

THE INSTITUTE FOR CLINICAL SOCIAL WORK

THE EXPERIENCES OF GAY MEN
WHOSE PARTNERS CONTRACT
ACQUIRED IMMUNE DEFICIENCY SYNDROME

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CHAPTER I

INTRODUCTION

In November of 1985, in the context of my clinical practice, I met Greg and Stan. Stan had been diagnosed with AIDS several months earlier. Our first meeting was harrowing for all of us. On the way to his first appointment, Stan had become disoriented, parked his car, and gotten lost. He arrived at my office an hour late, sweating and terrified, clutching a slip of paper with my name and address on it. In a trembling voice he tried to explain what had happened. Yes, he said, there was someone he could call. His lover should be home from work by now. Greg arrived shortly. The two men went to find the car. We all sat down to talk later that evening.

Greg and Stan were clearly overwhelmed. Not just by the evening's events, but those of the past few months. AIDS was rather new to Chicago then. They had encountered many losses and medical crises the last few months. Anxious uncertainty had come to dominate their lives. They wanted help, but were not quite sure what they needed. I was struck by Greg's attentiveness, his concern over the evening's events and the non-intrusive way he deftly supplied information that Stan was having difficulty recalling. Greg operated in such a way that Stan's growing cognitive deficits were modulated, rather than accentuated. Though a good deal of complementarity was present, I also sensed considerable tension in the relationship.

The couple phrased their request for help in asking for sources of acupuncture, meditation, massages, and other forms of alternative healing. Stan related a dream that conveyed not only his hope for such intervention, but also his conviction that he was, indeed, dying. I stated that I could not offer them alternative therapies and that I knew little about them. However, I could offer them a place to talk. I sensed that they had a great deal to talk about, but were having difficulty doing so. Stan appeared

disappointed, while Greg was obviously encouraged. After some hesitation on Stan's part, an appointment was made for the following week.

Several weeks before I met Stan and Greg, my first patient with AIDS had died. It had been a draining, at times gruelling experience for me. Tom was not only my first AIDS patient, but he had essentially a borderline personality structure. He was boarding with a man who had offered a room in his apartment to men with AIDS who had no other place to stay. Tom's family had been marginally involved, at times outright rejecting him during his illness. He was one of the first AIDS patients in the city and as such had experienced a good deal of anxiety and at times rejection at the hands of medical personnel.

A recovered alcoholic and polydrug abuser, Tom found a degree of comfort in his participation in several AA groups. He had also found a "home" in the support system of the Howard Brown Memorial Clinic an agency in Chicago's gay community which provided support services for people with AIDS. Tom's experience with AIDS was characterized by being kicked out of his family or home of origin, but gradually finding other homes and relationships to help him negotiate the illness. He was enraged by the multiple rejections but relieved to find sustaining relationships. His relief and comfort were mingled with a sense of angry beholding to the people he relied upon for a sense of comfort. Tom formed an intense, but quiet, attachment to me. He experienced the relationship as tolerating the wide range of his sadness, despair, and rage that he feared might rupture his other sustaining relationships. I quickly became a central person in his experience.

In contrast to Tom, Stan had a home, an enduring relationship and parents who were deeply concerned and who were providing funds as he awaited his disability benefits. Due, in part, to my being drained with my experience with Tom and relying on my social work background, I wanted

to maximize Greg and Stan's ability to sustain each other. I decided to work with them as a couple. It would be new territory for me. There was little in the way of clinical literature on AIDS at the time, and even less on work with couples. I assumed that providing the couple a forum where they could talk about what they were experiencing would provide some relief.

The next meeting with Greg and Stan went well. I saw them separately and together. I was struck by the contrast between the two men. Alone, Greg talked freely about his fear of losing Stan to the disease. Stan disavowed being terminally ill, but talked about his frustration with the disease and difficulties with his past employer over insurance benefits. When I saw them together, Greg appeared to actively support Stan in his disavowal. Stan remained adamant about not wanting to talk, rather, wanting acupuncture. However, he slowly began to relate his irritation with Greg about how they were negotiating the illness. A dialogue, moderated by myself, opened up between the two men. Both appeared relieved, and an appointment was made for the following week.

Over the next few days, Stan became ill for the second time with pneumocystis carinii pneumonia and was hospitalized. His condition quickly deteriorated and he was placed on a respirator in an intensive care unit. Greg and Stan's parents began holding a vigil at the hospital. I met with Greg and the parents several times in the ICU waiting room and in the hospital cafeteria. All were devastated. Each had sensed Stan's pain and torment since his diagnosis and urged him to seek clinical help. Stan had either become angry or not followed through on potential sources. All had unanswered questions about what Stan had been experiencing. All were hoping for a miracle. All feared that Stan was dying. There was some discussion about the issue of centrality. As next of kin, Stan's parents were signing papers, yet both viewed Greg as the central person in

their son's life. Stan's mother had great difficulty with her son's being gay, and blamed herself, if he were not gay, she thought, he would not have contracted AIDS, and this would not be happening.

Stan died before a third couple session could take place. I was shocked by the suddenness of it all. One week we were establishing a treatment relationship, the second and third I was with his partner and family while Stan gradually succumbed to pneumocystis. Greg went home to be with his parents for several weeks. We planned to meet when he returned.

While Greg was away I presented the case to a supervisor. He was also profoundly moved by Greg's plight. He wondered aloud, "I mean no disrespect to the man who died, but what about his lover? What about all of the other lovers? They have to somehow manage to carry on with their lives."

Several weeks later, Greg called me from his office. It was his first day back at work. He said he was afraid he was "losing it" and began to cry on the phone. He was confused and overwhelmed, he said, and he missed Stan terribly. We met that evening and began a journey that continues to this day. I was deeply moved by Greg's pain and sadness, and the depth of the loss he was experiencing. The theme of AIDS surfaced repeatedly. Greg tested positive for the HIV virus shortly after Stan was diagnosed. For the first few months after Stan's death, Greg experienced little concern for his own health, but gradually his fear of contracting AIDS became a major source of anxiety. I began to wonder what the effects on the mourning process would be. Here was a man infected with the same virus that had killed his partner. The death of Stan from AIDS and Greg's infection with the same virus were tightly woven together. Would they ever unravel?

A psychiatric resident who knew of my work with Greg and several other men with AIDS gave me the March 1986 issue of Psychiatric Annals. I read through it, hoping for help with my work with Greg. There was nothing. Partners were barely mentioned, and when they were it was in reference to them leaving after their partners were diagnosed. Something in the tone of the articles bothered me. Popular opinion at the time was presenting the disease as an affliction of promiscuous, polydrug-abusing, urban gay men. The professional articles were presenting gay men with AIDS as victims-victims of AIDS anxiety, homophobia, and their lovers. But this description did not fit with my experiences with Greg. It did not entirely fit with my experiences with other men with AIDS. I saw men who felt stigmatized and at times victimized, but who were also making strides at adapting to the illness and the hardships it brought them. I rationalized that the clinicians who were writing these articles just trying to get a grip on working with AIDS patients themselves, that it was still early in the course of what would be a long-term epidemic, and that research and writing on partners and the family would eventually evolve.

I kept coming across more articles, each one focusing on people with AIDS, and having little if anything to say about their partners. Physician friends told me that many of their AIDS patients had partners. The centrality and magnitude of the loss for Greg was evident. Why wasn't anyone writing about it? Why weren't people acknowledging partners?

In my academic life, the question of a dissertation was looming. I became increasingly certain that I wanted to study surviving partners. But, how, why, and what was my research question? I discussed my experience with Greg and my questions about the effects of seropositivity with the man who was to become my advisor on the project, Tom Kenemore, who encouraged me to pursue it.

In September of 1986, I went to the National Association of Social Workers convention in San Francisco. A day long symposium on AIDS had been scheduled. I hoped to get more ideas on work with partners. Instead, I was disappointed in the presentations, and resolved to proceed with this study. The one presentation that focused on established relationships was unhelpful, offering little insight into work with couples dealing with AIDS or surviving partners. A social worker spoke at length on "unusual family constellations" she had encountered in her work with AIDS patients. She had "discovered" seven "constellations" such as: married, bisexual, wife unaware of sexuality; married, bisexual, wife knows lover. At the bottom of her list of unusual constellations was: homosexual, engaged in relationship with another man. A general tendency of the symposium presenters to say very little about the people with AIDS they worked with. Very little was said about clinical intervention or clinical understanding of what people with AIDS encounter. Rather, people focused on policy, or outlined over and over again the hardships facing AIDS patients. Very little in a daylong symposium matched my experience with Greg or the men with AIDS that I had encountered.

On the way back to Chicago, no doubt somewhere over Kansas, I decided that I wanted to study what men who had lost partners were going through, and the effects of seropositivity on the mourning process. But how to do both? Three hours after my plane landed I was in Tom Kenemore's office complaining about the symposium, the lack of interest in partners, and people not wanting to get to know their AIDS patients, let alone talk about the myriad of clinical issues involved in working with AIDS. I was not sure how I could look at both what surviving partners were experiencing and the effects of seropositivity on the mourning process. I was directed to Glasser and Strauss and their Grounded Theory methodology.

An obvious question when putting together a research proposal is how

many people are effected by the problem under study. I called AIDS support agencies in New York, Washington, Denver, Chicago and San Francisco. Not one agency kept statistics on the partner status of the clients. The information was buried in their clients files, not readily available, especially to an unknown doctoral student. In any application for agency services in the general community, the third or fourth question is marital status. I thought, "Are we as a community buying into a belief that gay men do not form relationships? Why isn't anyone asking about partners?"

I enlisted two physician friends to help me get at least a cursory idea of how many gay men with AIDS were partnered. For six months a physician in San Francisco, the other in Chicago, kept track of the partner status of their current and new AIDS patients. Both physicians practices were composed predominantly of white, middle-to upper-middle class gay men. But at least it would give me an idea of the potential number of men with partners. The San Francisco physician found that 58% of her patients were partnered, the Chicago physician found that 60% of the patients in his practice group were partnered. I was surprised by the similarity and the actual numbers. I had expected around 30%. What myths had I subscribed to? Did I too want to think that nice people did not get AIDS? Had I constructed a myth to assure myself that AIDS would stay away from me? At any rate, I was convinced that the study was important and sorely needed.

Greg was giving me copies of a journal he had been keeping. Following the method of Glasser and Strauss, I began coding his entries. Several other men who had lost partners were referred to my clinical practice. I began to notice that they all started at the beginning; talking and writing about the early signs that something was wrong, their concern that it might be AIDS, and the confirmation that it was AIDS. True, this reconstruction of the experience could be understood as part of the

mourning process, but I realized that I was asking the wrong question. The question, "What are the experiences of gay men whose partner's die from AIDS?", was too narrow. A great deal appeared to happen before the actual death of the partner. The question was changed to, "What are the experiences of gay men whose partners contract AIDS?"

During a visit to Chicago, my physician friend from San Francisco told me she was following many of the partners of her AIDS patients. Repeatedly, she had encountered surviving partners who became preoccupied with their health status four to six months after the death of the partner. We both wondered, "why then, why four to six months, what could be happening in the mourning process the partner's status would become a focus of concern." Several hours later she convinced me to come to San Francisco. She would recruit participants from among her patients. A Chicago physician was equally excited, and offered to refer from his practice.

An article about the study in one of the gay community newspapers (Burks, 1986) brought good response. Men who called about the study were appropriately suspicious. They all asked me why I was doing this. When I replied that I felt that partners were being neglected, that no one was writing about what they experienced, and that I thought partners had their own unique experience. All who called agreed to come in and tell their stories.

This study has been quite a journey for me. I am afraid to, or just do not care to, count the tapes that fill two shoe boxes that now sit on a shelf. They represent interviews with well partners, surviving partners, partners with AIDS, physicians, nurses, social workers and support group leaders from Chicago, San Francisco, rural Minnesota, and Boston. The experiences related to me by these people were in sharp contrast to the articles and presentations that originally irritated me. Their experience was rich, sad, painful, resilient, and, at times triumphant. Very early in

the study, I found myself idealizing the well partners. They kept plugging away, doing their best to care for and sustain their ill partners. "What keeps them going?" was a central question that became more refined as the study progressed. At first each interview generated more questions. Gradually the questions were answered.

I got to know a great many people during the study. One of the hardest parts of the study came from getting to know the participants. During the study, three men died. I found myself "crossing fingers" during hospital stays and when survivors went to be tested. I came to recognize the particular sense of resignation in a well partner's voice as he realizes that the end of his partner's life is near. I cheered on survivors who were taking off in new directions with renewed confidence, and I was profoundly saddened by the experiences of seropositive and symptomatic surviving partners. I found myself in their homes, offices, and hospital rooms, learning to negotiate San Francisco by car, and two-steppin' with a participant in a country/western dance bar. I also found myself feeling guilty. I could listen to their experiences, be moved to tears as I coded them, be amazed at their resiliency and often be overwhelmed by the amount of work that the study required. But, while I participated in their experience to a degree, ultimately, I could leave it. I could go home at night. I only had to listen and write about it. I did not have to experience it myself.

As the study progressed, so has AIDS. Greg's T-cell count declined to the 250 range, then, went up in to the low three hundreds. His count declined again to 200 and he began taking AZT. He has endured a long and painful bout with shingles, and periodically hairy leukoplakia appears on his tongue. The last few months have been difficult for him, but he continued to strive to make the most of his life. When I first began working on the project in 1986, there were less than 20,000 cases nationwide. Now, in June of 1989 the total is over 90,000. Eighty

thousand new cases are projected for 1992 (Perreten, 1989). AIDS has also encroached into my social network. Several friends have tested positive, several more have contracted the disease and several have died. I recently stumbled on a secret hope. I once hoped that the study would be more or less obsolete by the time it was finished. Obviously it is not.

Of the 39,000 new cases of AIDS projected for 1989, 56% or 21,000 were gay/bisexual men (Perreten, 1989). Sixty percent (the potential number of partnered AIDS patients) of that number is 12,600. Assuming the partnership rates of the two physicians' practices were a reasonable reflection, it is conceivable that in 1989 alone, approximately 12,600 partnered gay men will contract AIDS. That figure is more than the total number of cases reported nationwide in 1985, the year Greg and Stan first walked into my office.