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Anthropology 101Q

Final Paper

**The Formation of Sisterhood:  
The Bonds and Spirituality Within a Support Group for  
HIV Positive Women in Rochester**

AIDS is quite prevalent not just in the United States but also on the local level: Rochester has the second highest population of HIV positive persons in the state of New York. Because of its method of infection, the HIV / AIDS virus carries with it the false stigma that only people on the streets or those who solicit sex can and do get it. However, this is far from the truth, as approximately one in every three hundred Americans today is living with HIV / AIDS. Many city-wide organizations work to raise AIDS Awareness within the community, and also to ease the suffering of those involved. Their services include everything from financial assistance to acupuncture, support groups to massage therapy. It is through such organizations that the population of those infected with this virus are able to better cope with their illness.

The group with which I chose to work is one such example of these organizations. They meet and have been meeting every Thursday evening since the month of April. Both hugs and tears abound as time passes the two hours of their session together. Their ages range from mid-twenties to well over fifty, and they come from a variety of backgrounds. Their cause of infection differs, but from this they share a common bond. These are the members of the support group Positively Alive, a group specially designed for women infected with the HIV / AIDS virus. Some are more talkative than others; some are positive and proud, others are still coming to terms with their illness. After spending many weeks getting to know the women of the group, I began to see the significance and meaning of a support group in their lives and the bonds formed from this

“sisterhood” as they refer to it. Also prevalent is the influence that spirituality has in a mental sense of conditional healing to these ladies. By contemplating these specific themes, I was able to see the women of Positively Alive truly come alive.

### **What is HART?**

Positively Alive is run under the HART (HIV / AIDS Residential Treatment) Center, a division of the Health Association in Rochester, New York. Established twelve years ago, and at its new location in downtown Rochester, the HART center began as a program to house HIV / AIDS victims at different government cleared housing available throughout the city. These clients, as they are referred to by the staff, for different reasons are in a difficult financial position to fund housing for themselves. HART finds available residencies, fixes up the apartments, and offers them to the next available client on the waiting list. The staff of HART consists of only five people: the program’s director, Loretta; her assistant, Charles; peer mentor, Gladys; Katherine, and Linda. The center is currently looking for another peer mentor to assist in the duties that are upon Gladys.

HART recently initiated a new program of holistic healing to their services, a program that incorporates the use of such techniques as massage therapy, acupuncture, and meditation. Everyone participating in these programs is a volunteer from the area looking to help the organization, its clients, and its goals. The center’s clientele consists only of individuals infected with the HIV /

AIDS virus looking for a healing alternative (in addition to) doctors and medications. It is also through this perspective that Positively Alive arose, this support group headed by Gladys, supporting empowerment to HIV positive women. The group now consists of about ten members a meeting. Some are regulars, some have only attended once or twice, but all are willing to share with each other their experiences and their words of comfort. They meet nearly every Thursday night, five o'clock to seven o'clock in the summer months and four o'clock to six o'clock in the winter months. (Due to the fact that it gets darker earlier in the winter months, the time is earlier.) If a client is unable to attend a meeting due to difficulty with transportation (e.g. health purposes do not allow for her to ride the bus), the director offers to transport her to and from the center's location. Also, the center provides bus tokens to those needing them for the ride home.

Based on my experiences with the group, the majority of the ladies are African-American and live in the downtown area. They range in age, the youngest in her thirties and the oldest in her sixties. My status at the center and in the group is as an "intern;" Loretta appointed me to this position. As a result of such, I will be handling any extra duties that need to be done around HART. Such jobs include searching the Internet for possible places for grant funding and decorating the center for Christmas. I visit HART every Tuesday and Thursday and spend around six hours there a week. I am even included in the employee board, where it is noted whether the person is "in" or "out" of the office.

Because of their status, many women in the group had their reservations about my purpose for being there. I had to wait until Gladys okayed it with the ladies before I could attend the sessions. At my first meeting, I had to sign a form of confidentiality stating I would not disclose any names of the persons involved. I also met with Charles, and he explained that the directors did not want me to write notes during the meeting, as he said the clients, “might feel threatened.”

### **The Meaning of Support**

I had never attended a support group meeting of any kind before visiting Positively Alive. To me, the term “support group” has come to be quite common and generalized in today’s definitions. What exactly is meant by this concept and what is the purpose of it? What does this idea try to accomplish? I was able to see the answers to these questions after attending only the first meeting of Positively Alive. By establishing a group where the people involved all share a common difficulty in life, a bond of connectivity is formed. The ladies always meet in the same room, a room furnished to look and feel like a living room in a house. They gather in a circle; this is a prominent symbolic aspect. By meeting in a circle, each woman is able to see each other, and make eye contact. By their mere shape, circles cannot exclude anybody. This is exemplified in the first meeting where the center director joins the clients to discuss my being there.

*At this time, Loretta, the center's director, enters and joins the circle. She looks around the circle at each individual person, right in the eyes.*

I could tell by this simple gesture that Loretta wanted to make everyone feel included. This was her way of connecting with each woman, including myself. By being immersed in the circle, I allowed myself to be in the same position as one of the clients.

This support group also gives each client something to look forward to during the week, a reason for getting up in the morning.

*The ladies are most appreciative of Gladys's work, and reflect this in their positive comments for the group. Each add their own comment on how the group gives them something to look forward to in the week, and how it empowers them and allows them to appreciate life.*

This offers personal testimonials to the integral importance of a system of support in each of these ladies' lives. As an observer to these individual statements of praise for the group, I could definitely sense the positivism that meeting altogether in a group of common interest brings to these ladies. In a later group session, one where a guest speaker discusses methods of relieving stress, the significance of support groups again comes into conversation:

*(The speaker) "Meeting with this group is another way for all of you to relieve your stress. I know that when I'm feeling low about myself and my condition, when I'm with others that can share that common feeling, I feel better and a little relieved that I'm not the only one in the world that's going through this at this moment."*

Though the speaker did not have the virus herself, she had a different condition for which she also attended a support group. Thus, the significance of support groups is universal and open to any topic. Through the group's discussions, I could get a sense that many days of their lives, the women feel alone because of their being infected. For most of the ladies, their biggest fear is having to deal with their sickness alone. This is one of the aims of the support group, to emphasize the fact that there are others to share in their pain and also, most definitely, their healing. One of the clients of Positively Alive also spoke of the importance of a different support group in her life, one for breast cancer:

*Anita explains that she has also been attending breast cancer support sessions. Belinda (another client) thinks it would be a good idea to get the two groups together (Positively Alive and a breast cancer group), as another form of support, to show that there are people out there that care for others.*

Again, this shows the universality attributed to support groups. The women involved in the two groups find a common ground with which they can associate with each other. Despite the different illnesses, the women of the two groups can share the same sense of overcoming a great obstacle. The support group offers to them a sense of a conditional healing, one to put their mind and feelings at ease.

They would discuss harboring this great secret from many around them just because they were not sure who exactly could be trusted. As stated by one group member, Beverly, *“One day I’m like, ‘Fuck it! Yeah, I have it (the HIV virus)!’ But others it’s like (bundling herself as if she’s in a coat), ‘Who me? Hell no!’”* I then realize that I only see these women as they are in group. How they act in public as opposed to their interactions within the group is different for most of them.

*Doris explained how once she was riding the bus to the AIDS Rochester building, and she was talking with someone she knew on the bus. Her stop came up, and she was wary whether or not to get off; would her friend (who didn’t know her status) know where she was headed? She got off anyway- this was a big step for her in dealing with her condition. Many times in the conversation the statement, “Yes, I have HIV. So?” came up. Claudia recalled how one day they were all at a charity function for AIDS Rochester, and she was all happy to be there, enjoying herself. Then she saw a photographer and bolted on out. “I’m not gonna do any pictures or anything!”*

It is thus apparent that the women act differently within their support group than they do out in the community. Perhaps, because of their illness, they feel threatened by the stigma that having AIDS brings with it, and for this reason are more careful with their openness when out in society than when within the comfortable confines of the circle of their group and familiarity of the people around them. By meeting regularly, this comfortable setting has been established for these women. Outside in the open world, this safety net of support is not as readily available, and the clients feel the need to be more cautious of their actions.

From this fact, the topic of secrets comes into play. One client in particular is very open with the fact that she still harbors a great secret from her own children, the secret of her being infected. This information arose one meeting after the opening reading:

*Beverly chimed in with her own experience. She stated her strong belief that there are certain people that you can't disclose this information to. She said it took her a while to tell anybody; her children still don't know, and she doesn't want to tell them yet. "They're my kids, I'll tell them when I'm ready to tell them." I couldn't tell from her statements how long she's known she's been infected. Doris also spoke, that she's come a long way since when she was first diagnosed, and that she is actually in terms with her having HIV. She told Beverly that*

*whenever you do decide to tell someone, it's such a relief, "like it's a weight off my shoulders. And... ah." Beverly said, though, that, "That only lasts for so long. What happens after that?"*

In this instance, the support group is a refuge from the secret that is weighing on the client's mind. Within that room she need not worry about saying something to give away this aspect of her life. She knows she can trust those around her, and that they can relate to the hardships and decisions she is facing.

The support group is also used as a mental divergence. The ladies do not discuss having HIV, or dying, or any other deep subject at every single meeting. They also meet to have dinner, or go to parties, such as a Halloween party thrown by AIDS Rochester. At an upcoming meeting, the ladies will be going on a tour of the town to see the Christmas lights. In this way, the group is used to create a little bit of a release from the constant struggles that these ladies obviously face every day because of their condition. It is used to take their minds off life, and create an enjoyable social environment.

### **Sisterhood**

With the concept of the aforementioned support group mentality comes a bond between the clients, a bond they refer to as a "sisterhood." They call each other, when speaking of another member of the group, sisters. I noticed this the very first day I spent with the ladies:

*Loretta then enters the circle. She brings up the news of one of their fellow “sisters,” as she calls them, who’s health is failing.*

They are not only fellow sufferers, or friends, but they take their relationship to a new level, that which is correlated to a sense of family. Because of their common condition, they possess a special bond with each other. I instantly notice this bond as I sit in on the group, even from the first day.

*Claudia asks me if I feel out of place among the rest of them, assuming that I am not HIV positive. I tell her exactly what I am feeling. I can definitely sense a strong bond between all of the ladies within the circle. They all share something that I can’t really relate to. However, I don’t feel uncomfortably out of place. They have welcomed me into their circle and into this intimate aspect of their lives. I know that I am there for research, but I feel like there’s something more.*

The way that I was embraced into the group reflects the sense of kinship that is expressed and brought out through the group. I had only known these ladies for an hour, and already I could sense that there was a connection among them. They adopted me into their group, and at times I truly felt as one of the sisters. I joined in their closing ceremonies (*Belinda said, “Uh huh. You’re getting in here. We’ve especially gotta serenitize you!”*) and was included in their good-bye

hugs. They became interested in what was going on in my life, too (*One of the members called out, as I was exiting the door, "We gotta keep up with you. You're our baby girl now!"*). By their language and gestures, it was apparent that they had accepted me into their bond of sisterhood.

At the first meeting, I was asked by the members exactly why I was interested in researching the group. I explained to them that I had never really been exposed to the disease and yet found it incredibly intriguing. My interest in the AIDS virus really began developing my junior year of high school. That year, my health teacher had wanted a section of the AIDS quilt to be on display at our school gymnasium in honor of AIDS Awareness week (which falls every year near December 1, AIDS Awareness Day). However, many of my school's administrators would not allow for this to happen; they harbored the typical small-town mentality that hardships such as AIDS could not possibly exist in our sheltered little town. My teacher and many students fought to emphasize the importance of AIDS awareness. They fought for four months until finally our high school held AIDS assemblies, at which infected speakers addressed the student population and spoke about having the disease. After hearing these speakers, I became quite intrigued by the disease. I now hope to be involved in AIDS research, searching for the celebrated "cure" for AIDS. I feel that it was because of my story that the women could so readily adopt me into their group. They were able to see how important this project was to me and that I really did

care what became of it. I feel that I won their respect and am quite thankful for the support they returned to me.

They are also supportive of each other. At one point, a member, Claudia, was hospitalized for back surgery. Many of the members would call her during the week to make sure she was okay and offer her their support and love. Many, especially Gladys and Loretta, would visit any “sister” that was in the hospital, such as the example of the aforementioned sister in failing health:

*Then, they discuss Shelly's condition. Four of the ten members present went to visit her since last week's update from Loretta. On Friday, they reported that she was okay, alert and responsive. However, Monday's report was not good at all.*

They would often times discuss the conditions of people they knew to be in the hospital or sick in bed, thus expressing a sisterly concern for the other members of the group.

Thus, they take their support beyond every Thursday night, and stretch it into many other aspects of their lives. In another instance, the ladies expressed their support for a different sister within the group, upon her announcement of being clean (off drugs) for five months:

*One client, Anna, in her introduction, states that it is her five-month anniversary of being clean. All the ladies are thrilled with this and so happy for her. They applaud, cheer, and give her hugs. "Way to go, girl!" some of them yell.*

The bond brought about by the support group is expressed through the clients' apparent ties of sisterhood. These reactions show a relationship that goes far beyond what would be expected for a group that meets only two hours a week. Another example of this is the greeting of a new member with one of the regular members. The new member had never come to HART before, and her first time there, the meeting happened to be cancelled. However, Lisa, an employee, and Doris, a client, both greeted her with open arms, giving her hugs and immediately aflutter in conversation. I think this gracious welcome is due to the fact that the ladies have such a powerful and significant commonality that they share to bring them so close together, despite the fact that they had only met just moments ago.

The meeting of the support group allows for the clients to exercise a bond that cannot be seen between them, one powerful enough to connect them as close as a familial sister relationship.

### **The Support of Spirituality**

I was not expecting to encounter such a sense of spirituality when with the group; however, I was exposed to this key theme immediately on the first day as I assisted Gladys with picking up the clients for the five o'clock meeting:

*We picked up the two other clients, and during this time the ladies talked about what a beautiful day it was, and how they were so blessed to have and see this day. One kept stating, "God is great in everything," to which they all agreed wholeheartedly.*

This sense of respect for a higher being carries on into the meeting, as every one commences with an opening prayer from the same book every week. Titled, The Color of Life: for Those of Us Living With AIDS, it is a book of daily prayer and meditation. Every week, after the reading, the ladies all comment on what is said in the prayer. Each reading offers a sense of healing and explanation, and seems to offer the women this sensation even as they listen to the words being read.

*Claudia reads an opening prayer from a book that Gladys provides for her. The main message in today's reading is that it's not what you did that makes you who you are. The ladies all rejoice in this saying, even while Claudia is reading, making clear their vocal, "Um humh." One says how she is so glad that it's not*

*what she did that truly makes her who she is, the drugs she's done or the fact that she has the virus.*

Some are so moved by the prayer for the day that they request to read it, stating, "I need this." These words signify the fact that this spiritual meditation must offer a deeper healing to the women, at least enough to bring them some inner peace. "Need" is such a strong word. This need must be greatly met by the words and meanings found within the reading. Often times during the reading the ladies will sit there, and appear as if they are really absorbing the words relayed through the reading. They are taking time to truly listen to what is being said and connect it with their own lives. The fact that the readings elicit a response from the members after their having been read also shows that the members try to connect what is being said in the meditation to what is going on in their own lives. After every reading, time is taken out to discuss what was said, as exemplified in the final sentence of the previous fieldnote excerpt.

Prayer also comes into the sequence of the meeting at the end of the session, as each week a prayer is said before all the ladies leave. Sometimes it is a, "Prayer of Serenity," as they call it, where they all recite a prayer asking God to grant them serenity, and thanking God for allowing them to wake-up and enjoy this beautiful day. Other weeks it is simply a prayer recited by one of the members, someone who usually volunteers, also a prayer to God asking for His guidance. Usually this closing prayer is recited with the ladies all in a circle,

their hands joined. It seems to be one final activity to join the ladies together as a group, emphasizing the power this prayer can bring and the fact that each person is not alone in life. This prayer also sends them off into the world outside of their support group, away from their safety, but instilled with the spirituality that seems such an integral part of many of the client's lives.

I am certain, after meeting with the group for two months, that this sense of spirituality is an aspect that draws the women to the group. It can be viewed rather as a selling point. The group members also seem to believe this.

*Belinda then takes this time to announce to the group that she will be doing an interview for POZ magazine (a magazine for HIV positive people), and that she will be mentioning Positively Alive in her interview. It is an article on spirituality, and she is happy that Positively Alive integrates so much spiritual belief into their sessions; she thinks there should be more groups like it, and the rest of the group agrees.*

Spirituality also plays into the group as the sisters try to assuage the feelings of exasperation of one of their fellow sisters, Anita, who has not only the HIV virus but also breast cancer. By using the support of a higher being, the sisters verbally express to Anita her meaning and importance for being in this world and living her life. Again, spirituality is used in an effort to heal the emotional pain that this one woman is experiencing. It is used rather as a mode of comfort and important for making their point of the worth of this woman's

life. In the example of Claudia with her back surgery, at the meeting prior to her surgery, she asked her sisters to pray for her, and remember her in their prayers. Again, this exemplifies the significance that prayer and spirituality have in the healing of these women.

The ladies are also involved in activities they discuss as being “retreats.” These retreats are held over the course of a weekend once every season. I was present at a meeting where three of the ladies were preparing for their three day retreat in Canandaigua, New York. I had located a copy of the RATFA (Rochester Area Task Force on AIDS) newsletter, and in it was an advertisement for this very retreat. The ad read, “A journey toward wholeness: Spirituality and HIV / AIDS. A conference for those affected and infected with HIV / AIDS.” The fact that this was being held in Canandaigua and pretty much open to anybody further supports the meaning of spirituality as a healing process for those infected with AIDS. The ladies were very excited to attend this conference, and the Thursday after their weekend reported to the rest of the group all that went on:

*I had asked Doris how her weekend was, as I knew that she had attended the retreat. She replied, “Very nice. Very spiritual.” The three ladies who had attended the retreat all raved about the weekend, commenting on how spiritual it was. Beverly said, “Claudia over there was like, ‘I’m not gonna be all rejoicin’ or anything.’ But then there she was (standing and waving her arms), ‘Ooh, ooh!’ We were laughin’, cryin’... and Jessica, you know I didn’t like that cryin’ stuff!”*

*She then added, "I was an African-American, Jewish, Hindu...everything all in one this weekend."*

Their actions at the retreat reflect their enthusiasm for the spirituality being practiced. Their reactions to the weekend indicate the importance that attending the spiritual retreat had in their lives. Also, the fact that it is termed a "retreat" implies that it is a time for a break in things, a time for reflection, which these ladies all seemed to want.

The last statement in Beverly's testimony supports the theory that it is not any specific spirituality or religion that these ladies must practice in order to gain the inner comfort for which they are searching. Many of the members comment on their going to church, and they compare which church service they attend. One in particular has a close connection with her pastor, while a significant portion never even mentions a regular weekly time of religious devotion. However, they definitely are instilled with spirituality. They need only to practice some aspect of spirituality in order to feel this healing. A guest speaker also spoke to the group on this fact, stating that people who are religious or have a sense of spirituality have lower levels of stress. By placing their lives in the perspective of there being a higher power over them to help control their problems brings them some sort of inner peace and relaxation. This, she said, is a researched psychological phenomena. She herself is a psychologist.

A topic also dealing with spirituality and inevitably encountered in a group with a deadly disease is that of death. This topic arises at different times

throughout the three months I spent with the group. The week prior to my joining the group, a fellow sister had been hospitalized and was in failing condition. We spent time at my first meeting discussing everyone's feelings on this:

*There are many teary eyes at this overall announcement (Shelly's failing health).*

*Claudia goes and gets the box of tissues, which she places in the center of the circle.*

The ladies are obviously affected by what is going on in Shelly's life. The fact that Shelly is dying seems to put their lives in perspective, as it does for me, too.

As Beverly states:

*Beverly explains that yes, they are empowered, but then things like Shelly come and you realize, "This is real shit."*

The subject of death is not one of taboo for the ladies involved. I think this is because of the spirituality they possess and because of the friendships contained within the group. They are afraid of dying, as in Anita's case:

*She says, crying, that she knows it will be breast cancer that kills her, not the AIDS, and she is scared.*

By discussing such a mentally difficult topic, the ladies are able come to terms with their emotions. It brings the themes of spirituality and sisterhood together, as they look to spirituality for an explanation and rely on sisterhood to get them through the difficult times.

*Beverly says how at first she was mad at Shelly for giving up her fight, but now she has come to understand her decision and accept her action. Gladys says she feels the same way. Shelly gave her so much hope; she was a great role model for her ("I wanna be just like her!"). Now she sees this and doesn't know what to think.*

By discussing death openly, the ladies exemplify the significance of spirituality in their lives. It also helps them to come closer together, again emphasizing the fact that none of them are alone in their fight with living with the disease.

These are just three of the themes I found to be represented by such an empowering group as Positively Alive. By being a participant observer I was able to pick up on the importance of these themes in each of the ladies lives. I felt extremely welcome in their close circle of sisters; on my final day, they made me promise to visit them next semester. I learned a lot about what a woman infected with HIV encounters in everyday life. I laughed with them at funny

anecdotes of Christmas shopping (*Beverly says how she had to chase a Chinese man on his scooter to find out where she could get one*); I cried with them as they remembered the life of a fellow sister. The experience and my fieldwork far exceeded any expectations I had entering the project, and for that I am most thankful. This was an ultimate learning experience, and I hope to continue working with the people of HART throughout my college career. By sharing this intimate two hours with each of the ladies present, I learned the true meaning of these words I once read in Charles' office:

*"You don't have to be INFECTED to be AFFECTED."*

*-Author Unknown*