

Nursing care partnerships at the Denver Nursing Project in Human Caring: An application and extension of caring theory in practice

Jean Watson's theory of nursing as the art and science of human caring provides the framework for practice at the Denver Nursing Project in Human Caring, a nurse-managed center for people living with HIV/AIDS. The purpose of this article is to describe the development, implementation, and evaluation of a new model of nursing practice at the Caring Center, called nursing care partnerships. Client and nurse narrative accounts are presented as a means of grounding the reader in the care partners' relationships that are formed during the journey of HIV/AIDS.

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JEAN WATSON'S THEORY of nursing as the art and science of human caring¹⁻⁴ guides the practice of nursing at the Denver Nursing Project in Human Caring. Also called the Caring Center, this nurse-directed outpatient facility provides nursing care to persons living with human immunodeficiency virus (HIV) and acquired immunodeficiency syndrome (AIDS). Recently, a new model of nursing practice based on Watson's work in transpersonal caring was implemented at the Caring Center. This model, called nursing care partnerships (NCPs), evolved out of clients' expressed needs for more comprehensive nursing care when negotiating the health care system. After several months of implementation, it appears that this innovative practice model is meeting its goal of empowerment of clients, nurses, and supporting agencies.

The focus of this article is threefold. First, an overview of the structure, functions, and theoretical basis of the Caring Center will be provided. Second, the development and

implementation of the NCP model of care in practice will be discussed. Third, the empiric efficacy of this new theory-based model will be demonstrated by presenting results of evaluation research, coupled with nurses' and clients' narrative accounts of the care partnership relationships. These narrative accounts are offered in an attempt to "... uncover meanings and feelings in ways that shed light on the contextual, relational, and configurational knowledge lived out in practice."^{5(p3)}

THE DENVER NURSING PROJECT IN HUMAN CARING

Program structure

The idea for a theory-based caring center for persons living with HIV/AIDS was initiated by hospital nurses concerned that these patients' health needs were not met in the traditional, cure-oriented disease care system. The Center was originally funded through cooperative agreements among three Denver hospitals and the University of Colorado School of Nursing, Center for Human Caring. In 1990, substantial grant funding from the Department of Health and Human Services, Division of Nursing, was awarded to the Center. The purpose of this funding was to expand the scope of outpatient nursing services and to investigate the viability of a nurse-managed HIV/AIDS center as an option in health care delivery.

Persons eligible to participate in services at the Center are those who obtain their primary HIV/AIDS care through one of the three sponsoring hospitals. Since 1988, the Center has recorded over 10,000 client visits; the number of client visits increases

monthly. The Center is utilized 400 to 500 times per month, primarily by men living with HIV/AIDS. Women comprise less than 5% of client visits, although numbers appear to be increasing slowly due to the increase in numbers of women with HIV/AIDS, coupled with special programs focusing on the needs of women.

The Center employs baccalaureate, masters', and doctorally prepared nurses as clinical nurses, clinical nurse specialists, researchers, and administrators. Levels of education differentiate levels of nursing practice at the Center, and nursing services are myriad. Medically supportive nursing services include IV fluid administration, blood transfusions, pentamidine treatments, medications, laboratory work, skin testing, and others. Independent nursing services include therapies to promote health and healing such as Therapeutic Touch, massage, and counseling. Nurses offer individual and group education regarding symptom management, disease processes, home management, stress management, medications, nutrition, safer sex practices, and others. Teaching, emotional support, counseling, and coordination of services often include both clients and their lovers, family, and friends. Client support groups are ongoing at the Center and are led by masters' prepared psychiatric nurses, psychologists, and psychiatrists.

Program theory

Watson's theory of nursing as the art and science of human caring¹⁻⁴ guides the practice of nursing at the Center. Watson's work provides nurses with a theoretical focus for humanistic, individualized nursing care to

persons living with HIV/AIDS and their family, friends, and lovers. According to Watson, persons are unitary wholes, subjective and unique, who possess inner resources and strengths that can be drawn on to meet health challenges. Rather than absence of disease, health refers to unity and harmony within mind, body, and soul^{2(p48)}; the goal of nursing is to help persons gain harmony within mind, body, and soul. This harmony generates "self-knowledge, self-reference, self-healing, and self-care processes while allowing increasing diversity."^{2(p49)} In Watson's work, care is primary to cure and is viewed as a moral ideal. Watson cites Gadow when positing caring as an end in and of itself, a commitment to the protection, enhancement, and preservation of the dignity of the other.¹ Watson's assumptions concerning person, health, nursing, and caring help nurses at the Center develop what Watson calls a "caring consciousness" as a guide to all nursing interactions. Watson states, "While such an ideal will not dictate specific behaviors, it will direct the nurse toward certain actions, and not toward others."^{4(p281)}

Program evaluation: The need for a new model of nursing care

Prior to 1991, a model of team nursing practice was in effect, with clients being cared for by any nurse available at the Center. In 1990, program evaluation research using focus group methodology was conducted to evaluate the strengths and weaknesses of the Center. Forty-eight participants formed the convenience sample for the focus groups; participants were clients; their family, friends and lovers; and staff

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persons of referring agencies. Results of the sessions indicated that the ability of the Center nurses to implement "caring behaviors" was considered the most important asset of the Center by all groups. These behaviors were described as flexibility, acceptance, unconditional support, lack of fear of contagion, touch, hugs (that smile and hug—makes a rough day better—it is that human connection), listening, competence, friendship, taking time out for clients, the ability to help clients make choices and be self-determined, and so forth. Analysis of areas to be improved determined several concerns, but the most recurrent was the need for better continuity and availability of Center nurses in crisis situations. A major frustration for clients who participated in the focus groups involved negotiating the complexities of the health care system during times of illness and wellness. Concerns were expressed over lack of formal follow-up of new clients or newly diagnosed persons with HIV/AIDS, and a more formalized system of support was requested for this vulnerable population. When interviewed about client follow-up, one participant stated, "We are victims of social dumping (family, work, insurance). For us (at the Center) to drop new people is criminal." The NCP model was designed to address these and other needs.

DEVELOPMENT AND IMPLEMENTATION OF THE NCP MODEL

The theoretical basis: Transpersonal caring-healing

Watson's framework of transpersonal caring-healing is the basis of the NCP relationships. According to Watson,⁴ transpersonal caring-healing is concerned with nurse-client relationships that preserve human dignity and humanity, rather than reducing persons to the status of object. This framework includes notions of both physical embodiment and transcendent metaphysical dimensions of caring-healing processes. The concept of intersubjectivity is central to transpersonal caring-healing relationships and is founded in the inseparability of humans from each other or nature.⁴ For Watson, transpersonal caring-healing involves an intersubjectivity between the nurse and other, a mutual entering into each other's lived experience through relationship. Both participants are influenced by the transaction, for both are in the process of being and becoming.⁴ Transpersonal caring-healing potentiates self-healing, for it "... is a means of communication and release of human feelings through the coparticipation of one's entire self in nursing. . . ." ^{2(p70)} In the process, both nurse and client may experience an intersubjectivity that enhances both participants' ways of being-in-the-world.

This notion of intersubjective caring-healing, as opposed to outdated models of terminal "care for" or "cure of" persons living with HIV/AIDS, is fundamental to the NCP model of practice. At the Center, both

nurse and client are considered equal participants in the care partnership relationship, and each participant has equal power to negotiate and renegotiate the parameters of the NCP relationship. As one client asked during a planning session, "If you're going to be my care partner, can I be yours?"

NCP vs case management models of care

Although the NCP model of practice emerged from discussions of nursing case management, traditional notions of case management were viewed as incongruent with Watson's assumptions of wholeness, individual choice and autonomy, intersubjectivity, and caring in nursing. Traditional methods of case management usually result in the implicit or explicit reduction of the individual to meet the needs of the health care system. Thorn⁶ describes case management in terms of first, second, and third generation models. First generation case management was physician controlled, acute in nature, and oriented toward cost-containment. Second generation case management was similar to first, but involved limited quality of care issues. Third generation case management is controlled by the person with the illness and committed to empowerment, self-care, improved quality of care, and cost containment. The primary point of contact for first and second generation case managers was an acute episode of illness that resulted in hospitalization; conversely, the entire course of a person's illness is considered the point of contact with third generation case management. The NCP model of practice is similar to Thorn's concept of third generation case management models of care.

NCP defined

Through conversations between the authors of this article, nurses, and clients of the Center, the NCP model of care was defined. NCPs are viewed as a care-enabling method that aims to establish authentic caring relationships between clients and nurses for the goal of mutual empowerment. NCPs are envisioned as the vessel that will help transport the client, with the help of the nursing care partner, through the often choppy waters of the health care system and the rough seas of HIV/AIDS. The analogy of journey is an appropriate one for both client and nurse. Although clients do not willingly choose the journey of HIV/AIDS, the nurse chooses to join the client, willing to share joy and pain, and willing to remain connected through caring processes.

The collaborative connecting process

When planning the NCP model, clients and nurses alike expressed a desire to choose their care partners; thus, in this model of care, both partners' wishes are equally considered when establishing and maintaining the NCP relationship. Role negotiation and renegotiation is recognized and valued as necessary for successful partnerships. Client participation in a care partnership relationship is voluntary, and not all clients actively participate.

New clients are initially interviewed by a nurse and encouraged to experience the Center for approximately 6 weeks before requesting a particular care partner. Clients familiar with the Center are invited to express their preference for a nursing care partner with the Clinical Specialist/Educa-

tor who, in consultations with the nurses, attempts to connect client and nurse preferences. Connections reflecting both partners' wishes were viewed as having the most potential for satisfaction for each partner. Partnership is viewed as a process, and the uniqueness of each client and nurse precludes any prescription for relationships. Instead, Watson's abstract notion of transpersonal caring-healing relationship is used by nurses as a guide for the care partnership relationships.

Phenomenologic, transpersonal caring interview

Congruent with the theory of human caring, initial and subsequent interviews of clients are approached using phenomenologic methods. Initially, clients are asked, "Tell me the story of HIV in your life." The nurse transcribes the client's story in narrative form, and, in varying ways, utilizes phenomenologic techniques (bracketing, analyzing, intuiting, and describing) in order to better understand the other's lived experience. "Is there anything else that you believe is important for me to know?" is asked near the end of the phenomenologic interview. Subsequent interviews are also recorded in narrative form. In addition, the current and future focus of the transpersonal relationship is documented through the use of Watson's carative factors.

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Carative factors applied and extended in practice

Watson's carative factors (CF) reflect the humanistic and scientific principles that are involved in nursing practice based on the theory of human caring. At the Center, no attempt is made to prescribe the use of the CF in documentation or in the care partnerships. Nurses individually select the CF they believe apply to the experience they are documenting. (See the box entitled "Watson's Carative Factors.")

An eleventh CF, "medically supportive care," was added by the authors to document medically supportive treatments such

as blood transfusions and medications, that were not explicit in the other 10 CF. The technical nature of giving medically supportive care at the Center is approached and guided by Watson's theory of human caring and the original 10 CF. Narrative phenomenologic notes concerning the NCP relationship follow the listing of carative factors. To document mutually determined plans and goals, the nurse indicates which CF may provide direction for present and future interactions (for examples of documentation using the CF, see the box entitled "Transpersonal Nursing Care Record Example").

Nursing care partner as consultant

Nursing care partners maintain contact when clients are hospitalized, both to provide emotional support and to facilitate the clients' wishes for care and to begin early plans for discharge. The nursing care partner is often the most knowledgeable health professional regarding the clients' current level of health, home living situation, and emotional needs; through consultation, this information can be quickly transferred to other professionals. Not only are hospital costs potentially reduced, but also the clients' wishes regarding treatment plans, emotional needs, home care, living wills, and so forth, are facilitated through this nursing consultation. Wallet-sized cards have been developed for clients to carry that designate the name of the nursing care partner and the Center's phone number. In the event of hospitalization, if a client feels the need for the care partner's assistance, the card is presented on admission. Instructions on the card are to call the nursing care partner for consultation regarding the client's care.

Watson's Carative Factors

1. Humanistic-altruistic system of values
2. Instilling faith-hope
3. Sensitivity to self and others
4. Helping-trusting human care relationship
5. Expressing positive and negative feelings
6. Creative problem-solving caring process
7. Transpersonal teaching-learning
8. Supportive, protective, and/or corrective mental, physical, societal, and spiritual environment
9. Human needs assistance
10. Existential-phenomenological-spiritual forces
11. Medically supportive care (added by authors)

Source: Watson J. Nursing: The Philosophy and Science of Human Caring. Boulder, Colo: The Colorado Associated University Press; 1979/1985.

Transpersonal Nursing Care Record Examples

Record 1

Present focus: CF4 (helping–trusting, human care relationship)
CF6 (creative problem-solving caring process)
CF8 (supportive, protective, and/or corrective environment)

Narrative: Client is very upset at having to discuss his sexual history with interviewers from Public Health. States he is worried about why they want all this personal information and what they are going to do with it. He is afraid they will ask him things he doesn't think they need to know and that the information will be used against him. Asked me to be present during interview, and I agreed. Public Health interviewer did not agree and told client "he had no choice" but to talk to them alone. Nursing staff supported client, and interviewer relented. Client was very cooperative during questioning, but often asked for my approval before he answered. Interview ended on what seemed a friendly note.

Future focus: CF4, CF6, CF8

Client greatly benefits by what he feels is a protective buffer between himself and "the system." He is easily overwhelmed by the numbers of people involved in his treatments and social services.

Also CF7 (transpersonal teaching–learning)

Will attempt to slowly introduce information about the function and purpose of different agencies, systems, etc, as they come up.

Record 2

Present focus: CF11 (medically supportive nursing care)

300 mg pentamidine given aerosolized per protocol. Vital signs prior to treatment—temperature 98.6, pulse 88, respiration 20, BP 110/70. Breath sounds clear bilaterally. Some bronchospasm during treatment, coughing. Posttreatment respirations 22 with scatter wheezes, pulse 96, BP 112/76. Alupent 0.2 mg/0.2cc normal saline, good relief after three breaths, pulse 100, respiration 24, BP 120/84. Normal, easy respirations in 15 minutes without color changes.

Future focus: CF11, CF6 (creative problem-solving caring process)

Will give short breaths of Alupent prn during next pentamidine administration in 4 weeks—continue in future treatments if helpful.

Caring for the nurse

The NCP program offers many opportunities for increased nursing autonomy, initiative, and innovation in practice; and Center nurses have discussed these factors as en-

hancing their satisfaction with the partnerships and nursing in general. The intensity and frequency of the care partnership interactions seem to increase as the symptomatology of AIDS progresses; nurses maintain relationships with clients and their families,

friends, and lovers during hospitalizations, home confinement, and hospice care. In order to do this, nurses self-schedule work times during the open hours of the Center. Self-scheduling enables the client and nurse to determine when care is needed, rather than trying to fit care needs into an externally imposed schedule.

Nurses are not expected nor encouraged to be immediately available outside the Center's open hours. Messages to care partners from clients received during the night are relayed to the nurse on the Center's opening. When hospital visits or consultations are required outside of open hours, nurses are encouraged to schedule time away from the Center in order to care for themselves. Nurses meet together at the end of each day at the Center for a brief period of mutual support and discussion of the day's events, called a "wind down." In addition, nurses often take advantage of the frequent therapies available at the Center such as massage, aerobics, Therapeutic Touch, support groups, Reiki, and meditation.

EVALUATION OF THE NCP

Program evaluation methods were built into the design of the NCP program in order to assess nurses' and clients' responses and to quickly implement changes as needed. These methods of evaluation included a nursing focus group about the partnerships, a random chart review of narrative documentation and use of the CFs, and an NCP evaluation survey that was mailed to clients. In addition, nurses and clients were asked to tell the researcher stories of their experiences in the NCP program. All are briefly discussed below.

Staff focus group

Focus group methodology was used to elicit the nurses' views of strengths and weaknesses of the NCP program. According to the nurses, the major strength of the program was empowerment of clients, nurses, and supporting agencies. For nurses, this empowerment meant several things: improved, more meaningful interpersonal relationships with clients and staff of referring agencies, increased knowledge of and ability to meet client needs, and increased continuity and responsibility in care for both clients and nurses. The nurses found the NCP program to be growth producing and "challenging, engaging, and mentally stimulating" for both their partners and themselves. Knowledge about clients was more easily transferred to other nurses, health professionals, and caregiving families, friends, and lovers when necessary. Nurses also felt better able to support each other with complex clients and better able to quickly recognize and intervene in the common problems in the health care system's treatment of people living with HIV/AIDS.

Potential cost benefits of the NCP for supporting agencies emerged from the focus group discussions. Nurses described themselves as better able to coordinate services, to assist clients to care for themselves at home, and to plan for home care when clients required hospitalization. Nurses cited several instances of supporting clients and families through health crises at home and agreed that emergency department visits or hospital admissions would have resulted had the partnerships not existed. Instances of decreased lengths of stay in hospitals, decreased "work up" time for other agencies, and decreased duplication of services were

also identified by nurses as potential cost benefits of the NCP.

Negative perceptions regarding the NCP program included the lack of undisturbed time to plan and coordinate services and confusion over new nursing roles. Nurses occasionally "felt lost" with the new role of care partner, usually when negotiating the social service system for clients. Ways to better utilize sponsoring hospital inpatient and outpatient social workers were discussed, and plans were made to formally enlist the help of experienced, long-term clients to assist newly diagnosed clients to negotiate the system. Although problems existed in the care partnerships, nurses decided unanimously to continue the program. It was apparent that the NCP model of care was highly valued by the nurses involved, with one nurse stating, "This is nursing."

Nursing care record documentation: Use of narrative and CF

After the NCP program had been implemented for several months at the Center, 20 randomly selected nursing care records were reviewed by the project director and research coordinator for narrative documentation, use of CF, and use of a present and future focus in documentation. Since the inception of the NCPs, 75% of charts reviewed contained narrative interview notes. Only 40% of the care records contained reference to CFs, and less than half contained both a present and future focus in documentation. Half of the charts reviewed evidenced continuity from one entry to the next. The most documented CFs were 4 (helping-trusting human care relationship), 6 (creative problem-solving caring process), 8 (supportive, protective, and/or corrective

mental, physical, societal, and spiritual environment), and 11 (medically supportive care). (See box entitled "Watson's Carative Factors.") During a staff meeting, the results of this review were presented to nurses in a form that preserved nurse and client anonymity. Ways to more meaningfully document the partnerships were discussed, and nurses elected to continue documenting the partnerships in narrative form, utilizing the CF. The meanings of the CF to each nurse were also discussed, with surprisingly high agreement between nurses regarding common meanings and situations of use.

Evaluation survey results

After 8 months of implementation, NCP evaluation surveys were mailed to all clients of the Center who agreed to allow mail to be sent to their homes. Response rate was expected to be low, for not all clients allow mail to be sent, and due to economic and health problems associated with living with HIV/AIDS, clients frequently change addresses. Because of HIV/AIDS anonymity issues, no return address or request to forward mail to a new address was used.

Of the 170 mailed surveys, 55 were returned; 26 were unusable because the respondents were not in an NCP relationship. Most of these respondents who were not currently in an NCP relationship were unaware of the program; others described themselves as physically well and not needing the service. Of those who had not yet been contacted to set up a partnership, nearly all indicated interest in the program, with several signing their names and requesting a care partner.

Twenty-nine of the respondents were currently in an NCP relationship, and results were tabulated for evaluation purposes. All

were male and ranged from 27 to 68 years of age. HIV status included 10% HIV positive, 48% AIDS related complex (ARC), and 41% diagnosed with AIDS. Self-reported quality of life and health status were highly related with those experiencing excellent health also rating quality of life as excellent. Conversely, those rating their health as "poor," also rated quality of life as poor.

The NCP program was viewed as "supportive" and "helpful" by all respondents. Ninety percent agreed the NCP relationship assisted them to better negotiate the health care system, while 92% agreed the nursing care partner helped them to understand their plan of treatment. When asked to write what they most liked about the NCP program, respondents wrote in "having an advocate," "the ability to translate what is happening," "using nursing help rather than hospital facilities," "emotional support, honesty, caring attitude," and "having someone to count on." Other written comments included:

I like how the level of information available through the NCP program is high as well as updated and current. It also gives me a broader perspective for decision making.

I like how someone familiar with the system and me is there to help me when I need it, when I am not able to handle situations. She knows what I want and can help greatly. I trust her ability and support.

When asked to write in what they most disliked about the NCP program, the lack of social service assistance regarding disability services was mentioned. Reflecting this concern, only 82% of respondents agreed that the nursing care partners referred them to social service agencies appropriately. As a result of this evaluation survey, better liaison with hospital social workers has been

established and more comprehensive efforts have been made to inform clients of the NCP program in order to set up the partnerships.

Client and nurse narrative accounts: The journey of partnership in HIV/ AIDS

As a final part of attempting to more fully understand the client and nurse's experiences in the NCP relationships, narrative accounts or stories about the relationships were elicited. At the Center, storytelling is viewed as a rich form of practice knowing, a means of grounding knowledge in the experiences of nurses and clients. At the same time, storytelling seems to assist both clients and nurses to make meaning of their experiences during the journey of HIV/AIDS. Bartol^{7(p565)} discusses how "story is a mode of self-knowledge that is characterized by both intimacy and distance." Bartol explains how telling stories enables humans to provide intimate accounts of experience that illuminate their own individuality, while at the same time allowing distance from and perspective on the situation.

Three nurses and three clients were asked to tell the researcher stories of being in an NCP relationship. All six people agreed to be interviewed, and each interview lasted less than 30 minutes. The six client and nurse stories follow.

Client 1

AIDS patients *need* nursing care partners, because once you have "AIDS dementia," confusion, or "history of poly-substance abuse" on your chart it's all over. No one hears or believes your symptoms anymore. It often feels like a constant fight with the health care system for us. Doctors and nurses seem

“The NCPs help the clients feel like they have somebody in their corner for a change.”

more worried about addiction to pain medications than about pain. The NCPs help the clients feel like they have somebody in their corner for a change.

I nearly died of a deep vein thrombosis that was ignored in spite of several trips to the emergency department; I think the doctors thought I just wanted pain medication. No one bothered to look at my foot or leg. I had no trust of doctors, and I thought I was dying; the pain was so bad. Then I got C (nursing care partner), and C looked at my leg and convinced them I needed to be evaluated and came over to the hospital with me that same day. I was admitted and had to stay for a month. The doctors told me I would have died if that deep vein thrombosis had continued untreated.

The same thing happened to my lover. M was burned during a procedure to the point that the plastic of the monitor leads burned into his skin. He kept saying he was being burned; please stop the test. At one point he stopped the test himself and sat up, saying he could smell his flesh burning, and no one bothered to look at his back. They just told him to relax and finished the test. Of course, once it was over and someone looked at his back, they got a doctor right away; he was treated for the burns. We wanted a way to make sure it didn't happen again to other people. Our NCP met with the patient representative and was assured that policies will be developed that at a patient's request (any patient, AIDS dementia or not), the test will be stopped and the patient's complaints listened to.

C was my guardian angel and probably will be again. She gives me perspective; some-

thing that is hard with AIDS. You never know if the fever will be anything, because to ignore a strange symptom sometimes means horrible things. C knows me and can see me through a lot of things that I might have had to go to the hospital for. I feel strongly about how much the nursing center can do for us and to save money and resources. Before, I had nobody to turn to, I'd lost my job and insurance. It feels like punishment to lose it all—the dukes go up. But C empowers me. She helps me review all my options, helps me handle things myself. If I could change one thing, it would be to make the Center available 24 hours a day.

Client 2

I'm very fond of my care partner; she is very good for me. Having one person as a liaison eliminates some confusion about who to go to about what with this disease. My care partner has taught me to ask for what I need and trust that I will get it. It's like having a strong support system in place. If I could change something, it would be to have more nurses at the Center; sometimes my care partner is busy with someone else when I need her. With AIDS, doctors often acknowledge that something is wrong, but at the same time say “there is nothing we can do”; there's a basic inequity with this disease. But I know I can always count on my care partner.

Client 3

When my care partner left the Center to go back to school, it was hard for me. I was close to S; we could sit and talk and laugh and cry together. I still talk to S sometimes, but it's not the same. I didn't come down for a few months after S left, and I realized that not coming to the Center was adding to my depression. I needed to be around people who cared about me. Coming to the Center was my only link here in Denver where people cared about me. I had to come back; they

care about me here. I'm beginning to get to know my new care partner.

Nurse 1

I think the NCP program helps avoid unnecessary emergency department visits. Often the clients are extremely anxious and don't know whether to trust their perceptions or not. Calling and talking to me is like somebody "holding" the disease for them for a while. With all these clients, the simplest thing can quickly brew into a very big thing, and at the same time they often deny they are even sick. Before the NCP program was started, one client had high fevers over a weekend; although he talked to a caregiver, he downplayed his symptoms. That evening his lover found him unconscious, and he was hospitalized in septic shock. If I had been in partnership with him and he'd talked to me, I would have known his patterns and told him to go on in to the hospital. He had a prolonged hospital course with that one.

Some of the clients have a medical problem list on their hospital charts whereby the first four problems are things like dementia, substance abuse, etc, and AIDS is last. This undermines their credibility with care providers. AIDS symptoms often need to be looked at right away, and clients become extremely anxious about their health. Sometimes the client is put off by the doctor or not listened to. AIDS treatment needs to be a cooperative relationship between client and caregiver due to the acute and chronic nature of the disease, but this often doesn't happen due to the paternalistic nature of the medical care system.

With this disease, it's not that uncommon that couples used to supporting each other in times of crisis become sick at the same time; the usual support system collapses so easily. When a client is caring for an ill lover, he often comes here for nursing support, someone to say "You did the right thing; sit down here and

have lunch; take care of yourself for a change." People become so selfless when the one most important to them is ill. This is a unique population, often alienated from family, depending primarily on their peers for support. Then their primary support system becomes ill, and they are in real need of assistance. It is often so overwhelming to work with these people; it is so hard to leave at the end of the day and leave the client behind. But I have to; I have to tell myself I've done all I can for him today. It's either that or I'll go under.

The NCP program is so important for this population; we empower them to know what to ask for, to know what is good care. We teach them the information they need *before* they go into crisis, and teach them to manage their own care in the hospital. We are in the process of doing an educational board on client empowerment, regarding what they need to know upon admission to a hospital. We put the care responsibility back on the client, because we can't be there all the time. It gives them a lot of work to do. I like the name "care partnership"; it means we both struggle through what happens in the course of the disease.

Clinical Nurse Specialist 1

One man I worked with came from a family that included an exwife, siblings, and children. None of the family knew that he was gay or HIV positive. Now he wanted to tell them the truth because he was ill, "to let them know who I am." We worked together several months to help him write letters to them all, telling them the truth. At first, he wrote one generic letter that over a period of months he was able to make member-specific. All the letters were sent out at the same time. This turned out to be a nice thing for the client; the family's reaction was positive. Perhaps more importantly, the process of writing out the letters helped the client gain clarity on his life and his relationships with his family. I think

the process of composing and sending those letters was more important than what he got back from his family.

I think my work with families (primarily mothers) of clients keeps clients out of institutions, because if the family is empowered to care for their children, everybody can get what they need. The ill child can die in a supportive, caring environment at home, and the family can lovingly care for the child throughout the process. I worked with one mother whose son was extremely angry and verbally abusive, taking his pain out on her. I worked with her about setting limits, what she was able to tolerate to continue to be able to care for him at home. He was able to stay out of the hospital, cared for by his own mother throughout his illness.

It often happens that a son has to move back home, sick, no job or insurance, and have to tell parents things they are not prepared for or willing to hear: he must tell them not only of his homosexuality or drug abuse, but also that he has AIDS. It is extremely difficult for both parents and children; a lot of autonomy is lost on both sides. My work is to get families together to talk to each other. It's tough, both sides are often angry and confused. But the rewards for all of us are worth it.

Clinical Nurse Specialist 2

A client with cytomegalovirus (CMV) retinitis was kept waiting for a long time by the eye doctor. When the doctor finally saw him, the client complained about the wait and the doctor said, "Don't be so impatient with me, it's not *my* fault you have AIDS." The client asked, "Are you implying it is *my* fault that I have AIDS?" The doctor said, "You would know your risky behaviors better than I." The client came over to the Center looking like he'd been punched in the stomach, sick, weak, and depressed. I went to the patient representative and complained in a rather

vocal manner; the representative was appalled and brought it to the chief of medicine. The eye doctor eventually apologized but refused to provide further care for the client. Later I overheard the client telling other clients at the Center how I'd stuck up for him. It was a source of pride for him that someone would go to bat for him when he didn't have the strength to do it for himself anymore.

Another instance I'll never forget is F and his pain. He was in so much pain and in a hospital system that wasn't responding to that pain. He needed IV pain medication, but hospital policy prevented administration of IV pain medication by nurses on the particular unit he was on. The nurses of the unit that *could* administer IV pain medications didn't want him; they had lots of issues about AIDS and communicability to other immunocompromised patients. After I worked with the patient representative and managers, the second unit finally relented and admitted the client.

I think throughout all this, F interpreted it as meaning he was getting ready to die and had better get his life in order. It was fall, and he decided he better have a Christmas party soon rather than wait for December. His family took him out on pass, and he bought everyone individual gifts and presented them at a party on the unit. I know that party was physically challenging for him, but he flourished being the center of attention, able to say goodbye. It was a nice ritual for his lover, sister, nieces and nephews, and for me too. The party was on Friday, and he died on Sunday—a peaceful death on IV pain medication.

It's a really different feeling working at the Center than in a hospital. On my first day there, a patient came in and said, "I have a problem and need to talk." I remember feeling kind of panicked and alone; in the hospital there are always lots of people to back you up. But that's also why I fell in love with the

place: I was able to make such a difference and do the right thing without having to beg for the privilege and go through all the obstacles to care that surround nurses in hospitals. It is the implicit honoring of *all* we do as nurses that is unique about the Center; the Center gives a sense of honor back to the clinical nurse. At the Center, we all realize that it is just as important to sit and hold someone's hand as it is to calibrate a central line for a cardiac output.

For me, caring is a willingness to fall in love (M.K. Maeve, unpublished data, 1988). There is a definite love relationship, but one which is different from the way I love my children, lover, friends, or family. It's very important that we are able to leave that love at the door when we go home for the night so we can continue to love in our own lives.

Eliciting client and nurse narrative accounts about the NCP relationships added contextual richness to the evaluation process, while at the same time being informative, focused, and congruent with Watson's transpersonal caring-healing work. It was apparent during this project that the intersubjective, transpersonal relationships that were formed during the care partnership model of practice assisted both partners to

find meanings in the journey of HIV/AIDS. The transpersonal nature of the NCP relationships is perhaps best described through the words of Marge Piercy:

. . . we walk at the wall very fast
holding hands and trying to act as if
we believe in an opening.
If we come through the stone
we come through
in an unknown place.^{8(p44-45)*}

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In response to client concerns for more comprehensive care, an NCP model of practice based on Watson's notions of transpersonal caring-healing was implemented at the Denver Nursing Project in Human Caring. Client and nursing responses have been very positive. It appears that integrating an NCP model of nursing with Watson's work in transpersonal caring is one means of applying and extending theory in practice.

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