The Emotional Experiences of People with HIV/AIDS in Relationship to Pregnancy

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Abstract

As the HIV/AIDS infection epidemic continues to increase the ranks of those afflicted with the chronic disease, and as the disease becomes manageable, the life choices faced by those who test positive now reach into areas that had not been considered previously. Just a decade ago, the idea of someone who is, or is in an HIV+ relationship, could never have imagined a prolonged life, let alone considered having a child with once receiving the diagnosis. Despite this being a possibility, and occurring even without planning, the understanding of the special challenges and emotional experiences these individuals and couples face are increasing, while the gap in awareness seems to be widening. This study underscores the widening gap by illustrating the individual experiences the patients in a specific population face, from a socio-economic and cultural standpoint, in the view of pregnancy, HIV, and the combination of the two.

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Introduction to the Problem

Statement of the Problem

Magic Johnson, the poster child of Human Immunodeficiency Virus (HIV), a person who has successively adapted to living with the virus is a demonstration of the possible (Bailey, 2011). While acknowledging Magic Johnson's successes it is also just as equally important to acknowledge the estimated 2.1 million people in the United States who are also living with HIV (Center for Disease Control and Prevention, (2012), (CDC), many of whom do not have the access to level of care and/or support that Magic Johnson has received. It also should be noted that out of those 2.1 million people in the United States living with HIV it is estimated one-third of those people are of childbearing age (CDC, 2012).

Despite the advances made in treatment of HIV and the extraordinary effort of those who are advocating for people living with it, HIV still carries the stigmas, myths, ignorance, and fears that continue to enable the oppression of those living with it. Nearing twenty years since its debut, the movie *Philadelphia* (Nyswaner, 1993) gave us an image of what someone living with HIV looks like, the weakened, thin, visibly sick person who is debilitated by his condition and shunned by his peers. This image of HIV was powerful and remains today.

In a recent article by Dawn Bridge, (2011), discussed how this image of HIV extends to all people, including those who are struggling with life's other decisions, particularly that of starting a family. Families face additional backlashes when as HIV+ individuals consider bearing children. The issues and stressors of how and if the unborn child will be affected by HIV+ parent(s) starts with them, and continues to the support networks. "The stigma is also alive and well. This is not only imposed stigma, but also perceived stigma" (p. 4). This Study explores the very concerns and issues that HIV+ individuals face in this circumstance, what are the emotional barriers they face with when wanting to bear children?

It is further important to understand that HIV+ women are less likely to expose their + status, and their pregnancy as an HIV+ mother, due to further stigmas of disclosure. This can add constraints and damage relationships of those in their support network, by being inappropriately labeled an irresponsible behavior, putting herself and the child at risk, and adding undue hardship on the caregivers. The responsibility of the Social Worker then includes the need to be sensitive and understanding not only with the clients, but to also work with them to develop plans and methods to disclose their status as HIV+, pregnant, or both, to their support networks in a manner that reduces the stressors as much as possible. It also requires that the Social Worker provide guidance and resources for coordinated support not only for the emotional and psychological needs, but also the coordination and support needs that result.

Background of the Problem

According to Avert (2011), Acquired Immune Deficiency Syndrome (AIDS) is what led to the discovery of HIV. It was in the early 1980s when a noticeable increase of people dying of AIDS increased the CDC's urgency to find answers of this looming epidemic. At the time the general public thought of AIDS as a disease that affected an undesirable and already stigmatized population of gay men and intravenous drug users. This identification between AIDS and gay men and intravenous drug users caused a sense of invulnerability to those other than them. It wasn't until the mid 1980s that the general public's attitude changed as the general awareness of the disease, most notably with the death of Rock Hudson and other prominent people being identified as having AIDS. As the public's sense of invulnerability withered the public outcry increased enough to influence the government officials at the time to implement policies and allocate monies to address this AIDS epidemic. Not long after, it was discovered that HIV was the virus that caused AIDS and the road to find a cure started to be laid. In the late 1980s the world was introduced to a young boy, Ryan White, who was infected with HIV through a blood transfusion. This little boy, who died in 1990, showed people a different face, an "innocent" face for HIV and AIDS.

Shortly after Ryan White died, Magic Johnson announced publicly that he was HIV+. Now the disease was no longer just something gay men, drug addicts and hemophiliacs got. This now was a disease that everyone could be susceptible to. This is when public funding and charity involvement grew to new levels, with programs for needle exchanges, safe sex education, and the incorporation of the risk of HIV and other STDs into sex education discussions and teachings. Despite the vulnerability of all groups of people, despite the continued awareness and education of the different ways to contract the disease, despite the outpouring of support and programs, the stigma remains. The current UN Secretary-General Ban Ki Moon (2008) wrote an Op-Ed article in the *Washington Times* titled *Ban Ki Moon: The Stigma Factor* within which he states, "Stigma remains the single most important barrier to public action…because people fear the social disgrace of speaking about it or taking easily available precautions." The false axiom that HIV is a punishment for personal irresponsibility, faulty morals and engagement in high-risk behaviors result in those with the disease continued to be looked down on and viewed as dirty.

After almost thirty years, advances in medicines and behavioral changes have dramatically improved the care of those who have tested positive for the HIV virus. Public education campaigns have introduced generations to the idea of safe sex and increased use of condoms. The casual spreading of the disease has been curtailed, although not eliminated. While the numbers of exposures continue to rise, they are not rising exponentially according to the increase in sexually active individuals. "From 2008 through 2011, in the United States and 6 dependent areas, the number of diagnoses of HIV infection among adult and adolescent females decreased; the number among males remained stable." (Centers for Disease Control and Prevention, 2012, p.2)

While the decrease in infection of females is significant, it is important to also note that additional advances in the treatment of those with the disease have now made it possible for these women who are HIV+, or with partners who are HIV+ to consider bearing children, without necessarily transmitting the disease to their partner or their child. Through the use of several different options, including home insemination, assisted reproduction, egg donation, and sperm washing, combined with the medications available now to manage the chronic disease, bearing children as a part of an HIV+ couple is not only a possibility, it is becoming more readily available. Still, the stigmas of acceptance of HIV and HIV parents remain an obstacle in a social and emotional well-being.

Theoretical Framework of the Problem

Understanding the interconnected challenges and emotional barriers for the HIV+ person begins with understanding the scope of their ecosystem to address the factors that are affecting the person and his or her extended social network.

Life is complicated. Living with HIV makes life more complicated. Living life with HIV and creating life is even more complicated. Add to that the stigma that accompanies HIV and it brings the stressors and complexities of life to a whole new level. HIV and its stigma does not just affect the HIV+ person, it affects the entire family, extended family, friends, and community. There are ethical issues, legal issues, issues of confidentiality, and more, and when looked at from the outside, seeing the multi-pronged influences, one can see the scope of an emotional rollercoaster that can easily derail.

An uncomplicated pregnancy is a complex process that involves a number of support personnel, economic factors, and medical professionals and provisions all functioning simultaneously to enhance chances of a successful pregnancy and experience. The emotional support for those facing pregnancy are vast, and varied depending on the family's situation and underlying factors affecting health and pregnancy overall. When one with HIV faces the idea of pregnancy, those emotional factors are exponentially increased. The best way to understand these factors is to view it through the ecosystem perspective (Poulin, 2010) as the individual faces this decision as they relate to themselves and their extended support networks. To research from the outside, reviewing studies and available resources would not incorporate the emotional stressors addressed in reality, rather would only then view it through a theoretical lens of what should happen. Addressing this directly with those who have faced this situation themselves will offer a view of what actually happens, what is real, how the challenges are addressed, and the outcomes.

Significance of Problem for Social Work Practice/Policy

People who are HIV+ and considering bearing children are faced with significant emotional and psychological challenges that are exacerbated by the social stigmas(Vazquez, 2012). Often their extended support networks, family, friends and peers, contribute to the stress and negative accusations resulting in even deeper stigmas and stressors(Periera & Canavarro, 2009). This is why it is important that Social Workers are able to provide and support these individuals in these vulnerable situations, in line with the SW Code of Ethics as well as to have an understanding and awareness of the barriers these people are facing.

Some of these barriers are obvious, the medical and economic challenges, but others are still deeper, the potential ongoing economic impacts, the psychological and emotional fears of the implications and possibilities of risking their families further, and the existing social and cultural stigmas. It is important that those consumers are provided with all the information they need to make their decisions and support their decisions once made. This includes providing the needed coordination for all the interrelated services and support throughout the process (Kanniappan, Jeyapaul, & Kalyawala, 2008).

Review of the Literature

There are a significant amount studies about HIV+ pregnancies however, few studies target the individual's emotional well being (Barnes & Murphy, 2009; Hult, Maurer, & Moskowitz, 2009) and decision-making process of those who find themselves pregnant, who to want to become pregnant, and/or who want to impregnate their partner. (Kirshenbaum, 2004; Kanniappan, Jeyapaul, & Kalyawala, 2008). The literature suggests that there is need for further reseach with HIV+ people wanting to bear children to better understand how to support and understand their emotional well being.

Characteristics of HIV/AIDS Persons Who Want to Bear Children

HIV/AIDS persons/couples' desires are similar to the larger population of childbearing age (Kirshenbaum, 2004). They live relatively similar lives of those with a chronic disease and manage health care as part of their daily lives. When it comes to family planning, they are also very similar. They practice safe sex and forms of birth control and consider family planning. They do, however, face additional concerns and considerations when planning for the future with children, given the nature of the disease (Anderson & Cu-Uvin, 2009; The Body: The Complete HIV/AIDS Resource , 2008). HIV/AIDS couples are also similar to all couples who may find themselves pregnant without having planned for it. Individuals and couples, potential parents, facing pregnancy with this chronic disease include a variety of situations, those where both parents are HIV+ (Seroconcordant), where there is only one parent is HIV+ (Serodiscordant), and within that group, the subset of the father or mother being the HIV+ individual. The concerns go to the care of the parents, the care of the unborn child, the future of the family, the reactions of society, and the support of their close network of family and friends. All of these situations are considerations that pregnant couples with or without chronic diseases face, but the added health concerns and social stigmas and discussions surrounding HIV/AIDS play a very pronounced role when it comes to pregnancy and family planning (Kanniappan, Jeyapaul, & Kalyawala, 2008).

Managing Physical Concerns about HIV/AIDS Pregnancy

Transmission.

The concern of the transmission of HIV/AIDS to the child during pregnancy is one of the most significant concerns facing an HIV+ couple when deciding to begin a family (Periera & Canavarro, 2009). While overall the transmission rate of infection to a child is less than 2% (Squires, et al., 2011, p 279) it represents one of the biggest concerns for the parents and the societal prejudices that they will face by their decision. This concern is raised whether or not this is a planned pregnancy, and one that each couple faces.

The available support and educational material for safer conception for HIV+ people wanting to bear children is reviewed in an article written by Mantell, Smit & Stein (2009). Their findings expose gaps in the sexual and reproductive health of HIV+ people. Their study suggests that the predominant ideology for policymakers and providers of services to HIV+ people are to prevent transmission, be it between mother-child and sexual partners. The article makes the argument that policymakers and service provides should take a proactive role in support of parenthood and safer conception methods that reduce transmission, instead of preventing pregnancies (Mantell, 2009).

While there are safe ways of preventing HIV transmission while trying to conceive a child, the barriers HIV+ couples/partners continue to face remain entrenched as societal norms. Finocchario-Kessler, et al., (2010) mentions in their study that 40% of HIV+ women surveyed reported they wanted to have children. Out of the 40% surveyed, 23% reported that they did not have any discussion with their healthcare provider about safe conception or childbearing planning. The authors point to stigma as being one of the reasons why HIV+ individuals experience the “fear of disapproval”(p 233) of their provider. This results in the reinforcement of the individuals’ resistance to disclose and discuss their desires to bear a child.

Fertilization.

Getting pregnant is a challenge for couples in general, and in circumstances where the couple is HIV+ there are further complications. There is the fear of cross transmission among the couple. Even if both are HIV+ they can infect the other with a different strain and therefore require a change or decrease in the effects of their own treatment. Stress can reduce optimal chances for ovulation and viability of the egg or embryo, and the use of fertility treatments and medications could interfere with the standard regimen of medications that an HIV+ mother is taking for her own health (The Body: The Complete HIV/AIDS Resource, 2008)

There are methods by which a couple with an HIV+ father can go through processes such as sperm washing or by using donor sperm, and then in-vitro fertilization to reduce the risk of infection of both the mother and child. Similarly in-vitro fertilization can also be used to protect the father from exposure when the mother is HIV+ (The Body: The Complete HIV/AIDS Resource, 2011).

Status Awareness.

There is also the issue of the timing of the pregnancy and the awareness of HIV status. Couples who are aware of their HIV+ status face the series of considerations when planning a family, but it is also possible that they have an unplanned pregnancy. At this stage, even though unplanned, ideally the couple is already undergoing antiretroviral treatments for their own disease management course, but do face the added monitoring and perhaps testing based on their status, such as cross infection of different strands, or monitoring for infection in the mother if only the father had been previously infected.

HIV tests are part of the variety of tests that are common, although not legally required, in pregnancy, so it is understandable that newly pregnant females may discover for the first time that they are, in fact, HIV+ early in their pregnancy (Webber, et al., 2008). This could also lead to a situation where the woman learns she is positive, assumes that the father is positive, but then after testing learns he is not. HIV testing and outcomes are not always immediate, and therefore preventative treatment in instances of possible exposure e.g., a pregnancy by an infected father to a non-infected mother could change that course of normal precautionary treatments due to the presence of an embryo (Kemper, 2008).

Clearly this situation adds to further stress in both the relationship and the effects on the pregnancy, and the decisions that are faced in the early stages of pregnancy. If the pregnancy is unplanned, and the HIV+ status is revealed in the early stages, the couple is faced with a short time period to process and address the news, and make decisions regarding the continuing of the pregnancy, the relationship itself, due to confusion over positive status and transmission and of course the health of the mother and the effects on the embryo with the initiation of antiretroviral medications in the early term of the pregnancy (Kanniappan, Jeyapaul, & Kalyawala, 2008; Squires, et al., 2011; Periera & Canavarro, 2009).

Physical & Biological Concerns of the Actual Pregnancy

The biological impact of a pregnancy on the body is significant on its own. Adding in the need to medically manage a chronic disease, complete with the ensuing symptoms and side effects of the care, to those of the symptoms and needs of pregnancy further strains the limits of the body's response to the changes it is undergoing. As the literature addresses, the concerns and issues they face include not only the considerations and understanding of the possibility transmission of the disease to the child during pregnancy, they also must address the impact of the medications they take on the developing fetus (AIDSinfo, 2012). As one article pointed out, the medication used to manage HIV can cause reactions in the individual, and then further interactions with any symptoms or medications used during pregnancy (Anderson & Cu-Uvin, 2009).

Managing Emotional Concerns about HIV/AIDS Pregnancy

Individuals & Couples

Individually and as a couple, parents face questions, concerns, fears and excitement over having a child in any circumstances. It is a time of extreme emotions regardless of health, socioeconomic, or emotional status of the couple. The addition of an HIV+/AIDS status into this mix compounds concerns and challenges to the individual parents and the couple unit, resulting in addressing the same concerns repeatedly, as individuals, couples, and then with society and support networks. Clearly the concerns over transmission are worrisome, and despite the low incidence rate 2% for vertical transmission, it will remain a concern and a question in any parent's mind. In addition to this is the cross transmission of the partners. Except in instances where in-vitro or intra-vaginal insemination was incorporated, there will be concerns over the transmission of the disease to the partner. Even if both are infected, the possibility of cross infecting of the strains of HIV can cause a change in the disease state and effectiveness of the current medication regimens (AIDSinfo, 2012).

Any pregnant woman faces life changes in healthy habits, from eating to exercise to managing morning sickness and other side effects of pregnancy. The pregnant HIV+ mother will need to address how to manage her own care, without compromising her health or treatment regimen, with the added stressors and symptoms the pregnancy itself will bring. According to Periera and Canavarro, (2009) there is a signifancant difference between the general population perceived stress levels and those of HIV+ women. One of the measures used in their study the *Brief Symptom Inventory* (BSI) demonstrated that HIV+ women experience higher "emotional fear, anxiety and anger"(Periera & Canavarro, 2009, p 305). If the mother is, or is possibly, HIV+ she is faced with the concerns over the effects of her own medications on the child, as well as any preventative measures to further reduce the risk of transmission to the child increasing emotional stress (Squires, et al., 2011).

As with the normal concerns of any parent, the concerns over what they are passing on to their child, and will they be able to be there for their child, and even if they will be able to financially support the child, are always at the forefront (Squires, et al., 2011). When the burdens of HIV+ status are included, the additional financial implications of the costs of medications and lifetime care, on top of the fear of passing on this burden through transmission can become overwhelming. The future planning for the care of the child is also extreme, as despite HIV+ no longer being a death sentence, in the fear of the moment the possibility of the child being orphaned by one or more parent due to the disease is strong. There is a potentially life-threatening disease at play, and that is a valid concern and consideration for the long term care of a child they may not be around to support, or to raise and watch grow into a strong, successful adult. In the study by Kanniappan, Jeyapaul, & Kalyawala, (2008), they determine these factors as being important in the decision making process of childbearing. Even the happiest parts of pregnancy and family rearing are tinged with fear, guilt and sadness (Barnes & Murphy, 2009).

The additional fears and concerns then begin, as the couple faces the fears and concerns over their exposure to the larger societal groups, including extended family members, medical professionals, friends and support networks, and the community at large. They have already been aware of the stigmas and stereotypes of HIV/AIDS, but now will face them again, with the added stigmas of the pregnancy.

Personal Support Network

Sharing the news of a pregnancy among their extended family and social support networks is a challenge to many couples regardless of their HIV+ status. Depending upon the nature and level of support they get through their networks, both financial and emotional, the revelation of a pregnancy can positively or negatively impact the relationships (Smith, Rossetto, & Peterson, 2008). In the instance where a couple is HIV+ this revelation and support is heightened, as the very concerns the couple faced themselves, the fears, concerns, guilt, will be highlighted once again, causing them to face the same issues. The response and reactions will of course depend on whether the networks such as friends, family and their social circle were previously aware and supportive of the status or not. Regardless, the needs for support for the HIV+ pregnant couple will increase (Smith, Rossetto, & Peterson, 2008). The couple will undoubtedly face societal backlash over the perception of their decision to put a child at risk, both from their community at large and their closer network, and be put on the defensive over their choices and decisions. According to Smith, Rossetto, and Peterson. (2008), "one-in-five adults in the U.S. still fears people living with HIV"(p. 1267), which gives credence to higher levels of stress levels experienced in HIV+ women reported in the study (Periera and Canavarro ,2009).

The otherwise joyful news and excitement will be tempered either publicly or privately by the stigmas of HIV infection: the responsibility of a high-risk pregnancy, questions over their own mortality and their moral convictions of bringing a child into a life of uncertainty, and the possibility of risking the life of a child (Squires, et al., 2011). While these are not specific to HIV+ pregnancies, the inherent nature of blame and accusations of irresponsibility will be heightened in the feedback the couple at least initially receives. The main issue, however, is that the couple does need support, both for their own managed disease state and the health of their child, but also to navigate and manage the very real concerns over the impact of their status of the future care and support of their child (Prackakul, Grant, Pryor, Keltner, & Raper, 2009).

Professional Support

All pregnant couples need pre-natal support during pregnancy. One of the biggest challenges in vulnerable populations is bringing mothers into the medical environment early in their pregnancies to ensure healthy behaviors and treatment. As the prevalence of HIV+ status is increased in these populations, this presents a different approach to the challenge. Due to the perception of discrimination “internalized negative views of the dominant culture,” (Wingood, et al., 2007, p. 109) African American women, and those in lower socioeconomic classes are less likely to self-report or seek testing to determine their HIV status. This could further prevent the access to pre-natal care for this population. In contrast, women in upper socioeconomic classes may be more likely to report their HIV+, and therefore are likely to already be under the care of a medical practitioner at the time of her awareness of pregnancy or her decision to become pregnant. It is important to consider that even women already under medical care may feel the discrimination and lower self-esteem, increased guilt and stressors and may not be willing to discuss the pregnancy early on. This is a challenge to the medical professionals to recognize that all women of child-bearing age should be approached to discuss their family planning interests and concerns, to begin the dialogue, especially those at risk or in care for HIV (Finocchario-Kessler, et al., 2010).

The challenge arises in the medical and social support systems understanding the special needs and risks associated with the HIV+ couple so that appropriate and proper support and services can be identified for their unique situations, and working to overcome the stigmas and biases in offering care and services. According to research done by Freid and Kelly (2011), women who were HIV+ and pregnant, or interested in becoming pregnant, noted a gap in education or support from their medical providers, and also experienced biases from their providers. Some of these included recommending against pregnancy, a lack of or withholding of information about ways to reduce vertical transmission, or even the suggestion of abortion when a pregnancy is announced. In an article written by Douglas (2009), the author noted, "Although HIV-seropositive patients cannot be discriminated against under the law and are protected by the Americans with Disability Act … caregivers often claim conscientious objector status and refer patients to programmes that accept and treat" (p. 262).

As previously noted, there is a strong desire to have a family among HIV+ couples, 40% of the sample reported this desire, but 23% noted they did not discuss this with their HIV/AIDS medical provider (Finocchario-Kessler, et al., 2010). HIV medical providers should be aware of this trend and begin the discussion of the topic and offer services or referrals for fertility and reproductive counseling for all patients of child be (Douglas, 2009).

Falling under the medical discussion is also the need for special pre-natal care that involves the entire care team, noting the special considerations for HIV+ treatment and transmission prevention practices, coordinating with standard pre-natal care needs.

Along with the medical needs, the emotional support needs of the individuals and couples who are HIV+ are significant as well. These correlate directly with all the previously noted needs for emotional and medical support, and the coordination of their care. Social workers, however, have a unique position of being able to communicate with their clients in a different manner, to also raise the question of family planning, pregnancy, and the need for coordination of care overall. The social workers should be aware of the increased stigmas and discrimination, from both the general and the medical community, that the pregnant HIV+ couple faces and the emotional stressors this causes (Wheeler, 2011).

Limitations in Current Literature

Aside from the consistently small sample sizes of the studies and surveys in the literature, the focus of the populations has been mainly on specific HIV/AIDS populations. Since the largest and fastest growing population of HIV/AIDS populations includes females in lower socioeconomic demographics (Centers for Disease Control and Prevention, 2012), the literature focuses heavily on the specific needs and vulnerabilities of these populations. While there is some mention of general populations, middle and upper-middle class couples considering family planning alongside HIV/AIDS diagnoses, the population is not well studied and not well understood specifically to additional needs or stigmas they may face. It is understood that many of the same considerations are faced, with the added benefit of additional support through medical providers, but this could merely be an assumption.

The studies and literature are heavily focused on the females and therefore the input, influence and concerns of the fathers as individuals are not addressed. They are included as part of the couple, and mentioned during the conception phase regarding transmission of disease, but there is little or no discussion regarding of the influence or concerns of the father in the decision of family planning. This may be consistent with the subject of family planning overall.

The limitations are also reflected in the self-disclosure nature of the research, with limited review or discussion with health care providers. One study for example (Finocchario-Kessler, et al., 2010) only surveyed representative female patients and the results were based on their own impressions and biases. The lack of review of medical practitioners and social workers for the studies therefore provides little insight into the standard practices and trends in addressing the topic of family planning and reproduction options of HIV+ couples.

The literature also exclusively addresses the topic from the perspective of the HIV+ individuals and couples, with no input or discussion with the extended family, friends and societal support networks. In addition, the stigmas and discriminations noted in the studies are presumed based on prevailing knowledge and external studies of HIV/AIDS perceptions overall, and do not specifically address the viewpoints of the extended society as it views family planning in HIV/AIDS couples. Similarly there is no discussion of increasing educational initiatives for the population at large, to provide current, updated information on living with HIV/AIDS and family planning within that community. The nature of the studies still address HIV/AIDS as its own category of chronic disease.

Questions that Remain Unanswered in Current Literature

As the limitation of the literature underscores, the topic of family planning and reproductive options for those individuals and couples living with HIV/AIDS does not appear to be a well addressed or discussed topic with the couples. While there is a great deal of available information and options on the topics, the communication of this information to the larger medical community and to the families themselves does appear to be limited. The lack of understanding and awareness of this topic can lead to a lack of discussion, further increasing the emotional barriers and sense of guilt and shame that these couples may face when considering bearing a family. The scope of this influence and how it affects the behavior and decision-making process of the individual and/or couple is not well understood or known.

There are also significant questions within the medical community regarding the effects on the pregnancy of an infected father but negative mother and possible exposure of the mother in addition to the pregnancy. While there are options for both preliminary precautionary treatment and transmission prevention treatments, there is no discussion of the affects of the treatment options on the fetus beyond the realm of possibilities. With the focus being on the prevention of transmission, the couple is left to weigh the additional health risks the treatments could pose to the mother or the fetus, or both.

In general the current literature lacks depth into the understanding of the impact of HIV's stigma and the overarching effects of the biases throughout the professional and social networks of the couple when it comes to emotional, spiritual and interpersonal relationships HIV+ individuals and couples encounter. While trying to answer the question of the emotional barriers facing HIV+ people when wanting to bear children, my investigation should be able to add additional first person accounts to the existing available data.

Methodology

This purpose of this research study is to explore and gain familiarity with the emotional experiences of HIV+ people in relationship to pregnancy through the telling of their personal stories about their relationships with self, partner, family, healthcare providers, community members and institutions that contribute to their emotional experience. It was imperative that the study be qualitative in nature using standardize open-ended questions to build a rapport with the participants through supportive conversations to obtain meaningful results. This will allow the reader to acquire greater insight in to needs of HIV+ persons who desire to bear children.

Research Design

While there is some understanding, both from formal studies and informal surveys, about the considerations and obstacles faced by HIV+ couples contemplating childbirth, the body of knowledge was limited. It focused mainly on the female perspective, and offered limited scope in the questions, based on single situational experiences, such as discussions with care providers, or facing objections from support groups. This research study was designed to be a qualitative study. A qualitative study "…emphasizes depth of understanding and the deeper meaning of human experience, and the aim to generate theoretically richer, albeit more tentative, observation" (Rubin & Babbie, 2011, p. 627). Using a qualitative approach in this instance further encouraged both parties in the couple to express their overall experience and reactions to it, and therefore gave a personal voice to the findings by using an exploratory qualitative design.

By conducting in-depth discussions with individuals and couples, the study was more of a discussion opportunity to not only answer the specific questions, but also to encourage the interviewees the opportunity to tell their own stories, their own concerns, and how they dealt with information, education, and obstacles. The interviews were conducted at central location, Action AIDS's west office, to allow for easy access as well as privacy. An important concern about the location was to allow for the opportunity to not be interrupted, which often happens in the home and when other distractions abound e.g., children, neighbors, family members, etc.

Definition of Terms

There are a number of terms that need to be defined which appear in the literature and findings. The term serodiscordant refers to couples in which one partner is HIV+ and the other is HIV-, also known as mixed or magnetic couples (The Body: The Complete HIV/AIDS Resource, 2011). When both partners are HIV+ they are referred to as seroconcordant couples (The Body: The Complete HIV/AIDS Resource, 2011).

For serodiscordant and seroconcordant couples there are a number of methods of insemination that also need to be defined. When referencing home insemination, this involves the man HIV- ejaculating into a cup then using a syringe to draw up the sperm and then insert and inject into HIV+ woman's vagina (The Well Project, 2011). Sperm washing is a process that separates the sperm from the seminal fluid, which lowers the risk of transmission (The Well Project, 2011). The term timed natural conception refers to the couples who decide to procreate after being on anti-retroviral therapy for a period of time and their viral load becomes undetectable and the female is ovulating (Loutfy, Margolese, Money, Gysler, Hamilton, & Yudin, 2012).

One other term that is important to define is emotional barrier, in that they have the capacity to diminish a person ability to function. Emotional barriers consist of subjective feelings that include physiological symptoms such as increased respiration and blood pressure, muscle tensing and restlessness to name a few and influence behavior. (Murphy, Marelich, Armistead, Herbeck, & Payne. 2010).

Sampling and Recruitment

Recruitment of participants occurred in a community-based organizations that provides medical and/or social services for HIV+ couples in southeast Pennsylvania. HIV+ couples who volunteered to participate in the study were required to be either serodiscordant or seroconcordant. They were also required to meet at least one of several stages as it related to child-bearing: be in the planning stage; be in the pregnancy stage; or being within two months post delivery. When participants were recruited the interviewer scheduled appointments and reserved a private location to conduct the interview. Nine participants were interviewed in total, three couples, and three individual females. The sampling methods used included purposive sampling, convenience sampling, and snowball sampling (Rubin & Babbie, 2011). Given the logistical limitations of this study these methods of sampling allowed the researcher to come into contact with the population that best met the criteria for this study. Each participant was compensated with $75 for participation.

Data Analysis

The process of gathering the data involved interviewing the participants through open-ended guided questions that allowed them to engage in more of a conversation and encouraged them expand on their own interpretations of what the questions evoked in them. The questions covered a progressive range, beginning with questions surrounding their initial thoughts on pregnancy given the HIV status of the couple, and moved further into the discussions of their support systems. This approach established early on their awareness of the options for HIV individuals as it relates to pregnancy, what risks and opportunities now exist after decades of research, and identified areas of gaps in educational and support programs. As the individuals became more comfortable and at ease, after answering the charged questions initially, they were more able to discuss those questions that dealt with their own specific situations, specifically the obstacles and support through their family and friends. This gradual process of questioning was deliberate, designed to gain both information and trust early on.

Using Grounded Theory Method to analyze the data allowed the researcher to compare and contrast the concepts that emerged from each data set. The data for this study came from the recorded interview sessions with participants based on the predetermined questions. This researcher first listened to the recordings then transcribed them verbatim. Then the researcher looked for the recurring ideas, themes or concepts and did an initial round of open coding, noting reactions and emotions. A second round of coding followed, focused on specifics and context through memoing (Rubin & Babbie, 2011), which then drew out the themes of the responses and emotions faced by the interviewees within the context of the study. This data enabled the researcher to form the analysis and draw conclusions from the study.

Validity and Reliability

According to Rubin & Babbie, (2011) there is no one set definition of validity in qualitative studies, however, validity can be determined if the interpretation of research findings is consistent, inclusive, compelling and meaningful. Having insight into the childbearing experiences of an HIV+ couple may be helpful not only to those who serve this population but also to give voice to those who participated in the study. Just as each person's experiences will be different, it can be concluded that the findings of this study are valid, as it brings to light common themes through their shared experiences.

The decision to bear a child and start a family is the most intensely personal and life affecting decision a couple can make. It is a private decision between two people who are choosing to dedicate their lives and their future to the raising of another human being. Inserting oneself into this process, for the purpose of an interview and study questions can be seen as adding an impersonal third party into this is a challenge, and required a near immediate sense of rapport and respect for the couple, their decision, a compassion for their specific struggles, which in turn engendered a level of trust and shared respect for the couple and the individuals. Reassuring the privacy of the identities due to the topic itself, and so the researcher was very careful, deliberate, and supportive, and required the continued confidentiality and anonymity of the individuals throughout the entire process be conveyed and reassured. Once this was addressed, the researcher posed the questions in an unbiased way to spur a discussion, so that the meeting became less of an interview and more of a conversation. This allowed the individuals and couples to paint a more honest, open, and spontaneous response to the overall process and their emotional responses to the decision points and challenges. It is important to note that despite the developed trust and open discussion, almost all of the participants mentioned at least one other time during the interview to be reassured of confidentiality, before going deeper into a response. According to Rubin and Babbie, (2011), mutual trustworthiness is a key ingredient to reliability.

Findings

The data collected during the interviews was much more than data, it was personal experiences, and to that end it was important that their voices had meaning. The stark data analysis would not apply in this situation and therefore their words, their thoughts, their discussions had to have meaning. Instead of data analysis points, there were themes in their struggles. The following is a representation of the voices of HIV+ people's emotions in relationship to pregnancy and support systems.

Participants Characteristics

In total there were two seroconcordant HIV+ couples, one serodiscordant couple and three individual HIV+ females who participated in the study. All participants were recruited from Action AIDS office in West Philadelphia where they receive HIV counseling and support. The median age of the participants is 27, the racial breakdown included four HIV+ black females, two HIV+ white females, one HIV- black male, one HIV+ white male and one HIV+ Hispanic male. All participants identified themselves as being heterosexual. The median years of known diagnosis is 4.5 years and median length of current relationship is 3.5 years. At time of the interviews there were two females who were currently pregnant, one pregnant serodiscordant couple, one female who gave birth to a child two months prior to interview, and two couples were actively pursuing conception. Only one participant was employed at time of the interview and all were dependent on their families and social services for their healthcare, shelter and food. The highest level of education attained by interviewees is high school.

Despite cultural and specific situational differences in the interviewees there was a consistency in the struggles that each of the individuals and couples faced. These themes emerged through the course of the interviews, stemming directly from some of the questions but also through the open discussions. The six themes that emerged include: 1) daily emotional distress, (2) emotional and physical abandonment (3) betrayal, (4) relationship commitment and support, (5) lack of education and awareness about HIV/AIDS, and (6) renewed purpose of living.

Daily Emotional Distress

The participants of this study identified and reported a number of daily emotions they experienced on a regular basis. The dominant universal emotion expressed by the participants was sadness. For example one participant found out she was not only pregnant but was also HIV+ at the same time. She was six months pregnant at the time. Her emotions were so profound that she though her life was over, evident by her saying,

> I was shocked; I was concerned; I thought that the father of my child was gonna leave me; I thought he wasn't going to love me no more; I actually thought he was going to kill me. I thought everything under the sun; I just thought my life came to an end, right there.

One of the male participants reported that he was taking anti-depressants to help cope with the daily stress of living while being HIV+ "Like me a lot of people who have HIV and AIDS are also on a lot of psychotropic medications because they can't deal with it without being medicated."

There were a number of other common emotions express by during the interviews including anger, shame, loneliness, feeling of powerlessness, a sense of being unlovable and worthlessness. One male participant reported that he becomes angry when he sees his friends enjoying their families.

> I get angry you know when I see, you know my friends, with their daughters and their sons and their kids and you know their families and that is all I ever wanted was a family and now that I am doing good, like, I just want a family.

Another source of emotional distress comes from the feeling that they are alone. Nearly every participant expressed the fear of exposure that they could not confide with their family members and friends. In one particular instance one female participant was feeling so alone that she could not even tell her child's father, her fiancé, that she was HIV+.

> I told you my God-mom called me last night and she was like, I told her I was pregnant because she didn't know I was pregnant and she was like, did you tell your partner that you have it, and I said no, and she said, girl, you know the um, people can come and get you and lock you up and this and that and he could kill you and I said I know. I know him, he's a little crazy so I'm just kind of worried and scared for my life because he is just throwed off.

Stress of pregnancy and family planning is significant, but adding the unique stress of being HIV+ and pregnant intensifies emotional distress. As these participants indicated, there are added stressors unique to their conditions that compound the daily concerns.

Emotional and physical abandonment

One influential and general theme was their experience and expression of emotional and physical abandonment. All felt abandoned by one or more of their support groups, such as their families, their partners, or their friends.

> My family members, when they first found when I had the baby, they called me at the hospital and I said, hello, they said hey [name], how you doing, I heard that you had such and such, I say yes, they say how have you been doing, you ok? I said, so far and ever since then they stopped calling so…like my brothers, they know, I don't really talk to them, like I don't really talk to my family at all.

Another participant couple talked about the fear of letting their daughters know. The father has a 23-year-old daughter, and the mother has a 12-year-old daughter who lives with them. Neither daughter is aware of the HIV+ status of their parents. They are concerned that the girls would reject them. This means that especially with regard to the 12-year-old, the couple has to hide medicine, lie about doctor's appointments and the parents are afraid of the repercussion of exposure. They are both concerned about how their daughters would be treated if others knew that their parents were HIV+, what others would say, assume, and then treat them differently because of this.

> Your mother has AIDS, she's a junkie, she got it from prostitution or picking up dirty needles out of the trash can and even though it wasn't, but I was a drug addict and that is the stigma that goes along with it and I feel like it is my burden. I don't want anyone to feel bad for me; I don't want my daughter to hate me.

Despite decades of awareness education regarding the spread of HIV and AIDS, the stigma of being positive remains not only for the individual, but for their entire family. For many it manifests in keeping quiet about their status, not seeking out the support they need.

For others it results in being ignored or distanced from their families, who themselves maintain the stigma of a "dirty disease".

Betrayal

Betrayal takes many forms, and in the desire to seek explanations, to go through the process of accepting the disease, which continues throughout the rest of their lives. In this process there were two individuals who stood out in how this manifested in their lives. Most felt betrayed in being infected, by someone who was not aware or concerned enough about their own health, lied about having been tested and being vigilant, or in one case, believed he had been deliberately infected.

> Excuse my language but my ex-girlfriend she was just like a low life, like I said, excuse my language, a scumbag fucking piece of shit and she did it to me on purpose and it's like she pretty much killed me you know?

One female expressed a sense of confusion and appeared to still be going through the acceptance process of having been diagnosed as HIV+. Here was someone who was always careful to be tested, yet still apparently did not practice safe sex. Yet her sense of betrayal is from another who infected her.

> This situation it's just…it broke me down a lot, it really did, it really did because at one point I thought I was invincible and this just proved to me that I wasn't and it hurt, it hurt that somebody wasn't alert about their own body. I know I get tested every

> month and it was crazy because every time I got tested it said negative, it said negative.

This is a common theme not only for this particular diagnosis, but also as a manner to explain negative occurrences. It is often easier, and even sometimes healthier, to blame others for your situation until you are ready to accept responsibility in a healthy way. But the sense of betrayal when deeply rooted during a pregnancy can lead to deeper fears and depression, and anger. Emotions run high during pregnancy, and every emotion is exaggerated. It is not unusual for these fears to become front and center during this time, and lead to irrational thinking or behaviors. This is underscored by the one woman who felt invincible because of continually testing negative before she was diagnosed. She now has that sense of invincibility back, and has stopped taking her medication.

Relationship commitment and support

When facing times of struggle and change, relationships face a turning point. They are either made stronger by it or the relationship becomes irretrievably broken. It is difficult to tell in the early stages of the changes, which way it will turn out. These relationships encompass both partnerships, such as spouses or life partners, or extended support relationships. In this group several couples spoke of their support for each other being strong, and noted that due to lack of family acceptance they have found outside assistance from other support networks.

> I have some family members that you know aren't really supportive of us having a child right now, but um, I think our support mainly comes from each other and like our case managers here at Action AIDS, they work very close with us if we want them

> to come to a like a doctor's appointment, they will come with us or take us, so we do have a little bit of support outside of…Yeah, because when we support each other it becomes hard sometimes.

If they did not have outside support networks they would tend to become each other's caregivers. This definitely can add strain to relationships and could result in neither getting the real support they need. It is important and beneficial that they found additional external groups and confidents that they can also turn to together and individually in time of need. This is further illustrated by another couple, which also reinforces that professional and like-minded groups allow them to find similarities and acceptance by others who are better equipped to understand the specific challenges, biases and obstacles they face.

> I would go to like support groups if I need to talk to someone, I have my caseworker, I have him, I have women in like the women's support groups. I just feel like if you don't know about it you won't know about it.

There was an interesting situation with a serodiscordant couple in which only the mother was HIV+. She had support from her family, but his family and friends were not aware of the situation. He had chosen not to tell others, which in the end leaves him without true individual support. He does, however, note that he finds support through her networks.

> Female: I have my family's support and it's a whole lot of family. That is pretty much it; just the family mainly and myself and my fiancé

> Male: I don't have nobody that I can actually talk to about cause she has and I don't. That is kind of hard. I don't want people discriminating against me or discriminating against her so I really don't have nobody but her family and the doctors to talk to about it.

This situation is difficult as he has not sought emotional care for his situation and has tended to rely on her more due to the stigma. He is aware that relying on her family is innately limited for him as an individual as he cannot be fully open about his concerns and long-term stressors.

Lack of education and awareness about HIV/AIDS

This population and the reactions to the disease, infection, and transmission of the disease to the child, demonstrated a significant lack of full awareness and understanding of the disease. Despite decades of education and research, they all considered the disease a death sentence, and when faced with the idea of pregnancy, several chose to have abortions previously rather than pass on the disease to the child.

> Well this would have been the second baby for HIV positive. The very first time when I found out I was HIV positive I was pregnant at the time and I had an abortion, but this one, it took me a couple years to actually sit up there and try to bear with having another child.

As previously noted, the stigma in the larger society played a significant role in their emotional stress and in the decisions to convey their status to family and friends. It is also clear that despite being involved in support groups through the Action AIDS, several of the participants still held on to misinformation regarding HIV and the transmission mechanisms and rates from mother to child. Even the treatment and care of the individual with the disease was misunderstood.

> I thought starches made it worse; I thought all types of things made it worse. I was making sure that I didn't want nobody else get it or anything. If I wasn't with his dad I wouldn't have sex, period. Not until they found a cure.

More than one participant indicated that they were not taking medication. One in particular acknowledged that she felt she was better, and noted that she was completely healthy and followed a regimen of a healthy diet and exercise. She never had symptoms of the disease and only had side effects of the medication. She had decided to stop taking the medication and instead continue on her previous approach, adding additional herbs to her diet to maintain her health.

Renewed purpose of living

At the core of all living beings is the desire for preservation, survival. This manifests itself in a preservation of self, then the preservation and transmission of DNA to continue the generations, and by extension, to preserve the larger self as within the community of like organisms. This boils down to living a healthy lifestyle, reproducing, and providing the foundation so that the next generation can continue the cycle. When faced with a life-threatening condition, perspectives change quickly. Each one of the couples and individuals expressed the sense of a death sentence upon learning the news of their HIV status. Additionally those who had not pre-planned the pregnancy immediately faced the fear of passing on a death sentence to their child. When those who chose to continue the pregnancy reached the decision, they also faced the third dilemma, that they may not be there to provide the necessary foundation for their child, or that they would be contributing to the spread of the disease in their community.

As another saying goes, a baby changes everything. Despite the fear, despite the depression, despite the concerns, all noted that they found a new purpose in caring not only for the child, but also for themselves.

> I do, but at times I don't; at times I just want to give up, I really do. I want to give up because there is no point of me being there, and then when I look down and I look at him, he's like, hey I didn't even start living yet, you should be here for when I graduate. That is the only thing that keeps me taking my medicine, really, to think I have a child because if I didn't I wouldn't be here. I really would commit suicide because to me somebody already did it for me.

Along the same lines the interviewees tended to blame themselves, even when blaming others for their disease. They were down on themselves and acknowledged that their opportunities were further limited by their condition. In a word they were deflated. As they became parents, however, their focus, as it tends to do when a child is born, changes from self to child. They have learned to care for their child they need to care for themselves. However, for the first two years the parents are left in a type of limbo as their babies go through testing to determine if they have been exposed to the virus. Instead of fearing for their own condition, they fear for that of their child.

> My heart is in my throat. Every time I go to the doctor's office and they tell me, oh he's negative, I'm like thank God. My heart is in my throat, I start crying. The first time they said it I burst in to tears. I really don't want to mess his life up. I have to be strong for both of us.

As these individuals learn to become parents, they learn self-confidence and purpose. They learn responsibility and a desire to do better for their child. Three of the interviewees have children who were born when one or both of the parents were HIV+. To date none of the children have tested positive. Through that they are beginning to reach an understanding of the disease and the complexities of how it manifests. Those who are still pregnant or newly parents still have to face this regular testing and the fears associated with it.

Discussion

This in-depth analysis sought to gain insight into the emotional experiences of HIV+ people in relationship to the planned and or unplanned pregnancy. While each participant tended to focus a majority of their discussion on their negative experiences, emotions and struggles, there were times during the interviews that the participants were able to demonstrate resiliency. The findings of this qualitative study not only support the need to understand the emotional needs of this specific population; it also exposes how prevalent the fear of stigmatization, ostracization and discriminated against seemed to greatly influenced their emotions. The findings also seem to be consistent with the ecological perceptive which acknowledges the importance of the social environment as it involves the "conditions, circumstances, and human interactions that encompass human beings" (Kirst-Ashman, 2008, p.22) giving insight into their life's experiences. The people that participated in this study also seemed to direct their focus towards the fear of transmission, stigma for their children, and fear of exposure of being HIV+. Only one participant identified ambivalence as source of constant distress. Another noteworthy observation was the lack of family support. While some participants were able to rely on family for support, it was limited to one or two family members. The participants all came from lower social economic status, presented that their HIV status was seen as an unwarranted and unworthy burden to for their family to bear, as they were already struggling to shelter and feed their household yet alone provide addition care and cost the accompany HIV healthcare, and now a new child who's health status will remain unanswered for up to two years.

This research study provides a window into learning about the emotions experiences of HIV+ people in relationship to pregnancy, but it also provides a window into understanding the ongoing stigmatization that at least this group faces being HIV+. The overwhelming concerns and stressors they held prior to becoming pregnant revolved nearly entirely around how others would react. Those fears and concerns multiplied as they then faced these same situations with the added stigma of being pregnant. Cultural sensitivities and understanding of the disease is still greatly lacking, and feeds the fears of young couples facing this challenge.

Implications for Social Workers

Fear was the underlying stressor of all participants in this research. While there is a certain degree of fear for any new parents or pregnant individuals, it is usually balanced by the sense of wonder and if not immediate, eventual joy of becoming a parent and bringing a life into this world. Even if the end decision is not to keep the child, one who chooses to maintain the pregnancy to it's end does get the sense that they are contributing something wonderful to the world. Individuals or couples who are HIV+ do not appear to have the time or bandwidth to relish in this joy as they are nearly constantly consumed with one fear or another. This is of critical importance to the social worker to understand. This fear has health implications first and foremost, and can jeopardize the individual's health and that of the child. It can add undue stress to the relationship of the parents, and to the extended support groups. Typically the main concern and focus for pregnant couples is to ensure proper pre-natal care, however with this group continued self care is critical. With such prevalence of lack of support systems the interviewees expressed it became clear that the social worker must stand in to provide additional support resources to the couple.

Understanding that the cultural, environmental and socio-economic lifestyles have unique challenges in acceptance of pregnancy and HIV status, stemming from a widespread lack of, or perhaps refusal of, educational awareness programs, lead to incomprehensible barriers and obstacles to what should otherwise be accessible resources, requires the social worker to be sensitive to these, and guide the participants to assistance rather than provide them with the information about the resources available. This is important because merely providing a list of resources to this group further risks them being exposed, therefore they are less likely to even keep any record of resources provided. Without accepting that they must remain in a type of hiding of their condition, it should be understood that for their own individual reasons they feel this need to; to protect themselves and their child. Being sensitive to the situation they are facing will allow for a better relationship with the client, and a better outcome for the pregnancy and the individual's ability to care for and provide for themselves and their children.

Another area of concern is the ongoing care and support resources for the couples, both as a unit and individually. Being pregnant does not lessen the need they have for themselves to have a support network in dealing with their health status, and being a parent with this underscores their need for professional and peer support groups that will allow them to identify with others, feeling less alone and ostracized, and enable them to grow personally. Knowing the ongoing fears of medical testing that their children will be going through for up to two years before, ideally, receiving a clean bill of health is traumatizing and emotionally exhausting for the parents; for parents who are already stressed about their own condition, and also stressed by the very nature of being new parents.

Limitations and Suggestions for Further Research

Given the small number of participants, by the nature of the numbers it is a limited study. In addition, all participants were based on convenience sampling, and all came from the same originating organization, which served a single socio-economic population. There was further limited cultural representation. In addition, the lack of experience of the researcher also contributed to potential missed cues for further discussion and deeper analysis during the sessions themselves. Overall the single most consistent issue was the lack of understanding and awareness of the chronic disease. From the individual participants to their descriptions of the cultural and societal implications, from the fears they held of their friends and family finding out, to the fears of backlash from their own partners, it was obvious that the lack of education directly manifested itself in fear. It is perhaps this very fear which further limited the pool of participants in this study, as few were willing to come forward, and even those that did were hesitant and required assurance of anonymity, and financial compensation for their effort.

References

AIDSinfo. (2012). Anti-HIV Medications for Use in Pregnancy. Retrieved October 25, 2012 from HIV and Pregnancy – Anti-HIV Medications for Use in Pregnancy: http://aidsinfo.nih.gov/contentfiles/DrugRegimensPregnantWomen_FS_en.pdf

AIDSinfo. (2012). Reproductive Options for HIV-Concordant and Serodiscordant Couples. Retrieved October 15, 2012 from aidsinfo.nih.gov: http://aidsinfo.nih.gov/guidelines/html/3/perinatal-guidelines/153/reproductive-options-for-hiv-concordant-and-serodiscordant-couples

Anderson, & Cu-Uvin. (2009). Pregnancy and Optimal Care of HIV-Infected Patients. Clinical Infectious Disease, 449-455.

Avert. (2011). History of HIV & AIDS: United States of America. Retrieved September 30, 2012 from Avert: http://www.avert.org/aids-history-america.htm

Bailey, P. (2011). Magic Johnson: Today's 'poster child' for HIV? Retrieved September 29, 2012 from Thirteen Percent: http://13percentmovie.wordpress.com/2011/11/09/magic-johnson-todays-poster-child-for-hiv/

Barnes, & Murphy. (2009). Reproductive Decisions for Women With HIV: Motherhood's Role in Envisioning a Future. Qualitative Health Research.

Bridge, D. (2011, March 4). Breaking the Taboos: Pregnancy Planning and Fertility Issues for People Living With HIV/AIDS in the United States. Retrieved September 29, 2012, from The Body Pro: The HIV Resource for Health Professionals: http://www.thewellproject.org/en_US/Womens_Center/Dawn_Averitt_Bridge_Presentation_at_AIDS_2010_Vienna.jsp

Centers for Disease Control and Prevention. (2012, March 14). HIV in the United States At A Glance. Retrieved October 7, 2012, from Centers for Disease Control and Prevention: http://www.cdc.gov/hiv/resources/factsheets/us.htm

Centers for Disease Control and Prevention. (2012, September 17). Basic Statistics. Retrieved September 30, 2012 from Centers for Disease Control and Prevention: http://www.cdc.gov/hiv/topics/surveillance/basic.htm#aidsage

Douglas. (2009). A systematic, multidisciplinary approach to address the reproductive needs of HIV-seropositive women. Reproductive BioMedicine Online, *19* (2), 257-263.

Finocchario-Kessler, Dariotis, Sweat, Trent, Keller, Hafeez, et al. (2010). Do HIV-Infected Women Want to Discuss Reproductive Plans with Providers, and Are Those Conversations Occurring? AIDS Patient Care and STDs, *34* (5), 317-323.

Freid, & Kelly. (2011, July 22). Gender, Race + Geography=Jeopardy: Marginalized Women, Human Rights HIV in the United States. Woman's Health Issues, 1-9.

Hult, Maurer, & Moskowitz. (2009). "I'm sorry, you're positive": a qualitative study of individual experiences of testing positive for HIV. AIDS Care, *21* (2), 185-188.

Kanniappan, S., Jeyapaul, M., & Kalyawala, S. (2008). Desire for motherhood: exploring HIV-positive women's desires, intentions and decision-making in attaining motherhood. Aids Care, *20* (6), 625-630.

Kemper, C. A. (2008). Pregnancy Counseling in HIV. Infectious Disease Alert.

Ki-moon, B. (2008). BAN KI-MOON: The stigma factor. Retrieved September 30, 2012 from Washington Times: http://www.washingtontimes.com/news/2008/aug/06/the-stigma-factor/

Kirshenbaum, H. C. B. (2004). Throwing the Dice: Pregnancy Decision-Making Among HIV-Positive Women in Four U.S. Cities. Perspectives on Sexual and Reproductive Health, 106-113.

Loutfy, Margolese, Money, Gysler, Hamilton, & Yudin. (2012). Canadian HIV Pregnancy Planning Guidelines. International Journal of Gynecology and Obstetrics, 89-99.

Mantell, S. S. (2009). The right to choose parenthood among HIV+ infected women and men. Journal of Public Health Policy, *30* (4), 367-378.

Murphy, Marelich, Armistead, Herbeck, & Payne. (2010). Anxiety/stress among mother living with HIV: effects on parenting and child outcome. AIDS Care, *22* (12), 1449-1458.

Nyswaner, R. (Writer), & Demme, J. (Director). (1993). Philadelphia [Motion Picture].

Periera, M., & Canavarro, M. (2009). Relational contexts in adjustment to pregnancy of HIV-positive women: relationships, social support and personal adjustment. Aids Care, *21* (3), 301-308.

Poulin, J. (2010). Strengths-Based Generalist Practice: A Collaborative Approach (3rd Edition ed.). Belmont, California: Wadsworth.

Prackakul, Grant, Pryor, Keltner, & Raper. (2009). Family relationships in people living with HIV in a city in the USA. AIDS Care, *21* (3), 384-388.

Rubin, & Babbie. (2011). Research Methods for Social Work (7th ed.). Belmont, CA: Brooks/Cole.

Smith, Rossetto, & Peterson. (2008). A meta-analysis of disclosure of one's HIV-positive status, stigma and social support. AIDS Care, *21* (10), 1266-1275.

Squires, Hodder, Feinberg, Bridge, Abrams, Storfer, et al. (2011). Health Needs of HIV-

Infected Women in the United States: Insight the The Women Living Positive Survey. AIDS Patient Care and STDs, *25* (5), 279-285.

The Body: The Complete HIV/AIDS Resource. (2008, March 8). Preganacy and HIV Disease: Issues That Positive Woman May Face When They're Pregnant. Retrieved September 20, 2012 from TheBody.com: http://www.thebody.com/content/art5532.html

The Body: The Complete HIV/AIDS Resource. (2011, August). Getting Pregnant: HIV-Positive Single Women or HIV-Positive Woman in the Same-Sex Relationship (Serodiscordant or Seroconcordant). Retrieved September 20, 2012 from TheBody.com: http://www.thebody.com/content/63396/getting-pregnant-hiv-positive-single-woman-or-hiv-.html

The Body: The Complete HIV/AIDS Resource. (2011, August). Getting Pregnant: HIV-Positive Single Women or HIV-Positive Woman in the Same-Sex Relationship (Serodiscordant or Seroconcordant). Retrieved September 20, 2012 from TheBody.com: http://www.thebody.com/content/63396/getting-pregnant-hiv-positive-single-woman-or-hiv-.html

The Well Project. (2011, August). Getting Pregnant and HIV. Retrieved September 30, 2012 from The Well Project: http://www./en_US/index.jsp

Vazquez, E. (2012, September/October). How One Therapist Helps HIV-Positive Women Learn to Take Care of Themselves. Retrieved September 30, 2012 from The Body: the Complete HIV/AIDS Resource: http://www.thebody.com/content/69036/how-one-therapist-helps-hiv-positive-women-learn-t.html?ts=pf

Webber, Demas, Blaney, Cohen, Carter, Lampe, et al. (2008). Correlates of Prenatal HIV

Testing in Women with Undocumented Status at Delivery. Maternal Child Health Journal, 427-434.

Wheeler, D. P. (2011). Advancing HIV/AIDS Domestic Agenda: Social Work and Community Health Workers Unite. National Association of Social Workers, 157-158.

Wingood, DiClemente, Mikhail, Hubbard, Davies, Hardin, et al. (2007). HIV Discrimination and the Health of Women Living with HIV. Women & Health, *46* (2/3), 99-111.

Appendices

Research Questions

- What were some of your first thoughts, your first concerns when you started to think of having a child?
- Did you talk to your health care providers about becoming pregnant? If so, which providers did you discuss this decision with? (OB/GYN, HIV treatment specialists, therapists, general practitioner, etc.) How did those conversations go?
- Becoming a parent is a life changing experience on it's own, what about your situation in this process has you most curious, concerned?
- What types of support systems do you both, and each, have, who you can turn to and rely on in need. (Parenting support such as educational, care taking training, financial advice, emotional support, etc.)
- How have your family and friends reacted to the news of your decision?
- Did the idea of discrimination surrounding your HIV+ status influence or your decision to start a family, or have it played a role at any point throughout your pregnancy?
- Have you been confronted with any additional discrimination during or after your pregnancy?
- Can you tell me a little about yourself such as age, relationship status?
- How long have you been together as family?
- How long ago were you diagnosed with HIV? (or for those couples where both partners are HIV+ how long ago were you each diagnosed with HIV?)

Informed Consent Form

Title of Research: Emotional experiences of HIV+ face when bearing children.

Researcher: [redacted]

Faculty Mentor: [redacted]

The purpose of this interview is to gather information for a narrative research project on the emotional experiences of HIV+ face when bearing children.[redacted], a second-year graduate student in the Master of Social Work program at [redacted] University [redacted] is conducting this study to gain insight into the participant's childbearing experience.

The interviews will be audio recorded by the researcher and later transcribed for the purpose of data analysis. The interviews will be conducted in a setting that is mutually agreeable to the participant and the researcher. The information gathered during this study will remain confidential during this project. Only the researcher and faculty research mentor will have access to the study data and information. There will be no identifying names on the audio recordings, and participants' names will not be available to anyone. The audio recordings will be destroyed at the completion of the study. The results of the research will be recorded in the form of a final research paper kept in the [redacted] [redacted] Graduate Social Work department.

Participation in this study is voluntary; refusal to participate will involve no penalty. Each participant is free to withdraw consent and discontinue participation at any time.

For any questions concerning the research project and/or questions regarding rights as a person in this research project, participants can contact the research, [redacted] at [redacted] or [redacted]@[redacted].edu or [redacted] (faculty mentor) at [redacted] or [redacted]@[redacted].edu.

This agreement states that you have received a copy of this informed consent. Your signature below indicates that you agree to participate in this study.

Signature of Participant #1 Date

Signature of Participant #2 Signature of Researcher

HELP WANTED

RESEARCH STUDY

[redacted] University Master of Social Work student is looking for participants to interview for a qualitative study exploring the emotional experiences of HIV+ individuals and couples with regard to family planning.

I am seeking to speak with those males, females and or couples who are planning to bear children, currently pregnant and or have had a child within the last six months.

Participants will be compensated $75 for a 30-minute audio taped interview session at time of interview.

Participation in this study is voluntary. Each participant is free to withdraw consent and discontinue participation at any time without penalty.

Contact [redacted] at [redacted] or [redacted]@[redacted].edu