

Working in the Trenches with HIV Infected “Boarder Babies”— Values, Skills, and a Prescription for Working with Stigmatized Populations throughout Epidemics

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Abstract

At the height of the crack epidemic, some mothers were very ill or dying from AIDS, and others addicted to crack/other drugs. Their HIV infected babies were left to “board” in hospitals across the nation. To capture this historic period, this article is a collaboration between: (1) a Registered Professional Nurse, Maxine Frere, who, while completing her M.A. degree in Health Education at Teachers College, Columbia University, inspired her academic advisor to conduct a formal interview that would permit codification of her work with “boarder babies” at Harlem Hospital Center; and, (2) the advisor, Professor of Health Education, Dr. Barbara Wallace, who felt the resultant article would make a valuable contribution to the special theme issue acknowledging the 30th anniversary of the crack epidemic. The article begins by placing the work of Maxine Frere in context by discussing contributions of other leaders who worked in the same trenches at Harlem Hospital: for example, Dr. Margaret Heagarty, Director of Pediatrics; and, Dr. Janet Mitchell, Chief of Perinatology. Next, the article presents Maxine Frere’s story of working four decades as a pediatric nurse, while emphasizing her work with the HIV positive boarder babies, as well as their mothers. The result is an historical record of great import that reveals how medical professionals working in the trenches persevered throughout overlapping epidemics of HIV/AIDS crack/other drug use, and violence by drawing upon core values and a particular set of skills: i.e., excellent communication skills, advocacy, and community outreach. An emergent prescription for working with stigmatized populations throughout epidemics highlights a role for: (1) professionalism; (2) respect; (3) knowledge; (4) recognition of a common shared humanity; (5) honesty; (6) being non-judgmental; (7) being forthright in response to non-compliance and non-adherence; (8) compassion; and, (9) love. Any caught within the “next epidemic” and at risk of stigmatization will desire care from health care providers following this 9 point prescription.

Keywords: boarder babies, pediatrics, HIV/AIDS, crack, stigma, advocacy

“It’s time for those who have the energy to tell the story to anyone who will listen.”
Stephen W. Nicholas, MD and Elaine J. Abrams, MD (2002, *American Journal of Public Health*)

Introduction

There was an era when Dr. Margaret Heagarty was Director of Pediatrics (1978-1999) and Dr. Janet Mitchell was Chief of Perinatology in the Department of Obstetrics and Gynecology (1988-1996) at Harlem Hospital Center in New York City. Exceeding their combined time, Maxine Frere (1969-2009) was a Registered Professional Nurse certified in pediatrics and HIV (human immunodeficiency virus) care at Harlem Hospital Center. Her service spanned four decades working in the trenches of the War on Drugs. At the same time, she was

also a “Harlemite”—a long-term Harlem resident, and advocate who was deeply engaged in community-wide activism in re-

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sponse to the AIDS epidemic (acquired immunodeficiency syndrome).

This article has roots in an interview with Maxine Frere (first author) that was conducted in the spring of 2011 by Dr. Barbara Wallace (second author) at Teachers College, Columbia University. The idea for the article arose while Maxine was completing requirements for the M.A. degree in Health Education. At the time of the interview, Maxine (shown in the photograph) had already ended her work in pediatric HIV, since formal employment had ended “grant-wise.”



However, as an Independent Health Education Consultant, she still works in HIV/AIDS as the leader of the Health Ministry in her church, which collaborates with the National Black Leadership Commission and Iris

House—an agency that has origins in assisting mothers who were dying from AIDS. In her last five years at Harlem Hospital, Maxine Frere helped to develop, implement and evaluate a program of Direct Observational Therapy (DOT) for Youth with HIV, in order to increase medication adherence. She was also actively supporting the activities of the youth with whom she remained close, since their days as boarder babies. When interviewed, she also envisioned a faith-based approach to improving medication adherence within her church, as well as others.

The purpose of the interview, and now this article, involves Maxine “telling her Harlem Hospital story” of four decades of service (1969-2009) in the trenches of Harlem Hospital Center during the War on Drugs. The story covers how she worked and lived in Harlem at the epicenter of multiple epidemics, being intimately aware of the

challenges posed by each epidemic, as follows:

- the late 1960s to early 1970s heroin epidemic, as babies were born to mothers on heroin and methadone
- the late 1970s when the babies began to mysteriously die within the, as yet, unnamed AIDS epidemic
- the early 1980s full blown AIDS epidemic, necessitating rapid advancements in pediatric research to address opportunistic infections
- the mid-1980s crack epidemic, including mothers who engaged in the exchange of sex for crack and prostitution, developing HIV/AIDS—then giving birth to HIV positive babies while mothers lost custody of infants at birth, i.e. the national crisis of boarder babies left in hospitals
- the 1980s period of advancements from AZT [Azidothymidine], permitting movement toward a standard of care for preventing mother-to-infant transmission of HIV
- the late 1980s, and across the 1990s, period of overlapping epidemics of HIV/AIDS, crack/other drug use, and violence—as the number of HIV positive boarder babies rose, while the number of foster parents willing to take them decreased due to fear and stigma
- the 1989 launch and 1990s period for pioneering a residence for boarder babies so they could leave the hospital setting, and wait for foster care or adoption—as some mothers were very ill or dying from AIDS, and others addicted to crack/other drugs, necessitating waiting until they might recover
- the new millennium reality of boarder babies not dying from AIDS, receiving special early interventions and developing

into schoolchildren and independent adolescents—including becoming sexually active, having to learn how to disclose to sexual partners their HIV positive status, and possibly getting pregnant and giving birth themselves

Clearly, Maxine was justifiably seen as having a powerful and compelling story to tell. It is a Harlem Hospital story that makes an invaluable contribution to the special theme issue acknowledging the 30th anniversary of the crack epidemic.

Specifically, this article will: (1) create the context for Maxine’s story by discussing the contributions of leaders in medicine who worked at Harlem Hospital (i.e. Dr. Margaret Heagarty, Director of Pediatrics and Dr. Janet Mitchell, Chief of Perinatology); (2) present Maxine’s story of working over four decades as a pediatric nurse, while emphasizing her work with the HIV positive “boarder babies” left behind to “board” in Harlem; Hospital; and, (3) conclude with emergent themes that arose from the qualitative data of the interview—including values, skills, and a prescription for working effectively with stigmatized populations throughout epidemics.

PART I - Examples of Harlem Hospital Leadership

There were medical doctors at Harlem Hospital who were in the very same trenches as Maxine during the War on Drugs at the time of the overlapping epidemics. This included the medical doctors already mentioned, Dr. Margaret Heagarty and Dr. Janet Mitchell, as well as the medical doctors who worked most closely with Maxine: i.e., Dr. Stephen Nicholas and Dr. Elaine Abrams. The leadership of Drs. Heagarty and Mitchell will be highlighted to provide context for the presentation of Maxine’s story. Meanwhile, references to the publications of Drs. Nicholas and Abrams will appear throughout the article, thereby highlighting their contributions as leaders.

PART I-A-The Leadership of Dr. Margaret Heagarty in Pediatrics (1978-1999)

Nicholas and Abrams (2002) opened the telling of their story on this historical period with a quote by Dr. Margaret Heagarty:

Since many children afflicted with AIDS are poor, it is our responsibility to ensure that they receive the medical and social care they need to live humane and civilized lives. It is our moral obligation to do so. (USDHHS, 1987)

Dr. Margaret Heagarty was an advocate for the children of Harlem, as well as a leading researcher in the field of pediatric AIDS and the effects of cocaine on unborn children (Watson, 1998). While Director of Pediatrics at Harlem Hospital Center, she received the *Ronald McDonald Children’s Charities Award of Excellence*, donating the \$100,000 award to the pediatrics unit (Watson, 1995). As per photographs provided elsewhere (i.e., Watson, 1998), Dr. Heagarty is shown, receiving the award, and at Harlem Hospital.



Dr. Heagarty explained how in the “early to mid-1980s we found these problems on our doorstep, and they had to be dealt with. The cocaine epidemic also resulted in an escalated amount of violence and trauma” (Watson, 1998). In the mid-1980s, Dr. Heagarty was facing the reality that more than 60,000 children were in need of foster care as a result of the crack epidemic, AIDS epidemic, and the overall social conditions of their mothers and families—leading to many children becoming trapped on hospital wards in urban

centers (Watson, 1998). This reality is described below:

Some... parents were too sick with AIDS to care for their children or had died from the disease, some were homeless, and others were junkies. At the time, HIV was still a big mystery; potential foster families worried about catching the disease from the children and a stigma was attached to the disease Many... were left in hospital pediatric wards for lengthy stays, while doctors and nurses acted as surrogate parents. (Watson, 1998, para 2)

A Visit by Princess Diana. As Harlem Hospital expanded beyond the pediatric AIDS unit and prepared to launch a residence for the boarder babies. Princess Diana played an important role:

Dr. Margaret Heagarty... proposed small community-based homes for children with HIV... [i.e. ICC].... Fortunately, something serendipitous happened one month before ICC opened: Princess Diana visited the Harlem Hospital pediatric AIDS unit and pictures of her cuddling a sick child were published throughout the world. The rate of recruitment of foster homes for children with HIV went from almost zero to a surplus of interested families. ICC placed 160 children—approximately two-thirds of the homeless HIV-infected children in New York City—in foster homes in its first two years. (Watson, 1998, para 3)



PART-I-B-The Leadership of Dr. Janet Mitchell in Perinatology (1988-1996)



There would be no babies born with HIV/AIDS unless there were mothers—in need of care. Thus, the work of Dr. Janet Mitchell (e.g. Mitchell, 1994; Mitchell, 1993; Mitchell et al, 1993) was also vital. Dr. Janet Mitchell persevered in the trenches with an awareness that arose when she worked across her postgraduate internship and medical residency at Harlem Hospital (1976-1980), as well as during her rotations for medical training at D.C. General Hospital while at Howard University College of Medicine (1972-1976). The awareness that arose for Dr. Mitchell was:

... 'there but by the grace of God—go I.' I have ever since devoted myself to the underserved and the most disenfranchised...I realized that medicine was what I was made for. (Changing the Face of Medicine, 2013).

Dr. Mitchell “recognized the benefits of preventing perinatal HIV transmission” and providing care to HIV infected women (The Dr. Linda Laubenstein Annual HIV Clinical Excellence Award, 2002, p. 7). The legacy of Dr. Janet Mitchell has been captured:

...[T]he daughter of a butler and a domestic servant, [she] grew up in the projects... She earned her

master's degree in public health from Harvard University in 1987.

While chief of perinatology...from 1988 to 1996, Dr. Mitchell ran the largest prenatal program for pregnant, drug-addicted women in New York City. In 1994, she successfully lobbied the National Institutes of Health to include black women in testing AIDS drugs during pregnancy. She was known for sending hospital staff out into the neighborhood to find patients who had missed their prenatal appointments, and refused to turn away uninsured, HIV-infected women. Her support of her patients led her to confrontation with a leading gay-rights activist group that questioned the inclusion of black women in drug trials. "I felt the activists were paternalistic and didn't understand the trial was an opportunity to have all the options available to them. Poor doesn't mean dumb," she added. (The Dr. Linda Laubenstein Annual HIV Clinical Excellence Award, 2002, p. 7)

Mitchell (1994) wrote powerfully on the topic within an Institute of Medicine (IOM) workshop and commissioned paper:

The focus on the underrepresentation of women of color in clinical studies has benefitted from the scrutiny of the underrepresentation of women and minorities in AIDS research and recent public attention highlighting the practice of routinely excluding *all* women from certain studies...

...The focus on the exclusion of women from clinical studies has as its basis *rejection* of the concept that men or “maleness” is the norm and that women are fundamentally no different from men and therefore findings in male subjects can be generalized to all persons whether male or female. Since until very

recently—white men—dominated the research field, including the setting of priorities, it stands to reason that they would view themselves as the standard. Although the numbers of women in the research arena have been increasing, again the increase has been basically “white women.” It is important to examine how research “norms” are then defined. In fact, it is important to examine how society defines itself and all “norms,” if one is to critically focus on issues related to people of color and by extension women of color. While those parties concerned with the exclusion of women from clinical studies are quite willing to recognize the premise of men being the standard as flawed, they are less willing to consider the possibility of defining society and norms on the basis of white Anglo- or Euro-centric beliefs may also be flawed. This country is not the melting pot that many would like to believe it is and, in fact, it is comprised of many diverse culture, races, and ethnicities—all of which have the same right to define society and norms from their own unique perspective. It is this premise that allows for the following perspective on the underrepresentation of women of color in clinical studies. (pp. 52-53)

Within that perspective, Mitchell (1994) understood how “women of color have specific issues that may be viewed as barriers” in the recruitment and retention of them into clinical studies (p. 55). For example, she acknowledged factors playing a role in missing appointments, or “lost to follow-up” such as: transportation problems; child care problems; mothers’ conflicts of time; lack of flexible clinic hours; problematic attitudes on the part of clinic staff; programs needing to provide study participation incentives (e.g. diapers, cribs, strollers); and, the need for programs to

provide care for children. These factors followed from how “most women of color are single by circumstances, not by choice” (p. 55); thus, women of color “bear the primary responsibility of providing sustenance, comfort, and support,” including that which may be “in any combination...financial, spiritual, moral, and/or physical” (p. 55). In this manner, Dr. Mitchell was also a powerful educator of other researchers who came to understand the key ingredients for bringing about success when women of color were participants within clinical trials and research studies. This allowed other researchers to follow her recommendations and achieve success in study recruitment and retention of women of color.

Even before this major contribution, it was early on in the HIV epidemic that Dr. Mitchell served on the New York State AIDS Advisory Council that was formed in 1983 by an Act of the New York State Legislature; and, in particular, served on the Subcommittee on the HIV-Infected Healthcare Worker, establishing policy emphasizing infection control procedures. Drawing upon her front-line treatment experiences and academic viewpoint (Assistant Professor of Obstetrics and Gynecology at Columbia University), Mitchell et al (1993) provided leadership in the establishment of guidelines for the care of pregnant women with HIV; this occurred via service as the Consensus Panel Chair (U.S. Department of Health and Human Services, Public Health Service) for a Center on Substance Abuse Treatment Improvement Protocol (i.e., TIP 2: *Pregnant, Substance-Using Women Treatment Improvement Protocol (TIP) Series 2.*)

Recognition and honors came from the New York State Department of Health AIDS Institute in 1994 when Dr. Janet Mitchell was recognized for making “unparalleled contributions to HIV care and prevention—being awarded their Dr. Linda Laubenstein HIV Clinical Excellence Award. The following explains why the purpose of the award:

...to recognize those doctors who were there early in the epidemic; to applaud those who educated others about emerging changes in the available scientific re-search and clinical infor-mation about HIV/AIDS; to acknowledge those who have participated in the process of establish-ing medical standards for HIV care; and to com-mend those physicians who serve both as clinical leaders and as compassionate care providers with every individual patient. The Laubenstein Award represents an opportunity for the AIDS Institute to highlight the contributions of physicians or other clinicians whose record of service has been extraordinary and to publicly thank them for their accomplishments (The Dr. Linda Laubenstein Annual HIV Clinical Excellence Award, 2002, p. 1)

PART II - The Harlem Story of Maxine as Registered Professional Nurse (1969-2009)

While working in the same trenches as Drs. Heagarty and Mitchell, as outlined, above, Maxine Frere provided outstanding leadership as a Registered Professional Nurse at Harlem Hospital Medical Center. Maxine was the first recipient of the 2008 *Pocketbook Honors Award for Courageous Love, Life and Enduring Commitment*, as a Harlem HIV/AIDS activist who, as of the year 2008, had engaged in over 20 years of service to the children of the AIDS epidemic. The award and Maxine’s service was described, as follows:

The Pocketbook Honors is bestowed to community leaders who have exhibited a commitment to promoting awareness and prevention of HIV/AIDS, with an emphasis on African-American women's sexuality, intimacy and responsibility...

A native of Harlem, New York, ... [she pursued] a career as a registered professional nurse. Upon graduating from the Harlem Hospital School of Nursing, she touched the lives of countless children and in the mid 1980s began what would become a lifelong mission - caring for children infected by HIV/AIDS. Much of the earlier part of her career was spent helping families prepare for death. But now, due to medical advancements, awareness and other champions of hope like Frere, she's able to help children and families facing HIV/AIDS to prepare for life. Whether helping a family plan for college or standing beside one of her "kids" at their wedding, her commitment to education, health, resilience and hope resonates throughout her community.

Now at the age of 61, Maxine's mission is as strong and vibrant as ever. She frequently talks to schools and churches offering much needed support, advice and encouragement to children and parents. She conducts educational programs on HIV/AIDS at her home church First A.M.E. Church: Bethel and has plans to pursue her Master's Degree in Health Education. (PRWeb, 2008, para 2-3)

PART II-A-Interview Method, Questions

Given her leadership role as outlined above, an interview was conducted in spring 2011 at Teachers College, Columbia University to obtain her Harlem Hospital story. The interview covered the span of three hours. In advance, Maxine was given the following set of questions:

1. In terms of the crack and HIV/AIDS epidemics, what did you observe at Harlem Hospital—in terms of the onset of the epidemics of HIV/AIDS and crack? And, how did you observe them as related to each other?
2. As you reflect on your 40 years working at Harlem (1969-2009), and consider the crack and overlapping HIV/AIDS epidemic, what has been the impact on infants, children, families, and the Harlem community?
3. What kind of practices and policies were introduced at Harlem Hospital, as a result of these epidemics? How did the practices and policies change over the years?
4. Are there any interesting cases or examples that you can share that exemplify how the epidemics started and progressed over the years—while maintaining client confidentiality?
5. How has the Internet and social networking impacted those “alumni” of the units at Harlem Hospital upon which you worked?
6. What additional observations might you share for those seeking to grasp the impact and meaning of the crack cocaine epidemic and related HIV/AIDS epidemic?
7. Do you have any new emergent insights that have arisen during this interview?
8. What are your concluding remarks?

The interview proceeded based on these 8 questions, while Maxine enjoyed the freedom to move back and forth, along her professional time-line. This allowed her recollections to freely flow as she told her story. In addition, she provided some additional reflections via e-mail days after the interview. She made corrections to the interview content, also, for accuracy. This resultant collaborative article includes commentary on the interview data, while the data is presented in an organized format with sub-headings that highlight emergent themes. In the final part of the paper, other emergent themes are italicized.

PART II-B-Background Information

My name is Maxine, and I am a registered nurse. My anniversary was April 14th 2011—marking 42 years as a registered nurse. I graduated from Harlem Hospital School of Nursing (HHSN). My parents had five

children and could not afford to send me to college. HHSN had an excellent program and reputation. It was close to home and the tuition was affordable. I graduated from HHSN in 1969. I received my BA degree in Health Administration from Lehman College. And, I received my MA degree from Teachers College, Columbia University. I will be 64 this year (i.e., 2011). I am a mother of two daughters, both of whom have received their Master's degrees; my oldest graduated from John Jay College of Criminal Justice with a M.A. degree in Forensic Psychology; and, my youngest received her M.S. degree in Fundraising and Non-Profit Management from Columbia University. I am also a proud grandmother.

PART II-C- Maxine Frere's Early Years

A 1969 Start on the Pediatric Intensive Care Unit (ICU). When I graduated from nursing school in 1969, I went to work directly in the Pediatric Intensive Care Unit at Harlem Hospital. Any working in a specialty unit were employed by Columbia University, given the advanced training required. First, I worked as a Head Nurse. After two years I was promoted to Clinical Nurse Specialist. I then decided to pursue my New York certification in General Pediatrics.

Infants Started to Mysteriously Die in the Late 1970s. Children started to die. We had no diagnosis of HIV at that time. They were coming in with fever of unknown origin and a failure to thrive. The Moms were mostly heroin addicts at that time, or on methadone. We decided that Jesus had to be the father, because there were no fathers involved in any of these children's care.

1981 Pediatric HIV Certification. Eventually, we knew why the babies on the pediatric ward were sick. They had HIV. I am still in touch with a child that came to the ICU as a sick infant in 1981. He is now 31 (in 2011 at time of the interview) years old and alive and well. He lived in the hospital for a prolonged period and was eventually sent to Albert Einstein for some "special

test." The result determined that he was HIV positive. I was already certified in pediatrics, but wanted to develop my expertise in HIV/AIDS. I took the state exam qualifying me as an AIDS Certified Registered Nurse.

PART II-D- The Boarder Baby Era Began

1982—Blue Room for Boarder Babies.

By 1982, I started working in HIV. It was a time of the first boarder babies, and clinical trials were starting for treating babies born with HIV. We started testing a lot of children. The Pediatric Department opened up the **Blue Room**—because it had blue carpet on the floor. The father of one of the doctor's laid the carpet. It was a six bed crib unit with isolation tables outside the door. But, we had no particular care for them. That was before the intravenous Gamma Globulin (IVIG) study started. These were the boarder babies, where the Moms had died from AIDS; or the Moms were very ill or on drugs—being unable to provide adequate care for their very ill child. Social services had taken the babies from the mothers. We were waiting for the Moms to get assistance (i.e. medical care, psychological care, drug rehab, self-empowerment). The plan was to reunite the Moms with their babies. The babies went into foster care when Moms abandoned them, or never showed back up, or died. A majority of the foster parents were the grandparents. The grandparents became the Mom.

Commentary on Interview Data—Boarder Babies and Advocacy. Colleagues of Maxine, Nicholas and Abrams (2002), shared their observations, as follows:

Boarder babies, however, presented a dilemma we were not prepared to solve. Soon, more than a dozen infants and children were housed on our wards, staying an average of 339 days; one child stayed 4 years... We found ourselves confounded by what amounted to a group home on our wards, but with the rules, restrictions, risks, and aesthetics of a

hospital. The cribs had cold metal frames. There were few toys. The children could not leave the hospital. Family visits were infrequent or nonexistent, and volunteers were sparse. Inadequate though it was, doctors, nurses, and other hospital staff took on surrogate parent roles, fuming with moral indignation about the inhumane predicament in which these children were caught. (p. 163).

There was no “New York Gay Men’s Health Crisis” (GMHC) to serve as “organizational intercessor” to advocate for the needs of boarder babies (Nicholas & Abrams, 2002). Thus, advocacy became an essential part of their work:

We began by telling the story to anyone who would listen: media, government officials, dignitaries. At the Surgeon General’s Workshop on Children with HIV Infection and Their Families in 1987, we highlighted the plight of boarder babies with AIDS and asked for preventive services to keep HIV-infected children out of foster care... (Nicholas & Abrams, 2002, p. 164)

Their advocacy included explaining how New York City had “the highest rate of pediatric AIDS in the nation; the community of Harlem, in northern Manhattan, had one of the highest densities of maternal–newborn HIV infection in the city” (p. 164). Further, “no hospital was more severely affected by the boarder baby crisis than Harlem Hospital Center, a Columbia University–affiliated municipal hospital in Central Harlem. Here, the number of children with AIDS doubled annually from 1983 through 1989” (p. 164). The resultant challenge involved how “3% to 5% of pregnant women were infected with HIV, and the epidemic was quickly moving from its original tight link with intravenous drug use to a more common association with heterosexual contact and use of crack cocaine” (p. 164).

Nicholas and Abrams (2002) also explained the social context for the explosion of boarder babies. “Nearly 10% of babies born in Harlem went directly into foster care, primarily because of drug-related social problems; these babies were 8 times more likely to be HIV-exposed than those babies discharged to their mothers” (p. 164). Despite the challenges, Nicholas and Abrams (2002) reported:

Though we were working “in the trenches” of a city hospital, beset by chronic underfunding and inadequate staffing, we were academic pediatricians who responded to this new epidemic boldly yet traditionally: we designed and implemented a model program to provide clinical care for families with HIV...; joined statewide efforts to define standards of clinical care...; worked with day care, foster care, and school authorities to create informed policies; studied the epidemiology of maternal–newborn HIV infection and its natural history in children...; [and] participated in the first experimental therapeutic trial for HIV-infected children; and created a clinical trials unit... (p. 164)

In her interview, Maxine was able to offer her recollections and description of her role in those clinical trials.

PART II-E-Search for Solutions: Clinical Trials

1984 to 1987—Major Pediatric HIV Research Studies. We had 325 children who had started their care from birth in the Pediatric Intensive Care Unit; we had this number from around 1985-1987. You must understand that during this period there was no known medical treatment for children with HIV. There were two major collateral studies going on at that time: one for IVIG (intravenous Gamma Globulin) and one for AZT. Children received AZT or placebo; it was a blind study. We did not know what

babies were getting. The IVIG was part of an open label trial for Study 045. Both the studies started in 1984. When the studies started in 1984, we had one doctor, and I was the IVIG nurse, or the intravenous Gamma Globulin nurse. I had my little bag with my I.V. and Gamma Globulin medication in it. I had a caseload of up to 4 children a day. Some, who were not hospitalized, I would meet in the emergency room, while others I would pick up from home or an agency, or their school. I did this every day, Monday through Friday. I would insert their I.V. and administer their medication over a 2.5 hour period.

While I saw them for the treatment, the doctor would see them for their well-care; (i.e.) vaccines, and treatments for any opportunistic infections they might have. My treatment session would include the doctor, psychologist, social worker, and other nurses. We had 7 year olds receiving treatment, not just babies. We started treating older children who needed intravenous Gamma Globulin (IVIG) for their chronic infections. Other children received AZT by mouth at home. The IVIG, protocol 045, ended around 1987, but the medication continued to be administered to children who were still getting opportunistic infections (e.g. severe ear infections, etc.); and, AZT was quite effective. The placebo or AZT study that started in 1984 had ended in 1987—once AZT was found to be effective. All the babies born to HIV positive Moms received AZT at birth.

1986—Protocol 076 at Harlem Hospital Starting. There was also the study 076. That was Dr. Janet Mitchell's on the effectiveness of AZT on Moms. They gave Moms AZT while pregnant to reduce the HIV transmission rate to their infants. The perinatal transmission rate was significantly reduced and AZT became the standard of care. By 1987, Moms who were pregnant and HIV positive, or at risk for HIV, were receiving AZT in the OB clinic (obstetrics); if they had not received prenatal care, as soon as they came to Labor and Delivery

they received AZT; and, once born, the babies got AZT for 6 weeks.

Commentary on Interview Data—AZT. Indeed, the positive results of 076 were reflected in numerous publications (e.g. Connor et al, 1994). For example, in Cotton (1994), and, in particular, in 1994 guidelines (CDC, 1998) provided by the Public Health Service on the use of Zidovudine: i.e., ZDZ, or, Azidothymidine, popularly known as AZT. The use of ZDZ became the standard of care in order to reduce the risk for perinatal transmission of HIV-1 (CDC, 1998). Through 076 (CDC, 1998), it was found that a three-part regiment of ZDZ could reduce Mom-to-child HIV-1 transmission by nearly 70%; first, oral administration was started for the Mom at 13-34 weeks' gestation, then continued throughout pregnancy, and intravenous ZDZ was provided during labor, followed by oral ZDZ being given to the infant across the first 6 weeks of life. The trial of protocol 076 was halted early after it was found that ZDZ cut the Mom-to-infant transmission rate by two-thirds (Cotton, 1994).

PART II-F- Pioneering Innovations

1986—The Family Care Center. We received grant money and re-named ourselves the **Family Care Center**. It started as an initiative of the Pediatric Intensive Care Unit. It still exists today, but now it is focused on the care of teenagers with HIV/AIDS.

Commentary on Interview Data—Family Care. The Family Care Center is a model that was replicated across the nation. As Nicholas and Abrams (2002) explained, "we designed and implemented a model program to provide clinical care for families with HIV" (p. 164).

1989—The Innovation of Adult Care in the Same Outpatient Setting. We found it easier to get the Mom and child to adhere if the Mom and child came together. Moms would come to bring their baby, but would

not come for themselves. So, we had an adult provider in the Pediatric Clinic. The Moms did not have to go to the Infectious Disease Clinic where they stood out, and everyone knew you had HIV. We added a physician who was an adult provider specializing in infectious disease—more than just HIV.

1989—Incarnation Children’s Center (ICC). There were too many boarder babies at Harlem Hospital. They were HIV positive, but they were not sick. They were not dying. The parents were not able to care for them. So we had to have some place to keep them to make sure they *did* get their medicine for their HIV. By this time there was a continuous cycle—a lot in foster care, and a lot stayed in the hospital. It was expensive, because you had babies there for social reasons, but no medical reasons. So, in 1985, we went to Albany, New York to look at this home for the boarder babies. It was a Convent. They were putting boarder babies in there. Community members would come into the facility and work with the babies, fall in love, and adopt them.

So, we found a place here in New York City in Washington Heights, an old Convent—a five story building. There, we started the **Incarnation Children’s Center (ICC)** in 1989; now it is an SRO (single-room-occupancy apartment building). The children with HIV were then placed there, instead of staying in the hospital. The community would come in and feed them, bathe them, fall in love with them, and adopt them. What was interesting is that the staff was largely Latina, and the babies were African Americans from Harlem Hospital, Columbia Presbyterian and St. Lukes. But, Harlem was the epicenter for the epidemic. We also had volunteers. The babies would live there, grow up there, and eventually go to school. Initially, we had children from infancy up to 8 years old. Now, as an SRO you can stay there until age 19.

The capacity of the Incarnation Children’s Center (ICC) was up to 25 children—in double bedrooms. They might stay in ICC for 1-2 years. A child left ICC because they were medically cleared and adopted, or

because they went into foster care, or were old enough to go to school. Then, a new child came in. Some were waiting for foster care. Some had siblings in foster care—i.e., where the foster care parent only took one child, so the remaining child would stay in ICC. Or, the grandparents could only care for one child, and the remaining child stayed with us in ICC. We would try to get the Mom involved in the life of the child left behind in ICC.

If the parent was coming back into their child’s life, the ICC was also used as a place to teach parents about: HIV medication administration to their child; the importance of medication adherence; parenting skills; and controlling their own drug use—because they were tested occasionally. If they relapsed, we allowed them to start the process again. We would not call protective services. We would work with them. The Mom might return after disappearing for 6 months. We would say to her, “Are you ready to get some help, and then see your child?” Parents were testing positive for heroin and crack and methadone. All the Moms had HIV.

Commentary on Interview Data—The ICC. Nicholas and Abrams (2002) would describe the ICC in these terms: “the creation of innovative community-based nurturing homes for HIV-infected children” (p. 164). They also characterized the ICC as having “played a pivotal role” in ending New York City’s boarder baby crisis, at a time when the sickest children with HIV were not being readily accepted by foster parents. Thus, the ICC was “one of New York City’s least well-known success stories” (p. 164)—as elaborated upon below:

...Just before the center opened in March 1989...Diana, Princess of Wales, visited Harlem Hospital Center. Her visit was widely publicized; not only did it sensitize the public to the needs of children with HIV/AIDS, but it was followed by an abrupt increase in the rate of foster parent recruitment throughout

the city. ICC began working closely with the city's 8 HIV-specialized foster care agencies, which, in response to the new surge of foster parents, opened foster homes so efficiently that the average length of stay at ICC was unexpectedly short: 1 month. During the program's first 2 years, more than 160 HIV-positive children (two thirds of New York City's AIDS boarder babies) were admitted to ICC, which was dubbed "the Ellis Island for homeless children with AIDS." (p. 164)

1985 to 1990—Positive Links. Parallel to what was happening with our work with the boarder babies, there was something happening to the Moms. By 1985, the heroin and methadone Moms were becoming empowered. The Moms formed the group called Positive Links. Positive Links lasted from 1985 to 1990. At first, the Moms were mostly on heroin or methadone. They did not know their HIV status until the babies were born. They came to the clinic with no men in their lives. Within the Positive Links program, some became counselors to other Moms. They would go to programs in the hospital and talk to other Moms who were HIV positive—including those newly diagnosed after the birth of their child. The women developed tremendous bonds with each other, and stayed in touch over the years. As the women became drug free, they attended each other's weddings, funerals, and some became godparents to each other's children.

Positive Links actually chose their members. They were an elite group of women, and some did not want the crack Moms to be a part of Positive Links. A lot of the Moms went on to get degrees and became HIV counselors at various organizations in the city—Harlem United, Volunteers of America, Iris House; those who are alive are still doing that work. Positive Links does not exist anymore, because the Moms were mostly using heroin.

PART II-G- Height of the Crack Epidemic

Early 1990s – 2007—Impact of Crack. Then, crack came into play. These mothers were now the crack Moms. In comparison to crack Moms, the heroin mothers had been wonderful; that was a great time. They shot up in veins and would show you which vein to use, if we wanted some blood. They would nod off a few times. But the crack Moms! These were the hard ones. The crack Moms were HIV positive.

Most of the studies were ending and a lot of the grant money was disappearing. So, it became generalized care and most of the Moms went to a general infectious disease clinic.

Newborns Immediately Removed from Crack Moms. With crack Moms, the babies were taken away immediately in the hospital. We worked with various agencies—like St. Mary's Foster Care Agency; Heart Share was another one; and, Harlem Dowling. There were about 10 agencies we were working with. The agency would pick the baby up from the hospital and take them to a foster parent's house. The baby was in foster care until the Mom got herself together—if she did.

Crack Dynamics—Social Dysfunction and Violence. We still had the Family Care Center, were open from 9-5, and were treating about 60 Moms. One crack Mom had 14 children—three HIV infected. Crack Moms were having babies like water. One foster Mom, also an adoptive Mom, had 7 of the same woman's babies. Once the adoptive mother allowed the crack Mom into the children's lives, she would get a call every time a new baby was born; she took the baby for the crack Mom. Usually the same adoptive Mom or foster Mom took the next baby. Sometimes the baby would go back to the original mother, if they cleaned up. Some cleaned up, a lot didn't.

A lot of the crack Moms were manipulative. They would call us at the Family Care Center and say, "I need this or that." And, we would go. Once a mom called me from her

apartment from 127th and Lenox and said she needed some pampers. And, foolishly, I went to her house. I walked into a crack bust. That was the last time I went out on a single person visit. We went out on teams after that.

Crack mothers had nothing. What *did* they have? Men who would abuse them; physical abuse was rampant—black eyes, cuts. They were prostituting, so they were abused out in the street, too. Violence! We tried “every which way” to get help for the violence, but the woman would disappear. They would start “hospital hopping”—i.e., go to Metropolitan, or Bellevue; we would see the records.

The issues were mostly social issues. Like taking their babies’ medicine from them and selling it in the street. Selling everything: formula, pampers (we provided). We went to one crack Mom’s house because the children were always hungry. We went with our social worker. We opened the refrigerator and saw a box of cereal, milk. But if you picked it up, it was empty. All the containers and cans were empty. She was selling the stuff. When the family case manager from Social Services made their home visits they had always reported that there was a lot of food. We had to report her. The daughters were placed in foster care and eventually adopted. Before the adoption, the natural mother made many attempts to clean up in an effort to have her girls returned to her.

PART II-H- Crack Epidemic Bright Spots

Amazing Social Support Networking. We had a unique period of networking. Another foster care Mom let the natural Mom and their friend become Godparents. So all three were in the child’s life; it was amazing. That is how it was. You didn’t do anything alone. You were not alone. That is what made the program very successful. You were never alone.

Positive Impact of Staff Living in Harlem—and Client Confidentiality. As Harlem residents, we would see Moms on the street and ask them to go back to the clinic. They might come back. They

“hopped” because they were back on crack or back prostituting and they were too embarrassed to let us know. We were their family. We were the shoulder they cried on.

Their families did not want them. The grandmother was sick of them, because they were still on drugs. Society in general didn’t want anything to do with them.

I think one of the biggest things about the team was a lot of us lived in Harlem. You walked down the street and saw your client. We would say, “Go to that house. We saw her on the street prostituting.” We would never call you out [i.e., violate a woman’s confidentiality as a patient] in the street. They had to learn that the important part about the team was confidentiality. I would never say “Hi” to you unless you said “Hi” to me first.

A Model Demonstrating Treatment Could Work. There was a concept that mothers of crack babies who were HIV positive could not give their children medicine. They could not adhere, could not care for them, and could not love them. So, the city plan in the late 1980s was for them all to have abortions; or for all the children to go into foster care if the mother was on crack. We found when we opened the Family Care Center that the mothers were able to come to the clinic and *could* give their children medication. They came faithfully, and brought children to clinic. We had 100% adherence for coming to the clinic—for *the babies*. *Medically*, they came to the clinic for their children, gave them medicine, got their vaccines, and adhered to almost anything we told them to do. They might have stolen the food, but they came. *Socially*, things were still in disarray in their lives.

Our team (not me, I did not go) made a presentation in California on how crack Moms could be adherent, give medication for their children, and how we could get them to the clinic. New York City did not implement our policy and approach; neither did the nation.

A Team Working Outside the Box: Engagement in Patient Advocacy and

Outreach. We were working outside the box. We did everything there. For example, there was a Mom, she called me at home and said she needed to be admitted: on crack, had poor attendance; she never came and did not care what we did. She called me and asked me to meet her in the emergency room. She had already been to two hospitals that wanted to do psych admissions. So she walked out and called me. I went to the emergency room and explained that she needed a medical admission, because she had *Cryptococcus* brain—crypto of the brain—which can make you appear like a psychiatric patient. AIDS was destroying her. I got her admitted. Then, I went and took her daughter, my patient, to another woman's house (i.e. another HIV infected Mom in our program). She died three days later from crypto of the brain. She had never adhered to care. Her daughter went to the father and is now age 20 (as of 2011).

Our team did all sorts of things. If a family needed you to sit with them for 4 hours, then we did that. In regards to hiring staff, no matter the position they were applying for, each member of the team interviewed them. If we did not see a Mom for 4 or 5 days, any of us would go to the house, bring them to the hospital, test them, refer them for inpatient detox, or psych admission. We were a special group of people.

Over 20 Years of Camp Hope. We also have Camp Hope. It was started by the Archdiocese about 20 years ago. They offered a week at camp. The Family Care Center would close for a week and we would take the kids to camp. The first year we took 10 kids and had 90 people working with us. We have taken as many as 75 children. We provide the medical care and they provide the camp and counselors. It is a fantastic thing. Wish I could get everyone to go up there. Only certain counselors can work that week—hand-picked. They have been coming back to volunteer for years, some from the very beginning. Some are now camp Directors.

Now, the big kids come up to work that week, too. We take intravenous fluids, everything they need, and have access to a hospital for emergencies. We had 3

hospitalizations across 20 years. We leave 1 doctor back at the Family Care Center, in case something happens in the city. The rest are at camp and stay for a week. The staff that no longer works at the Family Care Center still comes up to volunteer. Everybody comes back. It is such a unique program. It's a great camp.

One night a kid said, "I had never hoped to see the beautiful sky like I see tonight." So, we call it Camp Hope. It is a beautiful place. We go the last week before Labor Day.

One year one kid was critically sick. We took him from ICU to camp for 1 day—which was technically against the law. We had a big parade, then a party that night. He died the next week. It is a good place. I wish I could take you up there right now.

Making "Wishes" Come True—Family Trips to Disneyland. We got trips from the *Make-a-Wish Foundation*—for any chronic, fatal disease. You did not have to say you had AIDS, just a chronic disease. Every kid in our program over age 5 got a wish, and some got three wishes as they got older. For example, we granted wishes at age 5, then again at age 14. A child and their whole family went to Disneyland for a week, got picked up in a limousine, and were given \$1,000. Or, we used the *Marty Lyons Foundation*—a football player whose son had MS. All together, we oversaw at least 75 wishes. If the children did not go with family, then they went with the adoptive parent. You could get a wish for children up to age 18. We almost got kicked out once, because one of the crack Moms went to Florida and stole all the cameras—because they give you video cameras to film your vacation. This particular Mom stole the cameras, the pillows, the blankets. We were banned for a while.

PART II-I-The Reality of Death and Dying

Burying the Crack Addicted Women and Children Who Died From AIDS. Parents did not have money. We would go to the hospital, stay, leave, look for a burial plot, and call funeral parlors. We would take

up collections, and hospital staff would donate plots, services, and clothes.

The Bereavement Consortium of Central Harlem, Inc. My work with HIV, as part of my community service, involved the Bereavement Consortium of Central Harlem, Inc. It is composed of volunteers from hospitals such as Harlem, Columbia, St. Lukes, and also the community churches and funeral parlors. We started it when we found out that a lot of infants and children were dying, and they had no money to pay for burial and funeral services. They had no psychologist. They just grieved with no support and acted out. Some of them were violent and fighting, and went back on drugs—after a family member died, or if a Mom or child got sick.

If they went to the hospital it was a psychiatric admission, and they did not necessarily need that. They just needed someone to talk to. So, we started doing bereavement counseling. We still do bereavement counseling—24 hours—on our phone line if they need counseling. We became incorporated in 1989.

PART II-J-Case Examples, Special Visitors, Love, and Death

Staff Adoptions. A staff nurse, a Head Nurse on another unit in general pediatrics, adopted a boarder baby who was HIV positive. She had him for about 4 years before he died.

Case of Erica and Tea with Princess Diana. Princess Dianna came to the hospital, too. She came every year for 4 years to see Erica—from about the ages of 4-8. One day, Erika just walked up to Princess Diana and asked her “How can I be a princess?” Princess Diana fell in love with that.

They would have tea, together; and, invite about 5 other children and about 5 other parents. There is something about these kids with HIV. They are very outgoing. They make an impact on your life. When Princess Diana came to visit Erica, we would dress Erica up. She would be all cute that day.



You would also see Princess Dianna out in front of the hospital building with other children, but not the boarder babies. She loved children.

She was a teacher. I spoke to her myself (as shown in photographs, below).





Princess Diana's visits generated great excitement (as shown in the photograph, above). Eventually, Erica got adopted. She was a sick girl and was in the hospital a lot. Among the children Princess Diana would come to see and have tea with, Erica died first.

Case of James and First Lady Barbara Bush. When the First Lady Barbara Bush came to visit she fell in love with a little boy named James. She came twice to see him. There was something special about James: Mr. vibrant; a cry baby. He was the one my father fell in love with, too. He would hug you and kiss you; and, the next minute he would have a temper. James was in our hospital for 2 years; it was the only place he ever lived. He died when he was about 6 years old. I'll never forget. It was the day my Director of Pediatrics got married. We called her on her honeymoon to tell her James had died; that was her love. Barbara Bush sent money to rename the clinic after James. I think the money went into General Pediatrics.

Case of Tammy, Her Birthday, and Bicycle on the Unit. There was something about HIV kids—something angelic about them. It was like they knew they had a short life. They walked early, or liked to get into things. It was like they knew they were going to die early, so they had to get everything in that they could. For example, Tammy was a little girl who lived in the hospital. When she was turning 10 she insisted we buy her a bicycle for her birthday. She rode around the ward on her bicycle. She did get out the

hospital a few times. The Family Care Center was not just the staff. Family of the staff got involved, too. We spent as much time with them, as with our own families—buying Christmas presents, going to the market to buy food, taking food to the hospital. We did not trust crack addicts with money, so we would buy the food.

PART II-K-Developing from Crack Babies All the Way to Young Parents Having Babies

Special Issues in Early Childhood: The Need for Early Interventions. We anticipated the need for early intervention. Our psychologist was testing them—as young as pre-school, age 4. Then, they were referred for early interventions. Nobody knew they had HIV in school. They went to regular school, head start, day care—wherever they had interventions for them. They went to Columbia University's *Special Needs Clinic* for psychological issues. They went on medications, for example to treat ADHD (i.e. Attention Deficit Hyperactivity Disorder).

A Personal View on Crack Babies. From my experience, they all had early childhood interventions and caught up by second grade. The ones I saw caught up very easily—except for one boy who had suffered severe trauma at age 4.

Common Psychiatric Diagnoses—Childhood to Adolescence to Adulthood. Most are not on any psychiatric medication, now. We have some who are really ill and are on medication, but do not adhere. Typically, first they are diagnosed around age 6 with ADHD, and then with Bipolar Disorder as they get older. We do interventions across their development, as they get older. We had two with Autism, and two had to go in mental institutions and are still there now.

Commentary on Interview Data—Mental and Behavioral Issues. Staff who also worked with Maxine's kids (i.e., Kang et al, 2008) discussed the higher prevalence of diagnoses of ADHD within the population. They explain how the population

faces, as adolescents, “living with perinatal HIV-infection;” and, the task of navigating those “normative developmental issues common to adolescents living in poor urban cities”—suggesting the role of environmental risk factors (p. 228). It becomes important to focus upon and address how “adolescents living with perinatal HIV negotiate normative developmental transitions” and “weather the harsh realities of living with a stigmatized illness in poor urban environments” (p. 234).

Special Issues in Adolescence: Sex, Pregnancy, and Disclosure of HIV Status.

Then, they become adolescents and sexually active. Some of them have become sexually promiscuous as adolescents, so we are dealing with teenage pregnancy. Some of them feel that they don’t have anything and want a baby. Or, their parents are dead, or abusive, or on drugs. Every time you ask them “Why are you having a baby?”—they say: “I want something to love.” They are looking for love in all the wrong places. One of the girls said, “As soon as you find someone you can trust to tell your diagnosis to, they reject you, and you have to find someone else. Or you want to give the disease to somebody else, because it was given to you.”

The boys are using condoms and will bring a partner to us. The boys tend to fall in love “head over heels” and want you to meet their girlfriend, and want us to meet them. They seem to stay in relationships for a while. Some of the girls seem to have a different boyfriend every week. Some of their mothers were promiscuous; they were on crack, and prostitutes. A lot of the girls were not raised by their mother; they just know about their mother’s history. They have heard their grandmother say things like “Your mom was no good.” So that is the image they have of their mother. Some of them learn to hate their mothers, and hate themselves. So a big issue is the grandmother talking about their mothers.

Longevity Not Expected and Not Always Welcome. Some of the grandparents who took care of these kids were sort of like martyrs. They did not expect these kids to live

past age 5 or 6. Some of them felt like “I can take care of a sick kid for 5 years.” But, they did not expect the children to live to be 20, 22, 30—not that long. So, the anger they had toward their children was given to their grandchildren. One woman actually told a child “I am only taking care of you until you die. Your mother was no good.” Now, the children are outliving the grandmothers.

Commentary on Interview Data—Unexpected Longevity. Colleagues, Nicholas and Abrams (2002), offered the following, in this regard:

... With improved treatments for HIV, infected babies are surviving into late childhood, adolescence, and even adulthood... A small but increasing number of older HIV-infected children and adolescents are being rejected by their adoptive parents. Some of these parents confide that their bravery was geared toward babies who were expected to die; they did not foresee such longevity, complexity of care needs, and uncontrollable behaviors... (pp. 164-165)

2003 - Treating Babies of Our Babies: The Second Generation Born to Patients. A lot of the kids now live independently; with HIV as a disability, they have their own apartment. They started having babies. We started treating the “babies of our babies”—two generations at once. It is a little more difficult. We have about 9 babies of our babies. Right now, even today, I think 5 girls are pregnant right now; and they are all age 18 and under (as of 2011 interview).

Commentary on Interview Data—Teenage Pregnancy. Colleagues, Kang et al (2008), wrote about the issue, while citing data showing that the pregnancy incidence rate for a sample (n=638) of perinatally HIV-infected girls aged 15 to 19 in a multisite clinical trial (33.5 per 1000) was lower than that for non-HIV infected girls of similar age (86.7 per 1000). Meanwhile, there is a need

for research to “further clarify adolescents' decision making process regarding sexual initiation, condom use with casual or longstanding partners, and serostatus disclosure” (p. 232).

Discovering and Treating Pregnant Adolescents and Their Babies. At first, we did not expect a 16 year old to be pregnant. Back then, we did not know which medications to give them. Going back about 8 years (note: 2011 interview), they would get critically ill and die from not taking medicines during their pregnancy. For example, they would be maintained on Trizivir and Norvir. Then they get pregnant at age 16, and we did not know the effects of the medication during pregnancy, or the adolescent would not take it. So, across the pregnancy they would get more and more opportunistic infections. So by the time they delivered they might die 1-2 months after delivery. We had a few of our pregnant adolescents die in childbirth—complications. Not a lot, but it did happen. Then, by 1992, 1993 we found medications that safely worked during pregnancy.

The Family Care Center treats the adolescent Mom's babies upon birth. Again, if they take AZT, then none of the babies are born HIV positive. The oldest baby “of one of our babies” is 7 years old (as of 2011).

PART II-L-New Millennium HIV Epidemic among Harlem's African Immigrants

The African-Influx Starting in 2005: A New Population of Pregnant Adolescents. The African influx was completely different. It started in the mid-2000s. The women did not know they were infected, and did not speak English. They were also adolescents, ages 17-18; they just did not know what was going on. There was a man in control, who was married to about 3 of them. They were just brought to this country and told they had to come to the clinic. The man would come with them to the clinic, and give the medication to the women, but the women did not know why. The man would speak fluent English, mostly cab drivers, and mostly Muslim. The Iman from the Mosque was

more involved with them, would come to the clinic with them, and try to explain the need for the Mom to come and take the medication. The Iman would come with the father and say, “Yes, yes.” But, because we were women, they were not even concerned about what we were saying. At home, the women would get beat, if they asked questions.

Sitting in the clinic with all the other Moms, the African women started having conversations, and learned what the clinic was about. Then they would go home and ask a question and get beat up, and put out the house, and all sorts of things. They started getting empowered and moving out to a sister's house. They might find out that they had a blood sister who lived in the next building. For example, there were three sisters who had the same man in the building, while they lived in three different apartments. They would meet on the street and recognize each other. They would see each other in the clinic and gradually learn that they were siblings. The sisters got to know each other and would move out. I saw this happen in about 4 families; one had 3 sisters, the others were 2 sisters. The girls were ages 17, 18 (looked 25, but age 18); and, the men were about 30.

They had children and were coming because the last baby was born positive. They were not getting tested in Africa. Once here, they would then test 1-2 of the 5 kids, for example. One child might be positive; then they would send all the kids for pediatric care. The Moms were seen in the adult infectious disease clinic—which is in the same area as the new Family Care Center.

The men have money, but according to one of the Mom's, it is the responsibility of the African woman to take care of the children—food, clothing and shelter; he paid the rent, but had nothing to do with care of the children. The women did (braided) hair and sold clothing to make money. For Medicaid, the men refused to give information about their money. We would get money from drug companies to pay for medications for the mother and children, because the women could not get Medicaid. The women could not read or write in English. Eventually, the

women would learn English, and some went to school and became empowered.

We tried to find a way to get the women together. One of our case managers can now speak 5 African dialects. The case manager heard about us and came looking to work for us. She was working downtown. Most of the staff heard about our program, deciding to seek employment with us. The case manager has events for the women. They serve their own food and celebrate some of their holidays. They will invite us.

Camp Hope also includes the African children. Now, they attend, too.

Commentary on Interview Data—African Immigrants in Harlem and Little Senegal. According to Kumarathas et al (2014), among the Africans that have been arriving to Harlem in recent decades, the Senegalese immigrants are distinct. What is called Little Senegal has developed in the past 15 years. The Senegalese community is distinct for several reasons: they are gifted in business—which is why the area is not called Little Mali or Little Guinea; they tend to be entrepreneurs and do not work for others; they are 95% Muslim; speak French and the dialect Wolof; are well organized through the Senegalese Association; tend to resolve family conflicts with those of Senegalese culture (e.g. Iman); and, as in Senegal, view going to see a doctor as unnatural. Further, it is estimated that 90% of women immigrants from Senegal come to join their husbands; and, they may be involved in a polygamous relationship—while still having a smaller family than those in Senegal. Also, many of the women do not leave their homes in Harlem. Thus, opportunities to learn English and access education are limited.

Just like Harlem Hospital, another local organization, Harlem United, has added staff to meet their HIV-related needs.

Kumarathas et al (2014) reported that Harlem United has an African Community representative to expand their comprehensive HIV programming into the Senegalese community. Other efforts are focusing on educating community leaders about HIV

prevention and treatment so they can share it with others (Kumarathas et al, 2014).

PART II-M-Recent Changes and Trends

Changes in 2008—Adding a Mental Health Team. Over the years, there were just two nurses, two doctors, and one social worker on the Family Care Center staff. The programs changed around 2008. There was a need, so a mental health team was added in 2008, because the kids were older now, and had a lot of mental health issues—like disclosure. Some were just finding out they were HIV positive, because a foster care or grandparent did not want to tell them. The mental health team had one psychiatrist, three psychologists, two case managers, and a social worker.

Commentary on Interview Data—Need for a Multidisciplinary Approach. It was also in 2008 that Kang et al (2008) discussed how “the complex interplay of social, familial, and individual influences that affect the lives of many adolescents with perinatal HIV necessitates mental health care providers” (p. 234). Further, this need arose from “multigenerational influences of poverty and substance abuse” that can be “overwhelming, highlighting the limits of resilience among adolescents with perinatal HIV;” and, there was also the “reality of living with a stigmatized illness under the daily grind of poverty-related stressors” (p. 234). Thus, there was a need for multidisciplinary approaches (pp. 234-235). Also, as they age, a relevant issue involves entering into the awareness and knowledge that one is living with pediatric HIV infection; meanwhile there is still great stigma surround their status (Mellins et al, 2002).

Changes in the Year 2009. I retired in 2009. I was a research nurse, always on a grant—about 15 studies. The focus shifted for the Principal Investigator. The Family Care Center was seen as a pilot program for what could be done for pediatric HIV in Africa—through Columbia University.

Ongoing Networking and Use of Social Media—Facebook. The kids still network. They stay in touch on Facebook. Some became very good friends. I am on Facebook with them. I have to watch and see what they are doing. On Facebook one little girl had a naked picture of herself. I called her immediately. She said I'm sorry Maxine. We always did first names; they considered us family. I just look to see what they are talking about and who they are dating, and if they need some help, or are in college. I do not answer on Facebook. I call them and see how they are doing—from homework, to dating, to pregnancy. Not just me—other staff, too; we all follow Facebook and stay connected. We talk to each other all the time, even with the doctors who left. We still have a family bond, because we were dealing with life and death all the time

On Fridays we have a drop in center, play cards, take medicine, go out bowling. They date each other. Many have found it easier to date each other than to disclose their HIV status to someone else—which is crazy because some of them still do not understand how they are re-infecting each other. So we had to do training sessions. One couple got married. They have a baby. Two in college are dating and thinking about getting married. A few are heavily dating. So, a few have found romance out of the group. The parents are no longer a part of what we do. Though, some parents are still alive.

Changes in 2011. We were employed by the trustees of Columbia University. The City decided they could hire their own staff to do what Columbia University was doing at Harlem Hospital. The impact has been awful. Long-term employees are now considered new without benefits: no vacation time, no sick time. So, a lot of staff is retiring, leaving. The impact on the kids is not good. The kids would come up on Fridays, do homework, Facebook. But we went from using Columbia University computers to city computers—with no Internet access. So, they cannot gather there to use computers anymore. A lot of kids and parents will transfer to an adolescent program.

PART III – A Conclusion Highlighting Values, Skills, and a Prescription for Working throughout Epidemics

PART III-A-The Emergent Themes Coded from Qualitative Interview Data—Italicized

Overall Meaning and Impact of Maxine's Work—Case of Brandon's Love. I would paraphrase Brandon. He said, "If I never had HIV, we would never have met you and loved you." He still says he is in *love* with me. He first said that when he was about 8 years old. He is in upstate New York and age 22 (i.e. as of 2011 interview).

The Emergent Moral of the Story—Professionalism, Respect, Knowledge, Compassion, Love are Key to End Stigma. I was listening to a web conference, a workshop. Talking about stigma, they asked, "What does it take to eliminate stigma? What can we do to eliminate stigma?" *Professionalism, respect, and knowledge*; I see it as taking all three. You have to have *knowledge, compassion*. You have to step out of your role to make this work. It can't be written in a book, because, "A, B, C" is not going to work today. You have to be somebody who has *more compassion than professionalism*.

"This" (i.e., referring to herself) is the nurse they called when it was a critical situation, when children were critical, or when mothers were not adhering. The mothers knew I was coming, but they also knew that if they did not do what they were supposed to do, I was still going to *love* them.

Nobody went out in the street to intentionally get HIV. And, we all make mistakes in our lives...We all make mistakes in our lives [coded as *recognition of a common shared humanity, i.e. since all make mistakes, and any of us could be caught within an epidemic; while, this is also consistent with Dr. Janet Mitchell's mantra for working in the trenches, 'there but by the grace of God—go I.'*].

When you treat people with a disease, it is not just disease. You are treating an individual. And, they can feel how you feel

about them. You have to be very *honest*. There is no place for lying when you work with people with HIV.

You have to say, “I do not like what you are doing, or what you are not doing (i.e. being non-adherent, non-compliant), but I am still going to *love* you. I am still going to care for you.” It has nothing to do with being a doctor, or nurse, or social worker, or psychologist. You have to have *compassion and love* for people. It does not have to be HIV. You do not know what the next epidemic is going to be. Hopefully, none.

Additional Insights after the Interview Sent By E-Mail. After having time to reflect on the interview I did want to add the importance of the professional remaining *non-judgmental*, yet also being *forthright* when dealing with relapse prevention—be it non-compliance with a child’s medication, or a parent’s relapse. It is important to be *candid* with the women, telling them that, “I am aware of your drug use, and some of your negative behavior; but, I will continue to work with you until the time comes when I am no longer needed.”

Commentary on Interview Data—An Emergent Prescription for Providers Working with Stigmatized Populations Throughout Epidemics. The italicized themes that emerged from the qualitative data of the interview may be summarized as *Maxine Frere’s Prescription for Medical Providers Working with Stigmatized Populations*—which has 9 elements:

1. displaying *professionalism*
2. showing *respect*
3. ensuring possession of adequate *knowledge*
4. engaging in *recognition of a common shared humanity*
5. being *honest* with no lying
6. remaining *non-judgmental*
7. being *forthright* and *candid* about critical issues such as relapse, non-adherence, and non-compliance
8. showing *compassion*
9. being willing to *love*

PART III-B-Final Commentary on the Interview Data: Maxine’s Harlem Story as a Love Story

Final Comment (1)—What Permits Persevering in the Trenches? Through her story of Harlem Hospital, Maxine Frere has emerged as an incredible leader and a modern day heroine. This article began by noting how other leaders at Harlem Hospital persevered in the trenches. First, Dr. Margaret Heagarty was shown to have been driven to persevere through overlapping epidemics because of the core value of feeling a *moral imperative*. Second, Dr. Janet Mitchell was motivated to persevere by a *tireless devotion to the underserved and disenfranchised rooted in the awareness that ‘there but by the grace of God—go I.’*

For Maxine Frere, the telling of her Harlem Hospital story revealed how it was actually a “love story”—as *love* was a major emergent theme. The story repeatedly demonstrated how providers working with the most vulnerable and stigmatized populations end up discovering a role for love. Thus, it is also *love* that allows providers in the trenches to persevere through overlapping epidemics in order to treat those stigmatized and in desperate need of quality care.

Final Comment (2)—Three Other Key Skills for Work in the Trenches. However, there are also other concrete skills needed in the trenches:

I. Communication skills emerge as vital on the part of health care providers. As an online blogger, Maxine Frere once eloquently described the requisite communication skills:

For health care providers, the communication process involves sending a message, receiving information, interpreting, remembering and responding. The process would be used to help individuals make positive health decisions, and to prepare them to live or even die.

II. Advocacy is another vital skill for health care providers. Maxine’s special brand of advocacy for her patients was constant, wide-ranging, courageous and unyielding—whether seeking an emergency room admission for a patient, “wishes” for her kids so they could travel to Disneyland, or a day or week at camp for a sick child; and, her advocacy included taking action when patients died—whether advocating for family members’ receipt of bereavement counseling, or for access to what was needed for burial. She also engaged in advocacy on a community-wide level through varied organizations, earning accolades as an AIDS activist.

III. Community outreach constitutes another key skill. For Maxine, this was an especially courageous engagement in community outreach. It was consistent with the principle: “Go to where the people in need are to be found in their very own communities and engage in community outreach” (Wallace, 1996, p. 15); “their” community was also her very own Harlem Community. Her outreach was especially courageous, given the violence that accompanied the crack epidemic.

Conclusion

The result of the interview of Maxine Frere is an historical record of great import. The record reveals how health care providers working in the trenches at the height of the overlapping epidemics of HIV/AIDS, crack/other drugs, and violence drew on core values, while utilizing a skill set that included excellent communication skills, advocacy, and outreach. The story of Maxine Frere as one of the professionals working in the trenches of Harlem Hospital is ultimately a love story. The story culminates in a 9 point prescription for providers working with stigmatized populations throughout epidemics—highlighting a role for: (1) professionalism; (2) respect; (3) knowledge; (4) recognition of a common shared humanity; (5) honesty; (6) being non-judgmental; (7) being forthright in response

to relapse, non-compliance, and non-adherence; (8) compassion; and, (9) love.

This concluding prescription for providers seeking to work effectively throughout epidemics has implications for all of us; since, no one knows what the next epidemic is going to be, or the next stigmatized population. Any caught within the “next epidemic” and at risk of stigmatization will desire care from health care providers following this 9 point prescription.

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