Prologue

AIDS. God, that is scary. A premature death sentence.

When I began my project, those were my thoughts: "Gee, AIDS, scary." I mean, I've never known anyone with AIDS or the HIV virus. I've written many stories about the disease, but I've never come into contact with AIDS patients. I've never shaken the hands of someone with AIDS. I've never hugged anyone with HIV, comforted a man when his lover has died from the illness, and I've never wished so hard for someone to stay healthy. I never really knew, before, how painful it could be to see someone young face dying. I just never knew.

My interest in this project stems from living with my father, who is an acupuncturist, and possessing a great capacity for compassion. Mary Dye, program director at the AIDS Alternative Health Project (AAHP) felt very wary about my coming to the clinic and writing what I saw. She was worried about confidentiality, and she felt bothered that I would create problems concerning acupuncture and AIDS. At this time, Illinois does not license acupuncture practitioners. Thus, practicing acupuncture is not legal in the state; yet it is not illegal, either, and the clinic disseminates information about itself -- including the fact that acupuncture is practiced on-sight. Dye asked me to agree to refrain from using any references to acupuncture in my article, and I acquiesced. To me, this story was worth writing, with or without the acupuncture aspect. And I began what was to become the most emotional learning experience I have ever endured. Perhaps, it
is one of the best.

The first thing a journalism major learns is to not become involved in the story. Write, don't feel. Observe, don't touch. That's been my role, and I was good at it for the first few visits. I watched the clients and the doctors. I sat, detached, in my own little HIV-negative world, never knowing or feeling the emotions of the clients or the practitioners. Then William, a client, hugged me -- he touched me, welcoming me into his life. William told me of his experiences, let me feel his pain. And then Reg arrived. Appearing close to my age, Reg was suffering from full-blown AIDS. Suffering terribly. I could feel his agony. I could see his strength, and I could write his story. This thesis has become their story: The clients at AAHP and the men and women who must bear the AIDS cross, be ostracized by their peers, feel shame for their sickness, breathe with pain, but refuse to accept their "fate." To them, this disease must not be fatal. They can beat it. They will live. They will continue -- if not their generation, then the next will live a little bit longer. Their words do matter. They should be proud. They are survivors.

Jennifer Mirich

May 1, 1991
Jordan Wilson arrives for work a little before 9 a.m. Her tiny body exudes perkiness and enthusiasm as she begins to issue two hours of intense massage therapy. Hair rolled into a loose bun adorned with a single flower -- today it is an orchid -- Wilson can't wait to get started. As one of the many practitioners at Chicago's AIDS Alternative Health Project clinic, 3223 N. Sheffield Avenue, Wilson works individually with clients, talking and supporting them. She tries to address the specific needs of her patients, be it a good massage or a good listen. She provides both.

Walking into the small Oriental-style therapy room, Wilson lays out sheets and covers the pillow to be used on her body work table. Her station is one of six in this room, three perpendicular to one wall, facing the other three shooting from the other wall. The practitioners are free to circle their tables, talk with each other, and eavesdrop on other conversations. A family-oriented support system, the clinic breathes peace and tranquillity. It is a place where love and support flourishes, where clients find hope, where strength is evident.

Alex opens the heavy door to the AAHP waiting room and lets it slam shamelessly. His middle-aged face, red from high spirits and the blistering Chicago wind, breaks into a grin. Taking Wilson into his arms and hugging her, he hands her some fresh nut bread made with "all natural products." Only healthy food is allowed inside the AAHP sanctuary. Nutrition is a serious issue at the clinic.

Wilson kisses Alex on his cheek. He beams, flirting outrageously and praising Wilson's demeanor, character and talents. She is,
to him, one of his best friends.

The massage commences a little past 9 a.m. Wilson modifies her technique to match Alex's mood and needs. Picking up Alex's hand, she gently tugs and twists each finger, releasing tension and cramps this patient carries with him.

To be a client at AAHP, patients must test positive for the Human Immunodeficiency Virus (HIV) and be under the supervision of a Western-medicine doctor. No insurance is required, and treatments vary in price, though costs never exceed ten dollars per session. Those with financial difficulties are able to "work a deal," and some are exempt from payment until their "compromised situation" is resolved. "We have a sliding scale," says AAHP director Mary Dye. "Those on Social Security or disability don't have to pay."

The staff at the clinic doesn't hound or "double-check" financial claims. If clients say they can't pay, the staff believes them. "If they lie to us, that's their problem. That's their baggage to carry around," Dye says.

Born in 1986, AAHP offers a host of Eastern modalities (therapies) to about 150 patients. More than 100 other HIV-positive individuals bide time on a waiting list, though Dye takes into account the urgency and state of health of all potential clients. Acupressure, Chinese herbal therapy, chiropractic, craniosacral, mari-el, nutrition, myotherapy, and grief counseling are all offered, as well as massage. Many interns observe treatments and volunteer their time with the thirty practitioners who also donate hours to offer care to this needy population. Dye and two other employees
work part- and full-time. With such a large volunteer staff, seven practitioners can serve seven clients simultaneously.

On this February day, only Wilson and Alex are in the community room by 9:30 a.m. A regular client, Alex has come twice a week for the past two years, receiving massage, "chiro" and other traditional Chinese treatments. He is HIV-positive but shows no signs of illness. He is considered "asymptomatic" and relatively healthy. His living companion had just been diagnosed with AIDS.

"He realized that the past three years have been the best of his life," Alex says of his companion and fellow client at the clinic.

"I'm glad for that," Wilson says, gently rubbing the length of Alex's arm. The conversation moves from such intense personal issues to describe the clinic.

"It's a happy place," Alex says. "It's got spirit. We fight for slots with the practitioners."

"And we miss our clients when they're not here," Wilson responds. Her smile is as inviting as her demeanor. "One of the most treasured things is the friendship. They give me as much support and love as I am able to give them."

At some point one of the other practitioners who has begun to give care to another client changes the music from gentle New Age to soothing New Wave. The change supports the atmosphere of relaxing.

"I see AAHP as a refuge from the world, the job -- it's an escape. They've done a lot of research on stress," says Alex. "It's the long-term survivors of this disease that are the ones
that succeed."

Spending the half-hour session with Alex rubbing, kneading, and doing "light work addressing the body," Wilson says the massage is a "tune-up . . . But I know (Alex) loves it so much."

"It keeps me young," he purrs.

"Which you are, so beautifully . . . quite an admirable sixty-year-old, which I love saying."

Taking her hands quickly and firmly over Alex's body, Wilson uses her entire being as force to work each target muscle. She changes her speed, varies the pace. By 10:20 a.m., six therapists are administering therapy.

AAHP is open five days a week, though practitioners do not work on Fridays. Larry, the only full-time employee, manages the office everyday. He is organizer and secretary, answering calls, creating the weekly treatment schedule, handling fees, updating the AAHP mailing list, and maintaining supplies. He even suggests treatments, "very subtly, without recommendations."

"Until you have it, you never know what it's like," says Larry of trying all the modalities offered at the clinic. With paper clips stored and everything in its assigned spot, Larry is the epitome of order. He doesn't have a medical background; nor did he attend secretarial school. He's at AAHP because he wants to help, somehow, some way.

"I wanted to give in areas that matter." He tidies the already neat desk perched at the far end of the homey waiting room. "I just had known so many people impacted by the epidemic that I wanted
to do something. The longer I am here, the more people I'll get to know, and unfortunately, people don't always stay well, so you have to prepare -- if you can prepare. People you have relationships with don't always stay well."

Of the 150-or-so clients, about 80 percent are asymptomatic, Larry says. Only 20 percent has full-blown AIDS. Though Chinese medicine, like its Western counterpart, has no cure for the acquired immune deficiency syndrome, it can treat the symptoms of the many "opportunistic diseases" that strike Persons with AIDS (PWAs) because of their compromised immune system, program director Dye says.

Reg, one of the PWAs at the clinic, aches with the effects of Kaposi's sarcoma (KS), a rare cancer commonly found in AIDS patients that sprouts tumors anywhere on the body and involves internal organs. In Reg's case, the classic KS has invaded his body, leaving a trail of spots purple to brown in color across his skin. Lesions eat away at the delicate tissues of his inner mouth. Reg's Western doctors have applied chemoradiation to the inside of his jaw, but Reg's body racks with pain.

Covering his body with a sheet, Reg stretches along the body work table. His tall frame is lanky; his arms emaciated; his face marred with distress. He cannot speak.

Without talking, practitioner Janet places Reg's file on the ample space next to his body on the table. She consults a sheet charting the hundreds of "points" in the human ear. In an effort to relieve Reg's pain, Janet will manipulate these "points" to act as anesthetics. In the ear, hundreds of points correspond
to different organs of the body. By stimulating such points, relief can be given for different ailments, and a "balance" can be re-established.

Kneeling next to her patient, Janet, and now intern Robert -- from the city's Midwest Center for the Study of Oriental Medicine -- work together to identify and manipulate the desired points. Reg periodically cries out when certain sensitive spots are located. After twenty minutes, Reg is calm and somewhat in peace. According to Janet, the only help the practitioners could give this patient was respite from the pain brought about by the effects of Western medicine.

"Once a disease reaches a gross level," Janet says," it's hard for any medicine to control it." Chinese medicine offers herbs for skin problems and for improving blood circulation, but "the nature of KS seems to go beyond anything that we know of."

While Reg relaxes on the table, another young man comes into the clinic. He, too, has purple spots on his skin.

In terms of preventative health care, Chinese traditional medicine has the most to offer. While it can treat the symptoms of a disease, it can also improve one's body, establish and maintain a balance of the various "systems," or proper functioning of organs. That's what the majority of clients at the clinic are here for: to improve their immune system, stay healthy, and prevent the many opportunistic diseases from invading their already limited immune system. T-Cell counts -- an indicator of the shape of the body's immunity from disease -- are a constant conversation.
A number of clients receive preventive health care to delay the need for the Western drug AZT. At this time, AZT is the only prescription authorized by the Federal Drug Administration for use on PWAs, though other drugs are in experimental stages. However, while AZT has been tested and approved for the past few years, it still produces a host of uncomfortable side effects, and any longevity it may provide is questionable since the drug has been in use for less than ten years.

Martin, an AAHP client for the past three years, receives care to "tonify" his immune system. Sinus problems, bowel disorders, hemorrhoids -- these are only a sampling of the small irregularities with which he must contend on a daily basis. Frustration seeps into many aspects of his life. Sleep evades him. His lover lays near Martin on another table. They both are infected with HIV, though neither has been diagnosed with AIDS.

"How are your energy levels?" asks Janet.

"Actually, I'm feeling pretty well," Martin replies. Though he says he feels relatively well, he deals with the effects of AZT, as well. Diarrhea is his biggest ailment.

"I definitely feel the clinic is part of my healing process," Martin notes. "I come weekly. It's part of my routine. The problems I've had have been pretty minor."

Working full-time as an administrator in an AIDS education program, Martin is also a subject in an AZT experiment at Northwestern University. Taking 100-200 milligrams per day -- relatively small dosages compared to the levels he consumed in a previous study -- Martin and his Western doctors hope the drug will stop the chemical
reproduction of the virus. For him, AZT comes with a wealth of side effects: diarrhea, nausea, headaches, stomach pains, to name a few. "It's a deterrent to take it. It's probably kept my T-Cells up, but I'd rather approach it in another way . . . . The bottom line is me, not the study."

He continues: "Intuitively, I knew that a lesser dosage was what I needed, but (the first study) said to stay with the 1200 milligrams . . . and I stayed with it until the end. The doctors are very cautious for the point of the clinical study."

Janet quietly asks Martin to be silent to allow his treatment to soothe his frayed nerves. He agrees.

The faces at the clinic come with common symptoms and pains, and the family-style community room supports sharing commonalities. Darren, who is reluctant to reveal his age or how long he's had HIV, benefits from finding solace among friends.

"In a living sense, this AIDS epidemic can be very nonpersonal," Darren says while Wilson rubs his sore legs. "At this clinic, every client that comes here is addressed on a personal level -- called by name.

"I find that this epidemic is a decisive situation -- in the fact that it brings out the worst and best in people. Either you are comfortable with it, or you aren't."

During therapy, Wilson tugs limbs and applies pressure to sore parts of Darren's body. Sleek and firm, Darren bicycles and jogs. "I feel I can breathe better," he says of his massage. "It feels like my lungs are expanding, and I feel less weight."
I am relaxing and focusing on 'good thinking.'

Good thinking. Positive ideas. An escape from a world in which an employer fired Darren because of his HIV status. Symbolic imagery and visualizations. "I am putting myself into a healing mode. I accept the healing -- feeling well on the immediate level and knowing I can return here makes me feel comfortable."

The eyes behind the tiny circular glasses on George's face close to the dim light in the community room. On this April day, the heat of the sun is nowhere to be found. Friction warms George's hands as he rapidly rubs them together and sluggishly places them on the face of the client. Using his energy, George relieves tension in the client's forehead. Very slowly he rocks his body to-and-fro to the rhythm of the client's "opened energy channel."

It's quiet now. Sober. Healing and calm.

"My healing is a gift," George says in a whispery voice. "I believe it is in the giving that the gift is being used. In touching others -- there's so much healing. The energy flowing through me -- it hits them on all levels. It touches the spirit, mentally, emotionally and physically.

"The person on the table leads the massage. Wherever they are, I meet that level. You match their energy and lift them. You're in control, but they still receive as much energy as they can receive."

The only reflexology practitioner at AAHP, George works with feet. "Every part of the body is in your feet." Tiny nerve endings from every organ find position on the soles of mankind. It's George's
job to use these nerves to restore balance. He also gives a mean massage, his clients claim.

This place is "nurturing because they get the support emotionally and touch --a lot of them don't get touched now," George says.

Placing his hands on the client's chest and forehead, George takes a pulse. The client's hand curls softly at his side: Peace for a moment. From whatever daily problems this man faces, whatever complications his infection brings, George gives peace. For the client, he says this is a moment of intense freedom, though his mind is charged with thousands of thoughts.

Once again the community room is silent. Cida Rinse rests upon a Tupperware box of cotton balls on the white windowsill, a constant reminder of the necessary health precautions these practitioners must take. A small bottle of a bleach-water solution accompanies a clock. Each session is timed to a half-hour, though doctors and patients may work at their own pace -- often running over the set time limit. George runs over his time.

"As soon as you lay your hands on a person, they know whether they can trust you or not," George says. "Even before you begin the massage."

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For the Opening Day of Cubs baseball, when the city is bright with hope for a new season, the clients, practitioners, and staff mourn their own loss: Alex's lover. Since being diagnosed five weeks earlier with AIDS, he endured seizures and severe pain from brain cancer. His weak body could withstand no more.

"When someone dies, we light a candle," Larry says. The dim
flicker of the flame shines through the atmosphere of the waiting room. "This is the first time we've had to do it in a while. I've never had anyone pass away. We write their name up on the board when someone goes into the hospital or dies."

"We didn't have a close relationship," Larry continues. "I knew him when he was fine -- he didn't even have an AIDS diagnosis. And he went very fast. It was only five weeks. He had a few strokes. He couldn't verbalize. He could think but not talk. It was sad to see him deteriorate."

A large photo album rests upon the table dominating the waiting area. Inside, hundreds of pictures chronicle the highlights of the clinic: Parades, parties, and, of course, the faces of clients.

"How are you doing?" Interrupts Julian, a diminutive practitioner who just arrived at 4 p.m.

"How do you mean?" his client responds.

"How is life?"

"It sucks!"

"Well, that's all I need to know." Listening to the emotions of frustration, anger, or sadness, Julian tries to not feel responsible for the agitations his clients have. On the surface, Julian is dealing well. He has volunteered at the clinic for the past six months.

"I wanted to do something for this population," confides Julian. "We see here conditions and symptoms you wouldn't see in the private practice. With HIV, it makes things all the more difficult, all the more different."

Like the rest of the Eastern doctors, Julian wears no visible
protection: No gloves, no latex. The Cida Rinse and the many anti-bacterial washes in the bathroom are all he uses. "If you're afraid of transmission of the disease, you don't belong here," says he. "I have friends, and we talk about it. They just don't want to come. You don't have to do it. It's not a like a hospital where it's a job. I even heard of some latex gloves that the virus will go through, so how much do we really know?"

By 5 p.m., Larry is heading out. Julian tends to clients until 6 p.m., and Johnathan, another massage therapist, will turn off the lights, lower the thermostat, and lock the doors. Once his last patient is finished, Julian takes his coat and lays it over his tired shoulders. He has volunteered two hours. He's beat.

"I don't know how much longer I will be here," he says, his eyes lowered to the ground. "Their frustrations, their anger... I take it all home with me." Slowly and carefully he walks down the alley leading to Sheffield Avenue and looks back to the clinic and to the client who has walked the short distance with him.

"You going that way? I'm going this way." They smile, plan to meet again next week, and Julian tracks the path to his car. His day is over, but the emotions from the clinic will continue well into the evening. For him, it has been a long day.
Epilogue

As you can see, AAHP is a warehouse of peace. For a brief moment in time, clients find solace, comfort, support, and love. On that large table inside the clinic's waiting room, the photo album sits, full of events, publicity and faces. A few blank pages remain. They are ready for new memories. Hopefully, the disease will claim no new faces, and future pictures will be more of the happiness that seems so evident inside the clinic walls.