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Long-term interpersonal relationships between patients and primary health care providers in an AIDS clinic

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Long-Term Interpersonal Relationships Between Patients and Primary Health Care Providers in an AIDS Clinic: A Grounded Theory Study

by

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dedicated to

Constance Wofsy

and

Anselm Strauss

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This study is the result of questions which arose during my fourteen years as a nurse practitioner in the HIV/AIDS outpatient clinic at San Francisco General Hospital. During that time I have been a staff member of the University of California, San Francisco, San Francisco General Hospital AIDS Program, directed by Paul Volberding, M. D. I am grateful to the management of the program, and especially John Stansell, M. D., for allowing me the flexibility to do graduate work and research while a staff member. I am indebted to my physician, physicians' assistant, nurse, and most of all nurse practitioner colleagues for general personal support and clinical advice over the years, and for referring their patients as participants for this study.

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ABSTRACT

INTERPERSONAL RELATIONSHIPS BETWEEN PRIMARY HEALTH CARE PROVIDERS AND PATIENTS IN AN OUTPATIENT AIDS CLINIC: A GROUNDED THEORY STUDY

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 the relationships from their point of view, and develop theory to guide clinicians in forming such relationships. Theoretical sampling found patients in this clinic population involved in long-term interpersonal relationships with their providers. Open-ended interviews and memos were generated. These data were coded using the grounded theory method of constant comparative analysis.

Three phases of the relationship were found: *Accounting, Appraising*, and *Mutual Investment.* A basic process of *Negotiating Trust* was identified. Trust in these relationships is a state which 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 adherence to the complex medical regimens characterizing this period of the epidemic.

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CHAPTER 1

INTRODUCTION

Since the beginning of the Human Immunodeficiency Virus (HIV) epidemic, whether appropriately or not, the disease has been associated with certain minority groups in the population. This fact has polarized the disease and greatly colored the societal response to it. No aspect of the experience of either the afflicted or those caring for them has escaped the effects of the social polarization which has accompanied this epidemic. This has been a profoundly political disease (Adib & Ostrow, 1991; Singer, 1994).

While in the early days of Acquired Immune Deficiency Syndrome (AIDS) care, those of us involved had no idea what would happen in the future, most firmly believed that we would quickly "conquer" the new disease in the medical sense of "combating disease," and that a cure would be found quickly and losses would be minimized. However, this was not to be the case. As we now know, the epidemic would be of long duration. At the time of this writing, it is generally acknowledged that the HIV epidemic will be with us for the remainder of our health care careers.

In the early days of the epidemic, when "the cure" was seen as the only priority, clinical trials were begun to test pharmacological agents. Now, as the longevity of the epidemic has become apparent, the focus of research is becoming more broad. Although clinical trials of drugs continue, social research into the lives and responses of both patients and health care workers is being done by social scientists as well as clinicians. This large and long-term commitment to HIV and AIDS research is, in a way, sad to me, in that it carries within it a resignation to the long-term presence of the epidemic. Dr. Marcus Conant, on the radio program Fresh Air (National Public Radio, 12/1/94), recalled that he remembered when we thought of this thing as being like legionnaires' disease or toxic shock syndrome in that we thought we would quickly find a cure for it and move on. This, however, has not been the case. Now, over a decade into the HIV epidemic with so many afflicted and dead, the disease remains without cure and indeed the situation only looks like it will get worse world-wide, particularly in certain populations.

With the large amount of morbidity and mortality among relatively young individuals in San Francisco, the epidemic has had a major impact on the life of the community, shaping the experiences of illness, the sharing of grief, and the receiving and providing of health care. Gay men have unfortunately been the victims of an historical accident in the spread of this infection. In the western countries, due to the means of transmission of this virus, gay men have constituted an isolated group within the population in which transmission occurred more frequently than in most other sectors of the community (Vandevyer, 1993). By the time of the discovery of the causative virus, in 1985, many health care providers, including nurses, physicians, and others, had gotten involved in AIDS care. As a nurse practitioner who had previous experience in providing clinical care based in the gay male community, and in terms of the majority of the HIV clients in San Francisco having been gay men, I became involved early in providing care for those with HIV and AIDS.

In the gay male community, the disease has been politically and socially loaded. Some of us involved in HIV care in the gay male community like to think that the response of this community has been unique. The world-wide and even the national impact of HIV is too big a subject to deal with here, but I believe that the experience of the gay male community in the United States with the HIV/AIDS epidemic has some lessons for health care workers and qualitative researchers interested in understanding the response of the human individuals involved, whether as persons living with HIV/AIDS, caregivers, or community members.

This study is an exploration of interpersonal relationships between persons with HIV/AIDS and their primary health care workers. The setting is an outpatient clinic dedicated to HIV/AIDS care, in which persons with the disease who live in the community come in for pre-scheduled appointments on a regular basis with the physician, nurse practitioner, or physicians' assistant who is their outpatient care provider on a regular long-term basis. No specific length of time is assigned to "long-term," the relationships are based on the perceptions of the providers and patients. These relationships exist at the cutting edge at which health care takes place. Research into the outcomes of nursing interventions is important if applied programs of health care delivery are to be well designed (Zeller, et al., 1993). Equally important is to examine the experiences and perspectives of the persons actually involved in this activity, for programs to truly serve the people who need and receive their services (Denzin, 1989). This may especially true with the issue of adherence to the complex treatment regimens currently appearing in the lives of many personal living with HIV/AIDS.

Aim of This Study

My personal experience as a primary health care provider has been that this aspect of my own career has been profound. Personal connections with patients have often been the part of my work that has helped me to appreciate the diversity of human experience, and learn to analyze my own experiences and those of others (Denzin, 1989). In addition, I have learned to appreciate the experience of the meeting with the "other" in need, which some philosophers and theorists consider the most basic human interaction (Martinssen, personal communication, 1997; Paterson & Zderad, 1976; Buber, 1958). I undertake this research with the aim of trying to share this experience with my clinical colleagues and contribute to the dialogue among us, already ongoing, on how we process this overall personal experience as individuals as well as professional persons.

Research Goals

My research goals are (1) to use the interview process to capture the subjective experiences of the individuals participating in these relationships, and (2) to generate theory to help guide clinical practice in the HIV field. The research participants interviewed are persons living with HIV who are the "patients" in these relationships. A number of studies have focused on the experiences of nurses (Larson & Ropka, 1991), and it is important to learn about these relationships from the patients' point of view. Capturing the subjective experience is important because the worlds of the patient and the health care provider may be quite different, and relationships may fail due the provider's failure to be able to see the relationship from the patient's view. For example, it may be frustrating to me when my patient takes a "drug vacation," but do I really know what it's like to have to take a lot of pills every day with no end in sight? I may not like it when my advice isn't followed by patients, but do I really know the experience of hearing that advice from their point of view, or how the differences between us affect the advice-giving process?

Theorizing about clinical practice can be seen as the provider's own "dialogue with reality" (Zderad, 1978) as he or she reflects on practice with patients. Combining subjective reflection with available qualitative research methodologies can lead to the organized study of experience, which can fill in the missing pieces of understanding clinical practice, create strategies for better clinical practice, lead to the sharing of experience and wisdom among clinicians, and, most importantly, lead to a better quality of care for patients.

I used the grounded theory methodology, open-ended dialogic interviews, and my background in the HIV/AIDS clinical field, as influenced by assumptions of feminism and subjectivity which are parts of my theoretical stance. Grounded theory is descriptive and exploratory, and is useful in areas where little research has been done (Chenitz & Swanson, 1986).

In this study, as in my clinical practice in primary care, although in a field in which medical technology is highly utilized, I take the philosophical position that the basic element of nursing is an interpersonal relationship between two persons in their roles as "nurse" and "patient," as do the theorists cited in Chapter Two.

Summary of Contents

Chapter 2 describes the aim and background of this study in terms of building theory for health care practice for nurses and other health care professions, and the unique situatedness of the field of study of the interpersonal relationship between health care provider and patient within the domain of nursing. It also discusses the social and political contexts of the HIV epidemic, its relationship to the gay male community which brought me into HIV/AIDS care, and the issue of medication adherence which is currently an important issue in this clinical field. This chapter also includes a review of the nursing literature on this substantive area.

Chapter 3 discusses the methodology for the study and describes what happened in the field.

Chapter 4 contains descriptive data and provides some background into the clinical site. Chapters 5 and 6 contain the findings: Chapter 5 describes the phases of the relationship as a theoretical construct for health care providers to utilize in understanding the process through which the patient may go in the act of finding and receiving clinical care; and Chapter 6 discusses the basic social process of negotiating trust between the patient and provider.

In Chapter 7, I discuss the analysis of the data, linking it to current issues in practice, areas for further research, and I discuss limitations.

CHAPTER 2

BACKGROUND, CONTEXT, AND LITERATURE REVIEW

Background

I have specifically focused on the nature of ongoing interpersonal relationships between health care providers and patients during the HIV/AIDS epidemic. I have often discussed these relationships with fellow clinicians over the years. Many of us in the HIV/AIDS clinical field have observed that these interpersonal relationships influence the nature of the care the patient receives at the health care site. Many of us believe that a high quality interpersonal relationship between the health care provider and the person receiving care may influence such factors as the regularity of care, promptness of evaluation by the health care system at moments of crisis such as acute illness, and the acceptance of medications which may be highly toxic or controversial in efficacy, and adherence to medication regimens. These are only a few examples of possible areas in which the interpersonal relationship may have influence.

In nursing in general, experts acknowledge that although there is a large literature on the nurse-patient interpersonal relationship, this relationship is poorly understood and there is a need for research in this field (Garvin & Kennedy, 1990). This is part of nursing's general lack of middle-range substantive theories to explain the everyday world of nurses and patients interacting together (Hutchinson, 1993). In the HIV/AIDS clinical area in particular, many nurses believe that this relationship has value, but there is a paucity of research in this area (Morse, 1991). This is partly because of the initial and ongoing focus of research on medical treatment. As the epidemic goes along through time, however, it becomes important to recognize that it is indeed one of chronic long-term illness and ongoing need for health care; strategies for the periods of long-term patient role which many persons will experience are now appropriate concerns for research. Again, it is the intuitive belief of many clinical workers that the interpersonal relationships between health care providers and patients have value in this part of the epidemic, and therefore, the need for research in the area is an appropriate focus.

This study is located in the history and the nurse-patient interaction domain of the nursing profession (Kim, 1987). Among the clinical health care professions, nursing has the strongest academic alliances with the social sciences. Nursing's contemporary role is that of a discipline which straddles the space between the physical, social, and behavioral sciences (Morse, 1995). Nursing has a history of concern about the patient as a person, a literature about interpersonal relationships which is steady and cumulative, and a wealth of experience accumulated by nurses in the field who are the health care professionals who spend the most time with patients in most clinical situations. In the context of the present structure of health care delivery, the best site for this study is an outpatient ambulatory primary care clinic, the type of site in which the most long-term relationships between health care providers and patients tend to be found.

The postmodern movement in the social sciences leads me to immediately criticize the dualism I myself create with the division of the individuals involved in the relationships I speak of as "health-care workers" and "patients." The clinical area of research is invested in these roles, and it is only futile to challenge the assumptions about their existence. In addition, our roles in these relationships appear as dualistic, when "expert advice" or "knowledge" regarding health care options flows in one direction. The specific tactics I have employed to try to deal with this paradox of dualism and the postmodern influence include (1) dialogic interviews which attempted to capture the subjective experiences of patients, (2) attention to my own reflections, and (3) my best attempt to acknowledge my own stance as I developed theory about the relationships and the roles within them grounded in the data. I was also guided by Travelbee's (1971) marvelous assumption: "There are no patients, only human beings." As Paterson and Zderad (1976) believe, the moments of greatest uniqueness in these relationships may very well occur in the moments when the roles in them, the dualism, are transcended.

The Researcher

I became a member of the initial staff of the AIDS Clinic at San Francisco General Hospital at a time when I was coincidentally in San Francisco temporarily, with the intention of returning to the East Coast after spending a few months here. I chose to stay in San Francisco because the experience of working with AIDS was compelling and felt so important to the gay community, which was initially affected in the early days of the epidemic.

In this study, I take the position of an experienced clinician in the HIV/AIDS epidemic who has observed the clinical field from within. I often say I have seen the AIDS epidemic from the bottom of the bucket looking up. My background as a nurse practitioner has allowed me to see both the medical and nursing sides of primary care. My interest has drifted toward the interpersonal relationship from my observations of what seemed to work in addressing the personal issues for each patient and health care worker, and what worked to keep people going, to keep the flow, so to speak, of the medical and nursing care happening. It became clear to me the relationships that were established between provider and patient were extremely important in the continuity of care that was necessary for patients with HIV and AIDS. As well as for the care of the patient, I found that the compelling experience of being part of these relationships was a major factor in keeping me interested in my work, able to go on in frustrating, painful, and sad moments, and to avoid "burnout" for the fourteen years I spent working in the AIDS clinic.

I also entered the research field as an openly gay man in the nursing profession who has deliberately sought out situations as a nurse practitioner in which I would have the opportunity to provide clinical care directly to members of the gay male community. In the 1970's, I was part of the "gay health movement," discussed below, which was started by gay health care workers to focus on the unique needs of lesbians and gay men.

Socio-Political Context

The gay health movement grew up in the 1970's in the context of a particularly active period in the gay liberation movement. While it is important to recognize earlier homophile movements for their important work and their fates under repressive political conditions, this period of gay liberation in the 70's remains important, particularly in terms of health care. It is well known that this period began with the raid of a gay bar in New York known as the Stonewall in June, 1969. Shortly after this raid, the most recent incarnation of the gay liberation movement in New York came into existence; its gains for gay people, especially men, had the important effect of raising the awareness both of homosexual individuals and the society at large to the need for a better sense of self for gay people. It is also important to acknowledge that the gay movement occurred in the context of the civil rights and women's movements and borrowed from their ideology and organizing techniques.

The HIV epidemic was not the first recognition of the need for specific health care directed toward the needs of the lesbian and gay community. In the 1970's, the "gay health movement" was founded to focus on the unique needs of lesbians and gay men in health care by starting clinics to provide care, establish a lesbian and gay presence in existing health care and public health organizations, and submitting publications on lesbian and gay health matters to widely-read publications. In order to provide health care in their communities, openly gay nurses and physicians started clinics geared to these needs. In some cases, these clinics were parts of established municipal health centers, such as the Fenway Community Health Center in Boston; some were independent and free-standing, supporting themselves by grants and fee-for-service, such as the Saint Marks Clinic and the Gay Men's Health Project in New York.

Before the HIV epidemic, gay community health care was not based on particular diseases, but on the particular needs of gay people for health care based on their specific needs, and the political notion of being able to be open about being gay while giving and receiving health care. Examples of the unique needs of gay people at that time include lesbian women intimidated and lectured by gynecologists for not using contraception, or the failure of most physicians to recognize the existence of oropharyngeal or anal gonorrhea, or anal venereal warts in men, at a time when these had become real problems.

As an individual white gay man who has been immersed in clinical care of persons with HIV and AIDS since 1983, but not HIV-infected myself, I speak only for myself, from the point of view of my clinical involvement. I do not pretend to know the experience of or to speak for those who are living with HIV. I see myself in sharing in their experiences receiving health care and sharing with my co-workers in the experience of providing health care. However, I do see my position as equal to that of all gay men, regardless of HIV status, in the experience of being a member of the gay male community as it experiences this epidemic. I had worked in the AIDS clinic at San Francisco General Hospital for two and a half years before the virus was discovered. My own experience as a health care worker under these conditions has been profound and is the source of the research questions which are explored in this dissertation. I have investigated questions which arose directly from my clinical practice and link my findings back to that practice, in which I acknowledge both the subjective personal experiences of the persons interviewed and my own.

Interpersonal Relationships and Medication Adherence

Through most of my history as a nurse practitioner in the HIV clinical field, AIDS was an incurable and intermittently treatable disease. My experience had been that the interpersonal relationship has had value in its role in helping patients through the processes of maintaining optimal functioning for a time, and being supported through a terminal process. Although not my main interest at the time this study was started, one area which has become prominent in the HIV field since this study began has been that of "medication adherence." This area of interest has become important because of its role in the recent Protease Inhibitor medical therapies for HIV infection. These interviews were done before protease Inhibitor use became common, but the goal of the interviews, exploring interpersonal relationships, and the adherence issue have collided as researchers speculate that the relationship between provider and patient is a factor in the adherence issue (Chesney, 1977; Crespo-Fierro, 1997).

"Adherence" is basically synonymous with the older term, "compliance" (Crespo-Fierro, 1997), but it attempts to sound less patronizing and judgmental of the patient who does not go along with the provider's agenda for his or her treatment. Compliance has been defined as the extent to which a person's behavior, in terms of taking medications, following diets, or executing lifestyle changes, coincides with medical advice (Haynes, 1979), or more simply, as following medical advice sufficiently to achieve a therapeutic goal (O'Hanrahan & O'Malley, 1981).

The role of adherence has come into the spotlight as newer drugs have become available, since 1996, which can control HIV viral replication in the host body to the point where longevity and functionality are significantly preserved. For physiological reasons, strict adherence to treatment regimens is absolutely necessary for these regimens to remain effective. With the use of the protease inhibitor drugs, it is clear that viral resistance to the individual drugs, resulting in permanent loss of efficacy of that drug, may occur if serum levels are allowed to drop by intermittent dosing. The protease inhibitors are given in combination with drugs of the older group, nucleoside-analog reverse transcriptase inhibitors, so optimal therapy consists of at least three drugs at a time. Almost all of these agents have multiple daily dosing, many have dietary requirements (must be taken with food, without food, with certain types of foods, etc.), and all carry the risk of side-effects, especially in the gastrointestinal system. These dosing regimens lead to complex and patience-trying adjustments of the daily schedule (Chesney, 1997). As is, 70% of HIV-infected patients on outpatient therapies miss medication doses (Chow, et al., 1993). Sources of non-adherence include patients not understanding the importance of the dosing regimen; side-effects; or patients taking "drug holidays" for various reasons including participation in trials of other medications, travel, or simply exasperation. Monitored therapy has increased adherence in some clinical areas, such as with "DOT," "directly observed therapy" for treatment of tuberculosis. Common techniques for monitoring therapy include patient logs, pill return counts, and electronic dispensing devices, but all of these ultimately depend on patient cooperation. And it is widely speculated that this cooperation may be enhanced by a high quality interpersonal relationship between the patient and his or her health care provider (Chesney, 1997).

The Nursing Literature on Interpersonal Relationships

The clinical substantive area of the study of interpersonal relationships between health care providers and patients is consistent with the most recent developments in nursing research in terms of its relevance and appropriateness for qualitative research methodologies. This area has, in fact, been intimately associated with the interests of nurse theorists and researchers since the beginning of theoretical nursing. Although this area is complicated by the fact that there is much literature in nursing and nursing education that is not really theoretical, but of the "how-to" nature (Morse, 1991), some of the major nursing theorists have focused on the clinical area of the interpersonal relationship.

There have been three periods in the history of the nursing literature in the substantive area of the nurse-patient interpersonal relationship: I call the three periods (1) the psychiatric / psychological period, (2) the humanistic / existential period, and (3) the qualitative methodology period. The designation of these three periods is consistent with the history of nursing research and literature in that they (1) move from strictly theoretical to research-based findings; (2) move from borrowed and toward original theory; and (3) move away from a medical orientation and toward a social science orientation, paralleling nursing's move from the empiricist to the qualitative paradigm (Jacox, 1981). While the three periods in this construction lack certain parallel structure or equivalency in that the first two are based on theoretical writings and the third is based on research studies, they do capture the movement of academic nursing through time, from the borrowed, to the observed, to the theoretical, based on the analysis of data.

The nursing theorists selected for this review are those who have focused on the nurse-patient interpersonal relationship as the primary unit of analysis in their theories, as grouped by the Nursing Theories Conference Group (1980), and by Meleis (1991) as the Interactionist Theorists. The relationship itself is distinguished from theory based on related concepts such as caring, empathy (Olson, 1995; Sutherland, 1995), accountability (Cohen, et al., 1994), advocacy (Snowball, 1996), or patient satisfaction.

The first group consists of Peplau (1952), Orlando (1961), and Wiedenbach (1964). The second group contains Travelbee (1971) and Paterson and Zderad (1976). The third group consists of five recent authors who have studied the interpersonal relationship using qualitative methodologies, including May (1990), Morse (1991), Ramos (1992), Heiffner (1993), and Fosbinder (1994).

The Psychiatry / Psychology Period

Peplau (1952), who was probably the first nurse theorist after Nightingale [1860, reprinted, 1969] (Forchuk, 1991), defined nursing as an interpersonal process between nurse and patient and called the interpersonal aspect of nursing the most fundamentally therapeutic one. Her ideas grew out of her experience teaching psychiatric nursing. She was influenced by Harry Stack Sullivan, Erich Fromm and George Herbert Mead (Forchuk, 1991). She divided the process of nursing into its technical and interpersonal functions, and recognized four phases of the interpersonal function: *orientation, identification, exploitation,* and *resolution*; and later amended them (Peplau, 1965) to *orientation, working* (including identification and exploitation), and *resolution*. Peplau was also one of the first nursing theorists to construct the nurse-patient relationship as essential in nursing therapeutics.

Orlando (1961) was the next major theorist who addressed the nurse patient relationship. She came to her theory through her work in mental health nursing, but deliberately expanded the notion of the therapeutic relationship with the patient, recognized early in mental health nursing, to consider it an appropriate theoretical approach for all clinical areas. In this way, Orlando greatly expanded the notion of the importance of the interpersonal relationship. Orlando taught students to look for the underlying meanings in patients' behavior, verbal and non-verbal, and she taught us to interpret the patient's actions and statements in light of their underlying meaning.

Wiedenbach (1964) did not specifically state that her theory was based on the interpersonal relationship, but stated that the nurse's primary area of responsibility is the patient's response to his / her condition (as opposed to the responsibility of medicine, which is the condition itself). She divided the relationship into the phases of *identification* of need, *ministration* of help, and *validation* that the help provided has been that which is actually needed. A fourth phase of *coordination* is a separate domain for the reporting, consulting, and conferring functions of nursing.

The Humanistic / Existential Period

During the 1970's, in the period when nursing was most influenced by existential philosophy, there were two major theoretical nursing works on the interpersonal relationship. Existentialism, with its emphasis on experience and the moment, is interested in the meaning of the self (Stevens-Barnum, 1990). The first work was by Travelbee (1971), who considered the interpersonal relationship to be the primary value of nursing for patients. Travelbee considered observation and the development of inferences (impressions) to be of primary importance in the initial encounter between nurse and patient and, importantly, she considered these processes to be equivalent for nurses and patients. The process Travelbee observed was from that of stereotypical impressions to specific (interpersonal) knowing, in which process the relationship is built and becomes therapeutic. When the nurse and patient become so familiar with each other that the ultimate uniqueness of each is recognized by the other, the relationship becomes significant and has the potential to be therapeutic, and the nurse can begin the therapeutic "use of self."

Travelbee's construction of the phases of the relationship include the *original encounter*, in which the nurse and patient make initial judgments of each other in an impersonal, stereotyped way; the phase of *emerging identities*, in which the ability of each to see the uniqueness of the other occurs; the phase of *empathy*, in which the two share mutual comprehension, and the phase of *sympathy*, in which there is a basic urge to relieve the distress of the other. Travelbee calls the main component of sympathy "emotional involvement." Although she acknowledges the potential problems with sympathy as over-identification and pity, most nurses today would probably find Travelbee's approach patronizing.

A profound theoretical work about the nurse-patient interpersonal relationship which emerged during the 1970's was that by Paterson and Zderad (1976), the nurse theorists who focused on the primacy of the interpersonal relationship most strongly of all. They based their theory on existential philosophy (Stevens-Barnum, 1990) and Buber's (1958) "I-thou" relationship concept (Artinian, 1986) in which the uniqueness of both participants is recognized equally. They saw the relationship as a "salad tossing," or a "patchwork quilt tumble-drying," acknowledging its full fluidity and complexity. They challenged all the traditional restrictions on the nurse using her/his own individual personhood in relating to patients, and encouraged us to recognize subjectivity, context, and personal growth through the practice of nursing (Boyd, 1993) in a way that was greatly ahead of their time.

Paterson and Zderad also saw phases in the interpersonal relationship. These include *meeting*, in which nurse and patient come together with a purpose centering around a goal or an expectation. Their second phase is *relating*, which is described as an "intersubjective transaction" including mutual human responses to the other and "being with" the other. Their third phase is *presence*, that level of interconnectedness characterized by openness, receptivity, readiness, and availability; but also tempered by "professional reserve" and which "flows through a filter of therapeutic tact." The fourth and final phase of the *relationship* is that of call-and-response, the ongoing relationship characterized by open verbal and non-verbal communication.

The Qualitative Period

During the most recent period of academic nursing, in which nursing has embraced qualitative nursing methodologies, some qualitative studies have been published that have been consistent with each other and with earlier theoretical works on the interpersonal relationship. These studies have all acknowledged the interpersonal role of nursing and have found that quality and therapeutic value in the relationships studied have been enhanced by increasing individual recognition of the individuals involved. These studies have also found order in the construction of relationships, but tend to address types of relationships, rather than phases of "the" relationship, as the earlier theorists had mostly done. Perhaps this addresses the trend toward multi-focality.

Morse (1991) conducted the first contemporary qualitative study of the nurse-patient relationship, using grounded theory to describe the development of the relationship and to present an explanatory model for describing various types of relationships. Morse found that the relationship may be either unilateral or mutual, and that mutual relationships are of four different types: (1) the *clinical relationship* is brief, efficient, and not personal; (2) the *therapeutic relationship* is said to encompass most relationships and include both clinical care plus the recognition of the patient by the nurse as an individual, "with a life outside;" (3) The *connected relationship* occurs when the patient and nurse have enough time together and knowledge of each other for the nurse to view the patient as a person first, and a patient second; and (4) the *over-involved relationship* is the one which becomes problematic when nurse and patient may share needs and confidences beyond the therapeutic level. In this excellent study, Morse finds discreet identifiable types of relationships and a basic process, "mutual assessment," and does not hesitate to talk about the problematic level of relationships found in the data. It rings true to clinical experience, acknowledges the possible achievement of special relationships with therapeutic value, and points out real problems in the clinical field.

May (1991) studied the proposition that the concept of "involvement" with patients was a central aspect of the work of nurses, using grounded theory. Three contexts of "involvement" were found: (1) a general quality in nursing, (2) a specific attachment to individual patients, and (3) an investment in nursing skills, characterized by "professional distance." Three dimensions of the nurse-patient relationship were identified: (1) knowledge about the patient, (2) reciprocity, or mutual exchange between patient and nurse, and (3) investment of clinical and managerial skills to meet specific objectives in nursing care. This study finds three types of relationships: (1) *primary involvements*, characterized by congruency between the goals of nurse, patient, and institution; (2) *demonstrative involvement*, in which increased reciprocity (self-disclosure) occurs and leads to the relationship becoming problematic for the nurse in terms of over-involvement; and (3) *associational involvement*, where the relationship becomes overly organization- or technically oriented and tends to alienate the patient. This study found discreet levels of relationships in the data, and the author was also unafraid to discuss the problematic aspect of relationships found in the data. Although May stated that she used the methodology of Glaser and Strauss (1967), she takes the concept of "involvement" *a priori* and therefore does not actually discover theory directly from data.

Ramos (1992) used interviews with nurses to look at their closest professional relationships and found that most relationships fall into the "modified social relationship," which includes personal elements but remains more purposeful and less egalitarian than friendship. This is because nurses maintain control in these relationships in terms of active guidance to keep activities therapeutic, and they decide how much information to disclose to patients. Three types of relationships were found in the data: (1) the *instrumental level relationship* is task-oriented; (2) the *protective level*, with an emotional component occurs when a connection with emotional involvement begins; and (3) the *reciprocal relationship* is described as the emergence of a mutual relationship with a personal bond. This study concludes that relationships with patients are central to the professional satisfaction of nurses, and that institutional constraints, such as lack of time with patients, inhibits their development.

Heiffner (1993) used grounded theory methodology to study nurse-patient relationships and nurses' perceptions of connectedness in the relationship in a psychiatric nursing setting. Heiffner's themes include (1) *vulnerability*, including self-disclosure; (2) *commonality*, including inter-relating between nurse and patient; (3) *reciprocity*, leading to increased disclosure, mutual trusting, and risk-taking in the relationship; (4) *investment*, in which vulnerability and open-ness occur; and (5) nurses' *feeling valued* by patients. This study concludes that positive connectedness is a therapeutic state of interaction between patients and nurses that enhances the effectiveness of relationships, develops gradually, and results in a mutual investment which further enhances the therapeutic aspect of the relationship. The findings are limited in that the concept of connectedness was *a priori* and the setting is limited to that of the psychiatric unit.

Fosbinder (1994) used a qualitative ethnographic approach and the constant comparison method to identify the elements of a theory of interpersonal competence. Four major processes were: (1) *translating*, in which the nurse interprets the hospital environment for the patient; (2) *getting to know you*, in which interpersonal "clicking" occurs between them; (3) *establishing trust,* in which the patient's confidence in the nurse's ability to provide care grows; and (4) *going the extra mile*, which includes "being a friend." This last transcending phase seems similar to those of *sympathy* (Travelbee), and *presence* (Paterson and Zderad).

Related Literature

The medical literature contains many articles about subjects such as doctor-patient communication, interaction, and relationship-forming (Ong, et al., 1995). This literature consists of a variety of observational articles and quantitative studies relating the interpersonal relationship to such outcomes as patient satisfaction, decision-making, and compliance; there is no sense of a cumulative body of literature on this subject as in nursing, described above. I found neither works which considered the relationship as primary in providing medical care, nor any studies of the relationship using qualitative methodologies. There is acknowledgment of the importance of the relationship with the patient, but it is studied using quantitative methods (Wooliscroft, et al., 1994), so not included within the criteria of this review.

Chapter Discussion

The selection of the literature reviewed in this chapter demonstrates that nurses have looked theoretically at the nurse-patient interpersonal relationship since the early days of theory in nursing. Among the common threads throughout this history are (1) the interpersonal relationship as primary in the phenomenon of nursing, (2) potentially therapeutic relationships resulting from the process of increasing recognition of personhood and mutuality on the part of both nurse and patient, and (3) the construction of temporal progressive sequences of phases of the relationship as it moves through time. The present study is most closely associated with those in the most recent, qualitative period, in which all studies cited above have used interviews with nurses. This study builds upon their important points, and adds the dimensions of (1) interviews with patients rather than nurses, to look at the relationship from their points of view, and (2) its location in the HIV/AIDS clinical area, in which the relationship may be an especially potent ingredient in health care due to the current lack of cure, the stigma of most communities involved, and the issues of drug regimen adherence currently arising as new, more effective treatments for HIV infection become available.

CHAPTER 3

METHODOLOGY

Research Question

Strauss and Corbin (1990) say that the research question in a grounded theory study is a statement that identifies the phenomenon to be studied, is oriented toward action and process, and may be interactional, organizational, or biographical. The question for this study is: What are the properties of the interpersonal relationship between the health care provider and the patient in the process of providing ongoing health care to persons living with HIV/AIDS in San Francisco, in the outpatient setting? Because little is known about the properties of these relationships, it is its properties which are the phenomenon being studied. Because the relationship is an interaction between two persons, this is obviously an interactional question. Other than that, I tried to approach the question with as few preconceived notions as possible (Glaser, 1978).

Design of This study

This project is a qualitative study of the interpersonal relationships between primary care health care workers and patients in an out-patient AIDS clinic with the purpose of building theory about these relationships, both to reflect on their history in the epidemic, and to guide future clinical practice. The grounded theory methodology as taught in seminar by Strauss in 1994-96 was used.

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The Qualitative Paradigm

In nursing, the explosion of the use of the qualitative paradigm has led to several directions in research. While multiple qualitative methodologies are available, including phenomenology, ethnography, and grounded theory and other emerging methodologies (Lowenberg, 1993), I specifically chose grounded theory for this project. My choice rested on its appeal to me as a clinician due to its ability to synthesize qualitative methodology with clinically-based practice. Grounded Theory provides techniques that can deal with reports of actual experience in coding and interpreting data from interviews or observations. In its expressed goal of building theory inductively from such data, it addresses the needs of clinicians to turn their interpretations and learning experiences into a form that will benefit ongoing clinical practice.

In addition, in the "multiparadigmatic" environment of the clinic, where clinical trials are prioritized due to the urgency of finding cures for medical diseases and obtaining financial grants, the grounded theory methodology addresses the issues of rigor, which can differ between quantitative and qualitative studies, in terms that can be understood by both kinds of researchers. A successful grounded theory, based on qualitative research done in a familiar clinical site, can resonate for clinicians regardless of their methodological commitments or biases.

Grounded Theory

The grounded theory methodology, with its roots in sociology, was developed by sociologists (Glaser & Strauss, 1967) and has a rich history of application to health care situations. This methodology is based on Symbolic Interactionism, as originated by Mead (1938) and subsequently described by Blumer (1969) as a label for a relatively distinctive approach to the study of human lives. Symbolic Interactionism is based on three assumptions: (1) human beings act toward things on the basis of the meanings that the things have for them; (2) the meaning of such things is derived from, or arises out of, the social interaction that one has with one's fellows; and (3) these meanings are handled in, and modified through, an interpretive process used by the person in dealing with the things he/she encounters (Blumer. 1969). This is simply to say that meaning is the result of a process of interpretation by persons, and in order to understand the meanings of things to people, a researcher has to understand the interpretive process. These assumptions lead to the notion that, as Blumer said, the road to empirical validation lies not in the manipulation of the method of inquiry; it lies in the examination of the empirical social world. Naturalistic inquiry, embracing the dual procedures of exploration and inspection, is clearly necessary in the scientific study of human group life. The sum of these assumptions leads to the naturalistic inquiry (Blumer, 1969; Lincoln and Guba, 1985) of the qualitative paradigm, which acknowledges that persons have "selves" which are situated, historical, and capable of interpretation.

The grounded theory methodology was developed to build theory inductively and to be used with qualitative data. The developers of this methodology, Glaser and Strauss (1967), saw theory as an ever-developing process, not as a finished product. This is appropriate for research on human interpersonal relationships, which are similar in nature in that they are ever-changing and may vary under different circumstances (such as changes over time or between different cultures). Among the types of theory specified by Glaser and Strauss in their original book, this study dealt with substantive theory, or that which deals with an empirical area of inquiry, as opposed to formal, or conceptual theory. My purpose here is to guide clinical workers in the application of one particular area of their work: that of conceptualizing, forming, and therapeutically using their interpersonal relationships with their patients.

In addition, the grounded theory methodology contains assumptions in its basic writings and recent developments which make it adaptable for research on clinical practice which incorporates the concept of subjectivity. Recent trends in qualitative research acknowledge the concept of subjectivity, or personal subjective experience, as a field of substantive inquiry (Ellis & Flaherty, 1992). Subjectivity is the recognition of one's own subjective emotional experiences as an object of study (Ellis, 1991). Part of the link between nursing research and the qualitative paradigm makes the investigation of subjectivity timely in nursing as nursing develops both literature and methodologies that allow us to analyze subjective data. The latest contribution on grounded theory shows developments consistent with subjectivity including (1) acknowledgment of issues of power (class, gender), (2) recognition of obligations to the social worlds of the researcher, and (3) the suggestion that researchers may give information back to actors during the research process (Strauss & Corbin, 1994). This development in the grounded theory literature indicates a stance allied with the qualitative paradigm in recognizing the political issues in research and the lives of participants and researchers, dealing with the historic criticism of interactionist research as apolitical (Denzin, 1992).

In terms of the "schism" between Strauss and Glaser (Stern, 1994), I have chosen the methodological direction of Strauss for three specific reasons. First, as described above in this chapter, my situatedness in the multiparadigmatic clinical area leads me to need to address the quantitative bias of colleagues, and the Straussian rigorous matching of theory against data (Strauss & Corbin, 1994) allows this process more clearly than the "loose" practice of "letting theory emerge" in the present Glaserian version of grounded theory (Stern, 1994). Secondly, since Strauss remained in a school of nursing and Corbin is a nurse, their grounded theory methodology has actually been exposed to clinical nursing situations by students like me, and this has influenced their present direction; Stern (1994) described Corbin as "nurse-like" in her approach to methodological rigor. Thirdly, I have had personal exposure to both Strauss and to Corbin as a doctoral student at the University of California, San Francisco, and have been personally influenced by both their teaching, and their personal inputs on my analysis of this data. I feel free to borrow from Glaser's ideas (1978), but this project is "Straussian," for these reasons.

In addition to symbolic interactionism, feminism is a perspective which has influenced my own views for a longer period of time and which I believe influences me in this and other projects of inquiry. I should say feminisms, as it is widely acknowledged that there are multiple feminisms (Olesen, 1994). Feminisms have congruence with this project in that most feminisms have embraced personal experience and relied on self-report, are equally interested in the experience of the researcher and researched, acknowledge the importance of value and individual points of view (MacPherson, 1983), and openly acknowledge social inequality and the concept of oppression (Chinn & Wheeler, 1985).

As the grounded theory methodology has evolved in the work of Strauss and Corbin (1990, 1994), it has addressed the issue of conformity to scientific canons by addressing the need for changing and redefining canons to fit qualitative methodologies. In the methodology used for this study, rigor was problematic in that the criteria for rigor in qualitative research are still evolving (Sandelowski, 1986; Lincoln & Guba, 1985). These developments in the grounded theory methodology are useful for nurse researchers in the multi-disciplinary clinical areas where experiments and controlled clinical trials hold revered and sometimes monolithic status. Questions about scientific canons must be responded to coherently and appropriately in order for nurse researchers doing qualitative work to overcome the intertwined methodological and sexist biases shown toward nursing research.

Procedures

The procedures of this study consisted of interviews, theoretical sampling, data analysis, theory building, and verification. After obtaining approval to conduct the study, I recruited from among the patients in the clinic in which I am a primary care provider. I told them about the study, and if they seemed interested, 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 (see appendix A). No participant who showed up for the scheduled interview appointment refused to sign the consent form.

The Sample

Two goals of this study and one important methodological consideration defined the study population. In terms of the goal of studying long-term interpersonal relationships between primary health care providers and patients, participants were those individuals who attend the clinic as patients and who had these types of relationships with their individual regular primary health care providers. In keeping with the methodological technique of theoretical sampling, only participants in long-term relationships were sought.

Fourteen interviews were completed. Eleven participants were male, three were female. The male participants ranged in age from 30 to 57 years, with a mean of 43.7 years old. The females ranged from 33-34, with a mean of 33.3 years old. Ethnicity among the males included seven Caucasians, three Blacks, and one Latino; the females were all Caucasian. Only one male and one female participant 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 males, with a mean of 4.7 years; and ranged from 3 to 5 years for the females, 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, in which there is now a more equal gender ratio and a higher percentage of minority group members. There are no statistics for length of relationship with the provider. (See Appendix C for a graphic description of the sample.)

Primary Health Care Providers

The primary health care providers were Medical Doctors, Nurse Practitioners or Physicians Assistants. For the purposes of this study, these professions were considered a single group with similar functions when providing primary health care. 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). In the United States, these three professions are the ones generally acknowledged to provide this type of care (Sharp, 1996).

The Interview Process

The procedure in this study was the one-on-one interview between the researcher and the participant. These interviews were pre-scheduled, took place in patients' homes or in examination or interview rooms in the AIDS clinic where care usually takes place, and were tape-recorded. Interviews lasted about one hour. In keeping with the grounded theory technique of theoretical sampling [further discussed below in this chapter], I approached some of my own patients with whom I have had long-term interviews and asked them if I might interview them. I tried to approach not only patients with whom I have easy or pleasant relationships, but some with whom I have difficult or problematic relationships, but ones that are indeed long-term in spite of the difficulties involved. This is why the data emerged regarding the drug issues of some of my own patients. After I had gotten comfortable in doing these interviews, I branched out, asking my clinic colleagues, nurse practitioners, physicians' assistants, and physicians, to recommend patients of theirs who might be appropriate for these interviews; again, noting that I wanted not only the easy patients, but the ones they would consider as having something interesting to say about the relationship.

I asked open-ended questions [see Appendix D for sample interview questions]; I encouraged introspection and self-exploration on the part of the participants by trying to demonstrate these qualities myself by being spontaneous and frank in my responses to their comments. Among the fourteen participants, six of them were my own primary care patients. To discuss our own relationships and be in their homes, which I had not done before with any except one, at a time when he was acutely ill, was an amazing experience for me. It made me aware of how little I can actually know them while I think I know them well, and I learned a lot that helped me as a clinician with them afterward.

The interview is the process which best combines the goals of (1) theoretical sampling, (2) focusing on the specific area of the interpersonal relationship within the scope of the overall experience of providing and receiving health care (i.e. guiding the interviewee toward the interpersonal relationship aspect with open-ended questions) and; (3) treating both interviewer and interviewee equivalently, to the extent possible given the situations of power.

Interviews which obtain data directly from both the interviewee and interviewer are unstructured or semi-structured, and use open-ended questions. This type of interview, according to Reinharz (1992), maximizes discovery and description, produces non-standardized data, and allows researchers to make the best possible uses of the differences among individuals (a source of constant comparison for enhancing theoretical sensitivity). Lather (1991) also believed in the usefulness of open-ended interviews conducted in an interactive, dialogic manner that requires self-disclosure, sequential interviews of both individuals and groups to facilitate collaboration, and a deeper probing of issues and negotiation of meaning by recycling descriptions.

In order to incorporate the overall goals of this study, these interviews have attempted to incorporate a dialogic process between myself and the interviewee. I paid attention to my own personal authenticity and self-awareness, and issues of social power differences between us during the interview process. I wanted the interviewees to see the process of the interview as a joint collaboration between us in the process of capturing the nature of a specific experience. I tried to be relaxed, have fun, and freely express my own reactions to their stories. Kleinman (1991) pointed out that a researcher needs to be aware of her/his own feelings, recognize their significance, see them as clues to the research process, and use them as resources for understanding the phenomenon under study. I revealed aspects of my personal life, such as where I live, when it came up, in conversation because several of the interviews took place in the homes of participants.

Also, I took the stance that I, as the interviewer, had the right to share my own responses, in a personal way, with the participants during the process. Speaking about personal responses and feelings in the presence of the participants serves several useful purposes. First, the research process and a very preliminary version of the interpretation of data are immediately exposed to scrutiny. If authentic, this exposure could deepen the process and allow the creation of what Lather (1991) called "a click of recognition." Secondly, although most analysis of data does not take place immediately at the time of the interview, the responses of the researcher in the presence of the participants may begin the process of feedback to insure trustworthiness (Lincoln & Guba, 1985).

Theoretical Sampling

Theoretical sampling is the process of data collection for generating theory whereby the analyst jointly collects, codes, and analyzes data and decides what data to collect next and where to find them, in order to develop theory as it emerges (Glaser and Strauss, 1967). My own clinical practice was the place where the relationships I wanted to observe in natural settings were already happening. This is a unique setting with no equivalent, in terms of the amount of this type of care happening between so many people, for such a long period of time, and in a clinical site where the philosophy is to place nurse practitioners and physicians' assistants in situations of so much autonomy in taking responsibility for their case loads. So I based my theoretical sampling at the San Francisco General Hospital outpatient AIDS clinic on the assumption that this is the location where a concentration of these relationships is taking place in one specific manageable physical site. The outpatient clinic is the place where most patients continue to come back over and over again, and have the longest-time relationships with their health care providers . I wanted to look at these relationships over time, which is an important dimension of their nature. Some patients come to the clinic and see their providers regularly, on a monthly or more or less frequent basis, for a period of many years. I have had many patients for periods up to five years, and have gone through all the stages of their illness from asymptomatic through severe illnesses, to disability and death. My own personal experience with my longest ongoing relationship with a patient was about ten years (from February, 1984 until his death in April, 1994).

Not all patients have long term relationships with individual providers, for many various reasons about which I make no assumption or judgment. Some patients go from provider to provider for long periods, and some may choose to not enter the health care system until very late in their progression of disease; probably, there are some persons with AIDS who never enter the health care system at all. My stance in theoretical sampling has been to acknowledge that I am interested in certain types of relationships, to recognize that not all patients have these types of relationships, and to go to the site of these relationships. Again, the relationship is the unit of analysis in this study. (See Appendix D for the demographic specifics of the participants.)

Data analysis

In data analysis, I have used the techniques taught in class by Strauss and related in the Strauss and Corbin text (1990). Data obtained from interviews and transcribed into manuscript form were then coded. Coding is the operation by which data is broken down, conceptualized, and put together in new ways to generate theory (Strauss and Corbin, 1990).

Initially, open coding breaks down, examines, compares, conceptualizes and categorizes data. Categories are classifications of concepts that are compared against each other and which appear to pertain to similar phenomena. They are a means of grouping phenomena together into more abstract groups which show their commonalities. Strauss taught us to look at categories in terms of their properties and dimensions, constantly comparing them, and using these comparisons to see both similarities and differences.

The second type of coding, axial coding, is a set of procedures by which data are put back together in new ways after open coding, by making new connections between categories. The Strauss and Corbin text provides a technique of the coding paradigm for this type of coding, making it easier to remember to include all the elements including: conditions, context, action/interactional strategies, and consequences. Four analytic steps are considered important: (1) hypothetical relating of subcategories to categories by means of statements denoting their relationships, (2) the verification of hypotheses against actual data, (3) the continuing search for properties and dimensional locations, and (4) the search for variation in phenomena by constant comparison.

Selective coding is the process of selecting the core category from the data, that is the central phenomenon around which all the other categories are integrated, and relating it to all

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it to all other categories, further developing the relationships between them and developing the theory based on these relationships. This leads to the story line, or the conceptualization of the core category by a descriptive narrative about the central phenomenon in the data. This is integration, or the highest level of conceptualization of the phenomenon based on the relationships found within it. Strauss and Corbin say that selective coding is particularly difficult for practitioners doing research in their own fields, if they are unable to sufficiently distance themselves from the data to allow adequate description and conceptualization of the story line, or are unable to choose a core category. Fagerhaugh (1986) recommends that students report on only one basic process per study. I saw selective coding as the tool which I could use to actually tell the story about the relationships I studied, and do it in a way that rings true to both the health care workers and patients involved in them. This was the biggest challenge in terms of conceptualization, providing useful theory for clinical practice, and in writing ability.

Just as the phases of the relationship are not completely orderly, I did not move through the process of coding in the orderly way described above. I moved back and forth among the different types of coding rapidly and frequently. For example, I invested much of my coding in the category of "negotiating trust." This concept was arrived at by looking at descriptions of confrontation and problematic interactions with providers that I specifically asked patients to describe in the interviews (see Appendix E). When I compared the descriptions of the resolutions of the conflicts, very few of which contained the word "trust," it seemed that the negotiated re-establishment of trust in new terms, considering the content of the problem, was what had happened. It took several readings, codings, and comparisons to come up with the concept.

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Theory Building

While the Corbin and Strauss (1990) text is a good guide for techniques, for a theory building source, I also utilized the earlier sources in grounded theory to help me build theory. The initial grounded theory text (Glaser & Strauss, 1967) distinguished between the then-traditional function of verifying theory in sociology and generating new theory that was discovered in data. They saw the discovery of theory as a process. They stated that their position was not logical but phenomenological, a position which must have been radical at that stage of the qualitative response to positivism. Their point appears to have been to acknowledge the complexity of the process of generating theory from qualitative data, and especially to acknowledge the importance of the interpretive abilities of the social scientists involved in the process, which was, in a sense, an acknowledgment of subjectivity in qualitative research, which brings us forward to the trends we are seeing today.

As part of understanding the complexity of the process of generating theory from data, theoretical sensitivity is an important concept in the writings of the grounded theory methodology. This is the term used for what, in nursing, might be called the effect of personal experience, personal knowledge (Carper, 1978), or the use of self (Travelbee, 1971). Glaser (1978) defined theoretical sensitivity as the long-term biographical and conceptual build up that happens to the researcher that makes him/her "wise" about the data, allowing the researcher to detail its main processes and problems and explain and interpret them theoretically. Similarly, Strauss and Corbin (1990) defined theoretical sensitivity as a personal quality of the researcher in which he/she is aware of the subtleties of meaning of data, and has the ability to give meaning to data, the capacity to understand, and the capability to separate that which is pertinent from that which is not. I see the concept of theoretical sensitivity as related to the issues around doing qualitative

research in one's own clinical field (Field, 1991) in that the acknowledgment of complexity necessary in both grounded theory research and in clinical practice (and probably in most human activities that demand and create expertise) may be similar: in both areas, important elements are (1) understanding multiple choices and possibilities, (2) the ability to recognize subtle changes, and (3) the fact that these things take time.

Verification

Issues around standards of rigor are in a state of constant change in the qualitative paradigm. Rigor may be problematic in that it is one of the subjects in which there is perhaps the most divergence between the qualitative and quantitative paradigms.

Criteria of Rigor

Since the publication of the Strauss and Corbin (1990) text, the Straussian (Stern, 1994) grounded theory methodology is the qualitative area with the orientation closest to my own in that it addresses verification issues with the acknowledgment of multiple paradigms which must speak to each other.

The developments in the grounded theory methodology under Strauss and Corbin have the potential to be very helpful in this multidisciplinary clinical area where the clinical trial is considered to be the "gold standard." They addressed the issue of conformity to scientific canons by addressing the need for changing and redefined canons to fit qualitative methodologies (Corbin & Strauss, 1990). They cited the Gortner and Schultz (1988) canons as appropriate for qualitative studies: significance, theory-observation compatibility, generalizability, consistency, reproducibility, precision and verification. They provide specific techniques for analyzing data in consistent ways in

the specific types of coding. In addition, they provide the technique of the memo (Corbin, 1986; Strauss, 1987; Strauss and Corbin, 1990). The memo may be used as part of an audit trail, a tool for providing a record of both the ongoing development of theory from data, as well as the researcher's "reflexive journal" (Lincoln & Guba, 1985), an internal dialogue with the self during the inductive research process.

In addition to the work of Corbin and Strauss, Sandelowski's (1986) discussion of issues of rigor has been helpful to me. Sandelowski described two areas of major concern in applying standards of rigor to qualitative research: credibility and auditability. Sandelowski proposes that credibility replace validity as a criterion for qualitative research. Credibility considers the faithfulness of the description of phenomena by subjecting the description to the scrutiny of the participants themselves. This is a test of whether the report actually describes who and what was observed or said, and in addition, the process adds to the sense of participation and empowerment of research recipients. Sandelowski's "auditability" concept can be seen as the "decision trail" which will be left behind so that the process of the study can be followed and understood, consistently with the goal of the researcher. Again, the memo technique is good for creating the qualitative researcher's decision trail. Sandelowski (1993) has more recently stated that reality is accepted to be multiple and constructed rather than tangible, and that stories are acknowledged to change with time and reinterpretation. She means that although the trail can be retraced, one cannot expect to find the same results in the same places later, as conditions change over time.

Hall and Stevens (1991) proposed criteria for rigor similar to those of Sandelowski. Their concept of "dependability" is related to "auditability" in that it includes the use of a decision trail consisting of memos. They used the term "adequacy"

equivalently to "credibility" in that it includes the conditions that research processes and outcomes be well-grounded, cogent, justifiable, relevant, and meaningful, to both insiders and outsiders, to both researchers and subjects.

Member Checks

In order to address these issues of rigor in qualitative research, I used the member check technique in the style of Lincoln and Guba (1985). I gave copies of the analytic part of this study to some of my interviewees and to individuals with similar knowledge of the phenomenon under study. The reaction has been sporadic, in that only two participants handed in written critiques, but I have verbally asked some of the other individuals for feedback, and that feedback has been positive in that no-one thought the analysis was off the mark, and most gave positive feedback, indicating that they were able to relate the analysis of the interview data to their experiences. One patient who had been an interviewee told me he was surprised when he saw my write-up, he had expected me to produce a narrative which told the stories; but when he saw what I'd done, he realized it was an "analysis" (his word) and said he understood what I was doing and it made sense to him.

Likewise, feedback from my clinical colleagues to whom I have shown this analysis has been favorable, with knowledgeable persons saying that the analysis seems real and like I "got it."

Research Issues

The Site

I am a staff member at the clinic in which this study was carried out. In the qualitative paradigm, the "self" of the researcher is acknowledged as the primary data collection tool (Lipson, 1991). A number of qualitative researchers within nursing and the social sciences have advocated doing clinical research in one's own community or clinical practice site (Paterson & Zderad, 1976; Cook & Fonow, 1990; Sandelowski, 1991; Lather, 1991, Boyd, 1993). When doing research in a familiar setting, there may be an advantage in that one knows the rules and parameters and can both work within them and use them (Schutz, 1994).

Field (1991) discusses such potential problems as insider bias, the problem of recognizing what is significant, the potential role conflict in one's own setting between the clinical and research personae, and the risk of getting too involved as an insider. However, she concludes that, for graduate students in nursing, research in one's own clinical site may be possible under the conditions of a unique clinical setting where no similar site is available, where the research problem is clearly defined, where parameters are identified prior to the start of the study, and where the student is aware of potential problems. Where the researcher has personal experience, says Field, it is possible to become one's own expert informant, being able to focus on both what is happening in the group and on one's own response. In addition, the setting may not be so much of an issue when it is clear that the unit of analysis in the study is the interpersonal relationships

which are observed in the setting, which is actually the taken-for-granted background (Lipson, 1991).

Risks

Potential risks were the possibility of loss of confidentiality, and the possibility of emotional discomfort during the process of recalling or revealing to the interviewer certain intimate or uncomfortable feelings which may arise for the participant.

Methods of minimizing risk included the prior notification of participants of their right to withdraw from participation at any time; the familiar location of either the patient's home or the clinic, and the assurance to the participant that tapes would be heard only by the researcher and anonymously by transcriptionists, and that no identifying data would accompany written transcriptions.

I asked participants such questions as, "Are you okay?" or "Is it okay to keep going," periodically during the interviews as a way of "checking in" to make sure there were no unforeseen negative consequences of my questioning or their telling their stories. Fortunately, no adverse events occurred due to the interview process. Although informed consent forms had been explained and signed, I was prepared to maintain consent and minimize any harm by renegotiating the terms of consent if any unexpected results had occurred (Munhall, 1988).

Benefits

The potential benefits of participation included (1) the knowledge that participation may lead to the development of theory that will benefit future patients by facilitating the formation of beneficial relationships with clinicians sooner and more

easily; (2) the process of clarifying one's own feelings about the relationship with the primary health care provider by the thoughts brought out by the interaction with the interviewer, and (3) enhanced feelings of involvement and connection with the clinic, the primary health care provider, the interviewer as a staff member at the clinic, and active participation in their own health care.

In addition, some patients and I, as the interviewer, both benefited from the chance to learn more about each other on a personal level, yet in a controlled situation (the appointment for the interview) which created a context which allowed more intimate contact, but preserved the "therapeutic tact" (Paterson and Zderad, 1976) necessary to continue the relationship within the context of the health care system and the ultimate restraints of the professional situation. I also believe that several of my own patients enjoyed the opportunity to have me in their homes, due to the contexts of our long-term mutual acquaintance.

CHAPTER 4

ROADS LEADING TO THE CLINIC

Context

In the early days of the realization that the "gay plague" was to be a long-term problem needing a sophisticated level of medical and nursing care, some far-sighted health care workers in San Francisco took it upon themselves to start dedicated units for AIDS care at San Francisco General Hospital. At that time, the cause of the disease was unknown. The goal was to provide care to the persons affected with this syndrome, long before it was fashionable to do so. The inpatient unit, Ward 5B (later to be relocated to Ward 5A, where it remains today), and the outpatient clinic were started in the summer and fall of 1983.

The Community

It is generally acknowledged that the reason the HIV epidemic emerged so early and rapidly in San Francisco is due to the confluence of the arrival of the virus in the gay male community, as described above, with the strong presence and visibility of an openly gay culture and gay political clout unique to this American city. The history of San Francisco as a refuge for gay men and women is documented at least since World War II, but probably has existed long before that. Gay men with HIV see San Francisco as a refuge from the stigma associated with both gayness and HIV infection in the country in general.

> Unless you're in Dubuque, Iowa or something, and they just have ten patients a day with HIV or something, I mean I just don't know how anybody could remember everything [about AIDS].
>
> . . . if you lived in Des Moines, Iowa, or Saint Paul, Minnesota, or something . . . But no, this is San Francisco.

In addition, patients expect more from this gay refuge community than the national standard:

> If you don't have health insurance, you're just out of luck in this country. Luckily, that's not the case in San Francisco.

In San Francisco, relatively small for a major American city, the clinic is associated with the County hospital, where the uninsured go for care, and is widely known in the community. The central role of this particular clinic in the community creates many unofficial referrals from persons who have received care there, and from persons who are aware of its role in the county public health system.

The Site

Paul Volberding and Constance Wofsy, the first physicians on the University of California, San Francisco medical faculty to organize AIDS care, were given "Ward 86," the sixth floor of the building designated as Building 80 on the San Francisco General Hospital campus. Ward 86 had been deserted and unused for a period of about ten years, and had once been the obstetrics ward of the hospital. Building 80 is across the street from most of the hospital campus, so the top floor of this building turned out to be the location furthest from the center of the hospital but still part of the campus; this was a questionable coincidence, considering the general attitudes about AIDS at that point in its

history in 1983. When Volberding and Wofsy moved into the area in the summer of that year, half the floor was usable space; the rest was a construction site with beams lying about. That was how Ward 86 looked when I first saw it.

The building, consisting of two wings, called Buildings 80 and 90, presently houses the AIDS, refugee, tuberculosis and methadone clinics, as well as the family health center; most of the facilities any hospital might want to locate across the street or in a far corner. The building is an old one of red brick, a rare type of construction in contemporary San Francisco because of its vulnerability in earthquakes. The old-fashioned turn-of-the century copper and bronze work on the building is still unique and lovely to look at, if somewhat faded in its glory. The elevators, which malfunction frequently, have buttons marked "80" through "87" for the basement through seventh floors.

The interior of the clinic itself consists of an eclectic mix of decorating styles, reflecting the various attempts at improving and redecorating the facility over the many years, both as the AIDS clinic and in previous incarnations. Floors and walls dating from the original building mix with later added walls; doors are either venerable old oak or newer plywood, giving clues to their histories in the archaeology of the site; the older ones contrast with the industrial-looking gates over windows, dictated by fire safety policies. Long hallways of rooms remind one of the original design as an inpatient unit. The waiting room contains chairs and wall hangings from charitable donors that seem incongruent, with varying visions of the site. A large television plays constantly. The reception area contains many computers set on old hospital desks. The examination rooms have old oak doors and modern modular furniture hanging from the walls. Each room's telephone has a sign above it on the wall pleading with our patients not to steal it.

Looking out the windows treats one to a magnificent view across the Mission District with Twin Peaks in the distance and often the dramatic San Francisco fog coming over the hilltops, but the urgency of the stories that unfold in these rooms tends to make one forget to look out of the window for days at a time.

Ward 86 was the first AIDS-dedicated clinic in the United States, and perhaps in the world, when it was started in 1983. Today it remains among the country's largest AIDS outpatient clinics, accounting for about 3000 patient visits a month at the present time (J. Stansell, personal communication, 8/95). Although New York City, Los Angeles, and Miami have larger populations of HIV-infected individuals, San Francisco still has the highest per capita rate, and the most centralized care site. There is a critical mass of both patients who have survived with the disease for long periods of time, and clinical primary health care providers who have participated in interpersonal relationships with these patients for prolonged periods of time. The clinic has a very long-term staff of primary health care providers, with surprisingly little turn-over, particularly among the nurse practitioners and physicians' assistants; five of the six primary health care nurse practitioners and physicians' assistants have been on the clinic staff eight years or longer.

<u>Referrals</u>

> Well, I came here as a middle-class white boy with a college education, who would normally have his own private doctor, and I was insured and everything. And all of a sudden that was no longer an option for me. I had to face reality, that I just could not afford to keep my Blue Cross. [My private doctor told me] I would have to work with General Hospital, and get care there instead.

> Well, I went on like a really horrendous like drug and alcohol trip and I was like out of my mind, and I kept getting arrested by the police and I told them like, look, I've got AIDS and I don't know what to do. They said, like, three different times, they said, well, have you gone to Ward 86?

In the act of seeking medical evaluation shortly after testing HIV-positive, people frequently went to private doctors before coming to the public clinic. There existed a well-developed network of private-practice openly gay male physicians in San Francisco, and many gay men had personal friends or acquaintances who were physicians, or knew of friends who were. No one so far had a regular relationship with a physician or nurse practitioner before learning that he or she had HIV infection; health care had been very episodic, seen only for very specific symptoms, not as an ongoing need.

Some patients were referred to the clinic by non-medical HIV support services in the community such as the San Francisco AIDS Foundation, Shanti Project, or the Brothers Network (An African-American gay community HIV social service agency). Most seem to hear of the clinic by word-of-mouth in their communities and from professional persons with whom they come into contact for various reasons, including nurses. One interviewee told me that she was driven to Ward 86 by the police after an arrest (for sleeping in a vehicle). Most seek medical evaluation soon after learning that they have HIV infection, usually by being HIV tested at the anonymous test sites in the community. For some, it is a long tortuous process to approach the health care system for various reasons, including past experiences, admitting the seriousness of the problems to themselves, and economic issues. Some individuals were initially HIV-tested as part of participation in clinical or epidemiological studies. This would have been in the 1980's in most cases, during a period in which participation by gay men in these studies was high, and relations were generally good between health researchers and the gay male community in San Francisco. Some women initially met Ward 86 staff through Project AWARE, a women's HIV health study conducted at the clinic in the 1980's.

There was a period in the mid-eighties when the HIV antibody test first became available when many gay men were postponing being tested for political reasons, fearing that the results would be used to discriminate against them, to deny them health care, or even to put them in concentration camps. Nobody I interviewed mentioned these issues; the individuals involved in HIV testing during that period are gone by now.

Assignment to Providers

> I didn't make the appointment in the first place. It was given to me. My doctor was given to me like that, and that's just who I ended up with.

Generally, in the clinic where this study was conducted, people are assigned on a "first-come, first-serve" basis to their health care providers. Very few know of the individual provider they will see when they make their initial appointments. The way the clinic system works is that when a person telephones for an appointment, if they do not specify an individual health care provider by name, they get an appointment with the provider who has the next available "new-patient appointment." These are special slots in providers' schedules that are 15 minutes longer than the usual appointment slots. For patients who had been admitted to the AIDS inpatient unit at SFGH via the Emergency Room, an appointment is made by the inpatient unit clerk before discharge. No distinction is made, according to clinic policy, as to whether new patients get an appointment with a physician, nurse practitioner, or physician's assistant. Although no one I interviewed said that he or she was aware of me personally before coming to the clinic or asked for me by name when they called for an appointment, I know that some of my patients over the years have done so when friends had recommended me. I have also taken care of many couples, even some who come in for their appointments together. However, only one of the patients I spoke to in this study has a partner who also comes to Ward 86, and his partner sees a different provider.

Economic Considerations in Coming to the Public Hospital

San Francisco General Hospital is the center of the County public health system for San Francisco. It is where the medically indigent are expected to come for care, the cost of which is assumed by the county; for individuals on public insurance programs, such as Medi-Cal or Medi-care, it is often the sole resource due to the fact that many private practitioners and private systems (such as Health Maintenance Organizations [HMO's]) do not take these patients because state reimbursements for the costs of care are inadequate to cover the expense in this high-cost city.

> When I was unable to work for the first time because of HIV-related fatigue, I found myself going to the place where previously I had thought only poor people and minorities went for health care.

It was when people either found out the cost of laboratory tests in medical evaluation, or when they had to stop working and lost their job-related health insurance, that some patients found themselves coming to the public sector. Some had previously been seen by private physicians but could no longer afford the amount of laboratory monitoring necessary when they acquired HIV, or had lost previous employment-related insurance when they could no longer work for medical reasons or were laid off. These patients were often referred by their private physicians who were aware of Ward 86 because of its involvement in research, or were told about it by friends. It has been common for physicians in private practice in San Francisco to refer their own patients to Ward 86 when the cost of laboratory evaluation or medications overcame the patient's ability to pay for them. To some extent, this was a division between the gay community-oriented patients and the drug-culture-oriented patients, most of whom had

used the non-STD public health sector for a long time and were quite familiar with SFGH.

For some, the county system was stigmatized and thought of as "only for the poor or for racial minorities." The attitude of patients toward SFGH varies depending on their previous orientation to the public health sector; for some, it is a step down, socially. For one man, going to Ward 86 was an admission to himself that he was no longer middle class, going where the poor people and minorities go, as he put it, although he has had a good relationship with his provider and with the clinic.

CHAPTER 5

FINDINGS

Fourteen interviews with patients were tape recorded, transcribed, rechecked against the tapes, and analyzed according to the grounded theory method, incorporating reflection on my own personal responses to the data and my clinical experiences. Some theoretical concepts have emerged surprisingly consistently. These concepts comprise two analytic areas: (1) a template of the phases of the relationship; and (2) the recurrence and significance of the concept of "trust."

Phases of the Relationship

In the interviews, I asked persons to think of their relationship with their health care provider as a "story, with a beginning, a middle, and a present, since it obviously doesn't have an end at this point." The relationships, not surprisingly, had consistent trajectories, which could be described by thinking in terms of phases. This conceptualization comes from the data and links to the historical analysis of the nurse-patient relationship in the nursing literature.

Every individual interviewed is a current patient, and currently involved in the interpersonal relationship. Thus it was not necessary to invade these persons with HIV with speculations about the very troublesome future, so no final or ending phase of the relationship was identified. How these relationships end is probably the subject of another qualitative study. As a goal of this project to generate theory regarding the establishment

of interpersonal relationships, it was appropriate to look at the earlier rather than later phases of the relationship.

The present construction of the relationship in this analysis, paying attention to the trajectory through time of "beginning, middle, and present," acknowledges that we discussed relationships that are currently in progress. I identified three phases. The phase of *encountering* is the initial meeting between patient and provider; *appraising* includes the process of mutual assessment which occurs as the relationship forms; and *mutual investment* describes the period of the productive relationship when the patient and provider work together with a commitment to each other to provide care to the patient.

Encountering

The label of "encountering" describes the period of time surrounding the initial meeting between patient and provider. The term helps to connect this moment to the theoretical history in nursing, discussed in the previous literature review, which conceptualizes the relationship itself as the unit of analysis.

"Encountering" occurs when one of several possible sets of conditions described above brings individuals to the clinic in the patient role. It is common for the initial meeting to occur under the following conditions: the patient is quite apprehensive, newly dealing with the fact of known HIV infection and life-style changes it may bring (i.e. stopping working), in recent substance abuse recovery, and highly suspicious about the medical system. The effects of these conditions may range anywhere from mild to disabling, based on the patients' general ability to function, the circumstances under which he or she became infected and found out about it, and the level of trust or mistrust

of health care providers in general, and the county public health system, in particular. Feelings about individual providers are not yet factors at this point.

Initial Encounters Between Patient and Providers

> Well, when I first came to see you [the nurse practitioner], I wasn't sure who I was going to see, and I wasn't sure if I liked you or not. But I wasn't sure, and I gave you the chance . . . and sometimes it works, and sometimes it doesn't. So after giving you a chance, ... after three or four visits . . . I thought, I like him. You were short, sweet, and to the point.
>
> I remember being just totally closed off and not wanting to say anything more than I had to.

When initially meeting the provider with whom they have been paired, many patients think, as the one quoted above put it, I'll give this person a chance. The early visits include the processes of assessment of the provider, and observation of his/her personal style, such as willingness to respect patients' decisions, openness to alternative personal life issues, and acceptance of alternative or non-allopathic therapies. I have thought of this part of the initial encounter, leading to the earliest mutual assessment as the phase of "sniffing out," where the patient and provider circle each other, like dogs on initially meeting, or wrestlers at the beginning of the match, cautiously and intensely observing each others' strength, weaknesses, mastery, and style.

The assessment and observation processes range from the patients who want specific recommendations because they don't know what to do and want to be directed, to those who want to appraise the provider in terms of being acceptable in terms of the patient's agenda: If I don't want to take this antiviral treatment, will the person advocate it real hard, force me to take it, disagree with me, nag me if I don't? Among the participants,

the women tended more to want initial direction as to "what to do," reassurance regarding their situations, and advice as to whether to take anti-viral medications. Gay men living in the HIV community, often very up-to-date on therapeutic advances, were most likely to have agendas and appraise the health care worker in terms of his or her willingness to go along with the agenda. This trend by gender was remarkably consistent, and probably has to due with the greater likelihood of gay men living in communities where HIV issue awareness is high, and the general trend in our present society of men as being more likely to be traditionally conditioned to be assertive. Women tended to be in recent recovery from drugs and/or alcohol and less likely to be either knowledgeable in terms of HIV issues, or in as much control over their lives at the time of coming to the clinic.

The initial visit is a process, with the visual image of a paired mutual dance, of appraisal, evaluation, assessing ability to trust, speak the truth, acceptance of positions about antiviral therapy, or whether frankness in talk about sex (such as gayness, and specific sexual activities) will be okay. Individuals who use drugs, heroin or speed, may need to assess the provider's attitude regarding these issues, and they may take awhile before telling the health care worker about that part of their lives.

Attitudes toward Nurse Practitioners and Physicians' Assistants

> I thought I would only see you maybe year or two, and then you would change me over to a doctor. I kind of thought physicians' assistants were just early cases in terms of just providing maintenance until, say, a problem started to arise.
>
> I said something to you and I referred to you as "Doctor," and you said, "I'm not a doctor." And I thought, oh, great, what now, what am I doing? I'm not even seeing a person who's a full-fledged doctor. But then as time went on, I realized that you don't know any more or less than somebody, as far as I'm concerned, with an MD.

> My experience with nurse practitioners has been really good. It just seems, I don't know, maybe I got lucky, but the nurse practitioners seem to be more -- interpersonal.

Almost nobody was previously familiar with the roles of nurse practitioners or physicians' assistants before coming to Ward 86. This fact correlates with the generally low level of previous involvement in health care relationships among the patients interviewed. Many people who see an NP or PA first thought that their visits with the nurse practitioner or physicians' assistant would be a temporary arrangement, and that if they began to have more complex medical problems, they would be transferred to a physician. Some were thinking, "this person's not even a doctor". These individuals gave the relationship a chance anyway (probably there were some who didn't). Most were pleased; several spoke about how an NP is "better" than physician; the frequent perception is that they listen better, are more flexible about drug decisions, don't talk down to you, don't "act superior."

Sometimes, their previous experiences with physicians have been with the interns and residents while hospitalized. They have encountered physicians at their worst: tired, in groups, at 6 AM, and in a hurry. It is easy to see why people are open to non-physician providers after experiences such as these. Several patients told me stories of negative contact with physicians in the hospital, followed by much better relationships with their -providers in the clinic after discharge.

Appraising

The second phase of the relationship is that of *appraising*, a mutual process between the patient and health care provider which occurs under the conditions of having decided to continue the relationship for the short term at least. Here, the patient and the

provider begin to specify, prioritize, and make decisions regarding the issues which come up as significant in the relationship, based on the patient's history, medical condition, and personal needs, both stated and unstated.

Treatment Issues

> I'm glad I'm on them [antiviral drugs] in the sense that I'm glad I'm not having bad side-effects from them. I am willing to take them as long as I don't feel shitty from them, and I will continue to do that. . . . I will only subject myself to so much as far as certain drugs and their side-effects, because it's all a big question mark. . . If they start making me feel like crap every day, then I have to question: Well, what am I doing this for, exactly?

Patients seek flexibility on the part of the provider and openness to considering alternative treatment decisions, especially the issue of whether the provider recommends anti-viral drugs. First, some patients want to know who is in charge; they want to know if the provider is going to dictate treatments to them or whether they will have a choice in determining treatment. This is particularly true with antiretroviral therapies, which are controversial and limited in their efficacy. This is probably different for HIV than in most other clinical areas where the treatments are more clear in efficacy. However, there are also other clinical areas where treatments are controversial in a similar way, and in which similar issues about whether to take treatments comes into discussion (for example, chemotherapy for cancer patients). Some patients bring in their own ideas about what they will or will not take, their own agendas of what medications they want to have prescribed. Sometimes they want narcotics and benzodiazepines, but more often they have agendas about antiretroviral and prophylactic treatments directly related to HIV infection. They may seek a provider who agrees with them in principle, one who will listen to them, or one who will let them make or participate equally in treatment decisions, each of these becomes or serves as a particular strategy for achieving and

maintaining some control in what is essentially a relationship in which the provider, through the authority to prescribe drugs, holds considerably more power.

Alternative Therapies

> I look at my health care as like a pie. And I think that western medicine and working with the doctor, the nurse practitioner, whatever, is this part of it, and then therapy is another part. And then I also do Eastern medicine; I take Chinese herbs and I get acupuncture once a week, and massage, and I think that's another piece of the pie, and that part of staying healthy is the whole thing, not just one, not just coming here, and not just acupuncture or herbs. And I feel, like, to stay in control that I look at everybody, it's like everybody that's helping me, working on me, like my partners.

Some patients have an interest in alternative therapies. They use treatments considered non-proven by "western medicine" or want to have a medical provider but keep open the option of non-authorized treatments. Examples of non-proven therapies mentioned in the interviews include certain vitamin and nutrient supplements, aroma therapy, an unproven topical treatment supposed to stimulate the growth of new T-cells, and some intravenous infusions. Acupuncture and Chinese medicine are no longer considered alternative treatments; they are widespread and considered in this community to be adjunctive therapies that can be taken concurrently with allopathic medical treatment.

One interviewee spent part of his interview with me trying to convince me of an alternative treatment involving lemons which he wants to try but has not tried yet. Since I know of no toxic effects of lemons, I did not discourage him, but also steered the conversation away from the topic because it wasn't the point of the interview. I was not the regular provider with whom he had the relationship under analysis at the time. He vividly described the process I call "sniffing out," in his assessment of his provider's

openness to his participation in the lemon treatment. She (the provider) seems to have "passed" in that she had not discouraged him.

Power, the political aspect of interpersonal relationships, both in health care and in any area of life, comes into play in all personal relationships. Patients on the latter side of this set of dimensions want their judgment about treatment trusted; they also want to avoid confrontation. The position of being a patient is too powerless to risk direct confrontation for many people.

Illegal drug use

On the subject of illegal drugs, I have found two distinct trends in the data. These are contrasting agendas regarding drugs: one was addiction recovery and receiving support during that difficult period; and one was continuing use drugs, and using the relationship with the health care provider to obtain the necessary medications. One patient spoke a lot about how he had trouble getting started in his relationship with me: he said that I made him feel in his early visits as if he were asking for too much. During the interview, he told me, and I remembered, how it had taken him a long time, when we had started working together, to tell me he was heroin-addicted. After we already had known each other for awhile, he asked me to help him get on methadone. This was the first time he told me about his heroin addiction. Part of his appraisal process was his period of assessing whether he could tell me about his addiction. During this period, the reason he found me stand-offish, was because of my guardedness due to my sensing that he was withholding information. Thus the sniffing out period was prolonged between us. In our shared history, as we both recalled it during the interview, we both saw his "coming out" as addicted as a major time of moving ahead into a more established phase of our

relationship. (See the section, "Example of the Dance of Trust.") I am glad to say that he is now on methadone maintenance, and he presently considers his relationship with me as part of his support system for drug recovery. Part of that support is that if he has pain due to illness, I will give him adequate pain medication, rather than suspecting his motives in asking for drugs because this situation is clear between us. [He did not tell me this in the interview for this study, but told it to me once during a clinic visit.]

The other trend in illegal drug use is the patient whose sniffing out period includes the agenda item of whether or not the provider will supply drugs for him, usually in the form of Tylenol with codeine, said to be best at forestalling symptoms of withdrawal. One patient who I interviewed in his room in the Tenderloin said it was very important that I would give him a regular supply of codeine, which I have done. We had an episode of conflict a few months ago when he walked into the clinic without an appointment and asked me for codeine while in withdrawal. I refused, he got angry and stormed out. At his next visit, he said he was sorry about that time and we agreed to forget about it and move on. He needed to understand the limit that he would be given medications on a regular basis at his appointment times, and not on demand or by walking in unexpectedly and disrupting the visits of my other patients. I have tried to adhere to the Harm Reduction Model (Springer, 1991) with this patient and in similar situations. Harm Reduction is the philosophy that absolute abstinence for drugs is not feasible for the patient who has used drugs for a long time, and that it is best to plan goals based on serial behavioral changes that progressively, over time, reduce the number of harmful behaviors around drug use. Needle exchange programs are a good example of this approach. In the clinic, providing a certain amount of prescription narcotics on a regular basis, but setting up rules to avoid disruptive episodes regarding them, is an example of harm reduction as well. For the participant in the study described here, it has generally been important to him, and part of

his appraisal process, to insure a regular supply of medical narcotics from me as his provider. This is a common agenda item on the part of patients who are opiate-addicted.

Strategies for Access to the Clinic / System

Patients develop strategies to deal with the issue of access to their providers. First is to learn providers' schedules and know when they are regularly in the clinic, i.e. certain days of the week. Secondly is to know when their provider is going away on vacation or to a conference. When the regular provider is not available, strategies become more important. One such strategy mentioned by several patients is to get to know one or more of the staff nurses, or other staff members, and utilize those individuals for access to the pool of providers available when their own provider is not. Also mentioned is the strategy of leaving voice mail messages for the provider and letting the provider call them back to discuss whether to come in to the clinic with certain problems. One patient stated that he knew how to go to the level he needed: his regular provider was "highest," and then, "I go down the ladder," through the levels of ancillary staff who may be helpful in gaining access to the regular provider, or to a substitute primary provider if the regular one in truly unavailable.

Attitudes among the patients regarding the clinic's ancillary staff varied widely. Some patients found the staff very helpful and useful in terms of access. However, some spoke about the staff as unfriendly and useless to them in building a relationship with the clinic as a whole. One patient said he had been coming in monthly on a regular basis for quite some time and every month, the staff members who he encountered monthly treated him like they'd never seen him before. This was a man who would be among our oldest patients and one whom most of the staff would regard as being a member of a different

generation than themselves. Several younger men talked about how the staff was friendly, how they had gotten to know individual staff members, and how non-provider staff, such as RN's, nurses' aides, and clerks had quite personal relationships with them as well; some patients found these relationships to contribute to their sense of trust in and commitment to the clinic as well as their relationships with their actual health care providers. In terms of access, some of the patients saw their relationships with individual members of the ancillary staff as means of entry / access to care or other providers if their own provider was not available on a particular day; they would ask the staff member to approach the nurse or another provider on their behalf. I have been approached by staff members in this way many times, and I try always to respond, because I have long recognized the existence of this strategy and its legitimacy.

Mutual Investment

The third phase of the provider-patient relationship found in my data I call, *mutual investment*. People tended to tell of an initial period of finding their way to the clinic and getting paired with a provider, followed by a period of getting to know and trust the provider, and then, a major long-term phase of the relationship when the ongoing process of receiving and providing health care goes on. The ongoing process, in terms of the relationship itself, is based on a set of assumptions on the parts of the patient and the provider which are based on mutual assessments of trust, honesty, acceptance built up over a period of time, and access to care for the patient.

> I think it took quite awhile, I think it took about a year and a half for it to evolve on a full-fledged basis for both of us.
>
> We went on and on . . . after a couple of years, I trusted you, I really trusted you . . . I know that you would be there, and I know that I would be okay.

> It took months to see if he [the provider] was going to change . . . and I had to present myself to him in an angry manner before he changed his attitude toward me.

The phase of *mutual investment* represents the major amount of time spent in the provider-patient relationship, the usually long period during which both perceive the other as their "regular person," whom they see on a regular negotiated basis, usually for periodic clinic visits at mutually agreed upon intervals.

> You have become accustomed to me and I have become accustomed to you. So therefore our meetings are much more pleasant than they were before. It's not a stress situation like it was when I first met you.
>
> Sometimes it's that day, I gotta go to Ward 86, you know . . . But basically, I was just sort of fighting the fact that I had to go. At first, I didn't want to be bothered with [the nurse practitioner's] rhetoric. Now I go because I want to find out what's wrong with me.

During this time the patient usually considers his/her provider to be the primary resource in access to the health care system, the first point of contact for expected interventions, such as supplies of medications, or unexpected interventions such as sudden illness. The patient is clear about how to obtain access to the provider or the system that covers for the provider when that individual provider is unavailable.

Possible conditions under which long-term interpersonal relationships exist may include (1) the sense of *connection* made between the patient and his/her provider on a personal level, (2) *autonomy* in decision-making, and (3) the assessment of the provider (and the system of which he/she is part) by the patient as being worthy of *trust*, including forthcomingness, honesty, and acceptance or non-judgmental attitude.

Connection

"Connection," within the provider-patient relationship, is the feeling on the part of both that there is "something there" between them. Connection occurs with personal comfort, mutual assessment of needs, appropriate role behavior, and personal style. Personal comfort is an initial feeling tone between two individuals. Mutual assessment of needs refers to a mutuality of priorities, spoken or assumed within the conversation, which occurs as the two begin to explore each other's priorities in the phase of appraising. Appropriate role behavior refers to the provider's ability to assure the patient of a knowledge base, willingness to help, and limits which allow autonomy as well. Personal style, difficult to describe, is the sense between the two of a "fit" and "connection" which, while similar to "comfort," is considered more in the long term projection of the possible relationship. These qualities of the relationship build upon each other as the relationship moves through time, each succeeding step being of longer duration.

Examples of the process of connection include the patient who says, "I do what you tell me because I know that you know what you're doing;" or who says, "At first I thought you didn't touch me or examine me enough, but I began to realize that you know when to do it and when not to." Connection also has to do with access, the feeling of availability and accessibility: the provider who takes a non-judgmental stance, who acknowledges complaints, who does not dismiss problems, and who returns calls.

Autonomy

A major issue in the area of acceptance is that of personal autonomy, consisting of personal responsibility in the area of decision-making. When the provider and patient first

meet, the patient makes an initial decision about whether to continue seeing that provider as part of the initial assessment or "sniffing out" period. Many patients want health care workers whose priority is to accept the patient's own decisions. One strong example of acceptance of decisions regards the decision to take antiviral drugs. Antivirals are the drugs we offer to our patients which can stall the onset of AIDS symptoms while not eliminating the virus from the body. Whether to take them has historically been controversial among patients; the drugs demand daily discipline, have limited efficacy, and may produce serious side-effects. Many persons with HIV and AIDS have chosen not to take these medications, and may want to be assured that their health care providers will accept this decision. One patient spoke of how his previous provider "went off the deep end" each time he stopped a drug, disrupting his feelings of autonomy about his decision-making process. For this individual, the fact that the health care provider was so committed to anti-viral drugs and unwilling to listen to his skepticism about the drugs was the factor that drove a wedge into that relationship. After that experience, the possibility for autonomy became a critical factor in his initial assessment of his next provider.

> I was really against [anti-viral medications]. And then when my T-cells dropped to 200, and they did a viral load and it was really high, she talked to me and said, you know, first she asked me if I trusted her, and I said I did, and she said, well, there's something going on here and I think we need to fight it . . .
>
> So she just said it is preventative, it doesn't do any damage, and it would not hurt you, it would probably help you, and you should take it, and I said okay. But no anti-virals. I was taking those AZT and DDI before I moved here and unfortunately that health care provider was a guru for AZT and DDI. He used to go off the handle when he saw that I stopped it . ... I think it was at first a problem of setting up whether I was going to be one of those patients who was going to be "doc wild" and take whatever they give you and said here, take a prescription and take this and call me, or was I going to have my own mind and my own thing.

Alternative treatments may come up in the area of acceptance as well. Part of the patient's autonomous decision processes may include alternative therapies not offered in the medical clinic. These patients usually want their providers to accept their alternative health care practices. Patients already committed to alternative health care practices may initially "sniff out" their providers in terms of their openness to and acceptance of alternative practices.

Sex and Drug Use

Two major areas which can put the trust in the interpersonal relationship to the test that frequently come up for persons infected with HIV are (1) sex and (2) drug use. These can have significant implications in the development of trust in that, because they are means of infectious transmission, they are areas of disapproval by many members of the mainstream society. Persons with these issues in their lives must constantly be on guard against judgmental attitudes on the parts of health care providers with whom they must interact. Persons with these issues tend to be scanning for attitudes which make them feel rejected. In the relationship with the health care provider, trust may develop slowly due to this guardedness.

For one patient, one of the reasons his relationship with his health care provider got off to a good start quickly lay in the fact that he "sniffed out" rather quickly that he could talk frankly to his provider about his sexuality. This particular case involved the fact that he and his partner, both having trouble maintaining erections, were using dildoes in their sexual activity. He was reluctant to reveal this fact to his provider, but when he did, he found that the provider did not react with shock or disapproval, so his relationship with that provider got off to a good start and continued to grow with good results. That

patient spoke very well of his health care provider and the trust between them is very important to him.

Trust

> I'm not really a person who puts all my faith in one doctor.
>
> If I really like somebody, like 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.
>
> I think it took awhile to trust [the nurse practitioner] because I thought that when the study was over, she'd say no, but she told me its very important that I keep coming back.

Trust is built up slowly as part of the encountering and appraising processes, and trust may take awhile to develop, partly because of the patient's prior experiences in life in general, and especially with the health care system. Trust seems to occur under the conditions of a certain communication style, speaking plainly, or simply, or without condescension, as well as being frank about sexuality, including being "out" on the part of gay providers when working with gay patients. Patients with HIV and AIDS want to know that they will not be rejected as people because of their sexual or drug-use histories, as most of them previously have been by health care providers and in other areas of their lives; they want to feel out the health care worker's acceptance. Trust will be discussed in more depth in the following chapter.

Chapter Summary

This chapter has presented three phases of the relationship: *encountering, appraising,* and *mutual investment.* In the *mutual investment* phase, the part of the

relationship during which most of the ongoing work of the relationship takes place, the concepts include connection, autonomy, and trust. Trust is important enough that it is included in the basic process identified in this data, that of "negotiating trust," which will be discussed in the next chapter.

CHAPTER 6

BASIC PROCESS: NEGOTIATING TRUST

Negotiating Trust

Trust manifests itself as the tone of the relationship which evolves under the conditions of (1) a mutually agreed upon state of non-judgmental attitude, (2) frankness between the individuals, and (3) openness about sexuality and sexual identity. It begins to appear that trust is not a permanent or constant state which, once achieved, then settles down to be the bedrock of the relationship. Rather than a state of the relationship reached once during an initial period, trust is a process which goes on and is continually renegotiated throughout the history of the relationship. 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). At every turn in the relationship, at each moment of beginning to deal with a new issue, the assessment of trust in the health care provider is reassessed by the patient, and the decision whether to proceed in the relationship, to take therapeutic advice, to come back, and to continue to make the personal and emotional investment, is reassessed. Therefore, rather than a single point which can be reached and maintained, trust is a state of mutuality which is dynamic, volatile, capable of rupture, and is constantly negotiated and renegotiated during the course of the relationship.

"Negotiating Trust" as a Core Variable

The concept of "negotiating trust" is most interesting in that it appears to have the potential to explain a very wide range of behaviors, conditions and consequences. This gives it the status of a *core variable* (Glaser, 1978), in that it accounts 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 potentially therapeutic long-term interpersonal relationships, to the failure of the process, which results in the failure to achieve such a relationship.

Following are some quotes from the data which address the concept of trust from the patient's point of view and describe the successful completion of the process of negotiating trust, including patients' perceptions of both the process and the consequences of its success. Different patients have varying levels of perceiving the same process in terms of level of abstraction and conceptualization. Some may describe the consequences of the success of the negotiation of trust between themselves and their providers, without actually identifying the process of negotiating trust, as in the following quotes.

> It's nice to have somebody that knows you that long, and, you know, what's happening with you , and you don't have to keep explaining it over and over again . . .
>
> 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.
>
> And, you know, she never gave me the feeling like, you know, ooh, a drug addict, that kind of feeling like , you know, like they do downstairs. . . That was really degrading. I saw it before my name, they put "shooter," you know, and just kept going on and on about how bad drugs are . . .

Several patients identified "trust" quite specifically as the process which was meaningful and helpful to them.

> 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.

> You know, I trust [my nurse practitioner] because [she] knows me and she knows what I've been through and she knows, you know, my weaknesses and strengths, you know, if I need to know something, you know, she knows how to calm me down if I panic.

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

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, as in the following.

> 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.

These successes and failures in negotiating trust may be either on the part of the patient or of the health care provider. Examples of instances of providers failing to negotiate trust (from their patients' points of view, of course) include:

> 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.

> . . . 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 . . .
>
> 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, you know, it shouldn't alter you head about your own health. And I would think, oh my God, my T-cells are dropping, and I'd panic . . .
>
> I don't like that doctor-patient relationship where you feel like it's 'yessir, nosir.' I don't do this and I don't do that. 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 when I go to proctology, that's exactly what happens. 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.

Honesty Leading to Trust

The following quote illustrates the process of authenticity that leads to the development of trust.

> She talked to me and said what was good and I think 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 she like, as she gradually got to know me, talked to me more, and got me to come out and talk to her, I mean, she didn't try to just jump on me and talk to me, like I wasn't about to crack, because I was. 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 , at times, they're 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, and, you know, and then have to go in and like, I don't know, you know?

A major condition of the concept of negotiating trust lies in the perception of honesty, both in the spoken word, and in the feeling tone. Honesty seem to be the feeling tone, sense, intuition, and impression on the part of both patient and health care worker that there is a forthcomingness of information, an inclusiveness, and a lack of purposeful

withholding of information or emotion. Also, an important part of honesty for the patient is the feeling tone that there is no hiding, on the part of the health care worker, of a judgmental, condemning attitude about the patient. The success of the process of the assessment of honesty appears to be an important aspect of the development of trust. The consequence of perceiving the honesty of the other at each stage of the process of negotiating trust leads to a "next level" of building the relationship, either overall, or in the assessment of the short-term situation relative to each issue within the relationship as it comes up. One common political way to conceptualize the stigma in HIV is the concept of homophobia; for many persons with HIV, especially those who were infected by intravenous drug use, the concept of stigma, regardless of homophobia, may be just as large as an issue.

Trust and the "Cutting Point Between Hope and Despair"

> Of course, when other people say I can't do it, I mean that's always an impetus for me to go on. If somebody says, "you can't walk," I'm going to run. Or if they say, "you can't sit," I'm going to [stand], no matter what.
>
> 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.
>
> I may be dependent on you one day to put me in touch with all the services and if I get really sick and can't, probably a hospice, and you told me you could probably help me there too, and I realize that, if I get really sick . . .
>
> I dread the dementia thing. The mind goes bad. I really hope I do not want to walk around the streets, dirty, shabby, -- because I have lost my doctor.
>
> I really feel I have a lot to live for and I want to live and I feel that it is possible to go on about my business as I have and manage the disease as it is . . . And I'm still here. Whether I will be here in two years or not, I don't know.

One of the expectations that some patients have of their provider is presence, and even assistance at the end of life. These people, as previously stated, live in a community with a high prevalence and relatively long history of HIV infection in the community, regardless of whether each individual is a member of the gay male community or not. All know very well that HIV infection is considered terminal and that it will likely be so for themselves as well. Patients have varying personal styles and levels of personal support in dealing with this fact, and it is likely that those who are most directly dealing with the fact of mortality will bring it up in either their relationships with their providers, or in interviews like those conducted in this study.

To achieve authenticity, mutuality, and the qualities of connection, honesty, and, ultimately, trust, the mortality issue must be addressed frankly when it comes up. The edge on which these individuals are living, mostly relatively young and with a terminal diagnosis and an uncertain future including the likelihood of illness, pain, and suffering, must be acknowledged. The health care provider who runs from this truth, acts in a way which indicates discomfort with the actual discussions, or fear of death, will be at a tremendous handicap, and probably ultimately be incapable of achieving high quality relationships with patients.

Patients need to be able to achieve the kinds of health care relationships in which they can say the kinds of things in the quotes at the beginning of this section. In the health care relationship, barriers such as the legal status of such questions is superficial. Providers must allow patients to verbalize these topics and must both appear and actually be unafraid. A situation currently happening in the HIV health care community which is comparable on the level of legal and potential punitive issues is that of providing

"medical" marijuana. In both situations, regardless of the decisions the provider has made regarding the issue, he or she must be open to discussing the decision with patients.

Sometimes the failure to negotiate trust around an issue with legal and personal moral issues, such as in the first quote above, may be the limiting factor in reaching a successful relationship, and may be a reason for which a patient seeks another provider. For example, I can be clear with patients, but I am consistent in my positions, and some have chosen to leave me and find a provider who will comply with a specific agenda around end-of-life issues. This has happened to me recently with marijuana, and over the years with decisions about disability eligibility as well; that is to say, patients have sought other providers who they hoped would certify them as disabled, or authorize marijuana, under conditions when I would not.

> 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. And I understand the ethics of it, and I understand the legalities of it, but I feel bad and know its 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 . . . And I hate all that scurrying around like a rat in the dark that we have to go through, you know. . .

For providers, the discussion around end-of-life issues can be the point which brings out the transcendent nature of the interpersonal relationship with patients. This may be the point where authenticity as a person and the willingness to participate in discussions at this level can give the transcendent level to the relationship and lead to the appreciation of uniqueness which Paterson and Zderad (1976) write about. This may be the point at which nurses (and other providers) can experience the authenticity which makes the relationship unique and compelling, and allow the provider to continue in this field, despite the stress of these situations. It is important to be able to recognize this

point and at the same time, not have an investment in the suffering of others. This leads to what I have called the cutting point between hope and despair.

The cutting point comes up in medication decisions as well. Both hope and despair can lie in the message we give about the hopefulness that certain medications can "buy time" at the same time that they are not a cure. We ask patients to go on demanding regimens of expensive medications, at the same time telling them it's not a cure. We ask them, often by implication, to invest belief in the ability of the drug to make them feel better, and ultimately in the belief that something better will come along someday for therapy with more expansive goals, at the same time that we acknowledge that there is no guarantee. This is the provider side of the negotiation of trust: to provide information and reassurance without promising too much or sounding unrealistic in terms of the patient's often-sophisticated knowledge about the medications in the context of the community of San Francisco.

Gender and Trust

Although the gender balance of participants was unequal, with eleven men and three women, reflecting the HIV infected population in San Francisco, which is still very largely male (more so than in the country as a whole), I have made an observation based on gender from this body of data. Looking at the participants' individual descriptions analyzed as they move through time, there is a difference in the three women participants' stories that is noteworthy. For the women, there is a smoother course from initial encountering to mutual investment. Although appraisal and the negotiation of trust do occur, for the women, it has been a smoother process.

I loved her from day one; I really liked having a woman doctor.

The process of negotiating trust seems to have a trajectory over time that is more rough and multi-peaked in men than among women, in whom the trajectory of the process seems to be less convoluted. Men seem to go through more serial renegotiations and retestings of the provider several times on the trajectory through time toward a state of trusting; each major turning point in the relationship may need more testing and reassessment than is the case for women. For women, when the process of negotiating trust does occur, the process tends to be more direct. This is to say that for women, the successful negotiation of trust with the provider tends to reach a point of being an achieved state; once established, trust between them has fewer major points of negotiation. The women's HIV community is smaller and the data tells that there is more prior knowledge of the women providers among the women patients than among the men, but this gender difference may also tend to validate the status of women as an oppressed group in society with a set of mutual assumptions among the members, which, once established between two of the members, continues to govern the state of the interpersonal relationship. While also true among men who are gay, the sharing of assumptions may be looser because of the ever-present identity as men.

An Example of the "Dance of Trust"

The process of negotiating and renegotiating trust may be seen as a symbolic dance of the provider and patient circling each other, in states of being on guard, as they constantly look for signs of trustworthiness or its absence.

L. is a 56-year-old African-American man who lives alone in his small apartment in the Tenderloin, where he has lived for about seven years. He has severe

chronic obstructive pulmonary disease and wears an oxygen cannula almost constantly. He also has some problems with dysuria due to prostatic enlargement and has prostate surgery planned for later this year. He stated in his interview that for many years, he was unaware of any of his health problems because his only priority was getting heroin every day. It was only when he began to slow down on his heroin use that he became aware of how serious his shortness of breath was becoming, and he was HIV-tested when he sought methadone treatment. He believes that having HIV infection is not his first problem, but that it is third in rank after dealing with his chronic pulmonary disease and his heroin addiction, now on methadone maintenance treatment. When he first came for care at the clinic, he was very fearful and kept his addiction concealed. He later stated, in his interview for this study, that he felt like he was "asking for too much" in his early interaction with his clinic provider. He now acknowledges that his relationship with the same provider has become much more clear and comfortable for him since he revealed his addiction, and used his provider's support and resources to help him to get into methadone treatment. His provider also felt a hesitancy in trying to bond with L. on a personal level at first, and now understands that the withholding of essential information, about the addiction issue, was what made him uneasy and unable to make a full assessment of this patient's needs and priorities.

This relationship is an example of a process which was occurring in the "appraising" phase of the relationship and in which the fundamental issue was one of trust. Both the patient and the provider were hesitant, and unable to meet the patient's real needs because of the patient's withholding of information due to fear of being judged and the provider's discomfort as his intuition was able to perceive that something was

missing. This is where the "dance of trust" metaphor comes in: in the process of the two circling and observing each other, like wrestlers in that early part of the match, where they circle each other, slowly watching for each other's weak spots, before they move in to engage him. I think the participants may not be aware of this process even as they go through it. To appraise each other may not seem to be unusual behavior, as it mimics a behavior we all go through in forming and maintaining relationships in many different areas of our lives, starting with our families, continuing with our friends, and going on throughout our work careers.

CHAPTER 7

DISCUSSION

This study arose from my observation over the years in HIV/AIDS clinical work that the interpersonal relationship between health care provider and patient was important. Nursing has a deep, rich history of reflection and research in this substantive area, and it is a domain of health care in which nursing has previous academic and theoretical authority. Since my own experience has been as a nurse practitioner for the past fourteen years, I have focused on the primary care relationship, a type of relationship which most nurses, who are not primary health care providers, do not have in their work situations. However, with nursing's history of research in the area of the interpersonal relationship, nursing is the discipline in the multi-disciplinary clinical health care arena that is appropriate for this theory development.

Overall Narrative

Upon finding out that they have HIV infection, individuals in San Francisco get the message to find primary health care providers and establish a health care relationship. In the surrounding community, in which HIV infection has high visibility, this message may come from friends or professional persons with whom they come in contact . For many, especially those without medical insurance, the AIDS clinic in the County Hospital, commonly known as "Ward 86," is the choice of a care site, under conditions of choice, referral, or lack of availability of other facilities. When prospective patients come in or call by telephone to make an appointment, they are paired with the next available primary care provider, who may be a physician, nurse practitioner, or physicians' assistant. On the initial visit, patients begin a process of initially responding to the clinic and the individual provider. Responses in this initial period may include the processes of examining their feelings about their sense of the provider's acceptance of their points of view about health care, especially if they ascribe to unorthodox health care systems; whether their needs for certain medications will be acknowledged, especially if they are habituated to pain medications; whether stigmatized factors about their lives, such as gayness or drug use will be accepted; and the professional identity of the provider (MD, NP or PA).

At the initial meeting, the patient is faced with the response to the provider as an individual, and makes the decision whether to see the individual provider again. If a successful appraisal is made, a phase of variable length through time, begins, during which the patient appraises the provider in more depth, assessing the provider's flexibility about the patient's autonomy in care and medication-related decisions, the provider's flexibility about the patient's general needs, including pre-existing pain medication needs.

If the initial and following appraisals of the relationship are completed successfully and the patient chooses to continue to work with the provider with whom he or she has been paired by the appointment system, the phase of mutual investment in the relationship begins, in which the personal connection deepens and becomes a commitment, an understanding of mutual connection, ongoing expectations through time, specific personal knowledge of each other, and the basic process of negotiating and renegotiating trust begins and continues throughout the history of the relationship. The initial negotiation of trust begins in the transition from the earlier to the mutually invested states of the relationship and the successful negotiation proceeds, and is probably conditional to, each succeeding step. Steps of the mutual investment relationship tend to occur at moments of change in the relationship. Such changes may include the moments of decision about antiviral treatments, moments of confrontation and / or support about drug use, moments of limit-setting by the provider, or moments of mutual realization of truths about the relationship.

Discussion of the Data Analysis

Phases of the Relationship

"You can't not have phases" (H. Wilson, personal communication, 1997). While many nurse researchers in the area of the interpersonal relationship have offered theoretical frameworks of the phases of the relationship, and it may seem redundant to do so again, I believe it is compelling how clearly the phases present themselves in the data, how they can help frame the theorist's and the clinician's thinking about the relationship, and how a conceptualization of the phases can be useful in the clinical field in understanding and accepting the course of events through time.

[illegible]

Asked to "tell a story" about their relationships with their health care providers, almost all patients would construct the narrative with phrasing such as "first of all," and "and then." Almost all would tell of initial impressions, followed by dealing with these impressions, followed by getting to know the provider and accept that provider as an individual. This progression through time is consistent with the theories of Peplau (1952), Travelbee (1971), and Paterson and Zderad (1976) presented in the literature review in this dissertation. These are the three works in the literature which, like this study, reflect passage through time with increasing mutual recognition and cumulative depth of the interpersonal relationship. The first phase of *Initial Encounter* is analogous to Peplau's "orientation," Travelbee's "original encounter," and Paterson and Zderad's "meeting." The third phase of *Mutual Investment* relates to Peplau's "exploitation," Travelbee's "Empathy," and Paterson and Zderad's "presence" and "call-and-response" phases. What is different and may reflect the contemporary social situation is that in the phases of the three theorists mentioned, the second phase, between the initial meeting and the long-term working phase of the relationship is one of further development of depth: "identification" (Peplau), "emerging identities" (Travelbee), and "relating" (Paterson and Zderad). However, in the present study, the phase between the initial and the ongoing one is one of additional assessment, as well as development of depth in the relationship, before the level of depth in the third stage can be achieved. In addition, while the existential theorists in my literature review both have a final "transcendent" phase of the relationship, no identifiable phase of that nature came up in this data. While clinicians know that transcendent moments happen, and some have been related in the data of this study, again, the process of simply getting to a point of mutual trust may be more complex than it used to be. There appears to be a change through chronological time to a social situation of more wariness between persons and less assumption of mutuality due

[illegible]

to the recognition of power differences in society, and the issues of stigma and marginalization.

Recognition of the phases can help the clinician recognize progress in individual relationships which may seem difficult, in responding to patients in a way that meets their needs for information and reassurance at appropriate times and in appropriate terms, and in continuing to develop the relationship in a way that will make it ultimately a useful tool in both providing care for the patient and enhancing the provider's feelings of helping. For example, I have pointed out the relationship between AIDS and lives already lived in marginalization and stigma. It is precisely those persons who may have the most trouble forming relationships with others, and may need to go back and retest their first impressions again, or retest their appraisal of the other before they can feel the safety to enter the phase of mutual investment. The provider who recognizes the phases may gain clarity in understanding the patient's process and therefore be more able to participate in the process of building the relationship.

While the tendency of human beings, when telling stories, is to create temporal lines, it is also important to realize that the phases of the relationship can create a convoluted course through time, and the phases may not be in logical sequence, may repeat themselves, may jump from one to another in non-temporal sequences, may occur simultaneously at once, and some may not occur at all. This is similar to the interpretation of Kubler-Ross (1969) in her discussion of the phases she identified of death and dying.

Stigma and Marginalization

Stigma is a fact of HIV/AIDS in a way which was probably inconceivable to the earlier theorists, as none of them specifically dealt with the issue of stigmatized patients.

Stigma is defined as the mark of shame or discredit which occurs when certain groups or situations are seen as threatening to the majority in terms of values and safety (Saylor, 1990). Many other diseases have been stigmatized through history including syphilis, epilepsy, leprosy, plague, and mental illness (Nisbet & McQueen, 1993). The stigma of HIV/AIDS may be greater than any of these (Sontag, 1990), considering its newness in an age of such rapid travel and communication, its association with certain groups and the fact that the health care provider community may actively participate in the process of stigmatization (Burnard, 1993).

"Marginalization" is the process through which people are peripheralized on the basis of their identities, associations, experiences, and environments (Hall, Stevens & Meleis, 1994). Many, although certainly not all, of these participants are gay men, and there is a certain ability among gay men, as a group, to be both middle-class and marginalized at the same time, in a way not seen as commonly in other groups. The prevalence of HIV and AIDS is higher in the racial and ethnic minority communities than in the mainstream, "white" population, and race is well known to be a marginalizing factor in this country. In addition, many others infected with HIV who are not gay, are intravenous drug users and addicts. Oppression may be multi-dimensional, and one may take the point of view that all racial, sexual minority, drug-dependent, and HIV-infected individuals are marginalized, regardless of the economic status of individual members of these groups (Altman, 1971).

As I have stated in my study of a Tenderloin hotel (Carr, 1996), social marginality is a "risk factor" for HIV. The "Tenderloin" is a district of San Francisco where many marginalized people dwell and congregate, located near the downtown district and characterized by the lowest priced housing in the City and the central location of the

street drug and sex trades. About one third of the patients I have interviewed live in the Tenderloin; three in single-room-occupancy hotels (SRO's), so some "marginalized" persons do have ongoing interpersonal relationships with their health care providers and others. It is inappropriate to assume certain patients are incapable of either quality relationships or adherence due to their class, race, economic status or area of residence.

Personality Issues

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. The success of the initial meeting seems to be an important condition for the initiation of a long-term relationship. I am aware that many individuals never reach the mutual investment phase with any individual provider for various reasons.

Is there a connection between an individual's marginalized status and his/her ability to form interpersonal relationships? In my clinical practice, I have been influenced by the psychiatric concept of "personality disorder" to describe certain patients' behavior. Personality disorder is the concept used in psychiatry to describe the patient with affect regulations dysfunction leading to impulsivity, behavioral and cognitive instability, and difficulties with interpersonal relationships (Miller et al., 1994; Fraser & Gallop, 1993). It is common for nurses to respond to these patients in a non-empathetic way because of the difficulty which the patients themselves create due to the disorder (Fraser & Gallop, 1993).

San Francisco has a district where many marginalized people congregate, called "The Tenderloin." Although close to the city's major tourist and shopping areas, with large hotels and department stores within a few blocks, this district is one of older, more run-down apartment buildings and single-room-occupancy (SRO) hotels that provide relatively cheap housing in a city with very high rents. Here, the people with the least resources survive on tough streets, where unusual behavior and illegal business activity are tolerated, and where a population of the poor, marginally housed, and homeless finds refuge from the scorn they experience in more conventional neighborhoods (Carr, 1996). How much of marginality is socio-economic, and how much is based on these types of personality structure issues? What is the relationship between these factors that brings some persons to the marginalized "Tenderloin lifestyle"?

So far, I have spoken both to patients who have both 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 be identified by us as suitable for these interviews. I have approached five individual patients whom I know have had problems maintaining relationships with any provider, and all of these individuals either refused to give consent to be interviewed, or failed to keep interview appointments.

Adherence to Medication Regimens

The functional interpersonal relationship between patient and primary health care provider is speculated to have an influence on adherence, but more research is needed

regarding this question. Due to the high costs of these medications, and the clarity of the relationship between adherence and physiological benefit, this is an area in which the interpersonal relationship might have specific economic value to the health care system. Thus, it may bring the interpersonal relationship to the attention of health care policy planners who would not ordinarily care about the quality of the patient's or the worker's personal experience in the health field.

The field of adherence, or "compliance," has its land mines, as nurses know. While adherence is considered a desirable goal by the health system, the proper moral and ethical position for the nurse is in solidarity with the patient (Stevens & Hall, 1996). Our ultimate responsibility is to be engaged in ethical dialogues with our patients, learn the patient's own sense of what is best for him or her, and defend his or her autonomy, regardless of our own (possibly paternalistic) views of what is best for that patient (Hess, 1996). When we place the goal of adherence or medical outcome before autonomy, we give up some of our moral commitment to patients, and work against the relationship we think we're striving for. These considerations are particularly current in the HIV field, in which the debate over the role of these new medications is far from settled.

Trust

Trust is an important concept in clinical interpersonal relationships (Johns, 1996), as indeed in all aspects of human life and relationships. In nursing, trust has been viewed as both a process and an outcome, and previously described as both fragile, and built up 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). In this analysis, it is both the process between

the two individuals in the relationship, as well as the outcome or product of the successful negotiation of the phases of the relationship. Since the development of trust is described in the data as a process occurring through time, it must be asked what effect is had on the development of trust by the contemporary trend in health care of seeing patients as quickly as possible in order to manage economic efficiency (often referred to as managed care). This time factor may also have implications on the adherence issue, if trust in the provider is a factor in the acceptance and understanding of complex medication regimens. Further research into the concept of trust, its component factors, its role in clinical relationships, and its implications for patient care, is indicated.

Significance

The major way in which this study is a departure from previous studies of the nurse-patient interpersonal relationship is that it is based exclusively on interviews with patients and takes data from their points of view for analysis. Of the five qualitative studies reviewed in Chapter Two of this paper, four were based on interviews with nurses only (May, 1991; Morse, 1991; Ramos, 1992; Heiffner, 1993), and only one was based on interviews and observations with both nurses and patients (Fosbinder, 1994). Interestingly, the study which included patients is the most recent, so perhaps there is a trend in this direction. The group of patient respondents in Fosbinder was described as "predominantly white," possibly reflecting the population in mid-western Canada, while the population in this study was more racially and ethnically mixed [see Appendix C], reflecting the population of California.

In addition, none of the studies cited above was based in an HIV-infected population. The HIV clinical area may be unique in terms of the interpersonal relationship

for several reasons. For one, marginalization due to minority sexual orientation, personal history of drug use, and economic poverty may be a factor in the lives of many HIV-infected individuals. Certainly not all patients, but enough that these experiences influence the HIV community, society's response to this epidemic, and the health care professions' responses to it. Also, there is the stigma attached to this disease for the reasons just mentioned. While more research is needed, I speculate that these differences explain the occurrence of more appraisal before the point of mutual investment, and less "transcendental" phases than in those of Paterson and Zderad and Travelbee, the existential theorists.

Many of the health care providers caring for these patients enter into practice situations in which they care for HIV patients either exclusively or mostly. While the goal of this study is to develop theory to guide health care providers in practice, we must not ignore the situatedness of providers in the field with its stress, its "bottomless pit" of patient needs and care-related tasks, and the personal pain of both empathy and failure as we watch our patients inevitably suffer. This is especially true in my situation, as a provider researching his own practice. It is my hope that part of the uniqueness of this study is in addressing the experience of providers through my reflections on myself in practice, and that reading it and reflecting on it will provide health care workers with a mirror of their own experiences, a validation of their own perceptions, and an acknowledgment of their own work, as well as some hopefully useful clinical observations.

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, while 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. When I realized the "other side" of this category, I tried to seek out patients in the clinic who appeared to have failed to negotiate trust and were having trouble forming relationships with providers. All of these individuals refused to be interviewed, including two who made interview appointments and then did not show up. I made two appointments with each, and gave up after the second no-show. I have not yet explored the meaning of this experience, but if the same persons who appear to fail to negotiate trust also fail to be reachable to interview, the ability to fully research this category will be limited. I do not know what to do about this problem at this time.

A second limitation is that due to time constraints, this study was able to include only the patients' point 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. While 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 in health care workers in the HIV field (McKusick, et al., 1986). Our high level of professional satisfaction may be part of what we need to communicate to the other workers who may be fearful of AIDS patients and of working with them. Additional studies are need which will interview both patients and providers, or perhaps pair them for interviews.

Summary

This study of interpersonal relationships between health care providers and patients in an outpatient AIDS clinic arose directly from my personal experiences as one of these primary providers over a period of fourteen years. Based on my experiences in the clinic, I have been convinced of the importance of the relationship in providing optimal care to patients. This study has found three phases in the building and maintaining of the relationship: Encountering, Appraisal, and Mutual investment; and it has found a basic process of Negotiating Trust. These findings are consistent with my clinical experience, and I hope they will be useful to my fellow clinicians in building relationships with their patients. In addition, I hope that persons living with HIV, AIDS, and other chronic diseases will have their access to and quality of health care improved by supportive relationships with their health care providers, whether nurse practitioners, physicians' assistants, or physicians.

APPENDIX A:

CONSENT FORM FOR PATIENTS

CONSENT TO BE A RESEARCH SUBJECT

Long Term Interpersonal Relationships Between Health Care Providers and Patients in an AIDS Clinic

Purpose and Background

Gary Carr, RN MS, a staff nurse practitioner at Ward 86, San Francisco General Hospital, and a doctoral student in Nursing, and Juliene Lipson, RN, Ph D, Professor of Nursing, at the Department of Community, Mental Health and Administrative Nursing, School of Nursing, University of California, San Francisco, are undertaking a study of the nature of long-term interpersonal relationships between health care providers and patients in the clinical setting at Ward 86. I am being asked to participate because I am a patient at Ward 86 and I have this type of long-term relationship with my regular health care provider.

The purpose of this study is to learn more about these relationships so that both health care workers like Gary and his colleagues, and patients, such as myself, can understand these relationships better and perhaps gain a better quality of health care by using the new insights which are learned.

Procedures

If I participate, I will agree to be interviewed by Gary Carr about my relationship with my health care provider in the clinical setting. I will be asked open-ended questions, that is, questions where I am asked to examine my thoughts and speak awhile in order to answer fully. These interviews will take place at Ward 86 and will probably last about one hour. Interviews will be scheduled separately from my clinic visits. The interviews will be audio-taped if I agree to taping.

I may be called back after my interview by Gary at a later date in order for him to ask me some questions to clarify what I said, or to be shown some preliminary results of the study and asked whether I agree with them.

Possible Risks

I may be made uncomfortable by some of the thoughts that come up when asked to discuss my disease, my health care situation, or other personal aspects of my life during this interview. If Gary is my regular health care provider, I may be made uncomfortable by having to discuss with him our own relationship. I have the right to refuse to participate, or to refuse to answer any question, or to withdraw from the interview and the study at any time.

Participation in research in general and this study in particular may involve some loss of confidentiality. My name will not be attached to the tape of my interview or any transcript of the interview or research report that develops from this study. Only Gary, his

nursing faculty advisors, and a transcriptionist, who will not learn my identity, will hear my taped interview.

Benefits

There is no guarantee of benefit, but I might enjoy the knowledge of possibly helping other persons with HIV/AIDS develop better relationships with their health care providers based on things we learn here. In addition, the interview process may help me learn more about myself and my health care situation.

There will be no financial cost nor any remuneration for participation.

Alternatives

The alternative to participation in this study is to not participate. It is my right to refuse to participate.

Questions

If I have any questions, I may ask Gary Carr, the researcher, or his academic advisor, Juliene Lipson, RN, Ph. D., at the School of Nursing, University of California, San Francisco. Professor Lipson can be reached by telephone at (415) 476-3981. If I have concerns which I cannot discuss with Gary or his advisor, I may call the Committee on Human Research at the University of California, San Francisco, Mondays through Fridays, 8 AM to 4 PM at (415) 476-1418, or write to the Committee at Box 0962, University of California, San Francisco, San Francisco, CA 94143.

I have been given a copy of this consent form and of the Experimental Subject's Bill of Rights.

APPENDIX B:

PARTICIPANT DEMOGRAPHIC DATA FORM

Participant Code____________

Gender Male _____ Female _____ Transgender _____

If transgender, gender at birth ________

Age __________ Ethnic Identity

____

Highest grade in school completed __________

(two-digit number, for example, completed high school = "12")

Current employment status

____

Living Situation

Alone _____

With spouse/partner _____

With room-mate _____

With family _____

Sheltered housing _____

Other _____

Do you receive

SSI, SDI _____

General Assistance _____

AIDS Emergency Fund _____

Open Hand meals _____

AIDS Food Bank _____

Other Assistance

____

Length of time seeing present primary health care provider _______months / years

Spiritual/Meditative Practice (if any)________________________________

Alternative Therapy (if any)________________________________

APPENDIX C

Demographics of Sample

Fourteen interviews were done for this study. Of the participants, 11 were male and 3 female.

	MALE	FEMALE
Age	Range 30 - 57 Mean 43.7	Range 33-34 Mean 33.3
Ethnicity	Caucasian 4 White 3 Black 3 Mexican-American 1	Caucasian 2 American 1
Education	Range 12 - 16 Mean 14.5	Range 6 - 15 Mean 11.7
Employment	Employed 1 Unemployed 4 Disabled 4	Employed 1 Unemployed 2
Living Situation	Alone 5 With spouse/partner 4 With room-mate 2	Alone 2 With spouse/partner 2
Years with primary provider	Range 3 - 12 Mean 4.7	Range 3 -5 Mean 4

APPENDIX D

SAMPLE INTERVIEW QUESTIONS

"Please think of your relationship with your present primary health care provider as a story with a beginning, a middle, and a present, as there is no end yet. Tell me a story about that relationship. Start at the beginning."

"How has your relationship with your provider changed over time?"

"Please think of a day when you saw your provider and things did not go well, for instance, a day when there was disagreement or conflict between you, and tell me about that day."

"Please think of a day when you saw your provider and things between you went particularly well. Tell me about that day."

"Is there anything else you would like to say about your relationship with your health care provider?"

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