HIV and AIDS including information for persons living with HIV/AIDS and their dental care providers.	<a href="http://www.hivdent.org">http://www.hivdent.org</a>
<b>HRSA HIV/AIDS Bureau</b>	Website of the HIV/AIDS Bureau in the Health Resources and Services Administration (HRSA), the federal agency that administers the Ryan White CARE Act funding. Information and publications supporting care of people with HIV, including Special Projects of National Significance (SPNS).	<a href="http://www.hab.hrsa.gov">http://www.hab.hrsa.gov</a>
<b>Kaiser Family Foundation</b>	Organization that informs the U.S. HIV/AIDS policy discussion and funds global HIV prevention.	<a href="http://www.kff.org">http://www.kff.org</a>
<b>National Network to End Domestic Violence (Hotline)</b>	Organization that provides domestic violence hotline and local resources for women and advocates legally, legislatively, and educationally against domestic violence.	<a href="http://www.nnedv.org">http://www.nnedv.org</a> 1-800-799-SAFE
<b>Women Children, and HIV</b>	Website with information and provides on prevention of perinatal HIV transmission and HIV pregnancy and pediatric care, with a global focus, created by the National Pediatric Resource Center	<a href="http://www.womenchildrenhiv.org">http://www.womenchildrenhiv.org</a>
<b>The Well Project</b>	Web Portal for women living with HIV with treatment information, discussion groups, organizational tools, slide sets, searchable clinical trials listing, and resource information.	<a href="http://www.thewellproject.com">http://www.thewellproject.com</a>

**Table 5: Selected National Resources for Patients<sup>20</sup>**

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<b>Resource</b>	<b>Description</b>	<b>Contact Information</b>
<b>AIDS Alliance for Children, Youth, and Families</b>	National association providing advocacy, education, and support for children and families affected by HIV/AIDS.	<a href="http://www.aids-alliance.org">http://www.aids-alliance.org</a> 1-888-917-AIDS
<b>AIDS info</b>	Website of the U.S. Public Health Service treatment guidelines, continually updated (living documents), clinical trials, and drug and vaccine information.	<a href="http://www.aidsinfo.nih.gov">http://www.aidsinfo.nih.gov</a> 1-800-HIV-0440
<b>American Psychological Association Office on AIDS</b>	Organization that provides information, training, and technical assistance on HIV/AIDS related topics associated with coping, mental health services, prevention, community collaboration, and ethics.	<a href="http://www.apa.org/pi/aids">http://www.apa.org/pi/aids</a>
<b>The Body</b>	Website with comprehensive HIV information and resources for consumers.	<a href="http://www.thebody.com">http://www.thebody.com</a>
<b>CDC National Prevention Information Network</b>	Comprehensive reference, referral, and distribution service for information on HIV/AIDS, sexually transmitted diseases, and tuberculosis, with information specialists who can assist in identifying appropriate resource materials.	<a href="http://www.cdcnpi.org">http://www.cdcnpi.org</a> 1-800-458-5231
<b>HIVdent</b>	Website with information on the dental manifestations of HIV and AIDS including information for persons living with HIV/AIDS and their dental care providers.	<a href="http://www.hivdent.org">http://www.hivdent.org</a>
<b>HRSA HIV/AIDS Bureau</b>	Website of the HIV/AIDS Bureau in the Health Resources and Services Administration (HRSA), the federal agency that administers the Ryan White CARE Act funding. Information and publications supporting care of people with HIV, including Special Projects of National Significance (SPNS).	<a href="http://www.hab.hrsa.gov">http://www.hab.hrsa.gov</a>
<b>National AIDS Hotline</b>	A website and phone hotline to answer consumer questions and provide referrals about HIV and AIDS. Confidential inquiries about prevention, risk, testing, treatment, and other HIV/AIDS related concerns.	<a href="http://www.ashastd.org/nah">http://www.ashastd.org/nah</a> 1-800-342-AIDS
<b>National Association of People with AIDS</b>	Organization that advocates for and provides information and support to people with HIV/AIDS.	<a href="http://www.napwa.org">http://www.napwa.org</a> 1-202-898-0414
<b>National Network to End Domestic Violence (Hotline)</b>	Organization that provides national domestic violence hotline and local resources for women and advocates legally, legislatively, and educationally against domestic violence.	<a href="http://www.nnedv.org">http://www.nnedv.org</a> 1-800-799-7233
<b>Project Inform</b>	Organization that provides consumers with treatment information and tools for living with HIV, including confidential treatment information by phone and ProjectWise, a program focused on HIV/AIDS treatment information and advocacy for women.	<a href="http://www.projectinform.org">http://www.projectinform.org</a> 1-800-822-7422
<b>The Well Project</b>	Web Portal for women living with HIV with treatment information, discussion groups, organizational tools, slide sets, searchable clinical trials listing, and resources.	<a href="http://www.thewellproject.com">http://www.thewellproject.com</a>

## **2.0 MATERIALS AND METHODS**

### **2.1 PROGRAM DIRECTOR RECRUITMENT LETTER**

At the time of this investigation, there were 32 genetic counseling graduate programs in the United States and Canada. In order to assess current educational materials in each genetic counseling program, it was decided that the program director(s) of each program would be invited to participate in our study. An invitation letter to participate was created and approved by the University of Pittsburgh Institutional Review Board, application number PRO10010209. A copy of the IRB acceptance letter can be seen in Appendix A. The purpose of this letter was to introduce program directors to the project and provide them with a link to access the survey on the internet. This letter was emailed to each program director using the program directors email list serve. A copy of this letter can be seen in Appendix B.

### **2.2 SURVEY DESIGN**

A survey was designed for distribution to genetic counseling programs in the United States and Canada. The survey investigated the availability of educational materials addressing HIV in pregnancy as well as the need for additional materials addressing these issues. Assistance in the design and content of this survey was obtained by professionals in both HIV education and

genetic counseling. The content of the survey was approved by the University of Pittsburgh Institutional Review Board, application number PRO10010209. A copy of the print version of the survey can be seen in appendix C.

As an introduction to the survey, participants were informed that the purpose of the study was to ascertain curriculum content regarding the counseling of HIV-positive pregnant women. Participants were asked to answer a series of questions regarding their program's existing educational practices as well as questions about need for educational materials addressing issues related to counseling HIV-positive pregnant women. There were no risks associated with the completion of the survey and no payment was given when concluded. Participants were reassured that the survey was completely anonymous and results could not be identified in any way. It was stressed that participation in this research project was voluntary and participants had the right to not answer any questions they did not feel comfortable with. Any questions regarding the purpose of the content of the survey were to be targeted to the primary investigator, SLC.

The first part of the survey asked questions regarding the size of the program. This was included to help determine if the size of the program impacts a program's current offering of educational content or need for additional HIV-related content.

The second part served to assess the current state of existing education on HIV-positive pregnant women within genetic counseling programs. Participants were asked if they currently provide education regarding HIV-positive pregnant women in their curriculum. If yes, program directors were asked how they offered the material – through lectures, movies, required readings, etc. Space was provided for directors to write in answers if a method used by the program was not listed as an option. The programs that offer education were next asked specific questions

about the topics covered within their curricula. Specifically, programs were asked if the following topics were addressed: transmission risks during pregnancy and breastfeeding, the 2006 CDC testing recommendations for pregnant women, current states which include HIV on their newborn screening panel, current clinical management recommendations for HIV-positive pregnant women, the psychosocial needs of HIV-positive pregnant women, and resource identification for HIV-positive pregnant women. Spaces were provided for directors to write in answers if an appropriate option was not available.

Programs that did not offer testing were asked to describe the reasons why this was. Directors were encouraged to choose their top three choices among those suggested (see Appendix B), and were also permitted to write in their own reasons if an option was not listed.

The final part of the survey was a needs assessment to assess if programs would benefit from the development of additional materials addressing issues specific to HIV-positive pregnant women. All programs were asked if they would benefit from the creation of additional materials, regardless of how they responded regarding their program's current availability of educational material addressing HIV in pregnancy. If a director answered that they did not think their program would benefit from the creation of additional educational materials addressing issues pertaining to HIV-positive pregnant women, they were taken to the end of the survey which thanked them for their participation.

If a director answered that they would benefit from the creation of additional educational materials, they were then asked which topics they would like to see included. Specifically program directors were asked if they thought the materials should address transmission risks during pregnancy and breastfeeding, the 2006 CDC testing recommendations for pregnant women, current states which include HIV on their newborn screening panel, current clinical

management recommendations for HIV-positive pregnant women, the psychosocial needs of HIV-positive pregnant women, and resource identification for HIV-positive pregnant women. Space was provided for directors to write in responses if they thought an additional topic should be covered that was not listed as an option.

The final part of the needs assessment asked what types of products directors would most benefit from. Participants were asked to pick their top three choices. Choices included production of webinars, PowerPoint presentations on relevant topics, a pocket guide for genetic counselors, clinical case examples, and packets or relevant peer-reviewed articles as well as other types of potential educational materials. To see the complete listing, please see Appendix B.

Following the completion of the needs assessment, program directors were taken to the end of the survey, which thanked them for their participation.

### **2.3 SURVEY DISTRIBUTION/RESULTS COLLECTION**

In order to efficiently distribute and collect the results for the survey, the survey was made available electronically through SurveyMonkey, [www.surveymonkey.com](http://www.surveymonkey.com).

The survey found in Appendix B was transferred into an online format using SurveyMonkey. The only changes made to the survey in Appendix B was the re-ordering of some questions due to the incorporation of skip logic. Skip logic allows for better organization and helps streamline the process for those taking the survey. Instead of following directions such as, “If you answered yes, skip ahead to question 6”, skip logic sorts answers accordingly and automatically directs participants to the next appropriate question.

To direct participants to the survey, a link was created that directed directors to the start of the survey. This link was distributed in the email sent to program directors. A list of the program directors can be seen in Table 6.

**Table 6: Genetic Counseling Programs Contacted for Participation**

Program Name	Location
University of Alabama at Birmingham	Birmingham, AL
University of Arkansas Medical Center	Little Rock, AR
University of California, Irvine	Orange, CA
California State University – Stanislaus	Turlock, CA
Stanford University	Stanford, CA
University of Colorado, Denver	Denver, CO
Howard University	Washington, DC
Northwestern University Medical School	Chicago, IL
Indiana University Medical Center	Indianapolis, IN
Johns Hopkins University/National Human Genome Research Institute	Baltimore, MD
University of Maryland School of Medicine	Baltimore, MD
Boston University School of Medicine	Boston, MA
Brandeis University	Waltham, MA
University of Michigan	Ann Arbor, MI
Wayne State University	Detroit, MI
University of Minnesota	Minneapolis, MN
Mt. Sinai School of Medicine	New York, NY
Sarah Lawrence University	Bronxville, NY
University of North Carolina at Greensboro	Greensboro, NC
Case Western Reserve University	Cleveland, OH
University of Cincinnati, College of Allied Health Sciences	Cincinnati, OH
University of Oklahoma Health Sciences Center	Oklahoma City, OK
Arcadia University	Glenside, PA
University of Pittsburgh	Pittsburgh, PA
University of South Carolina	Columbia, SC
University of Texas Graduate School of Biomedical Sciences at Houston	Houston, TX
University of Utah	Salt Lake City, UT
University of Wisconsin-Madison	Madison, WI
Medical College of Virginia/Virginia Commonwealth University	Richmond, VA
University of British Columbia	Vancouver, British Columbia, Canada
University of Toronto	Toronto, Ontario, Canada
McGill University	Montreal, Quebec Canada

The survey was initially sent on July 15, 2010. A reminder email was sent on August 1, 2010 and the survey was closed on September 1, 2010.

Responses were collected and analyzed using features found on SurveyMonkey. SurveyMonkey allows administrators to download responses, sort answers by certain characteristics, and create figures. SurveyMonkey is compatible with Microsoft Excel, and results were downloaded directly into this program for easier access and analysis.

## **2.4 DATA ANALYSIS**

For analysis, responses were tabulated and compared. The majority of the responses were “yes/no” questions that did not require any statistical analysis. Tables and figures were made summarizing tabulated responses and percentages for each question. Some responses were stratified by size of program, specifically questions asking about availability of educational material and need for additional material. To determine if differences existed between size of program and availability of education or need for educational materials, Jonckheere-Terpstra (J-T) tests for ordered categorical data were completed. The J-T test determines if there is a statistical difference between observed values which are presumed to have ordered differences. Fisher’s exact test was used to determine if there was a difference between the availability of educational materials in a program and the need for additional materials. This test is appropriate because of the small size of some observed values. SAS Version 9.2 was used for all statistical analysis.

To determine the types of educational materials that should be produced, it was decided that the top three responses requested by program directors would be areas of focus. Topics for



inclusion in these materials would depend on the responses provided by genetic counseling programs who thought they would benefit from additional educational materials.

### 3.0 RESULTS

#### 3.1 SURVEY RESULTS

Of 32 programs surveyed, 26 chose to respond. This corresponds to a response rate of 81.26%. Programs were asked to indicate how many students were in each year of their program. The results can be seen in Figure 6.

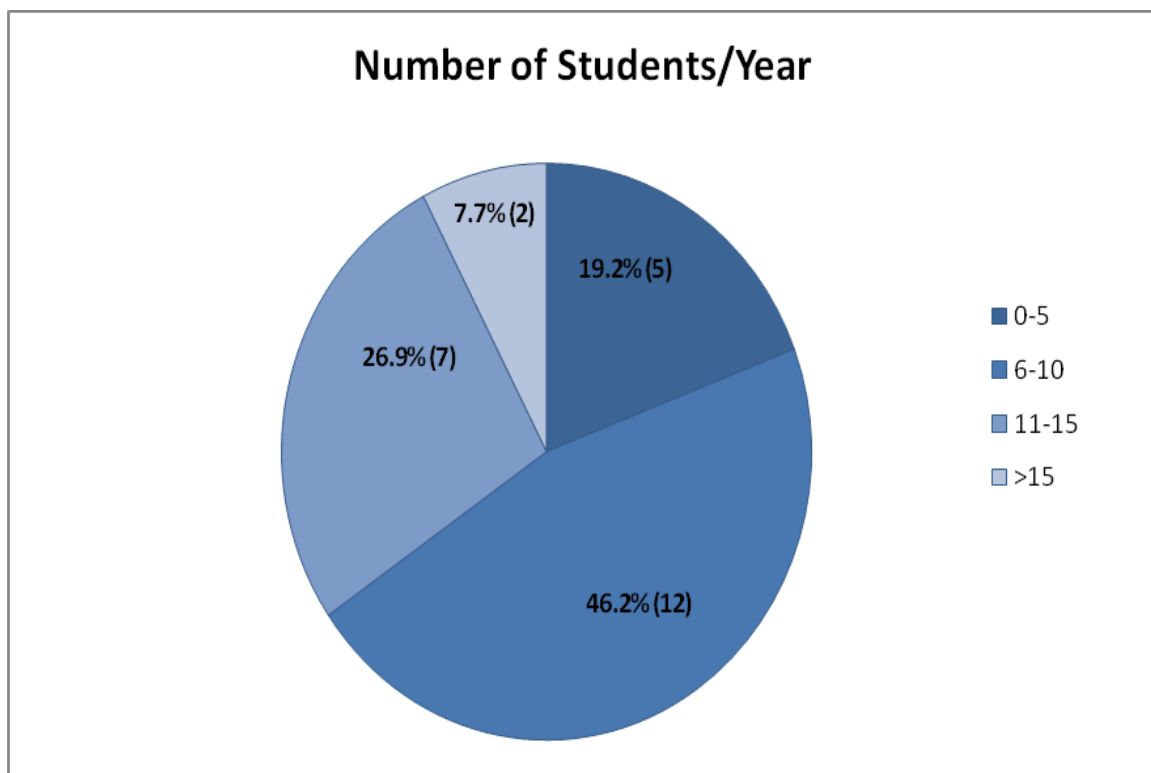


Figure 6: Number of Students Per Year in Surveyed Programs

Of the programs surveyed, 46.2% had 6-10 students in each year of their program, 26.9% had 11-15, 19.2% had 0-5, and 7.7% had >15.

Programs were next asked if they offer any education regarding HIV in pregnancy within their curricula. Education regarding HIV-positive pregnant women was reported as part of existing curricula by 65.4% of the respondents.

To determine if there were differences between program size and availability of educational materials addressing HIV in pregnancy, responses from this question were broken down by program size. This can be seen in Table 7.

**Table 7: Size of Program vs. Availability of Educational Materials**

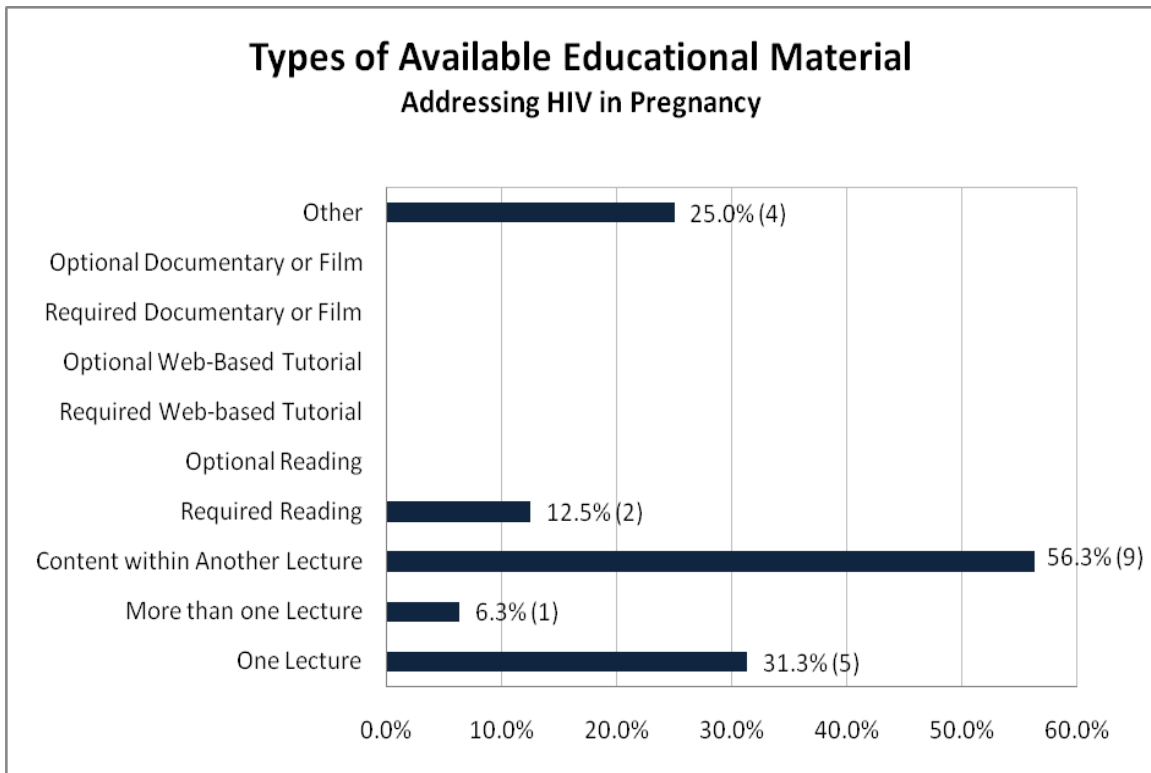
Size of Program	0-5	6-10	11-15	>15
Offer Material	3 (60%)	7(58.3%)	5 (71.4%)	2(100%)
Do Not Offer Material	2 (40%)	5 (41.7%)	2 (28.6%)	0 (0%)

To determine if the observed differences were statistically significant, the J-T test was performed. This test generated a one-sided p-value of .3750, which indicates that the variances observed did not significantly differ for programs of different sizes.

### **3.1.1 Programs that Offered Educational Content**

Of the 17 programs that provided education regarding HIV and pregnancy, 16 answered the following questions regarding the types of education provided.

Participants were asked how the existing content was structured within their curricula. Participants were asked to choose all options that applied. The results of this question can be seen in Figure 7.



**Figure 7: Type of Educational Materials Addressing HIV and Pregnancy Utilized by Genetic Counseling Programs**

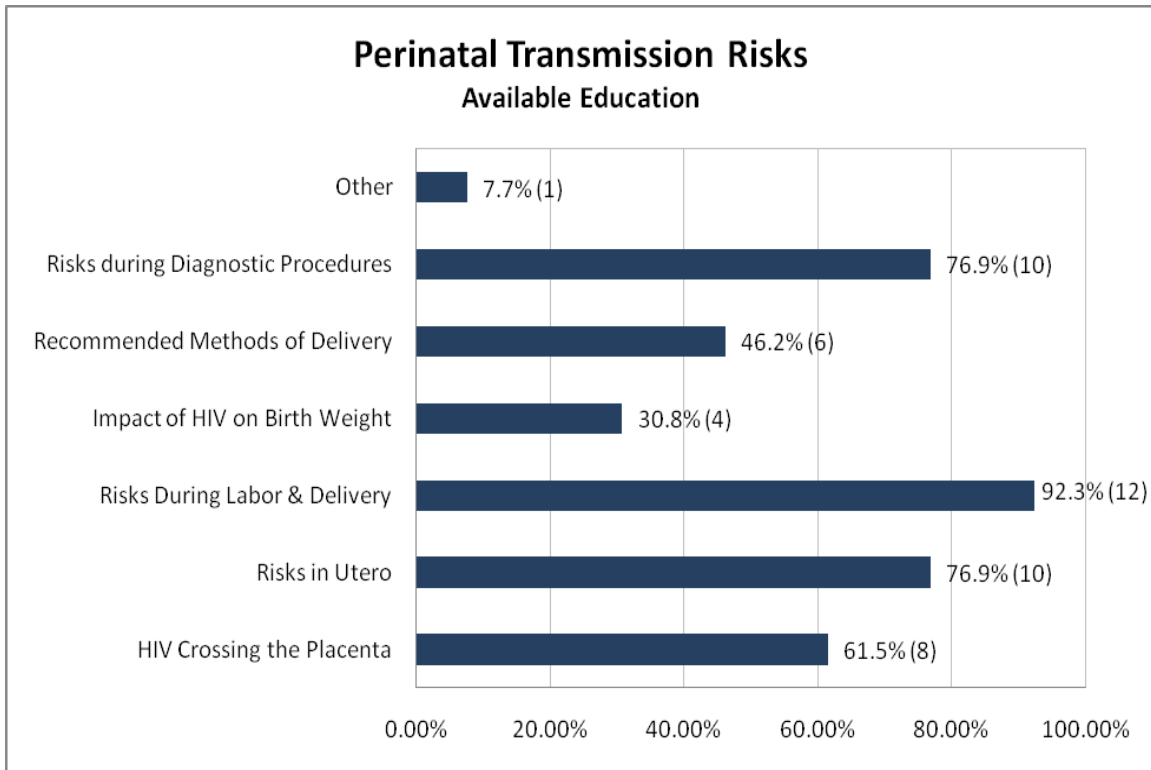
The most common type of educational material used by programs is to address HIV in pregnancy within another lecture, which accounted for 56.3%. The next most common type of education was an entire lecture dedicated to HIV in pregnancy, which was represented 31.3% of the responses collected. Required readings on HIV and pregnancy represented 12.5% of existing curricula and more than one lecture on HIV and pregnancy corresponded to another 6.3%. In addition, four separate responses were included in the ‘Other’ option. These responses included

“a very brief mention of HIV in prenatal genetics class”, “more info on HIV and pregnancy is covered in epidemiology course”, “component of teratogen module”, and “we view the film *And then the Band Played On* as an introduction to the HIV epidemic”. No programs reported offering education in the form of required web-based tutorials on HIV in pregnancy, optional web-based tutorials on HIV in pregnancy, required documentary or film addressing HIV in pregnancy, or optional documentary or film addressing HIV in pregnancy.

The next series of questions asked specifics about the exact topics addressed by genetic counseling programs.

#### **3.1.1.1 HIV Transmission Risks**

Of the programs who provided education, 93.8% included content addressing the risk of perinatal transmission. The programs that answered yes were asked more specifically which topics were covered regarding perinatal HIV transmission risks. The results of this question are seen in Figure 8.



**Figure 8: Specific Topics Included by Programs who Provide Education Addressing Perinatal Transmission Risks of HIV**

The three most commonly discussed topics were transmission risks during labor and delivery, transmission risks in utero, and transmission risks during early invasive diagnostic procedures. These topics were covered by 92.3%, 76.9%, and 76.9% of programs respectively. The risk of HIV crossing the placenta was addressed by 61.5% of programs. The remaining responses were less commonly included in existing curricula; 46.2% discussed the current recommended methods of delivery for HIV-positive women, 30.8% discussed the effects of HIV on birth weight, and 7.7% indicated that they covered ‘Other’ topics. The ‘Other’ response referred to “retroviral recommendations to lower viral count”.

Program directors were next asked if perinatal transmission risks due to breastfeeding were included within course materials. This topic was included by 64.3% of programs.

### **3.1.1.2 CDC Testing Recommendations**

Of the 16 programs that provided educational content addressing HIV and pregnancy, 14 chose to answer the question regarding inclusion of the 2006 CDC testing recommendations. CDC HIV testing recommendations were discussed by 57.1% of programs, while 42.9% did not provide education on this topic.

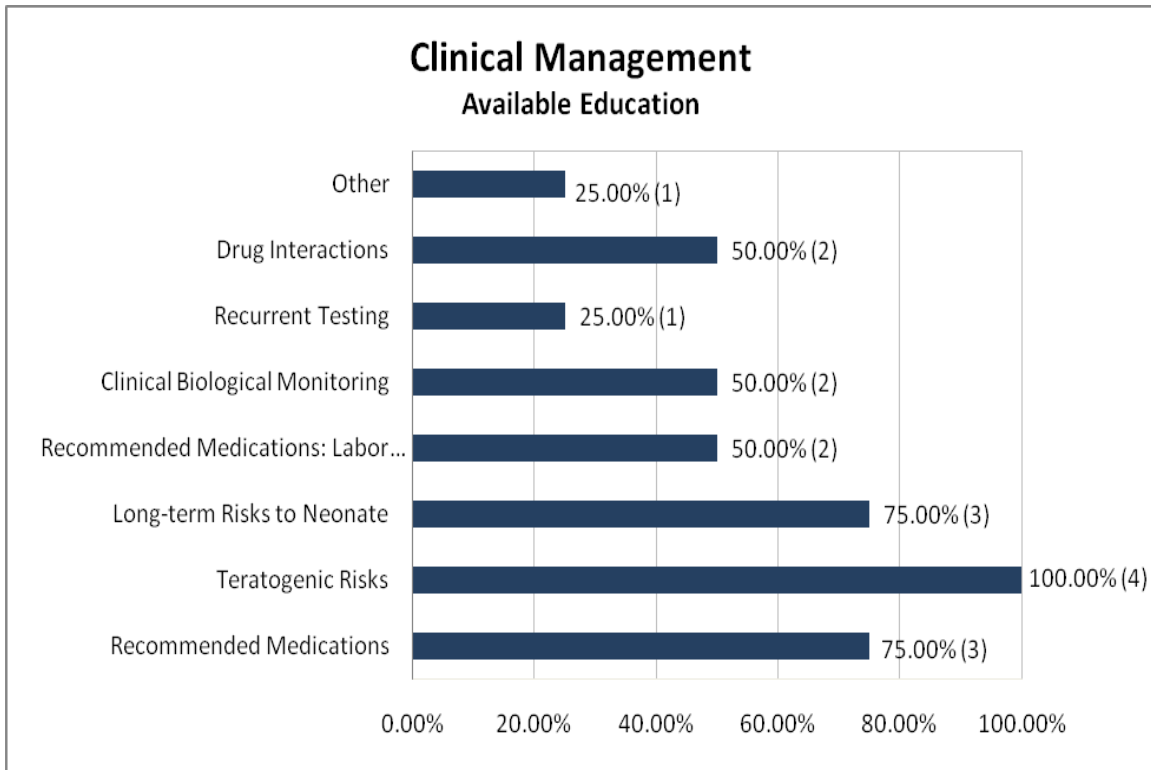
### **3.1.1.3 Newborn Screening**

Of the 16 programs that provided educational content addressing HIV and pregnancy, 14 chose to answer the question regarding newborn screening guidelines for HIV. Newborn screening for HIV was included in 28.6% of the program's existing curricula. The majority of programs, 71.4%, did not include this topic within their discussion of HIV and pregnancy.

### **3.1.1.4 Clinical Management**

Of the 16 programs that provided educational content addressing HIV and pregnancy, 14 chose to answer the question regarding guidelines and recommendations for the clinical management of an HIV-positive pregnant woman. Of the respondents, 28.6% indicated that they covered this issue, while 71.4% did not.

Programs that answered "yes" were asked more specifically which topics they covered regarding clinical management. The results of this question can be seen in Figure 9.



**Figure 9: Specific Topics Included by Programs who Provide Education Addressing Clinical Management of HIV-Positive Pregnant Women**

All programs included the discussion of the teratogenic risks of HIV antiretroviral medications within their curricula. The next most commonly discussed topic regarding clinical management was the recommended antiretroviral medications for the treatment and management of HIV-positive pregnant women, which was addressed by 75% of programs. In addition, 75% of programs also addressed long-term risks posed to the infant following in-utero exposure to antiretroviral medications. Of the programs who responded, 50% reported that they address recommendations for antiretroviral medications during labor and delivery, the interactions between antiretroviral medications and other medications, and clinical/biological monitoring for women during pregnancy. Another 25% of programs discussed the need for recurrent testing

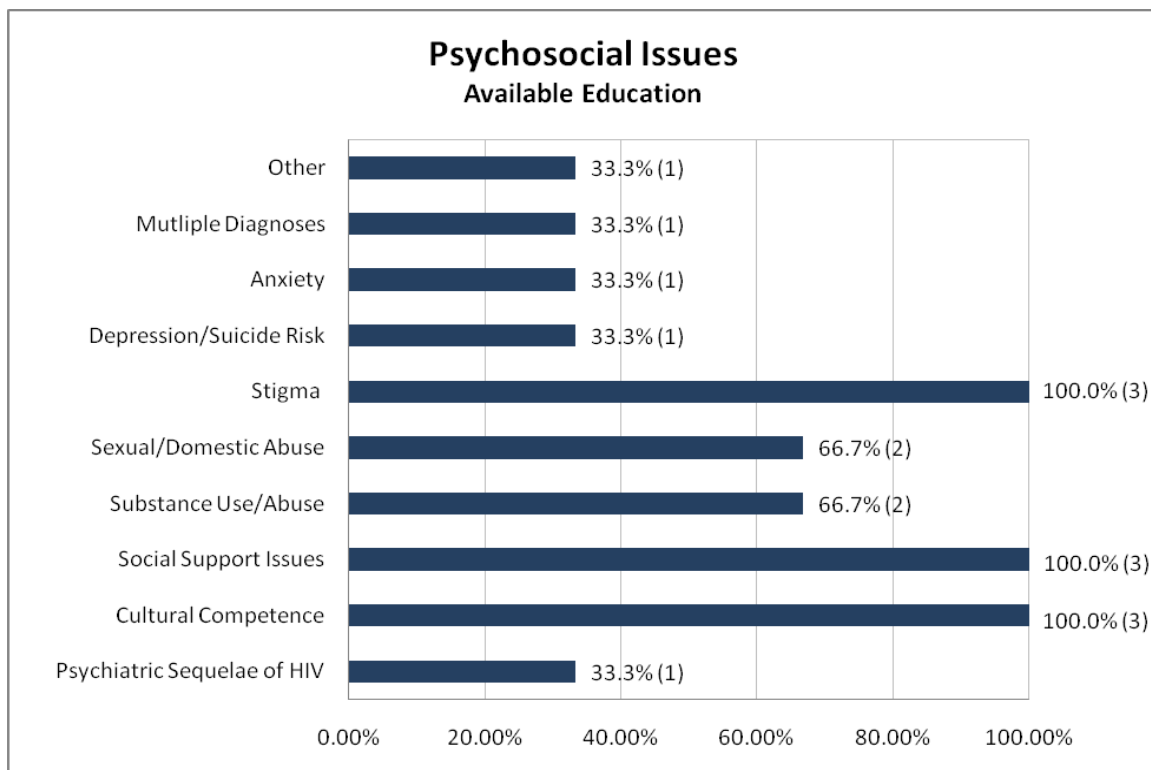


during the course of pregnancy and at labor and delivery. Finally, 25% of those who answered chose ‘other’ which corresponded to ‘done within the context of a series of teratology lectures’.

### 3.1.1.5 Psychosocial Needs of HIV-positive Pregnant Women

Of the 16 programs that provided educational content addressing HIV and pregnancy, 14 chose to answer the question regarding the psychosocial needs of HIV-positive pregnant women. Of the programs surveyed, 21.4% included instruction regarding these needs, while 78.6% did not.

Programs that answered yes were asked more specifically which topics they covered regarding psychosocial issues. The results can be seen in Figure 10.



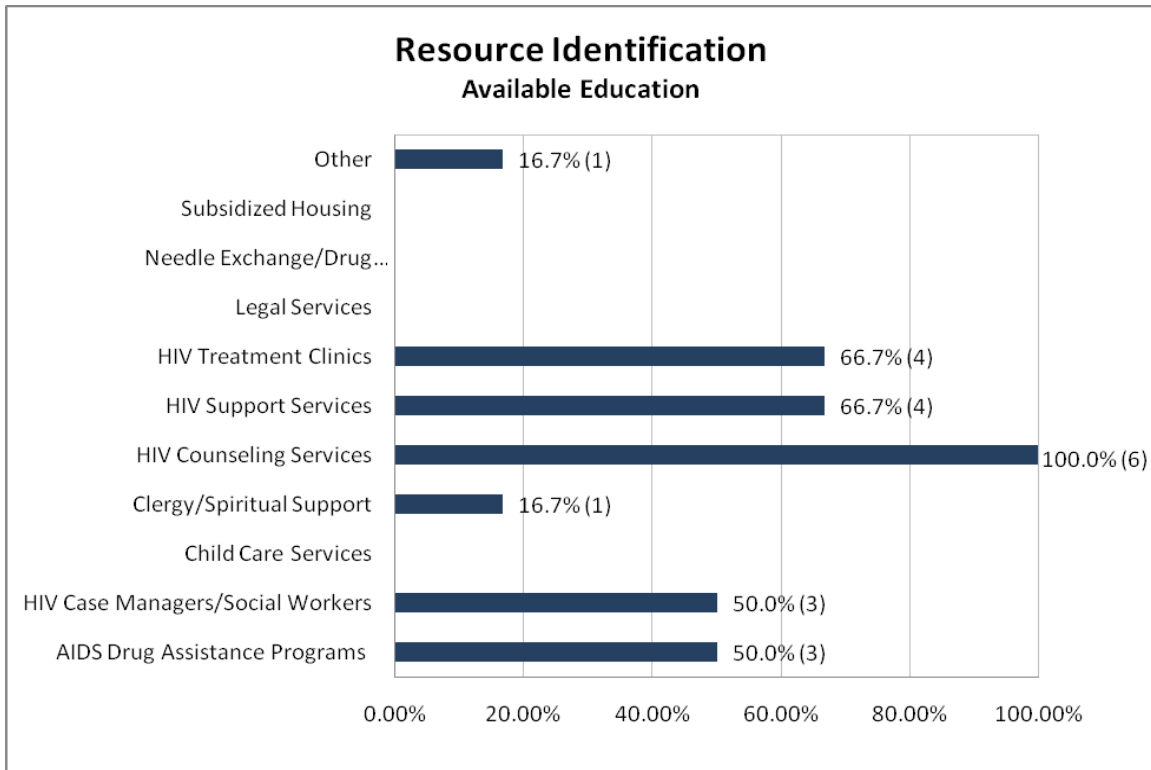
**Figure 10: Specific Topics Included by Programs who Provide Education Addressing Psychosocial Issues for HIV-Positive Pregnant Women**

All programs provided a discussion on cultural competency, social support issues, and stigma associated with the diagnosis of HIV. Substance abuse/use and sexual violence/abuse were addressed within the discussion of psychosocial needs of HIV-positive pregnant women by 66.7% of programs. Finally, 33% of programs responded that they cover psychiatric sequelae of HIV, depression/suicide risks, anxiety, and multiple diagnoses. One final respondent answered ‘other’, which corresponded to “done within the context of addressing these issues in a variety of settings”.

#### **3.1.1.6 Resource Identification**

Of the 16 programs that provided educational content addressing HIV and pregnancy, 14 chose to answer the question regarding resource identification for HIV-positive pregnant women. Of the programs surveyed, 42.9% provided education about resource identification, while 57.1% did not.

Programs that answered yes were asked more specifically which topics they covered regarding resource identification. The results can be seen in Figure 11.

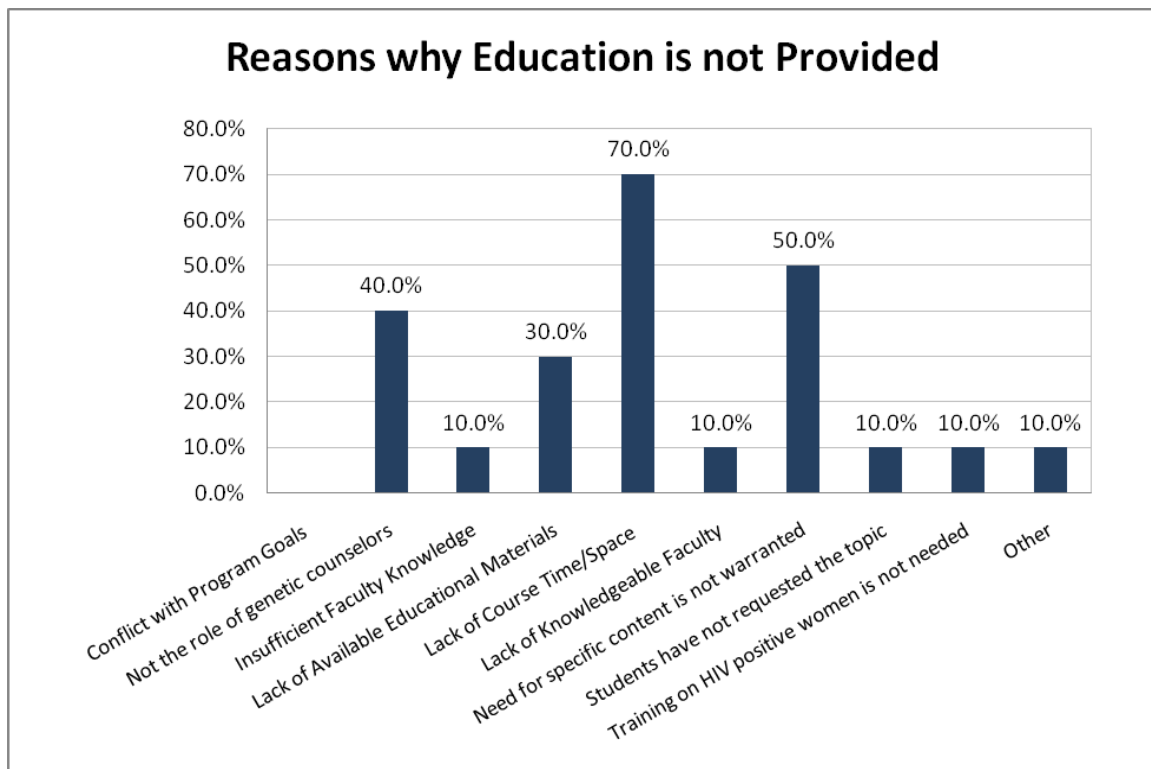


**Figure 11: Specific Topics Included by Programs who Provide Education Addressing Resource Identification for HIV-Positive Pregnant Women**

All of the programs surveyed provide education on resource identification discussed HIV counseling services and 66.7% discussed HIV support groups and treatment clinics in their areas. Of programs that responded, 50% provided information on HIV/AIDS drug assistance programs and social workers/case workers who specialize in providing care to HIV-positive individuals. An additional 16.7% indicated that they address clergy/spiritual support or “Other” resource identification topics, which corresponded to “Most of this material is covered in the prenatal clinical settings”. Finally, no programs indicated that they discuss child care services, legal services, needle exchange programs/substance abuse rehabilitation programs, and subsidized housing for HIV-positive persons.

### 3.1.2 Programs that did not Offer Educational Content

Of the 26 respondents of the survey, 9 did not offer any education within their curricula for genetic counseling students addressing HIV in pregnancy. These respondents were then asked to identify the top three reasons why education was not provided. The results can be seen in Figure 12.



**Figure 12: Reasons Programs do not Offer Educational Content Addressing HIV and Pregnancy**

The top three reasons for not including information regarding HIV and pregnancy within their curricula were a lack of time/space to incorporate the topic, the need for specific content is not warranted because the patient population is not large enough, and counseling about HIV is not the role of genetic counselors. These options were chosen by 70%, 50%, and 40% of programs surveyed, respectively. In addition, 30% of programs reported that a lack of available

educational materials was one of the top three reasons they did not offer discussion of HIV and pregnancy within their curricula. The remaining 10% of respondents indicated that the reason education was not included within existing curricula was due to insufficient faculty knowledge regarding HIV/AIDS during pregnancy, lack of knowledgeable faculty, students have not requested the topic to be covered, and training on HIV-positive pregnant women is not needed. Finally, 10% chose 'Other' as one of their top three reasons, which corresponded to "Not covered in class, but hope that students gain some exposure/experience during clinical rotations". No programs indicated that the lack of education was due to a conflict with program goals.

### **3.1.3 Needs Assessment**

Following the completion of the portion of the survey that dealt with existing curricula, programs were asked to complete a needs assessment. The needs assessment focused on determining if programs would benefit from the development of additional educational materials, topics desired for inclusion, and types of materials desired for development.

#### **3.1.3.1 Utility of Additional Educational Materials**

The 16 programs that offered educational content on HIV and pregnancy were asked if they would benefit from the creation of additional educational materials. Of the 16 programs who offered educational material, 14 chose to respond to this question. The majority of programs, 64.3%, indicated that they would benefit from the development of additional educational materials addressing issues regarding HIV/AIDS and pregnancy, while 35.7% answered that they would not. Results were then stratified by size of program to see if any

trends existed for size of program and need for existing educational materials. The results can be seen in Table 8.

**Table 8: Programs That Currently Offer Education: Need for Additional Materials by Size of Program**

Size of Program	0-5	6-10	11-15	>15
Would Benefit from Additional Materials	1	2	4	2
Would not Benefit From Additional Materials	1	4	0	0

To determine if the differences observed were statistically significant, the J-T test was performed. The results of this test resulted in a one-sided p-value of .25, which indicates that the observed differences are not statistically significant.

The 9 programs that did not offer any education within their curricula regarding HIV and pregnancy were also asked if they would benefit from the development of additional materials. 88.9% of programs said they would benefit from additional materials addressing issues regarding HIV/AIDS and pregnancy and 11.1% indicated that they would not. Results were then stratified by size of program to see if any trends existed for size of program and need for existing educational materials. The results can be seen in Table 9.

**Table 9: Programs That Do Not Currently Offer Education: Need for Additional Materials by Size of Program**

Size of Program	0-5	6-10	11-15	>15
Would Benefit from Additional Materials	1	5	1	0
Would not Benefit From Additional Materials	1	0	0	0

To determine if the differences observed were statistically significant, the J-T test was performed. The results of this test resulted in a one-sided p-value of .25, which indicates that the observed differences are not statistically significant.

Comparing the numbers of programs that thought additional materials would be beneficial to those who would not regardless of program size, it was seen that programs who didn't currently offer education were more likely to ask for educational materials. The results can be seen in Table 10.

**Table 10: Need for Additional Educational Materials vs. Current Availability of Educational Material**

	Offered Education	Did not Offer Education
Would Benefit from Additional Materials	9	8
Would not Benefit From Additional Materials	5	1

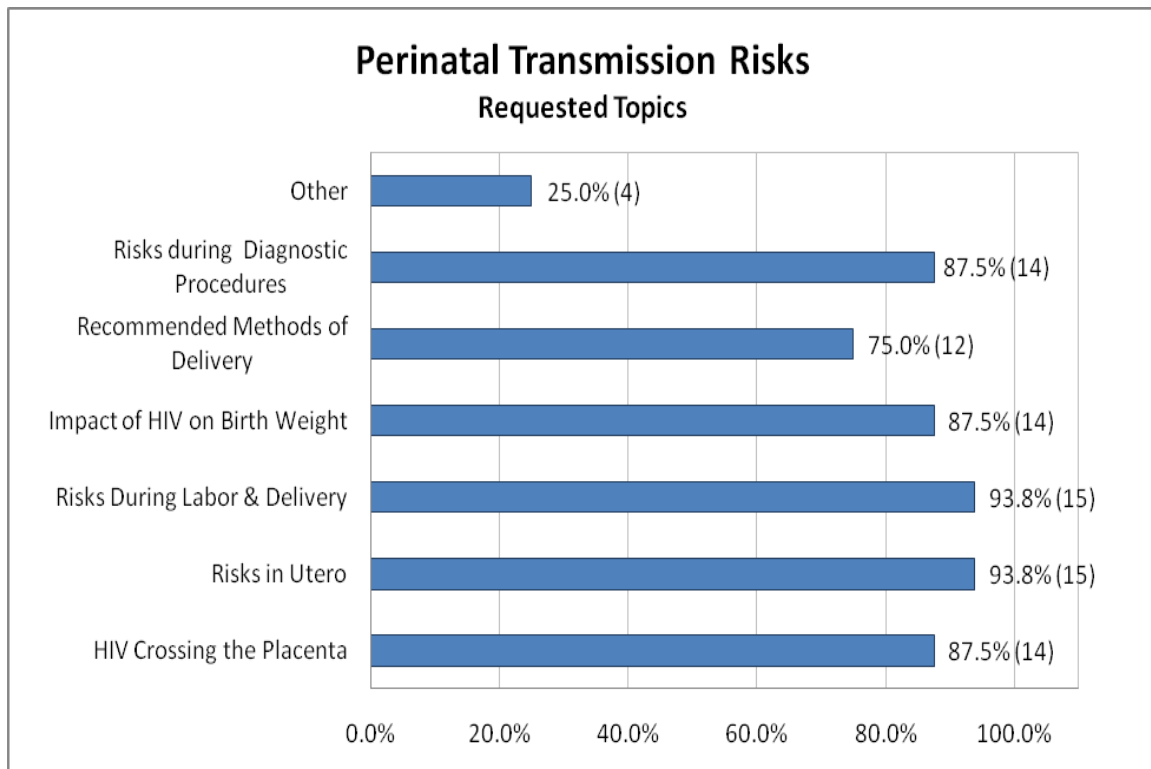
To determine if the observed differences were statistically significant, Fisher's Exact Test was performed. This test yielded a p-value of .340, which indicates the observed differences are not significantly different between programs who offered education and those that did not.

### **3.1.3.2 Topics to be Included in Educational Material**

In order to assess which subjects should be included, the 17 programs that would benefit from additional materials were polled on what topics they would like to see covered.

### *HIV Transmission Risks*

Of the programs who felt that their program would benefit from additional materials, 94.1% of programs thought that the materials should address perinatal transmission risks. Programs that wanted information on perinatal transmission risks were polled regarding which specific topics they would like to see addressed. The results can be seen in Figure 13.



**Figure 13: Specific Topics Regarding HIV Perinatal Transmission Risks Requested for Inclusion in Developed Educational Materials**

Information addressing transmission risks in utero and during labor and delivery was requested for inclusion in the developed materials by 93.8% of the programs surveyed. In addition, 87.5% of those polled indicated that HIV crossing the placenta, the impact of HIV on birth weight infants, and the transmission risks during early invasive diagnostic procedures



incorporated. Current recommended methods of delivery were requested by 75% of respondents. Finally 25% of those who answered indicated they would like “Other” topics covered. These topics included “newborn screening issues”, “similarities between HIV counseling and genetic counseling”, “psychosocial needs of affected women”, and “how to facilitate discussion regarding HIV with partner(s)”.

Program directors were asked if the materials should address transmission risks that occur as a result of breastfeeding. Of the programs that responded, 76.5% indicated that they would like to see this topic covered, while 23.5% said they would not.

### ***CDC Testing Recommendations***

Programs that wanted additional materials were asked if developed materials should include information regarding the 2006 CDC Recommendations for HIV screening of pregnant women. Overall, 88.2% thought this topic would be worthwhile to include in materials, while 11.8% said they did not think it was needed.

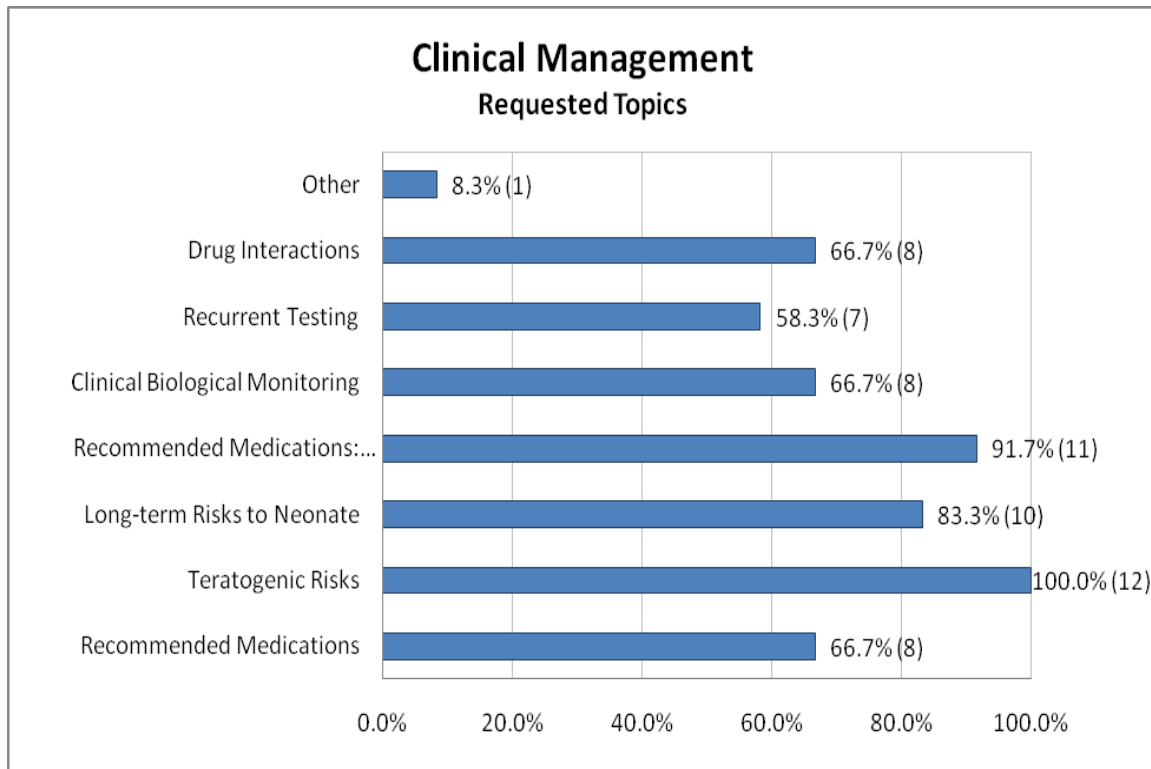
### ***Newborn Screening***

Programs that wanted additional materials were asked if developed materials should include information on the subject of newborn screening for HIV. Of the programs that responded, 88.2% of programs surveyed indicated this topic should be included in developed materials and 11.8% did not.

### ***Clinical Management***

Programs that wanted additional materials were asked if developed materials should include information on current clinical management guidelines for HIV-positive pregnant women. This topic was requested by 70.6% of programs. Programs that wanted this subject

included were asked about specific topics to be addressed in developed materials. The results can be seen in Figure 14.



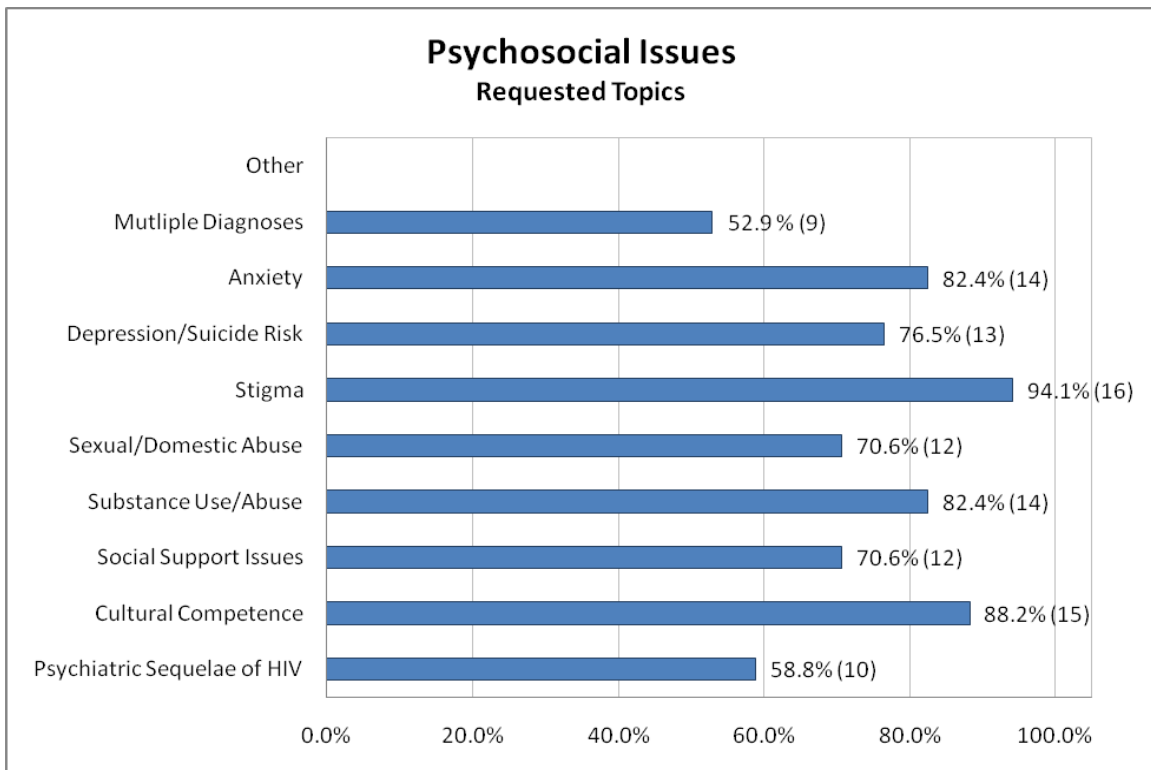
**Figure 14: Specific Topics Regarding Clinical Management Requested for Inclusion in Developed Educational Materials**

All of the programs who responded requested that teratogenic effects of HIV antiretroviral medications be discussed and 91.7% thought that the recommendations for the use of HIV medications during labor and delivery should be addressed. The long-term effects of HIV medications were requested to be included by 83.3% of programs. Current recommended HIV antiretroviral medications, clinical biological monitoring during pregnancy, and interactions between HIV medications and other medications were requested for inclusion by 66.7% of the programs. In addition, 58.3% thought that the need for recurrent testing following the entry of

care by an obstetrician and at labor and delivery should be included in potential materials. Finally, 8.3% of those polled chose “other”, which corresponded to “support needs of patients”.

***Psychosocial Needs of HIV-positive Pregnant Women***

Programs that wanted additional materials were asked if developed materials should address the psychosocial needs of HIV-positive pregnant women. All of the programs surveyed thought this was a topic that should be included. The programs were next asked which psychosocial needs should be addressed specifically. The results can be seen in Figure 15.

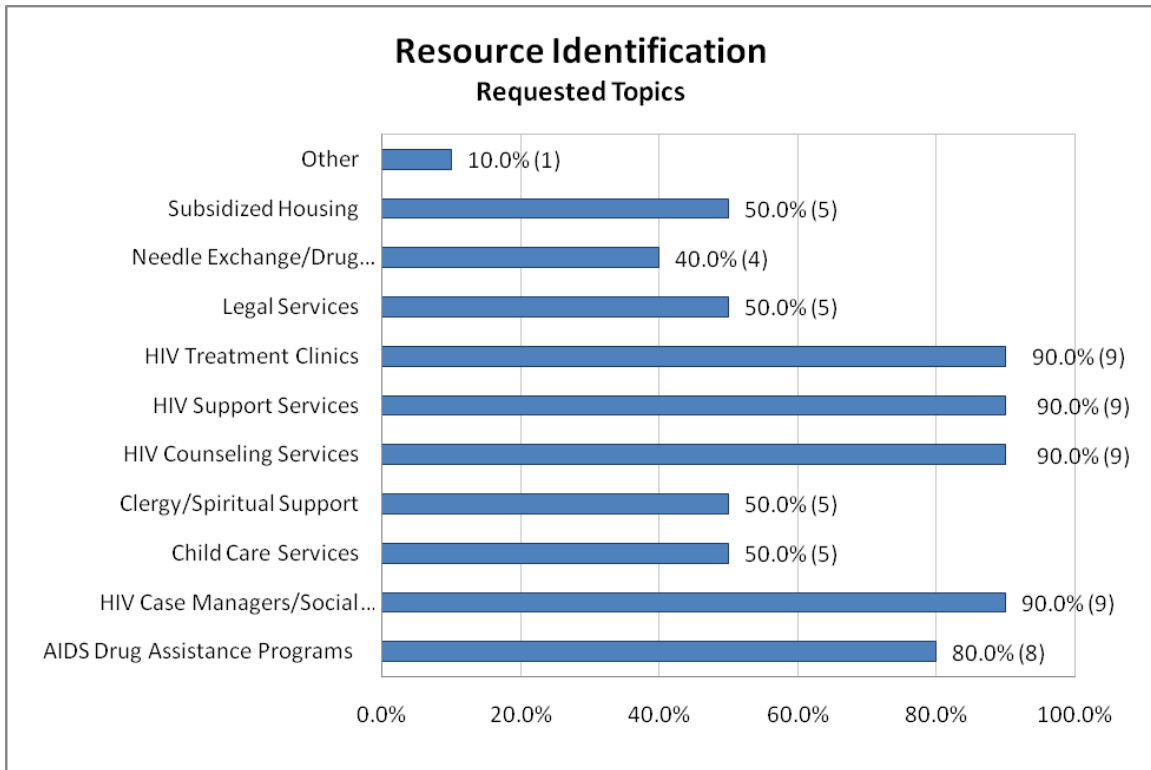


**Figure 15: Specific Topics Regarding Psychosocial Issues Requested for Inclusion in Developed Educational Materials**

Stigma associated with an HIV diagnosis was requested for inclusion in developed materials by 94.1% of programs. The next most commonly requested topic was cultural competency, at 88.2%. In addition, 82.4% of programs thought that substance abuse and anxiety associated with a diagnosis of HIV should be included. Depression and suicide risk were the next most commonly requested topic, at 76.5%. Of the programs that responded, 70.6% of respondents thought that social support issues and sexual/domestic violence should be addressed. The least commonly requested topics were psychiatric sequelae of HIV, at 58.8%, and multiple diagnoses, at 52.9%. No programs chose 'Other' as a response.

### ***Resource Identification***

Programs that wanted additional materials were asked if developed materials should include information on resource identification. Of those surveyed, 58.8% thought that the materials should address this topic, while 41.2% did not. The participants who wanted additional materials addressing resource identification were then asked which specific topics should be included. The results can be seen in Figure 16.



**Figure 16: Specific Topics Regarding Resource Identification Requested for Inclusion in Developed Educational Materials**

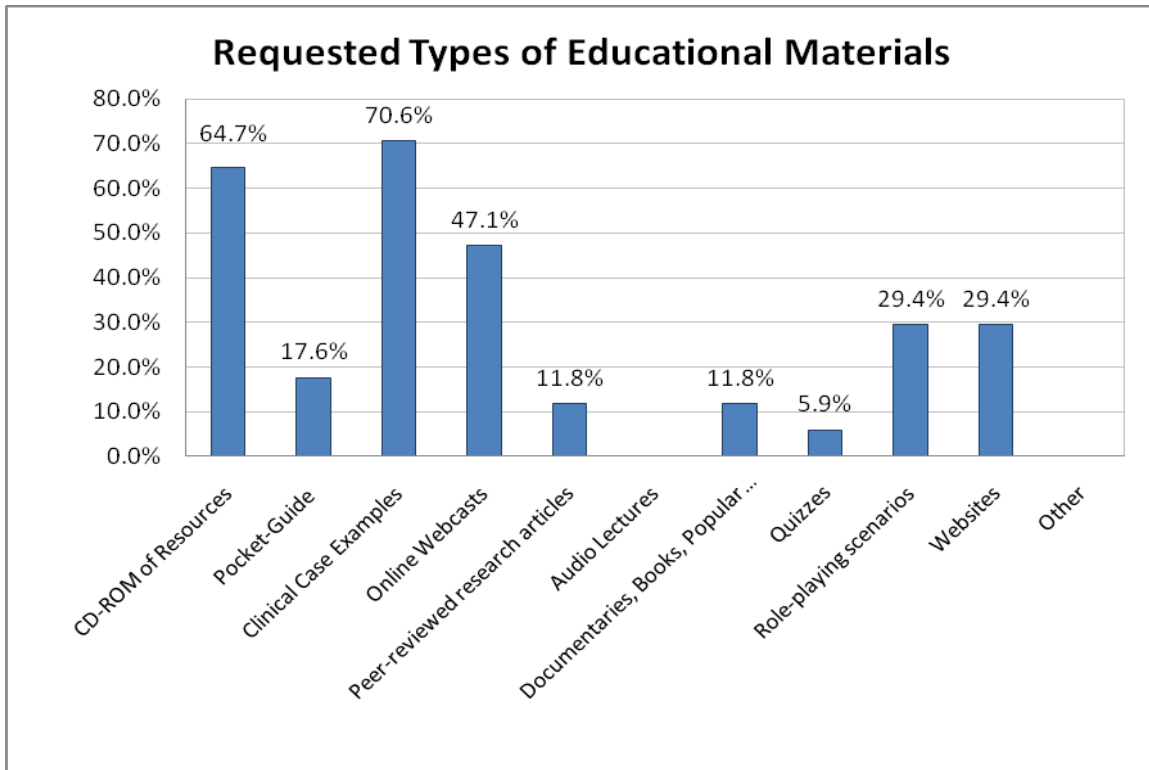
Of the programs that responded, 90% thought that the materials should address identification of available case managers/social workers, HIV counseling services, HIV support groups, and HIV treatment clinics. AIDS drug assistance programs were requested by 80% of programs. In addition, 50% of programs asked that child care services, clergy/spiritual support, legal services, and subsidized housing for HIV-positive persons be discussed. Finally, 40% of programs thought that needle exchange programs and substance abuse treatment programs should be included in the developed materials.

### *Other Topics*

In order to determine if program directors desired materials addressing topics not already mentioned, respondents were asked if there were any additional topics they would like to see covered. Of those polled, 18.8% indicated they would like to see other topics included. When prompted to describe these additional topics, the following responses were received: “Important to continue to develop strategies to identify women who may be at risk of abuse or domestic violence although unstated”, “ethical issues”, and “facilitating the discussion of HIV with sex partner(s)”.

#### **3.1.4 Types of Materials Requested**

Following the completion of the needs assessment, programs who requested additional materials were asked to choose types of materials which would most benefit students. Programs were asked to choose their top three choices and the results can be seen in Figure 17.



**Figure 17: Types of Materials Addressing HIV and Pregnancy Program Directors would Most Benefit From**

The three most requested educational materials were clinical case examples which can illustrate key points of counseling HIV-positive women in a genetic counseling practice; a CD-ROM of PowerPoint lectures addressing HIV basics, perinatal transmission risks, current CDC recommendations for HIV screening during pregnancy, and the implications for genetic counselors of counseling HIV-positive pregnant women; and a series of online webcasts that could be viewed at any time by students at 70.6%, 64.7%, and 47.1%, respectively. In addition, 29.4% of programs requested role playing scenarios that could be used in class by students to practice skills learned and a list of websites that would contain valuable resources for faculty and students. Less commonly requested materials were an HIV pocket guide, requested by 17.6% of programs, and packets of relevant peer reviewed articles or lists of current documentaries, books, popular movies, etc. that illustrate the needs of an HIV-positive patient, requested by 11.8% of

programs. Quizzes on relevant topics in HIV education for genetic counselors were chosen by 5.9% of respondents as being one of the top three most useful educational materials that could be developed. No respondents indicated that a series of audio lectures or ‘Other’ materials would be in their top three choices for developed educational materials.

## **3.2 DEVELOPMENT OF MATERIALS**

As discussed, the three most common educational materials requested by program directors were webinars, clinical case examples, and a CD-ROM containing PowerPoint presentations and other resources addressing issues related to HIV and pregnancy. These materials were developed for distribution to genetic counseling programs.

### **3.2.1 Webinars**

Program directors indicated that webinars would be a desirable educational material produced to address issues pertaining to the counseling of HIV-positive pregnant women, so it was decided that two webinars would be developed. The Pennsylvania/MidAtlantic AIDS Education and Training Center (PA/MAAETC) is a non-profit organization funded by the Health Resources and Services Administration (HRSA) HIV/AIDS Bureau that is located in the University Of Pittsburgh Graduate School of Public Health. The PA/MAAETC serves to develop educational programming for clinicians addressing the needs of HIV-positive patients. The clinicians traditionally targeted by the PA/MAAETC are physicians, physician assistants, nurses, advanced-practice nurses, dentists, and social workers. The programs developed by the AETC



cover all areas of HIV epidemiology, risk assessment, prevention, and management. The PA/MAAETC is dedicated to bringing HIV education to all types of health care professionals, and graciously agreed to coordinate, fund, advertise, and distribute the webinars for this project. Funding for the webinars was made possible by a grant from HRSA, HIV/AIDS Bureau, Division of Training and Technical Assistance, Grant No. HFAHA00060.

The webinars were advertised by the PA/MAAETC through e-mail to genetic counselors as well as other healthcare professionals targeted by the PA/MAAETC. Thirty days following the completion of the live webinars, the presentations were archived on the PA/MAAETC's website to be viewed at participant's convenience, free of charge. The archived webinars can be found at [www.pamaaetc.org](http://www.pamaaetc.org).

### **3.2.1.1 The HIV-positive Pregnant Woman: Transmission Risks, Management, and Recommendations**

The first webinar developed served to address transmission risks, management, and recommendations for the care of HIV-positive pregnant women. This webinar was presented by Katherine Bunge, M.D., an associate professor of obstetrics and gynecologist at Magee Womens Hospital in Pittsburgh, PA. Dr. Bunge is an expert in providing care to HIV-positive pregnant women and is a frequent speaker for the PA/MAAETC on this topic.


The webinar was designed to last 60 minutes and involved a lecture accompanied by a PowerPoint presentation. Participants were able to ask questions following the conclusion of the presentation. Development of the webinar focused on addressing issues identified by program directors for inclusion in developed educational materials. Topics covered included perinatal transmission risks, current recommendations for delivery, the effect of maternal/fetal HIV on fetal birth weight, transmission risks during invasive procedures such as amniocentesis and

chorionic villus sampling, and basic clinical management guidelines for HIV-positive pregnant women. In addition, the webinar addressed some epidemiological data on HIV-positive pregnant women, such as pregnancy trends and the change in the number of HIV-positive infants born since the beginning of the epidemic. Objectives for participants completing the webinar were to understand the transmission risks for infants born to HIV-positive pregnant women, describe management recommendations for HIV-positive pregnant women, and gain insight into the effects of HIV on the fetus and the newborn.

A flyer developed to advertise for this program can be seen in Figure 18.

# Webinar Wednesdays

Pennsylvania/MidAtlantic AIDS Education and Training Center  
University of Pittsburgh • Graduate School of Public Health • Department of Infectious Disease and Microbiology



Save the Date    Certificates of Attendance & PA Nursing Credit Provided    Time: 1pm-2pm

## The HIV Positive Pregnant Woman: Transmission Risks, Recommendations, and Management

March 2, 2011

**Katherine Bunge, MD**  
Assistant Professor  
Department of Obstetrics  
Gynecology and Reproductive Sciences  
Division of Gynecologic Specialties  
Magee Women's Hospital  
University of Pittsburgh Medical Center  
Pittsburgh, PA

**Intended Audience**  
Physicians, Physician Assistants, Nurses, Nurse Practitioners, Genetic Counselors, Midwives, Social Workers, and other members of the HIV treatment team.

**Program Overview**  
This program will discuss basic information regarding management of the HIV Positive Pregnant Woman including transmission risks, recommendations for care, and management guidelines.

Upon completion of this program, participants will:

- Understand the transmission risks for infants born to HIV positive pregnant women
- Describe management recommendations for HIV positive pregnant women
- Gain insight into the effects of HIV on the fetus and newborn

**Accreditation Offered**  
PSNA: This continuing nursing education activity was approved by the PA State Nurses Association, an accredited approver by the American Nurses Credentialing Center's Commission on Accreditation. This activity qualifies for 1.0 contact hours.

**Faculty Disclosure**  
The following faculty have no relationships to disclose: Katherine Bunge, MD

**Funding Acknowledgement**  
This program is made possible by a grant from HRSA, HIV/AIDS Bureau, Division of Training and Technical Assistance Grant No. HFAHA00060.

### Registration

**These webcasts are free and open to the general public.**

Visit the Pennsylvania/MidAtlantic AIDS Education and Training Center website to register.  
<http://www.pamaaetc.org/events.asp>






Figure 18: Flyer Advertising “The HIV-Positive Pregnant Woman: Transmission Risks, Recommendations, and Management”

### **3.2.1.2 Women and HIV: Approach to Comprehensive Care and Psychosocial issues**


The second webinar developed served to address approaches to care and psychosocial issues specific to HIV-positive women. The webinar was presented by Linda Frank, PhD, MSN, ACRN, FAAN and Patricia Lincoln, BSN, RN, ACRN. Dr. Frank is an Associate Professor in the Department of Infectious Diseases and Microbiology at the Graduate School of Public Health at the University of Pittsburgh in Pittsburgh, PA. In addition, Dr. Frank serves as the Principal Investigator and Executive Director of the PA/MAAETC. Ms. Lincoln is the Local Performance Site Director for the Delaware/Christiana Care Health Services local site of the PA/MAAETC. Dr. Frank and Ms. Lincoln are experts in the field of HIV education and patient management.

The webinar was designed to last 60 minutes and involved a lecture accompanied by a PowerPoint presentation. Participants were able to ask questions following the conclusion of the presentation. Development of the webinar focused on addressing issues identified by program directors for inclusion in developed educational materials. Topics covered included cultural competency and how it relates to HIV, social support issues, substance use/abuse, sexual and domestic violence, stigma associated with an HIV diagnosis, depression and suicide risks, mental health concerns, approaches to care, and resource identification for HIV positive women. Objectives for participants completing the webinar were to recognize the impact of stigma on HIV-positive women, correlate the risk of anxiety/depression with an HIV diagnosis, explore the importance of social support networks for HIV-positive women, summarize skills health professionals can use to assist in coping with an HIV diagnosis, describe the approaches to care for HIV-positive women, and discuss barriers to treatment for HIV-positive women.

A flyer developed to advertise for this program can be seen in Figure 19.

# Webinar Wednesdays

**Pennsylvania/MidAtlantic AIDS Education and Training Center**  
University of Pittsburgh • Graduate School of Public Health • Department of Infectious Disease and Microbiology



**Save the Date**      **Certificates of Attendance & PA Nursing Credit Provided**      **Time: 1pm-2pm**

## Women & HIV: Approach to Comprehensive Care and Psychosocial Issues

**March 16, 2011**

**Patricia Lincoln, BSN, RN, ACRN**  
Local Performance Site Director  
Pennsylvania/MidAtlantic AIDS Education and Training Center  
Delaware/Christiana Care Health Services  
Wilmington, DE

**Linda Frank, PhD, MSN, ACRN, FAAN**  
Associate Professor  
Department of Infectious Diseases and Microbiology  
Graduate School of Public Health, School of Nursing  
Principal Investigator and Executive Director  
Pennsylvania/MidAtlantic AIDS Education & Training Center  
University of Pittsburgh  
Pittsburgh, PA

**Program Overview**  
This program will discuss psychosocial issues and approaches to care for women diagnosed with HIV.  
Upon completion of this program, participants will:

- Recognize the impact of stigma on HIV positive women
- Correlate the risk of anxiety/depression with an HIV diagnosis
- Explore the importance of social support networks for HIV positive women
- Summarize skills health professionals can use to assist in coping with an HIV diagnosis
- Describe the approaches to care for HIV positive women
- Discuss barriers to treatment for HIV positive women

**Intended Audience**

Physicians, Physician Assistants, Genetic Counselors, Nurses, Nurse Practitioners, Midwives, Social Workers, and other members of the HIV treatment team.

**Accreditation Offered**  
PSNA: This continuing nursing education activity was approved by the PA State Nurses Association, an accredited approver by the American Nurses Credentialing Center's Commission on Accreditation.  
This activity qualifies for 1.0 contact hours.

**Faculty Disclosure**  
The following faculty have no relationships to disclose:  
Linda Frank, PhD, MSN, ACRN FAAN; Patricia Lincoln, BSN, RN, ACRN

**Funding Acknowledgement**  
This program is made possible by a grant from HRSA, HIV/AIDS Bureau, Division of Training and Technical Assistance Grant No. HFAHA00060.

### Registration

**These webcasts are free and open to the general public.**

**Visit the Pennsylvania/MidAtlantic AIDS Education and Training Center website to register.**  
<http://www.pamaaetc.org/events.asp>






Figure 19: Flyer advertising “Women & HIV: Approach to Comprehensive Care and Psychosocial Issues”

### **3.2.2 Clinical case studies**

Program directors indicated that clinical case examples to illustrate issues that could arise when counseling an HIV-positive pregnant woman would also be valuable. To meet this need, six case examples were drafted. The case examples were developed in the context of prenatal genetic counseling sessions for referral reasons which are familiar to genetic counseling students. By incorporating the issue of an HIV diagnosis into the examples, students were prompted to discuss some key points of counseling, risk assessment, and management for patients with HIV who may be receiving genetic counseling. A diverse patient population was used to help students think of different issues that could result from counseling women of different age groups and ethnic backgrounds.

Case examples were reviewed and revised by genetic counselors as well as HIV professionals to make sure that issues for both fields were relevantly incorporated. The clinical case examples will be included for distribution on the CD-ROM that was also developed for genetic counseling programs.

The clinical case examples developed can be seen in Table 11.

**Table 11: Clinical Case Examples Designed For Genetic Counseling Programs**

<b>Clinical Case Examples</b>
<p><b>V.C. is an 18 y/o African-American woman referred to genetic counseling because of a personal history of diabetes and to have first trimester screening done. While reviewing her records, you see that her prenatal labs were positive for HIV and she is currently taking Efavirenz as part of her HAART regimen. She is currently 12 weeks pregnant. What risks should you discuss with V.C. during the counseling session in addition to her diabetes-associated risks? What tests should she be offered to help clarify these risks?</b></p>
<p><b>D.S. is a 24 y/o Ashkenazi-Jewish woman who is referred to genetic counseling for carrier screening. During the session, D.S. informs you that she recently found out she was HIV-positive and is considering termination because “she knows that her baby will be infected with HIV.” What risks would you provide her for transmission during pregnancy? What intervention methods would you discuss with her to lower these risks?</b></p>
<p><b>N.E. is a 31 y/o Caucasian woman who is referred to genetic counseling following an elevated quad screen. Her risk for Down syndrome came back 1:40. While reviewing her records, you see that she is HIV positive and is currently receiving HAART therapy. Would this change her quad screen result? How would you explain the findings to the patient? What tests would you recommend?</b></p>
<p><b>S.C. is a 41 y/o Asian female who is referred to counseling for advanced maternal age. She is 11 weeks 4 days pregnant and wants to have a chorionic villus sampling. While taking her history, S.C. tells you that she has HIV. How would you counsel her regarding the risk of perinatal transmission associated with CVS?</b></p>
<p><b>M.D. is a 27 y/o female of Hispanic ethnicity who is referred to counseling because of a personal history of neurofibromatosis. During the session, she becomes emotional and discloses she was just told she was HIV-positive. She is afraid to tell her family because she is afraid of their reactions. How would you counsel her? What resources could you provide her to help in the disclosure process as well as coping with a new diagnosis?</b></p>
<p><b>R.W. is a 32 y/o Caucasian woman who just delivered a baby who tested positive for HIV and cystic fibrosis on newborn screening panels. She is referred to you to discuss the results of these tests. What do the baby’s test results imply for R.W.? Should she breastfeed her infant?</b></p>

### **3.2.3 CD-ROM of PowerPoint Presentations and Additional Relevant Resources**

The third most common resource requested by program directors was a CD-ROM of PowerPoint presentations and other materials addressing issues specific to HIV during pregnancy. The PowerPoint presentations from the webinars, clinical case examples, and additional resources that would be beneficial to providing education to genetic counseling students were included on this CD-ROM. The additional resources included are listed in Table 12.



**Table 12: Resources Included in the CD-ROM Developed for Genetic Counseling Programs**

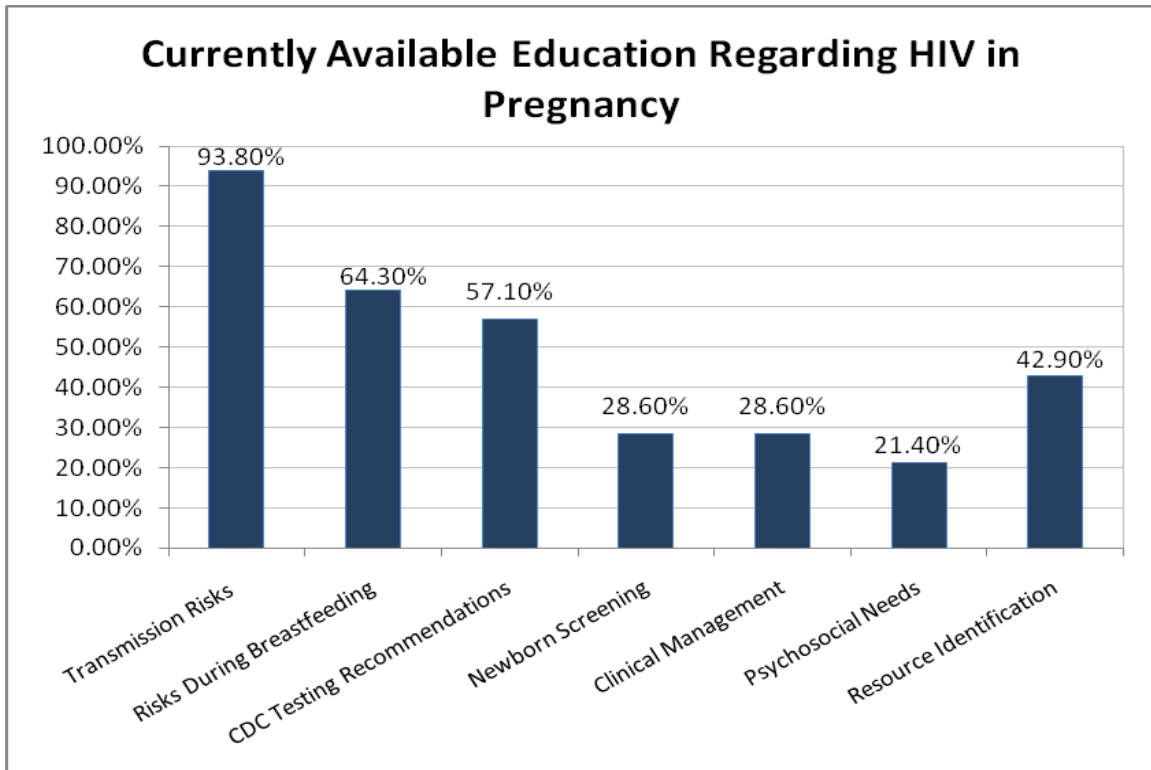
Title	Source
2006 Revised Recommendations for HIV Testing of Adults, Adolescents, and Pregnant Women in Health-Care Settings.	Centers for Disease Control and Prevention
Panel on Treatment of HIV-infected Pregnant Women and Prevention of Perinatal Transmission Recommendations for Use of Antiretroviral Drugs in Pregnant HIV-1-Infected Women for Maternal Health <i>and</i> Interventions to Reduce Perinatal HIV Transmission in the United States	AIDSinfo: A Service of the U.S. Department of Health and Human Resources
Supplement: Safety and Toxicity of Individual Antiretroviral Agents in Pregnancy	AIDSinfo: A Service of the U.S. Department of Health and Human Resources
A Guide to the Clinical Care of Women with HIV, 2005 edition.	U.S. Department of Health and Human Services, Health Resources and Services Administration, HIV/AIDS Bureau
<p><b>The Invisible Epidemic: Women with HIV in the United States</b></p> <ul style="list-style-type: none"> <li>• <b>Women, HIV, and HAART: The Basics</b> <ul style="list-style-type: none"> <li>○ Provider Counseling Guide</li> <li>○ Patient Booklet</li> </ul> </li> <li>• <b>Women, HAART, and Pregnancy</b> <ul style="list-style-type: none"> <li>○ Provider Counseling Guide</li> <li>○ Patient Booklet</li> </ul> </li> <li>• <b>Women and Adhering to HAART</b> <ul style="list-style-type: none"> <li>○ Provider Counseling Guide</li> <li>○ Patient Booklet</li> </ul> </li> <li>• <b>Women, HAART, and Side Effects</b> <ul style="list-style-type: none"> <li>○ Patient Booklet</li> </ul> </li> <li>• <b>Women, HAART, and Healthy Living</b> <ul style="list-style-type: none"> <li>○ Provider Counseling Guide</li> <li>○ Patient Booklet</li> </ul> </li> <li>• <b>Resource Guide</b></li> </ul>	<p><b>Annenberg Center for Health Sciences, Association of Nurses in AIDS Care, Postgraduate Institute of Medicine, Health Matters Continuing Medical Education, and Tibotec.</b></p>

#### **4.0 DISCUSSION**

Genetic counselors will rarely be faced with a woman who is HIV-positive that is referred only because of her HIV status. It is more likely that an HIV-positive woman will be referred to genetic counseling because of additional concerns regarding her pregnancy in addition to her HIV status. If an HIV-positive pregnant woman is being referred to genetic counseling, it is likely that she is receiving prenatal care, and that her obstetrician/gynecologist is helping manage her care regarding her HIV diagnoses. Genetic counselors should not be expected to direct care regarding a woman's HIV status, but should be familiar with issues that can have an impact on the pregnancy and are relevant to genetic counseling sessions. Issues including transmission risks, teratogenic impact of HIV medications, psychosocial issues, and newborn screening policies are all subjects which are important to genetic counselors for a variety of conditions, not just HIV. Based on the experiences of this author, it was hypothesized that genetic counselors do not offer adequate education regarding HIV in pregnancy. This is the first study conducted which investigates the inclusion of educational materials addressing HIV in pregnancy within the curricula of genetic counseling programs in the United States and Canada. The purpose of this study was to investigate the current availability of education addressing HIV in pregnancy and the needs of HIV-positive pregnant woman in genetic counseling programs in the United States and Canada. This study also served to conduct a needs assessment for the development of additional educational materials that would benefit genetic counseling programs.

The majority of genetic counseling programs in the United States offer some education on HIV and pregnancy. Of the programs surveyed, 65.4% of currently address HIV in pregnancy, and the availability of education varied based on program size. As seen in Table 7, as program size increased, the availability of education addressing HIV in pregnancy also increased. It was hypothesized that this could be explained because larger programs have access to more resources as compared to smaller programs. To determine if the differences observed were statistically significant, the Jonckheere-Terpstra (J-T) was used to determine if the trends observed were significantly different. The results of the J-T test indicated that there was not a statistically significant difference between availability of HIV education and size of program. This could be because the sample size was not large enough to detect differences. This limitation in sample size is difficult to overcome because of the limited numbers of genetic counseling programs in the United States and Canada.

The mode of delivery of education also varied between programs. The majority of programs, 56.3%, addressed HIV in pregnancy within another lecture and 31.3% of programs dedicated an entire lecture to HIV. The results of this question are not surprising because the majority of programs only address a few topics regarding HIV in pregnancy. A summary of the availability of different subjects that programs include within their curricula can be seen in Figure 20.



**Figure 20: Topics Addressed by Genetic Counseling Programs Regarding HIV in Pregnancy**

The majority of genetic counseling programs who responded, 93.8%, address perinatal transmission risks. Thinking about the components of a prenatal genetic counseling session, this finding is not surprising. Perinatal transmission risks are an important topic for genetic counseling students to understand so they can accurately present these risks to their patients. Other topics regarding HIV in pregnancy were not as frequently discussed in genetic counseling programs. This could be because a lack of familiarity with some of these topics, such as the 2006 CDC testing recommendations, clinical management, and resource identification for HIV-positive pregnant women. More surprising is the finding that the majority of programs that offer educational content regarding HIV in pregnancy do not cover the psychosocial needs of HIV-positive pregnant women or newborn screening programs that include HIV. Education addressing the psychosocial issues of various patient populations is an important component of

genetic counseling training programs. As discussed, women with HIV have a unique set of psychosocial considerations which differ from women without HIV. Genetic counselors may benefit from education addressing these issues so they are familiar with the specific needs of these patients and can counsel them appropriately. Newborn screening is also an important topic covered in most genetic counseling curricula. Newborn screening is a major public health program that has addressed genetic conditions for over 50 years. The inclusion of HIV is still a relatively new practice, but it is a logical extension of a service already in place. Although HIV is not a genetic condition like others screened for on newborn screening, it is one where a documented intervention has been established to prevent the development of further symptoms of clinical infection. Because the inclusion of HIV on newborn screening panels varies based on state, it is possible that the majority of programs do not discuss it because it is not relevant because they are located in a state that does not include it on its screening panel.

Programs that did not offer educational material were asked about reasons why they did not incorporate these topics into their curricula. Programs were encouraged to choose the top three reasons which accurately described their rationale. This question was important to understand a program's reasoning behind not including information and also producing additional educational materials. By understanding the reasons why programs do not offer education, it is possible to construct the educational materials in a way to take into consideration the constraints and barriers to providing this education in the first place.

The most commonly reported reason why programs do not address HIV in pregnancy within their coursework was a lack of time and space to incorporate the topic into existing curricula. This response was chosen by 70% programs a major barrier to providing education within their curricula. This response suggests that programs would like to incorporate

educational material on HIV in pregnancy if they were able to do so in a manner that was efficient and did not take a large amount of time away from other topics.

In addition, 50% of programs indicated that one of the reasons they did not include HIV in pregnancy within their existing educational content was that the need for the content was not warranted because the patient population is not large enough. This is an interesting response for genetic counselors, as the majority of genetic conditions are rare in the general population. No studies have been done to examine the numbers of HIV-positive pregnant women who are referred to genetic counseling each year, so it is difficult to clearly identify how large the patient population actually is. It is also possible that in the past genetic counselors were not aware of their patient's HIV status because it was not included on standard prenatal blood tests or because patients did not disclose their infection status, so the patient population may have been perceived as smaller than it actually was. It is also possible that counselors do not have an adequate understanding of the extent of the HIV epidemic in women and are not aware that women now represent 26% of the HIV disease burden in the United States. A limitation of this study is that program directors were not asked about their knowledge regarding issues specific to HIV and pregnancy prior to initiating the survey. It is possible that program directors are not familiar with the issues specific to HIV-positive pregnant women and thus would not see how this information would be useful to include within curricula for genetic counseling students. If programs were to be provided with some background information on the frequency of HIV and women and also the numbers of HIV-positive pregnant women choosing to become pregnant each year, it is possible that they would re-think that the patient population is too low for HIV and pregnancy to be included in education for students.

Finally, 40% of programs indicated that counseling about HIV counseling was not the role of genetic counselors. When comparing this result to that of the needs assessment, this result is surprising. The relative frequency of this response suggests that a large proportion of programs do not think that HIV in pregnancy is an important topic for inclusion within genetic counseling program curricula, and thus would not benefit from the development of additional educational materials addressing these subjects. However, the needs assessment found that the majority of programs that did not offer any education addressing HIV in pregnancy within their curricula felt that they would benefit from the development of additional educational materials. The reason for this discrepancy is difficult to determine. It is possible that program directors do not want to take time themselves to develop educational materials addressing HIV in pregnancy, but they would gladly accept materials that were developed for them. It is also possible that they would want to receive additional educational materials to review them and determine if they should be included as a regular part of their program's curricula. A final possibility is that counselors do not feel comfortable providing education on HIV because of the stigma associated with the condition. HIV is not a condition that is traditionally focused on within genetic counseling programs, and program directors may benefit from learning more about the condition and its impact on women.

Overall, the needs assessment found that genetic counseling programs in the United States and Canada would benefit from the development of additional educational materials addressing HIV in pregnancy. This is an important finding that has previously not been investigated. The results indicated a need for additional material among programs that did not offer educational material as well as those that did, but the overall need was greater for the

former group. Fisher's exact test was used to compare the need for additional educational materials between the two groups, but a statistically significant difference was not identified.

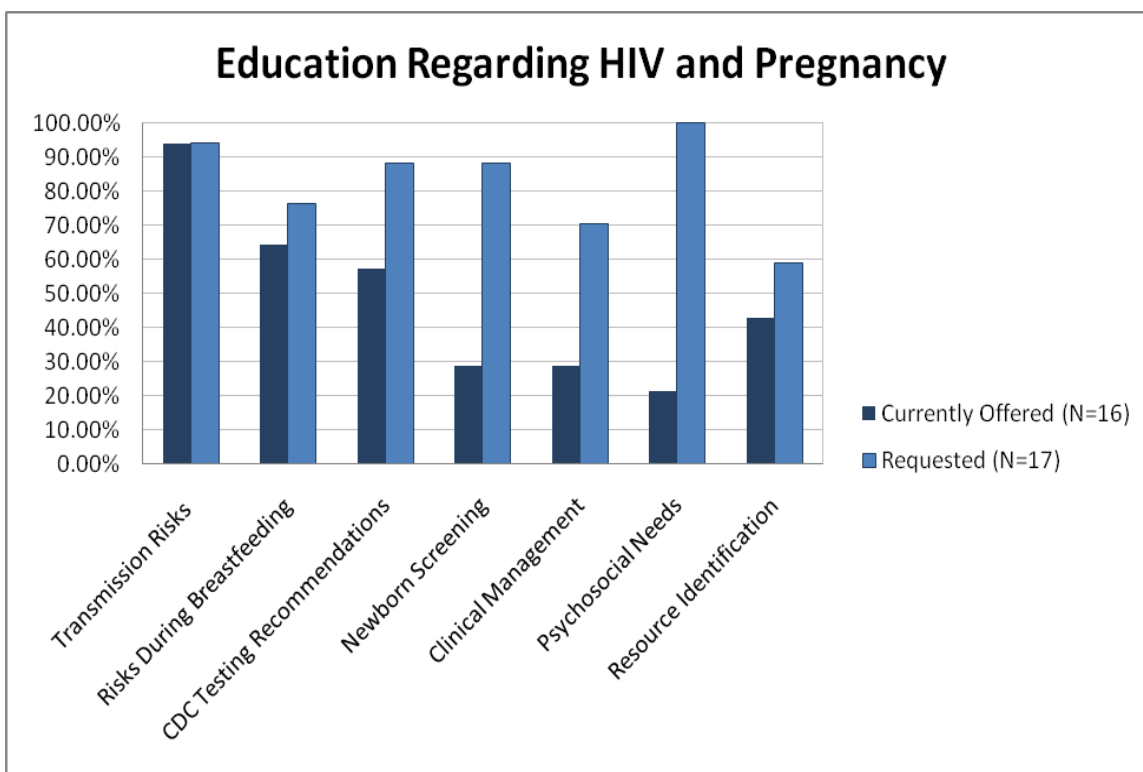
The needs assessment served to understand if programs would benefit from the development of additional educational materials. As mentioned above, the majority of programs that did not offer any education addressing HIV in pregnancy, 88.9%, felt they would benefit from additional educational materials. It was hypothesized that differences in need would vary among programs of different sizes, specifically that smaller programs would have greater need because of more limited resources related to program size. When the sizes of program were compared to the overall need for additional education, the results were not statistically significant, although trends were observed suggesting that smaller programs were more likely to request additional materials. Again the inability to identify a significant difference is likely due to small sample size, which could not have been corrected in this study because of the limitation of the number of programs in the United States and Canada.

For programs that currently offered education, the needs assessment found that 64.3% of programs felt they would benefit from the development of additional educational materials. This result is somewhat surprising, but highlights that although the majority of programs currently offer some education regarding HIV in pregnancy, the majority also feel as though more information would be beneficial for the instruction of their students. As hypothesized that the size of program may impact the need for additional materials, with smaller programs being more likely to believe they would benefit. Interestingly, the trends seen for programs that offered educational material were opposite what was expecting, with larger programs being more likely to want additional educational materials as compared to smaller programs. As expected because of this trend, the results of the J-T test did not identify a



statistically significant difference between programs of different sizes. It is not clear why this finding was observed, although it is possible that because larger programs were already offering education, they were more likely to want additional materials to help strengthen their existing content addressing HIV in pregnancy.

When reviewing the topics that program directors requested for inclusion in potentially developed educational materials, it is interesting to compare them to what is currently available. A comparison of broad topics regarding HIV in pregnancy can be seen in Figure 21.



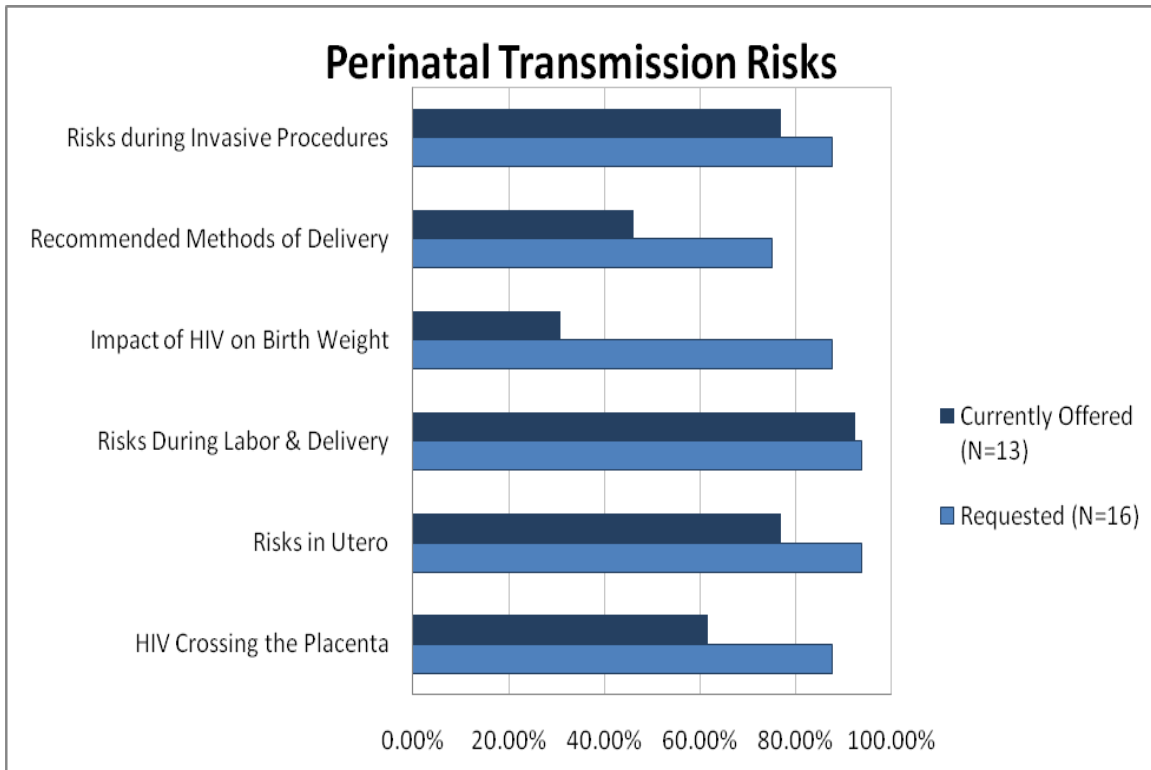
**Figure 21: Availability of Education Regarding HIV and Pregnancy in Genetic Counseling Programs vs. Need for Additional Educational Material**

As seen, all topics suggested were requested by over than 50% of programs and all but one, resource identification, were requested by greater than 70%. When comparing the currently

available topics compared to the requested, it is important to remember that the requested topics were submitted by both programs who currently offer education and those that offer none. The high response rate for transmission risks during pregnancy and risks during breastfeeding indicate that there is a high need among programs who do not offer education and a need for additional information on these topics from programs who already address them. These results also indicate that a clear need exists for additional HIV education beyond transmission risks in genetic counseling programs, specifically for materials addressing the 2006 CDC Testing Recommendations, Newborn Screening, Clinical Management, and Psychosocial Needs of HIV-positive pregnant women.

For transmission risks, clinical management, psychosocial needs, and resource identification, programs were also asked to discuss in more detail what topics they currently cover or what topics they would like to see included in developed materials.

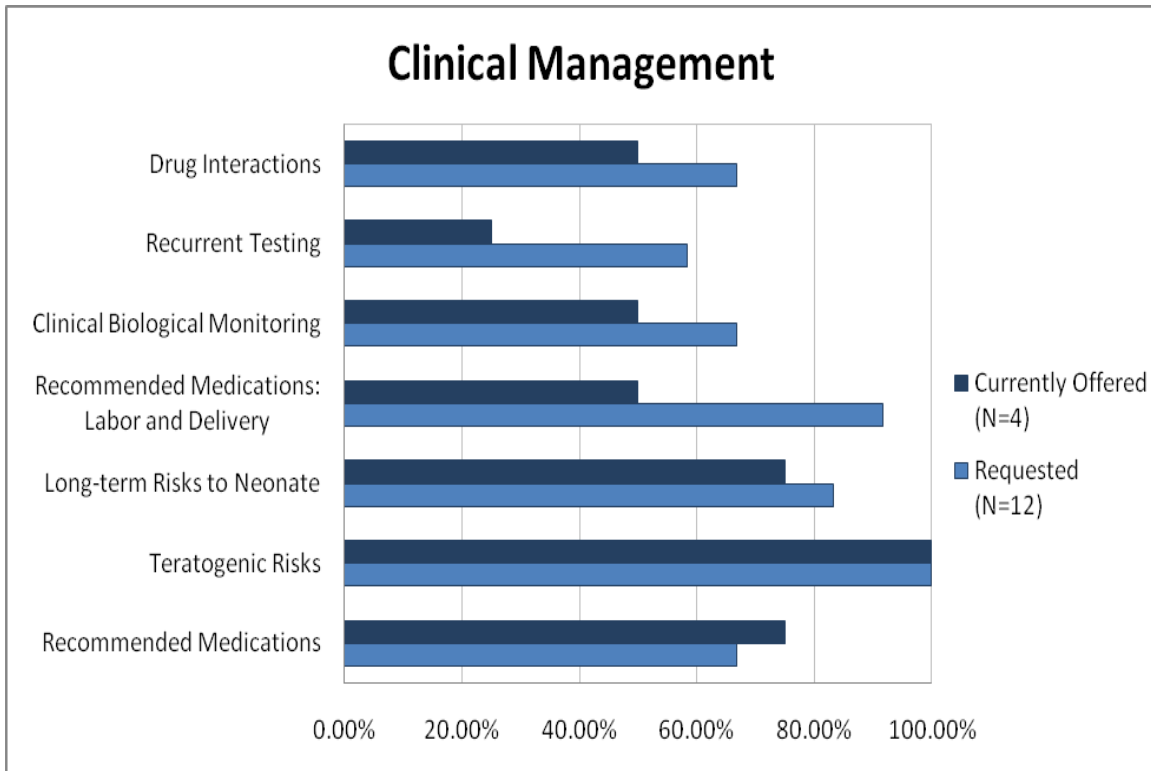
Figure 22 compares the availability of specific subjects within perinatal transmission risks and those that were requested by program directors.



**Figure 22: Comparison of Specific Topics Regarding HIV Perinatal transmission Risks Between Programs who Currently offer Education and Programs who Requested Additional Materials**

The majority of genetic counseling programs who offer education currently discuss transmission risks in utero, risks during labor and delivery, and risks associated with early invasive diagnostic procedures like amniocentesis and chorionic villus sampling. These topics were also requested by the majority of programs who wanted additional material, again suggesting that both programs who offer education and those who don't think they are important for inclusion in genetic counseling curricula. A need for development of materials exists for recommended methods of delivery, impact on HIV on birth weight, and the risk of HIV crossing the placenta, as these were heavily requested but not frequently discussed within currently offered discussions addressing HIV and pregnancy.

Figure 23 compares the availability of education addressing specific topics for the clinical management of HIV-positive pregnant women and the need for additional educational material regarding these subjects.

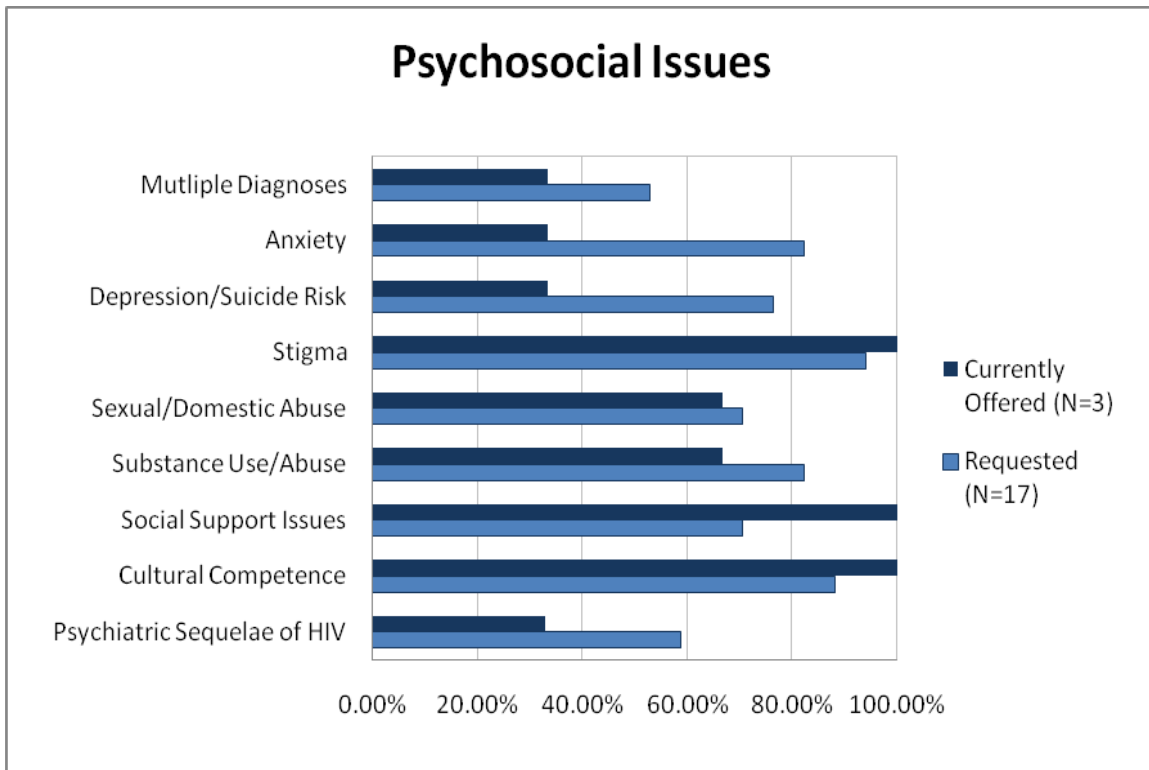


**Figure 23: Comparison of Specific Topics Regarding Clinical Management Between Programs who Currently offer Education and Programs who Requested Additional Materials**

The majority of programs that offered educational material to their students regarding the clinical management of HIV-positive pregnant women addressed teratogenic risks associated with antiretroviral medications as well as recommended medications during pregnancy. These are important topics for genetic counselors to know so they are able to identify potential risks associated with the use of these medications. Additionally, the majority of programs currently offering education addressed long-term risks to the neonate following exposure to antiretrovirals in utero. These three topics were also highly requested by programs who felt they would benefit

from additional educational materials. The data also shows that a significant need exists for education addressing the recommended medications during pregnancy and delivery, and recommended clinical/biological monitoring for HIV-positive pregnant women. Less than 60% of programs felt that the issue of recurrent testing should be addressed in additional educational materials, indicating that this topic isn't of great importance to genetic counselors. To help support this claim, only about 25% of genetic counseling programs that provide education on clinical management include this topic in their discussion.

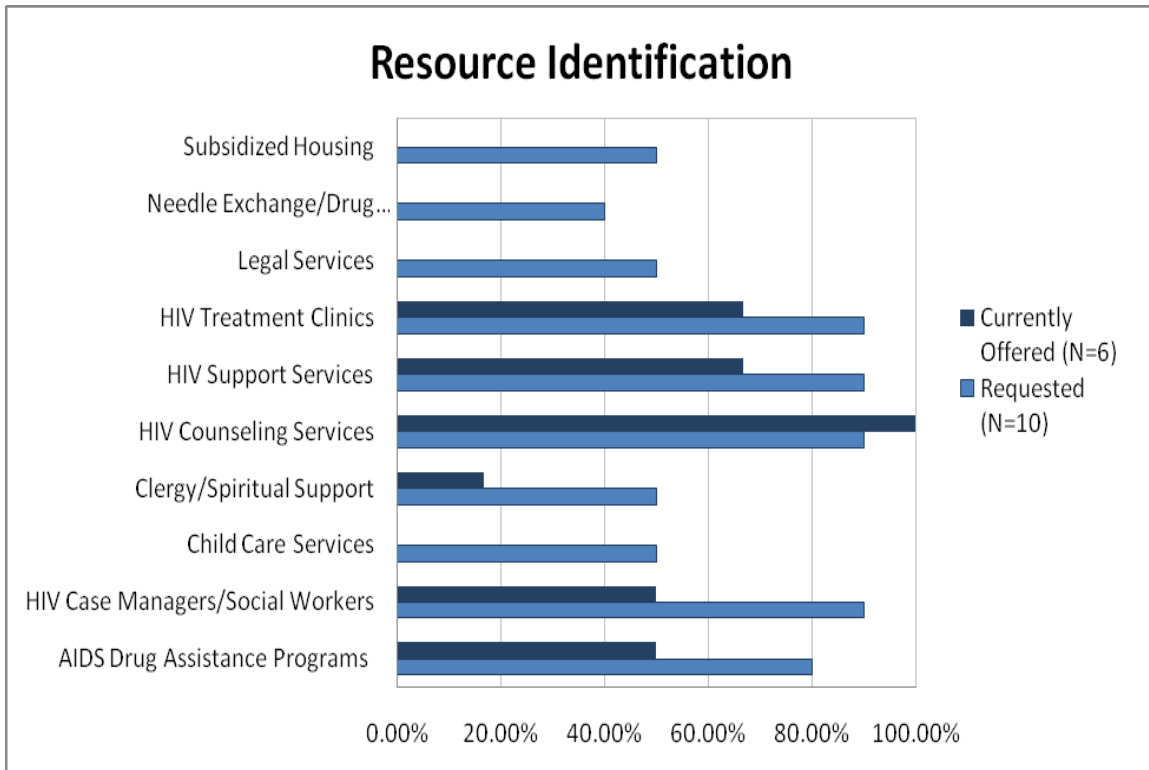
Figure 24 compares the availability of education addressing specific psychosocial issues HIV-positive women may face and the need for additional educational material regarding these subjects.



**Figure 24: Comparison of Specific Topics Regarding Psychosocial Issues Between Programs who Currently offer Education and Programs who Requested Additional Materials**

The development of content addressing psychosocial issues was the most requested topic for inclusion in educational materials. All programs surveyed indicated that these topics should be included. Because of the importance of education regarding the psychosocial issues of various patient populations within genetic counseling curricula, this result is not surprising. When examining the specific psychosocial issues that programs currently address, the most commonly discussed are stigma associated with diagnosis, social support issues, and cultural competency. It is important to remember, however, that only a few programs currently addressed psychosocial issues within their curricula. As was made clear by the needs assessment, development of additional materials addressing was very important to program directors, and this topic indicated the greatest area of need regarding HIV in pregnancy. Programs indicated that a need existed for nearly every psychosocial issue listed, except multiple diagnoses. It is possible that multiple diagnoses was not felt to be as important because genetic counseling program directors were familiar with this terminology. If this study were to be repeated, this term would be better explained to mean that women with HIV often have multiple diagnoses including other sexually transmitted infections, other chronic infections like tuberculosis, or psychiatric illnesses.

Figure 25 compares the availability of education addressing specific topics for resource identification for HIV-positive pregnant women and the need for additional educational material regarding these subjects.



**Figure 25: Comparison of Specific Topics Regarding Resource Identification Between Programs who Currently offer Education and Programs who Requested Additional Materials**

Resource identification was the least requested topic chosen for inclusion in developed educational materials. Less than 60% of programs asked that it be included in developed educational materials. The need for this topic was similar to the current availability of this topic within genetic counseling programs. This may be due to the fact that programs who do not offer education believe they would benefit from its inclusion whereas programs who educate their students on resource identification do not think they would benefit from additional educational materials. Additionally, it is possible that because programs do not offer education on a wide variety of topics regarding HIV in pregnancy, they are not familiar with the variety or availability of resources for individuals living with HIV. Regardless of this, for program directors who did indicate that resource identification should be a part of developed materials, a definite need was observed specifically for information addressing the availability of HIV case

managers/social workers, HIV support services, AIDS Drug Assistance Programs, HIV counseling services, and HIV treatment clinics. Less commonly requested topics were information on subsidized housing for individuals with HIV, needle exchange/drug rehabilitation programs, legal support, clergy/spiritual support, and child-care support. Interestingly, the majority of these previously mentioned topics were not already included by genetic counseling programs who provided education addressing resource identification for HIV-positive pregnant women, indicating that programs may not have enough space to incorporate them into existing curricula or feel as though individuals with HIV would be better served to learn about these resources from other professionals.

To help address the needs of genetic counseling programs in the United States and Canada, the final objective of this project was to develop educational materials designed for genetic counseling students addressing issues specific to HIV and pregnancy. Program directors indicated that the three educational materials they would benefit most from were a series of online webinars that students could view at any time, clinical case scenarios, and a CD-ROM of PowerPoint presentations and other relevant resource materials. The goals of developing the educational materials were to address the topics specified by program directors while keeping in mind reasons why programs do not currently offer education addressing HIV and pregnancy. Comparing the reasons that programs currently do not provide education addressing HIV and pregnancy as well as the specific materials requested, it appears as though counselors chose materials that would be relatively simple to incorporate into their existing curricula without the addition of much classroom time. Genetic counseling students could be assigned to view the webinars on their own time and then discuss some of the issues presented during class. The clinical case scenarios could be given to students as homework or to do in groups within class.



Finally the CD-ROM could be distributed to genetic counseling students to review and explore outside of the classroom or even as a resource to keep on hand during clinical rotations in case a patient with HIV ever presented.

Working with the PA/MAAETC, the three most-requested materials were developed. As discussed in the results section, two webinars were designed keeping in mind the needs identified by genetic counseling programs. The first webinar addressing care for HIV-positive pregnant women including transmission risks, management, and recommendation was presented live on March 2, 2011 and had 106 participants. 5 of these participants identified their primary function role as genetic counseling. The second webinar addressing the psychosocial needs and approaches to care for HIV-positive women was presented on March 16, 2011 and had 65 participants. 7 of these participants identified genetic counseling as their primary function role. These webinars will be available on the PA/MAAETC's website for future viewings, and it is hoped that program directors will incorporate them into their existing curricula or recommend that students view them outside of the classroom to better understand the needs of women with HIV.

The clinical case examples and CD-ROM discussed in the results section were also developed keeping in mind the needs identified by genetic counseling program directors. The clinical case scenarios were designed to weave together common referral reasons that a woman/couple may be referred to genetic counseling as well as relevant issues that pertain to pregnancy and HIV. These case examples were designed for students to discuss in a group setting or in groups to help initiate discussion and develop skills that could be used in a clinical setting. The resource CD was also designed to provide resources and materials which could be used to provide education for genetic counseling students. The resources provided are designed

as reference materials as well as quick-access education guides for health care providers. Specifically, the Invisible Epidemic series provides a series of patient handouts and health-care provider reference sheets addressing issues specific to women with HIV.

A future extension of this project will be distributing these educational materials to genetic counseling programs in the United States and Canada. In order to do this, programs will be contacted using an email form. The educational materials will be described, and if program directors would like to receive copies of them they will be able to contact the author with the proper mailing address to send out the materials.

Because this is the first study of its kind investigating the current inclusion of information addressing HIV in pregnancy and the need for this education in genetic counseling programs, there will be a need for follow-up studies. Following the distribution of materials, it will be important to assess program directors' thoughts on the quality and relevance of the materials. Identifying the percentage of programs who requested materials and comparing it to the percentage who indicated in this study that they would benefit from development of additional materials will be interesting to see if the numbers correlate. Next, it will be important to assess program directors' opinion of the quality and utility of the developed materials. Although the materials were designed keeping in mind the issues specified from the needs assessment, program directors may feel as though the materials could place more emphasis on different issues or include additional topics. Another important issue to be included in follow-up studies will be the ease of incorporation of the educational materials into existing curricula. The materials were developed keeping in mind some of the major reasons programs indicated they currently did not provide education, especially a lack of time and space to include issues specific to HIV in pregnancy. Students within genetic counseling programs should also be asked how

they perceive the utility and relevance of the educational materials and if they feel they were helpful in their training as genetic counselors. Assessing the developed educational materials in this manner will assist in revisions of content as well as form, and can help aid in the development of additional materials which may meet program directors' needs.

Long-term evaluation for this project would also be interesting to assess the relevancy of the information in genetic counseling practice. Because this survey was designed and distributed only to genetic counseling program directors, the results cannot be applied to practicing prenatal genetic counselors due to concerns with external validity. To examine the relevancy of these materials in genetic counseling practices, students who originally received the educational materials could be re-surveyed in several years to gauge how relevant the information presented is to their current practices. Because genetic counseling graduate programs are two years in length, it might be possible to complete this follow-up study 4 years following the delivery of educational materials. If the educational materials developed for genetic counseling programs are successful, it might be possible to extend the delivery of these materials to all genetic counselors practicing in a prenatal setting who have graduated prior to the development of the materials.

A larger study that would be an important contribution to the development of this topic within the literature is to investigate the number of HIV-positive pregnant women are currently receiving prenatal genetic counseling in North America. These statistics are currently not available because this topic has never been investigated. This would help clarify the relevance of providing education on this topic within genetic counseling programs, categorize the reasons why these women are being referred to genetic counseling, and identify additional needs for HIV-positive pregnant women that may not have been addressed within this study.

Although this study did identify a need for educational materials addressing the needs of HIV-positive pregnant women, it is not without its limitations. One limitation of this study is the limited number of genetic counseling programs to survey within the United States and Canada. Although the majority of programs who were contacted to participate completed the study, the numbers were still not high enough to identify statistical differences between response rates. This allows for a qualitative analysis of the findings, but limits the quantitative analysis. Because the number of programs is fixed, the low number of responses could not be avoided and this should just be an accepted limitation of this study.

A major limitation of studies done using surveys is non-responder bias. Responder bias is the idea that the individuals who did not respond to the survey differ from those who did. For this study, 32 genetic counseling programs were surveyed, and 26 chose to respond. Although the response rate, 81.26%, is high, it is possible that the 6 programs who chose not to answer differ from those who did choose to respond. Because all data collected from this survey is anonymous, it is difficult to compare the responders with the non-responders. It is possible that the programs who chose not to respond did not feel as though the topic studied within the study was valuable to their program or due to a lack of interest in the study itself. If this were the case, it would be likely that these individuals would have indicated that their program would not benefit from the development of additional educational materials addressing HIV and pregnancy. This would mean that the findings of this study overestimate the need for information addressing issues specific to HIV-positive pregnant women in genetic counseling programs. Other reasons that programs could not have responded to the survey include improper delivery of the email messages or a lack of time.

In addition to the non-responder bias, it is also important to consider that two programs chose to begin the survey but did not complete it. These two programs both indicated that they currently offered some form of education addressing HIV and pregnancy within their curriculum. They did not answer questions regarding the type of materials they used to provide the education or what topics they included within their curricula. These two programs also did not participate in the needs assessment. An important consideration is what caused these two programs to stop the survey and also consider if these programs differ from those who completed the survey. Comparing the two programs with the little information available, it was observed that one program had 0-5 students per year and the other 11-15. Because these two programs did not have the same number of students per academic year, it can be assumed that the size of the program did not play a role in the willingness to complete the survey. It is difficult to speculate as to why these programs chose not to finish the survey, but it is possible that after beginning the survey, they thought that the rest of the survey was not applicable to them, because of a misunderstanding of the questions. It is possible they thought the rest of the survey corresponded only to programs who did not offer educational content addressing HIV and pregnancy. It is also possible that these two programs did not complete the survey because they felt that the remaining content was not valuable to their programs. If this latter possibility were the case, it is reasonable to assume that these two programs might have indicated that their programs would not benefit from the development of additional educational materials. The rationale for this could be different from the programs who chose not to respond to the survey altogether, however. Because these two programs already offered content, it is possible they feel as though they would not benefit from any additional materials. This would again inflate the findings of the study that a need exists for additional content addressing HIV and pregnancy.

Other reasons why these two programs chose not to conclude the survey are a lack of time, or an interruption that caused them to stop in the middle. It is possible that these programs intended to return and complete the survey, but were unable to because they forgot, deleted the email, or the survey was closed before they could return and complete it.

Another limitation to this study is that the individuals surveyed were all program directors of genetic counseling programs. Assuming that program directors represent a relatively homogenous group of people with similar backgrounds and training, the results of this study could be biased and difficult to extend to other groups. It is also possible that such a large need for additional education was found because this population is relatively open to incorporating new topics into existing curricula.

A final limitation of the study is that the issues investigated were specified by the authors of the survey. These topics were hypothesized to be an important part of education for genetic counseling students, but it is difficult to separate out if program directors would have specified these topics without being presented them in this format. Also, although program directors were given space to indicate additional topics or thoughts, relatively few programs used this option to discuss additional topics they felt they would most benefit from or different types of educational materials. When examining the topics listed under the 'other' category, the majority can be incorporated into an already existing topic header. It is possible that a study which allowed program directors to fill in their needs without any prompting by options would have identified different results.

In conclusion, this study was the first of its kind to investigate the current availability of education addressing HIV and pregnancy within graduate level genetic counseling programs in the United States and Canada. In addition, this study also examined the programs' needs for the

development of additional education addressing HIV and pregnancy. This study found that although the majority of programs offer some education addressing HIV transmission risks, the majority of programs do not address newborn screening, psychosocial issues, clinical management, and resource identification. For programs who do not offer education addressing these subjects, the most commonly cited reasons were a lack of time to include these topics within their curricula, the feeling that the patient population was not large enough to warrant specific education, and the belief that counseling regarding HIV was not the role of genetic counselors. Despite these reasons for not including education, the needs assessment found that a need does exist for additional education within both programs who already offer education and those that do not currently address these topics within their curricula. A substantial need existed for education addressing transmission risks during pregnancy, risks associated with breastfeeding, clinical management, psychosocial issues, and newborn screening. A need existed for education including information regarding resource identification, but the need was not as great for the other topics. To help meet the needs specified by genetic counseling programs, a variety of educational materials were developed for distribution in collaboration with the Pennsylvania/MidAtlantic AIDS Education and Training Center. The developed materials included two webinars which will be able to be accessed anytime online, clinical case examples, and a CD-ROM containing PowerPoints and relevant resources for genetic counseling students addressing subjects related to HIV in pregnancy. A future direction of this project is to distribute these materials to genetic counseling programs in North America. These newly developed training materials will help newly trained genetic counselors provide better services to these HIV-positive pregnant women and improve the curriculum of genetic counseling programs in the United States and Canada.

## APPENDIX A

### INSTITUTIONAL REVIEW BOARD APPROVAL LETTER



#### University of Pittsburgh *Institutional Review Board*

3500 Fifth Avenue  
Pittsburgh, PA 15213  
(412) 383-1480  
(412) 383-1508 (fax)  
<http://www.irb.pitt.edu>

#### Memorandum

To: Ms. Sara Chadwick  
From: Sue Beers, Ph.D., Vice Chair  
Date: 5/26/2010  
IRB#: [PRO10010209](#)  
Subject: Investigation of Existing Educational Content Regarding HIV Positive Patients in American Genetic Counseling Programs

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The above-referenced project has been reviewed by the Institutional Review Board. Based on the information provided, this project meets all the necessary criteria for an exemption, and is hereby designated as "exempt" under section 45 CFR 46.101(b)(2) Tests, surveys, interviews, observations of public behavior

Please note the following information:

- If any modifications are made to this project, use the "**Send Comments to IRB Staff**" process from the project workspace to request a review to ensure it continues to meet the exempt category.
- Upon completion of your project, be sure to finalize the project by submitting a "**Study Completed**" report from the project workspace.

Please be advised that your research study may be audited periodically by the University of Pittsburgh Research Conduct and Compliance Office.



## **APPENDIX B**

### **PROGRAM DIRECTOR LETTER**

Dear Program Director,

My name is Sara Chadwick and I am a second-year genetic counseling student at the University of Pittsburgh's Graduate School of Public Health. I am also employed by the Pennsylvania/MidAtlantic AIDS Education and Training Center (PA/MAAETC), a non-profit organization funded by the U.S. Public Health Service's Health Resources Service Administration (HRSA). The (PA/MAAETC) recognizes the complicated issues of providing quality HIV/AIDS care and focuses on the entire health care team including physicians, nurses, dentists, advanced practice nurses, physician assistants, pharmacists and other health care professionals. The AETC custom designs programs, taking into account the providers' rural or urban settings, experience, and volume of HIV patients.

For my master's thesis, I am conducting a survey of program directors of genetic counseling programs in the United States and Canada. This survey asks questions regarding existing curricula content available for genetic counseling students on HIV/AIDS in pregnancy. Specifically, this survey considers issues regarding HIV-positive pregnant women.

A study conducted by Emory University indicates that the average lifespan of a person following an HIV diagnosis has increased from 7 years in 1993 to 24 years in 2006. Due to treatment improvements, HIV is now largely becoming a chronic disease requiring lifelong management. Today, many women with HIV may consider having children due to increased life expectancy and increased quality of life. The CDC estimates that approximately 6000 to 7000 women living with HIV will choose to become pregnant each year. Perinatal transmission of HIV is the leading cause of HIV in children in the United States. However, treatment of HIV-positive pregnant women with antiretrovirals during pregnancy can drastically reduce the risk of perinatal infection, and this has led the CDC to recommend HIV testing in all pregnant women. This has also prompted some states to include HIV testing in their newborn screening programs. Because of the increasing numbers of HIV-positive women who are living longer and thus may be making decisions to have families and the decision of states to include HIV testing of newborns,

the needs of HIV-positive women will likely become relevant in the field of genetic counseling. HIV is not a genetic condition that would be the object of focus during a counseling session; however it is clear that women with HIV have unique psychosocial needs and medical issues that should be taken into consideration during a counseling session. HIV is part of a woman's medical history, and this diagnosis can have implications on treatments, medication interactions, and recommendations for certain procedures during pregnancy. Women with HIV are not just women with HIV, they are women who are being referred for counseling due to advanced maternal age, genetic risk, medication exposure, and any other number of reasons that a woman without HIV would seek genetic counseling.

I would greatly appreciate it if you would take a few minutes to complete the survey I have designed and uploaded onto survey monkey.com. The link for this survey is [Existing Educational Content Regarding HIV-positive Pregnant Women in Genetic Counseling Programs](#). All answers collected from this survey will be completely anonymous, and will help serve to investigate the current educational HIV content utilized by genetic counseling programs in the United States and Canada and help me develop educational materials to facilitate the incorporation of the special needs of an HIV-positive woman receiving prenatal counseling into existing curricula.

Thank you so much for your participation in my survey and helping me complete my master's thesis. I greatly appreciate your time and cooperation.

Sara Chadwick, MPH, CPH

## APPENDIX C

### SURVEY FOR GENETIC COUNSELING PROGRAMS

Introduction: The purpose of this survey is to ascertain curricular content regarding the counseling of HIV-positive women in a prenatal setting. Please answer these questions regarding your program's availability of education for its students on the topics described as well as what materials might be valuable to you as a program director. The survey should take approximately 15 minutes. There are no foreseeable risks associated with this project, nor are there any direct benefits to you. You will not receive any payment for participation. All answers collected from this survey will be completely anonymous, and your responses will not be identifiable in any way. All responses are confidential, and results will be kept under lock and key. Your participation is voluntary, and you may withdraw from this project at any time. If you have any questions or wish to contact me, my e-mail address is [slc84@pitt.edu](mailto:slc84@pitt.edu).

1. How many students are enrolled in each year your program?

\_\_\_\_\_ 0-5  
\_\_\_\_\_ 6-10  
\_\_\_\_\_ 11-15

2. Does your Genetic Counseling program provide educational content about HIV/AIDS in pregnancy in any courses?

Yes \_\_\_\_\_ No \_\_\_\_\_

If yes, do you provide education in the form of:

\_\_\_\_\_ One lecture on HIV in pregnancy  
\_\_\_\_\_ More than one lecture on HIV in pregnancy

- \_\_\_\_\_ Content on HIV and pregnancy within another lecture
- \_\_\_\_\_ Required reading on HIV in pregnancy
- \_\_\_\_\_ Optional reading on HIV in pregnancy
- \_\_\_\_\_ Required web-based tutorial on HIV in pregnancy
- \_\_\_\_\_ Optional web-based tutorial on HIV in pregnancy
- \_\_\_\_\_ Required documentary or film addressing HIV in pregnancy
- \_\_\_\_\_ Optional documentary or film addressing HIV in pregnancy
- \_\_\_\_\_ Other. Please describe briefly in the space below.

If you answered yes, proceed to question 3.

If you answered no, proceed to question 10.

3. Do you provide educational content in the curriculum on HIV in women and the risk of HIV perinatal transmission?

Yes \_\_\_\_\_ No \_\_\_\_\_

If yes, do you address: (check all that apply)

- \_\_\_\_\_ HIV crossing the placenta
- \_\_\_\_\_ Transmission risk in utero
- \_\_\_\_\_ Transmission risks during delivery
- \_\_\_\_\_ Impact of HIV in pregnancy and lower birth weight babies
- \_\_\_\_\_ Current recommended methods of delivery
- \_\_\_\_\_ Risks of transmission during amniocentesis/chorionic villus sampling
- \_\_\_\_\_ Other. Please describe briefly in the space below.

4. Do you provide educational content in the curriculum on the risk of HIV perinatal transmission to babies born to HIV-positive mothers by breast feeding?

Yes \_\_\_\_\_ No \_\_\_\_\_

5. Do you provide curriculum content on the 2006 Center for Disease Control and Prevention's Recommendations for HIV screening in pregnant women?

Yes \_\_\_\_\_ No \_\_\_\_\_

6. Do you provide curriculum content on the current states where HIV screening is included in newborn screening programs?

Yes \_\_\_\_\_ No \_\_\_\_\_

7. Do you provide curriculum content on the current clinical management of HIV infection in pregnant women?

Yes \_\_\_\_\_ No \_\_\_\_\_

If yes, do you address: (check all that apply)

\_\_\_\_\_ Current recommended HIV antiretroviral medications

\_\_\_\_\_ Teratogenic risks of HIV antiretroviral medications

\_\_\_\_\_ Long-term risks to the neonate from HIV antiretroviral exposure in utero

\_\_\_\_\_ Recommendations for HIV antiretroviral medications during labor and delivery

\_\_\_\_\_ Clinical biological monitoring (CD4+ count, viral load) during pregnancy

\_\_\_\_\_ Need for recurring HIV testing upon entry to Ob/Gyn care and at labor and delivery

\_\_\_\_\_ Interactions between HIV medications, other prescribed medications, over the counter drugs, and street drugs

\_\_\_\_\_ Other. Please describe briefly in the space below.

8. Do you provide curriculum content on psychosocial needs of pregnant HIV-positive women who receive counseling?

Yes \_\_\_\_\_ No \_\_\_\_\_

If yes, do you address the following: (check all that apply)

- \_\_\_\_\_ Psychiatric sequelae of HIV
- \_\_\_\_\_ Cultural competence
- \_\_\_\_\_ Social support issues
- \_\_\_\_\_ Substance use/abuse
- \_\_\_\_\_ Sexual/domestic violence
- \_\_\_\_\_ Stigma associated with diagnosis
- \_\_\_\_\_ Depression/suicide risk
- \_\_\_\_\_ Anxiety
- \_\_\_\_\_ Multiple diagnoses
- \_\_\_\_\_ Other. Please describe briefly in the space below.

9. Do you provide curriculum content on available resources in your area?

Yes \_\_\_\_\_ No \_\_\_\_\_

If yes, do you address the following: (check all that apply)

- \_\_\_\_\_ AIDS drug assistance programs (payment for medications)
- \_\_\_\_\_ Available HIV case managers/social workers
- \_\_\_\_\_ Child care services
- \_\_\_\_\_ Clergy, spiritual support.
- \_\_\_\_\_ HIV counseling services
- \_\_\_\_\_ HIV support groups
- \_\_\_\_\_ HIV treatment clinics in the area
- \_\_\_\_\_ Legal services
- \_\_\_\_\_ Needle exchange programs/ substance abuse rehabilitation programs
- \_\_\_\_\_ Subsidized housing for HIV-positive persons
- \_\_\_\_\_ Other. Please describe briefly in the space below.

Please skip to question 12.

10. If you **do not** provide any education to your students on HIV/AIDS, why not? (check TOP THREE CHOICES)

- \_\_\_\_\_ Counseling about HIV is not the role of genetic counselors
- \_\_\_\_\_ Conflict with program goals
- \_\_\_\_\_ Insufficient faculty knowledge regarding HIV/AIDS during pregnancy
- \_\_\_\_\_ Lack of availability of educational materials
- \_\_\_\_\_ Lack of course time/space to incorporate topic
- \_\_\_\_\_ Lack of knowledgeable faculty
- \_\_\_\_\_ Need for specific curriculum content is not warranted (patient population is not large enough)
- \_\_\_\_\_ Students have not requested the topic to be covered
- \_\_\_\_\_ Training on HIV-positive pregnant women not needed
- \_\_\_\_\_ Other (please identify below)

11. If you **do not** provide education to your students on HIV/AIDS, do you think your program would benefit from the development of educational materials designed to address issues regarding HIV/AIDS and pregnancy?

Yes \_\_\_\_\_ No \_\_\_\_\_

If you answered yes, please proceed to question 13.

If you answered no, you are done with this survey, thank you for your input!

12. If you do provide education to your students on HIV/AIDS, do you think your program would benefit from the development of additional educational materials that are designed to address issues regarding HIV/AIDS and pregnancy?

Yes \_\_\_\_\_ No \_\_\_\_\_

If you answered yes, please proceed to question 13.

If you answered no, you are done with this survey, thank you for your input!

13. Which of the following topics do you think the educational materials should address?  
(check all major categories that apply, and then check specific topics within that category)

- Content on the risk of HIV in women and the risk of HIV perinatal transmission
  - HIV crossing the placenta
  - Transmission risks in utero
  - Transmission risks during delivery
  - Impact of HIV in pregnancy and lower birth weight babies
  - Current recommended methods of delivery
  - Risks of transmission during amniocentesis/chorionic villus sampling
- Content on the risk of HIV perinatal transmission to babies born to HIV-positive mothers by breast feeding
- Content on the 2006 Center for Disease Control and Prevention's recommendations for HIV screening in pregnant women
- Content on the current states where HIV screening is included in newborn screening programs
- Content on the current clinical management of HIV infection in pregnant women
  - Current recommended HIV antiretroviral medications
  - Teratogenic risks of HIV antiretroviral medications
  - Long-term risks to the neonate from HIV antiretroviral exposure in utero
  - Recommendations for HIV antiretroviral medications during labor and delivery
  - Clinical biological monitoring (CD4+ count, viral load) during pregnancy
  - Need for recurring HIV testing upon entry to Ob/Gyn care and labor and delivery
  - Interactions between HIV medications, other prescribed medications, over the counter drugs, and street drugs.
- Content on psychosocial needs of pregnant HIV-positive women
  - Psychiatric sequelae of HIV



- \_\_\_\_\_ Cultural competency
- \_\_\_\_\_ Social support issues
- \_\_\_\_\_ Substance use/abuse
- \_\_\_\_\_ Sexual/domestic violence
- \_\_\_\_\_ Stigma associated with diagnosis
- \_\_\_\_\_ Depression/suicide risk
- \_\_\_\_\_ Anxiety
- \_\_\_\_\_ Multiple diagnoses
- \_\_\_\_\_ Content on available resources in your area
  - \_\_\_\_\_ AIDS drug assistance programs (payment for medications)
  - \_\_\_\_\_ Available HIV case managers/social workers
  - \_\_\_\_\_ Child care services
  - \_\_\_\_\_ Clergy, spiritual support.
  - \_\_\_\_\_ HIV counseling services
  - \_\_\_\_\_ HIV support groups
  - \_\_\_\_\_ HIV treatment clinics in the area
  - \_\_\_\_\_ Legal services
  - \_\_\_\_\_ Needle exchange programs/ substance abuse rehabilitation programs
  - \_\_\_\_\_ Subsidized housing for HIV-positive persons
- \_\_\_\_\_ Other/Additional Topics (please describe below)

14. Which of the following educational materials do you feel that you might use as a program director in educating your students about HIV in pregnancy? (check TOP THREE choices)

- \_\_\_\_\_ CD-ROM of PowerPoint lectures addressing HIV basics, perinatal transmission risks, current CDC recommendations for HIV screening in pregnancy, and the implications for genetic counselors of counseling an HIV-positive pregnant woman
- \_\_\_\_\_ Pocket-guide on HIV in pregnant women for genetic counselors (a pocket guide is a condensed summary of important material on a topic)
- \_\_\_\_\_ Clinical case examples which can illustrate key points of counseling HIV

- \_\_\_\_\_ positive women in a genetic counseling practice
- \_\_\_\_\_ Series of online webcasts that could be viewed at any time by students
- \_\_\_\_\_ Packets of relevant peer-reviewed research articles which can be used to facilitate discussion
- \_\_\_\_\_ Series of audio lectures that address HIV and pregnancy
- \_\_\_\_\_ List of current documentaries, books, popular movies, etc. that illustrate the needs of an HIV-infected patient
- \_\_\_\_\_ Quizzes on relevant topics in HIV education for genetic counselors
- \_\_\_\_\_ Role playing scenarios that could be used in class by students to practice skills learned
- \_\_\_\_\_ List of websites that would be valuable resources for faculty and students
- \_\_\_\_\_ Other. Please describe briefly below.

Thank you for your input!

This survey was created by the following:

Sara L. Chadwick, MPH, CPH

Linda R. Frank, PhD, MSN, ACRN, FAAN

Elizabeth Gettig, MS, CGC

Robin E. Grubs, PhD, CGC

Last updated: June 2010

## BIBLIOGRAPHY

1. Organization WH. Malaria and HIV/AIDS Interactions and Implications: Conclusions of a technical consultation. 2004.
2. HIV/AIDS Policy Fact Sheet: Women and HIV/AIDS in the United States. *The Henry J. Kaiser Family Foundation*. 2010.
3. CDC HIV/AIDS Fact Sheet -HIV/AIDS among Women. *Centers for Disease Control and Prevention*. 2008.
4. Schackman BR, Gebo KA, Walensky RP, et al. The lifetime cost of current human immunodeficiency virus care in the United States. *Med Care*. Nov 2006;44(11):990-997.
5. Manfredi R. HIV infection and advanced age emerging epidemiological, clinical, and management issues. *Ageing Res Rev*. Jan 2004;3(1):31-54.
6. Lee CW. HIV Patients will spend \$600K for lifetime care. *New York Times*. Nov 10, 2006, 2006.
7. Kohli R, Klein RS, Schoenbaum EE, Anastos K, Minkoff H, Sacks HS. Aging and HIV infection. *J Urban Health*. Jan 2006;83(1):31-42.
8. Lloyd-Smith E, Brodtkin E, Wood E, et al. Impact of HAART and injection drug use on life expectancy of two HIV-positive cohorts in British Columbia. *AIDS*. Feb 14 2006;20(3):445-450.
9. Pregnancy and Childbirth. *Centers for Disease Control and Prevention*. 2007.
10. Mother-to-Child (Perinatal) HIV Transmission and Prevention. *Centers for Disease Control and Prevention*. 2007.
11. Minkoff H. Human immunodeficiency virus infection in pregnancy. *Obstet Gynecol*. Apr 2003;101(4):797-810.
12. Branson BM, Handsfield HH, Lampe MA, et al. Revised recommendations for HIV testing of adults, adolescents, and pregnant women in health-care settings. *MMWR Recomm Rep*. Sep 22 2006;55(RR-14):1-17; quiz CE11-14.
13. United States: HIV Testing for Mothers and Newborns. *The Henry J. Kaiser Family Foundation*. 2008.
14. Genetic Counseling as a Profession. *National Society of Genetic Counselors*. 2005.
15. Catalan J, Beevor A, Cassidy L, et al. Women and HIV infection: investigation of its psychosocial consequences. *J Psychosom Res*. Jul 1996;41(1):39-47.
16. Moore J, Schuman P, Schoenbaum E, Boland B, Solomon L, Smith D. Severe adverse life events and depressive symptoms among women with, or at risk for, HIV infection in four cities in the United States of America. *AIDS*. Dec 3 1999;13(17):2459-2468.
17. Koenig LJ, Whitaker DJ, Royce RA, Wilson TE, Callahan MR, Fernandez MI. Violence during pregnancy among women with or at risk for HIV infection. *Am J Public Health*. Mar 2002;92(3):367-370.

18. Wainberg MA, Jeang KT. 25 years of HIV-1 research - progress and perspectives. *BMC Med.* 2008;6:31.
19. Prevention CfDCa. Basic Information about HIV and AIDS. 2011.
20. Anderson JR, ed *A Guide to the Clinical Care of Women with HIV.* Washington, DC2005.
21. Prevention CftDCa. Living with HIV/AIDS. 2007.
22. De Clercq E. Antiretroviral drugs. *Curr Opin Pharmacol.* Oct 2010;10(5):507-515.
23. Fischl MA, Richman DD, Grieco MH, et al. The efficacy of azidothymidine (AZT) in the treatment of patients with AIDS and AIDS-related complex. A double-blind, placebo-controlled trial. *N Engl J Med.* Jul 23 1987;317(4):185-191.
24. Wynn GH, Zapor MJ, Smith BH, et al. Antiretrovirals, part 1: overview, history, and focus on protease inhibitors. *Psychosomatics.* May-Jun 2004;45(3):262-270.
25. Hariri S, McKenna MT. Epidemiology of human immunodeficiency virus in the United States. *Clin Microbiol Rev.* Jul 2007;20(3):478-488, table of contents.
26. Prevention CfDCa. AIDS Surveillance - Trends (1985-2008). 2011.
27. Hall HI, Song R, Rhodes P, et al. Estimation of HIV incidence in the United States. *JAMA.* Aug 6 2008;300(5):520-529.
28. Blair JM, Hanson DL, Jones JL, Dworkin MS. Trends in pregnancy rates among women with human immunodeficiency virus. *Obstet Gynecol.* Apr 2004;103(4):663-668.
29. Massad LS, Springer G, Jacobson L, et al. Pregnancy rates and predictors of conception, miscarriage and abortion in US women with HIV. *AIDS.* Jan 23 2004;18(2):281-286.
30. Sharma A, Wanchu A, Bansal V, Singh S, Varma S. Improvement in CD 4 counts in HIV positive patients treated with HAART and antitubercular drugs: an observational study from North India. *Indian J Pathol Microbiol.* Oct 2007;50(4):905-907.
31. Murphy DA, Mann T, O'Keefe Z, Rotheram-Borus MJ. Number of pregnancies, outcome expectancies, and social norms among HIV-infected young women. *Health Psychol.* Sep 1998;17(5):470-475.
32. Wendy R. Uhlman JLS, Beverly M. Yashar, ed *A Guide To Genetic Counseling.* Second Edition. ed: Wiley-Blackwell; 2009.
33. Counselors NSoG. Primary Specialty Area Among Clinical Genetic Counselors. In: ENVIRONMENT PSSW, ed2010.
34. Nussbaum RL, ed *Thompson & Thompson Genetics in Medicine.* 7th ed. Philadelphia: Saunders Elsevier; 2007.
35. Dimes Mo. Genetic Counseling. *Trying to get pregnant* August 2007; [www.marchofdimes.com](http://www.marchofdimes.com).
36. Administration FAD. *Federal Register.* 1980;44:37434-37467.
37. Modell B, Darr A. Science and society: genetic counselling and customary consanguineous marriage. *Nat Rev Genet.* Mar 2002;3(3):225-229.
38. Lehman DA, Farquhar C. Biological mechanisms of vertical human immunodeficiency virus (HIV-1) transmission. *Rev Med Virol.* Nov-Dec 2007;17(6):381-403.
39. Cibulka NJ. Mother-to-child transmission of HIV in the United States. Many HIV-infected women are now planning to have children. What are the risks to mother and infant? *Am J Nurs.* Jul 2006;106(7):56-63; quiz 64.
40. Prevention CfDCa. Revised Recommendations for HIV Screening of Pregnant Women. 50. 2001;RR-19.

41. Buchanan AM, Cunningham CK. Advances and failures in preventing perinatal human immunodeficiency virus infection. *Clin Microbiol Rev.* Jul 2009;22(3):493-507.
42. Force PHST. Recommendations for Use of Antiretroviral Drugs in Pregnant HIV-Infected Women for Maternal Health and Interventions to Reduce Perinatal HIV Transmission in the United States. 2010:1-90.
43. Safety and Toxicity of Individual Antiretroviral Agents in Pregnancy. *National Institutes of Health.* 2009.
44. Szyld EG, Warley EM, Freimanis L, et al. Maternal antiretroviral drugs during pregnancy and infant low birth weight and preterm birth. *AIDS.* Nov 28 2006;20(18):2345-2353.
45. Brossard P, Boulvain M, Coll O, et al. Is screening for fetal anomalies reliable in HIV-infected pregnant women? A multicentre study. *AIDS.* Oct 1 2008;22(15):2013-2017.
46. Yudin MH, Prosen TL, Landers DV. Multiple-marker screening in human immunodeficiency virus-positive pregnant women: Screen positivity rates with the triple and quad screens. *Am J Obstet Gynecol.* Oct 2003;189(4):973-976.
47. Somigliana E, Bucci AM, Tibaldi C, et al. Early invasive diagnostic techniques in pregnant women who are infected with the HIV: a multicenter case series. *Am J Obstet Gynecol.* Aug 2005;193(2):437-442.
48. Fowler MG, Lampe MA, Jamieson DJ, Kourtis AP, Rogers MF. Reducing the risk of mother-to-child human immunodeficiency virus transmission: past successes, current progress and challenges, and future directions. *Am J Obstet Gynecol.* Sep 2007;197(3 Suppl):S3-9.
49. Jones TB. Psychosocial dimensions of HIV infection in pregnancy. *Clin Obstet Gynecol.* Jun 2008;51(2):456-466.
50. Saharan S, Lodha R, Agarwal R, Deorari AK, Paul VK. Perinatal HIV. *Indian J Pediatr.* Apr 2008;75(4):359-362.
51. Prevention CfDCA. U.S. Public Health Service Recommendations for Human Immunodeficiency Virus Counseling and Voluntary Testing for Pregnant Women. *Morbidity and Mortality Weekly Report.* 1995;44(RR-7).
52. Podhurst LS, Storm DS, Dolgonos S. Women's opinions about routine HIV testing during pregnancy: implications for the opt-out approach. *AIDS Patient Care STDS.* May 2009;23(5):331-337.
53. Kaye CI, Accurso F, La Franchi S, et al. Introduction to the newborn screening fact sheets. *Pediatrics.* Sep 2006;118(3):1304-1312.
54. National Newborn Screening Status Report. *National Newborn Screening and Genetics Resource Center.* 2011.
55. Birkhead GS, Pulver WP, Warren BL, et al. Progress in prevention of mother-to-child transmission of HIV in New York State: 1988-2008. *J Public Health Manag Pract.* Nov-Dec;16(6):481-491.
56. New York State Comprehensive Newborn Screening Program. *State of New York Department of Health.* 2001.
57. Alverson BK, Alexander N. Routine newborn HIV testing: an idea whose time has come. *Pediatrics.* Feb 2009;123(2):e362-363; author reply e363.
58. Psaros C, Geller PA, Aaron E. The importance of identifying and treating depression in HIV infected, pregnant women: a review. *J Psychosom Obstet Gynaecol.* Dec 2009;30(4):275-281.

59. Whetten K, Reif S, Whetten R, Murphy-McMillan LK. Trauma, mental health, distrust, and stigma among HIV-positive persons: implications for effective care. *Psychosom Med.* Jun 2008;70(5):531-538.