
Negotiating Trust: A Grounded Theory Study of Interpersonal Relationships Between Persons Living With HIV/AIDS and Their Primary Health Care Providers

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This grounded theory study is an exploration of long-term interpersonal relationships between patients and their primary health care providers, including physicians and nurse practitioners, in an urban outpatient HIV/AIDS clinic. Many providers believe that the positive interpersonal relationship enhances the health care experience for the patient, but there is a scarcity of research in this area. Persons who are patients were interviewed (N = 14) to look at these relationships from their points of view and develop theory to guide clinicians in forming such relationships. Theoretical sampling was used to find patients in this clinic population involved in long-term relationships with their providers. Open-ended interviews were conducted. These data were coded using the grounded theory method of constant comparative analysis. A basic process of negotiating trust was identified. Trust in these relationships is a state that is dynamic, volatile, and constantly renegotiated during the trajectory of the relationship through time. The trusting relationship is personally supportive for patients and may be a factor in the satisfaction found among health care providers in this clinical field despite the nature of this epidemic.

Key words: *HIV/AIDS nursing research, HIV/AIDS nurse practitioners, nurse-client relationships, health care provider-patient relationships, grounded theory, qualitative nursing research*

Persons living with HIV (human immunodeficiency virus) infection or AIDS (acquired immune deficiency syndrome) must call on all available resources to help

themselves deal with their situations. The individual health care professionals with whom they come into contact during this period may become sources of personal support. Since the early days of the HIV/AIDS epidemic, clinicians in this field have noticed that some patients may identify and use their personal relationships with their health care providers as parts of their personal support networks. Personal connections between persons living with AIDS (PLWAs) and their clinical health care providers may evolve into long-term relationships and remain supportive for long periods of time. As life expectancy continues to increase among PLWAs, clinical care remains an important part of maintaining wellness through medications and monitoring. In addition, the interpersonal relationship between the health care worker and the person living with HIV may continue to increase in importance.

The purpose of this study was to explore the nature of interpersonal relationships between persons living with HIV/AIDS and their primary health care providers. The research question was the following: What are the processes and properties of the interpersonal relationship between the health care provider and the patient in the act of providing ongoing primary health care to persons living with HIV/AIDS? The grounded theory method was used for data analysis. This method, developed by Glaser and Strauss (1967), is used to build theory inductively from qualitative data. Its founders viewed theory as continually developing, never a

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finished product, and similar to the nature of human relationships. Grounded theory is descriptive and exploratory (Chenitz & Swanson, 1986) and is especially useful in areas such as this one in which little research had been done until recently (Garvin & Kennedy, 1990; Morse, 1991).

Review of the Literature

As the HIV epidemic evolves, social research into the experiences of those living with the disease has become a research focus in addition to clinical research on the treatment of disease. Nursing has strong ties to the social sciences (Morse, 1995) and has its own substantial literature on interpersonal relationships between nurses and patients. Therefore, nursing is in a good position to take a leadership role in this type of research.

Interpersonal Relationships

Nursing theorists have examined the interpersonal relationship in nursing care since the earliest days of theoretical nursing. Peplau (1952) defined mental health nursing as an interpersonal relationship, and Orlando (1961) expanded this definition to include other clinical areas as well. Travelbee (1971) considered the interpersonal relationship to be the primary value in the nursing of patients. Paterson and Zderad (1976) theorized that the uniqueness of each individual—nurse and patient—be recognized equally in the relationship; they deconstructed the history of teaching personal reserve and detachment in nursing, advocating increased personal involvement with patients. This type of involvement is happening in the HIV/AIDS clinical field as well as others, and a greater understanding of this phenomenon is needed to use this involvement for its potential therapeutic value. The process found in the present study, negotiating trust, helps to clarify the components of these relationships.

Four qualitative studies in the substantive area of interpersonal relationships, which were based on interviews with nurses only, were reviewed (Heiffner, 1993; May, 1991; Morse, 1991; Ramos, 1992). Each of these studies acknowledged the role of the interpersonal relationship in nursing and found the quality of

the relationships to be enhanced by increased recognition of the individuality of the other person involved.

One study based on interviews and observations with both nurses and patients was by Fosbinder (1994). In this study, Fosbinder used a qualitative ethnographic approach and found the following four processes that addressed the dynamics of the relationship: (a) translating, in which the nurse interprets the health care environment for the patient; (b) getting to know you, in which “interpersonal clicking” occurs between them; (c) establishing trust, in which the patient’s confidence in the nurse grows; and (d) going the extra mile, which includes the nurse being a friend.

Trust

Trust is an important concept in clinical interpersonal relationships (Johns, 1996) as in all aspects of human life and relationships. In nursing, trust has been viewed as both a process and an outcome and has been previously described as both fragile and built over time through a process (Morse, 1991). Washington (1990) described trust as a continuing process in critical care nursing. Trust has been shown to be a factor in patient acceptance of treatments (Semmes, 1991). Recent researchers have speculated that the trusting relationship between provider and patient is a factor in HIV antiviral therapy adherence (Chow, Chin, & Fong, 1993; Crespo-Fierro, 1997).

Methods

Grounded theory methodology (Glaser, 1978; Glaser & Strauss, 1967; Strauss & Corbin, 1990, 1994; Strauss, 1987) performed in a clinical site can resonate for clinicians, even those not previously familiar with the methodology. The goal of this grounded theory is to discover processes based on the perceptions of patients of which clinicians may be aware as they engage in clinical practice. This methodology is based on symbolic interactionism, originated by Mead (1938) and subsequently described by Blumer (1969). Symbolic interactionism is based on the following three assumptions: (a) Human beings act toward things on the basis of the meanings that the things have for them, (b) the meaning of such things is derived

from or arises out of the social interaction that one has with one's fellows, and (c) these meanings are handled in and modified through an interpretive process used by the person in dealing with the things he or she encounters (Blumer, 1969). This is simply to say that meaning is the result of a process of interaction plus interpretation by persons; to understand the meanings of things to people, a researcher has to understand the interpretive process.

Sample

Fourteen interviews with individuals diagnosed with either HIV infection or AIDS were completed by the author. Interviews lasted approximately 1 hour and were tape recorded and later transcribed by a transcriptionist with no knowledge of the clinic. Of the participants, 11 were male and 3 were female. The male participants ranged in age from 30 to 57 years, with a mean of 43.7 years. The females ranged in age from 33 to 34 years, with a mean of 33.3 years. Ethnicity among the men included 7 Whites, 3 African Americans, and 1 Latino; the women were all White. Only 1 male and 2 female participants were employed; the remainder were living on unemployment or disability benefits. The time in the primary care relationship with the present provider ranged from 3 to 12 years for the men, with a mean of 4.7 years, and ranged from 3 to 5 years for the women, with a mean of 4 years. In terms of gender ratio, age, and race, these individuals approximate the HIV-infected population of San Francisco but not that of the nation, which may now have a more equal gender ratio and a higher percentage of minority group members.

Primary Care Providers

The primary health care providers are physicians, nurse practitioners, or physicians' assistants. For the purposes of this study, these professions are considered a single group with similar functions when providing primary health care. In the United States, these three professions are the ones generally acknowledged to provide this type of care (Sharp, 1996). Primary health care is the provision of integrated, accessible health care by clinicians who are accountable for addressing a large majority of personal health needs,

developing a sustained partnership with patients, and practicing in the context of the family and community (Institute of Medicine, 1996).

Procedures

This research process consisted of semistructured interviews. These interviews were prescheduled and took place either in private rooms in the clinic or in patients' homes. They lasted about 1 hour. After obtaining the approval of the appropriate human subjects committee to conduct the study, I recruited from among the patients in the clinic in which I am a primary care provider. Following the selection technique of theoretical sampling, I approached patients identified as having long-term relationships with their providers. Some of the interviewees were my own patients; some interviewees were referred to me by primary care provider colleagues who were aware of my research. I sought out patients who had well-functioning relationships and also those who had difficult or conflict-filled relationships. In theoretical sampling, the researcher collects and analyzes data at the same time so that emerging theory determines the direction of subsequent interviews (Glaser & Strauss, 1967). I told patients about the study, and if they were willing to participate, I made an individual appointment for an interview. When we met for the interview, the participant read and, if willing, signed an informed consent form. No participant who showed up for the scheduled interview appointment refused to sign the consent form. There were five appointments made for interviews that were not kept by the patients. In these cases, I acknowledged the power differential that makes it difficult for some people to directly say no, followed up with a phone call, and asked the patient if they would like to reschedule. If not, I told the patient it was okay not to participate and reassured them there would be no consequence regarding their clinical care. The issue of no-shows is discussed in the Discussion section of this article.

Doing research in one's own clinical site remains controversial. A number of qualitative researchers in nursing have advocated doing research in one's own community or clinical site (Boyd, 1993; Field, 1991; Paterson & Zderad, 1976; Sandelowski, 1991; Schutz, 1994). Field (1991) pointed out the potential problems

and concluded that research in one's own clinical site may be possible in a unique clinical setting with no equivalent, when the research question is clearly defined, and when the researcher is aware of potential problems. The site and researcher in the case of this study met Field's (1991) criteria. Also, the units of analysis in this study were the relationships being observed in the setting, not the setting itself (Lipson, 1991).

Findings

Basic Process: Negotiating Trust

A process is an analytic conceptualization for explaining change over time and explaining why actions and interactions either succeed or break down (Strauss & Corbin, 1990). The process discovered by this study has been called *negotiating trust*. In this case, the process is a concept central to the dynamics in the interpersonal relationship between health care provider and patient that helps to explain the formation of these relationships and has potential to help primary health care providers to be more aware of the importance of these relationships when participating in them. Processes have trajectories, or courses of movement through time (Strauss, 1987). *Trajectory* is a condition of the process of both initially developing and then later in time of negotiating trust. Although we have a tendency to think of a process moving through linear time, it is important to realize that the process can create a convoluted course through time, double back and repeat itself, jump suddenly in a nontemporal sequence, and of course, not occur at all.

The concept of negotiating trust has the potential to explain a very wide range of attitudes, conditions, and consequences. This gives it the status of a core variable (Glaser, 1978) in that it may account for most of the variation in the behavior about the problem. It can span the range from the completion and success of the process of negotiating, which results in long-term interpersonal relationships, to the failure of the process, which results in the failure to achieve such a relationship.

Development of Trust

Trust is built slowly over time as part of a process, including encountering and appraising the other. Trust may take a while to develop because of both the patient's prior experiences with life in general and with the health care system specifically. Having been treated as stigmatized or marginalized due to sexual orientation, intravenous drug use, or other unconventional activities, these individuals' attitudes about the health care provider are initially cautious and show resistance to the process of negotiating trust. The quotes that follow show initial attitudes on the parts of participants that demonstrate initial caution about trusting the health care provider. For example, one participant states his resistant attitude directly in the following statement: "I'm not really a person who puts all my faith in one doctor."

This participant is cautious but willing to compromise, showing an openness to negotiate a tentative relationship with the nurse practitioner but also setting limits and reserving an option should the relationship fail.

Another participant states, "If I really like somebody, I would be willing to work something out with [the nurse practitioner] if we had conflicts. If I didn't really like the person, I might just switch and not talk about it." This individual, who initially met her nurse practitioner through her participation in a clinical trial, reflects back on the process of negotiating trust with the nurse practitioner. She had expected to see the nurse practitioner only during the trial, and the event that allowed her to develop trust was the nurse practitioner's willingness to continue the relationship past the phase initially called for: "I think it took a while to trust [the nurse practitioner] because I thought that when the study was over, she'd say no, but she told me it's very important that I keep coming back."

Several patients identified trust quite specifically as an important condition in relating to the health care provider. It can be seen how trust is both a condition and an outcome of the process of negotiation. In the following statement, another participant expresses the need for trust going into the relationship before the specific provider is identified:

I tend to get people I really trust. And if I'm seeing someone that I don't really trust a lot, I'll switch people. It's a person who listens to me, really listens, doesn't just go "uh huh," but really listens. I know the difference, you know.

Another individual reflects on the effect of time contributing to the development of the relationship. The passage of time during which the relationship with the nurse practitioner goes on leads to more intimate mutual knowledge and the deepening of the connection between them.

As the years passed, like in any relationship you have with a person, whether platonic or intimate, we began to know each other on a personal level. And I found [the nurse practitioner] to be exciting, very funny, but serious and knowledgeable about my disease.

The following two quotes from the data demonstrate the patients' defensive attitudes when they come into contact with the health care system and how the individual nurse practitioners were able to overcome these attitudes by demonstrating acceptance of the patient. In the first quote, the defensiveness comes from the patient's perceptions of health care providers based on his own previous treatment.

She [the nurse practitioner] never gave me the feeling like, ooh, a drug addict, that kind of feeling like they do downstairs [in the Emergency Department]. . . . That was really degrading. I saw it before my name, they put "shooter," and just kept going on and on about how bad drugs are.

The next quote from a different participant shows the patient's process of negotiating trust with the nurse practitioner based on the nurse practitioner's skills and the quality of the interactions between them despite the participant's initial and ongoing awareness of the class differences.

She [the nurse practitioner] talked to me and said what was good and what she thought we should do. And I said, "Well, do you really think so?" And she said, "Yes." And I said, "Okay." I'm not

sure what it was, but as she gradually got to know me, talked to me more, and got me to come out and talk to her, she didn't try to just jump on me. Like I was really vulnerable, and I think she recognized that and just let me get to know her and she never made me feel stupid when I asked questions. . . . I think that a lot of doctors are oblivious to your own personal situation and what you might be going through in your life besides dealing with them. I mean, they might be perfectly good people, but they don't have a clue as to what it's like to sleep in Golden Gate Park and be beat up, you know?

Conditions Under Which Trust Develops

The next two participants identify trust as an important ingredient in the specific relationships they already have with individual health care providers and are able to describe the conditions under which trust has developed. For one of these participants, the condition is relieving fear, and the way the condition is realized is by the nurse practitioner accepting and explaining.

I guess it's just the trust I have. [The nurse practitioner] has never made me feel scared, never made me feel like I didn't know what I was doing, or always explained to me what was going on in ways I could understand. I've never been scared to ask anything.

For this participant, the condition of trust is the nurse practitioner's personal knowledge and understanding of her: "I trust [my nurse practitioner] because [she] knows me and she knows what I've been through and she knows my weaknesses and strengths. If I need to know something, she knows how to calm me down."

The conditions under which trust can develop are those that are necessary for the process of negotiation to go forward. In the following statement, another participant describes one of the conditions he needs for the negotiation of trust, that of stability through time: "It's nice to have somebody that knows you that long, and what's happening with you, and you don't have to keep explaining it over and over again."

The Range of Consequences of Negotiating Trust

The basic process of negotiating trust has power because of its possibility to explain a wide range of consequences of the process. These successes and failures in negotiating trust may be either on the part of the patient or the health care provider.

Personal authenticity plus the development of a high level of trust can lead the relationship to a transcendent level and lead to true appreciation of the uniqueness of the other (Paterson & Zderad, 1976). The most desirable consequence of the development of trust is a relationship for the patient that contributes to his or her support system. Some patients have impressive insight into the process of creating the relationship, the role of trust in the relationship, and the consequences of development of trust.

And my relationship with [the nurse practitioner] helped me more than any medicine did, my self-esteem, my feelings about life, and just about the person that I am. The relationship we developed . . . enabled me to make relationships in the future with other people because I can open up and trust a little bit more with everybody.

For the health care provider, the situation of these relatively young individuals with terminal diagnoses and uncertain futures, including the possibility of illness, pain, and suffering, must be acknowledged. The mortality issue must be addressed frankly when the patient brings it up.

Basically, I don't think about the future. I think about what is happening now, just really zooming in on the present day, and what is going on, and I don't feel like, oh, now, I'm on D4T and 3TC and I'm just going to be fine. . . . I really feel that I have a lot to live for, and I want to live, and I feel it is possible to go about my business as I have and manage the disease. And I'm still here. Whether I will be here in 2 years or not, I don't know.

A consequence of the successful negotiation of trust that may cause conflict for providers is the expectation some patients have of their provider for "presence" and even assistance at the end of life.

The only other thing I feel bad about in our relationship is "the end." And that to me involves that some people die un-self-delivered. I understand the ethics of it, and I understand the legalities of it, and I know it's not your fault as much as society's, but I feel bad to think that there will be a time when it comes to the end, you know; I would really like to feel that you would, you could be there.

The health care provider who acts in a way that indicates discomfort or fear during the actual discussion of death risks failing to create the trusting relationship with the patient, the most negative consequence in this situation.

In addition, patients provide descriptions of other perceived failures on the parts of providers to negotiate trust from their patients' points of view. One failure of trust on the part of an emotionally smothering physician to appear sincere is described as follows: "One particular doctor, I know it was from her heart, but she was always cuddling and would say, 'You have been through horrible trauma, darling,' and that was just as bad as putting up a wall."

The failure to provide adequate information is another perceived failure on the part of the provider.

She really never told me too much about my T cells. I really had to crank it out of her because she was telling me the T cell count was something to look at, but it shouldn't alter your head about your own health. And I would think, "Oh my God, my T cells are dropping."

The patient's perception of the provider as "burned out" also accounts for a failure to negotiate trust.

If it is a constant thing, month after month, illness after illness, then either the health care provider is not providing the health care the patient deserves, or he is just going through the motions because he is totally burned out.

Of course, a patient's perception of the hierarchical nature of a typical traditional health care relationship as well as a defensive stance regarding perceived homophobia on the part of providers creates a barrier very quickly.

I don't like that doctor-patient relationship where you feel like it's "Yes sir, no sir." I'd much rather feel like I could be honest and say, "I've been putting coke bottles up my butt and that's why it's hurting but we need to repair it." So that you know what's going on. You know, I don't like to play those games. And they don't want to listen, they just immediately assume because you're a homosexual with AIDS that this is what you've been up to and you don't know any better to stop.

Discussion

Trust

The concept that participants mentioned most consistently in all interviews was that of trust. Trust appears not to develop in a linear fashion and then once achieved stabilize and become the bedrock of the relationship. At various times in the relationship, the trust in the health care provider is reassessed by the patient, and decisions are made whether to continue to make the personal and emotional investment in the relationship, to take therapeutic advice, and to come back. Therefore, rather than a single point that can be reached and maintained, trust is a state of mutuality that is dynamic, volatile, capable of rupture, and may be negotiated and renegotiated at various times during the process of creating and maintaining the relationship.

Trust in the Interpersonal Relationship

The importance of the interpersonal relationship between nurse and patient has been a part of nursing's traditions at least since Peplau (1952) and continues to be a current area of theoretical interest in nursing (Gastmans, 1998; Hartrick, 1997). As nurse practitioners integrate the traditions of nursing with the primary care role, it is hoped that they will carry humanistic models of nursing practice and research based on nursing's interest in the interpersonal relationship into their primary care practices (Gastmans, 1998; Pateron & Zderad, 1976). In doing so, the concept of trust continues to be an essential aspect of the relationship, based on listening to people who have been in relationships with nurses (Hartrick, 1997) and with other

primary care providers (physicians and physician assistants).

The cumulative development of trust is a consequence of the process of negotiating trust. At the initial meeting, the patient responds to the provider and makes a decision whether to see the provider again. If the initial encounter is successful, further appraisal is made in terms of the patient's expectations. If the patient decides to work with the provider, for however long a period, they enter a period of mutual investment in which their commitment to work together on the patient's health care, their personal connection, and their trust of each other continue to develop and be negotiated. Awareness of the complex and variable course of the growth of trust over time may help primary health care providers to maintain their commitments to certain patients when the relationship is difficult and frustrating, as well as to maintain empathy.

Trust in the Institutional Context

As well as an interpersonal dynamic, trust occurs in the context of the institutional health care environment and is created within the context of the social relationships of health care (Gilbert, 1998); there exists an organizational dimension of trust (Johns, 1996). In this analysis, trust is both the process between the two individuals in the relationship and the outcome or product of the successful negotiation of the nature of the relationship (Morse, 1991). As the product of negotiation, trust has the properties of a collective process that exists in an institutional context (Johns, 1996). Because the development of trust is described in the data as a process occurring in context and through time, it must be asked what the effect has been on the development of trust by the contemporary trend in health care of seeing patients as quickly as possible to manage economic efficiency (often referred to as *managed care*). The time factor may have implications for the medication adherence issue: Is trust in the provider a factor in the acceptance and understanding of complex medication regimens? In addition, mergers of hospitals, an unstable situation regarding availability of primary care offices, and fluctuating hospital and clinic staffs due to increased privatization of health care may lead to uncertainty for consumers, which may greatly impair the development of both personal trust in providers

and trust in health care institutions (Johns, 1996). Further research into the concept of trust, its component factors, its role in clinical relationships, and its implications for patient care is indicated.

Limitations

This study is small in numbers, and further qualitative research is needed to develop some of the concepts and explore other possible categories not reported here. For example, whereas the core category of negotiating trust is exciting in its potential to explain a wide range of possible relationships, only the positive side of the spectrum is discussed here. There are questions on the part of the patient that must be answered before the successful completion of the early process of appraisal can occur and a comfortable relationship with a provider can begin.

For this study, I spoke to patients who have stayed with the provider to whom they were initially assigned and to some who have switched around among providers within the clinic. These patients have been identified as having long-term relationships and seem to be capable of the flexibility to adapt to the provider to whom they are assigned or perhaps the second one they "try out." Those who switch around repeatedly may be the patients who are least capable of forming relationships altogether and may not have been identified as suitable for these interviews. I approached five individual patients who I knew have had problems maintaining relationships with any provider, and all of these individuals failed to keep interview appointments. They may be the patients with the least ability to form relationships and who fail to get the care they need because of this inability.

Another limitation is that this study includes only the patients' points of view. Providers are equally active in the formation of relationships. I believe that the quality of the interpersonal relationships that we have with patients may be a factor in the process of providers finding satisfaction in the HIV/AIDS clinical field despite the high stress level. Although it is acknowledged that work with HIV is more stressful than many other fields of health care, it is also possible that intellectual stimulation and career satisfaction may be higher with health care workers in the HIV field (McKusick, Horstman, Abrams, & Coates, 1986). Our

high level of professional satisfaction may be part of what we need to communicate to the other health care workers who may be fearful of AIDS patients and of working with them. Additional studies are needed that will interview both patients and providers or perhaps pair them for interviews.

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