

**TURNING POINTS IN IDENTITY:  
BECOMING A SURVIVOR  
OF HIV INFECTION**

**By**

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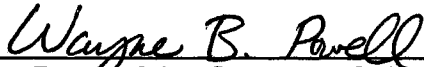
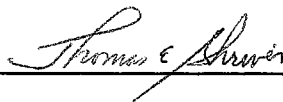

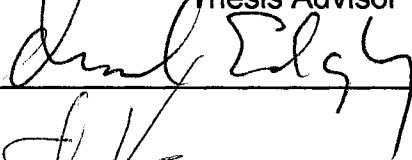
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## NOMENCLATURE

AIDS	Acquired Immune Deficiency Syndrome
CDC	Centers for Disease Control
CMV	Cytomegalovirus
GRID	Gay-Related Immune Deficiency
HIV	Human Immunodeficiency Virus
KS	Kaposi's Sarcoma
PCP	Pneumocystis Carinii Pneumonia
PLH	Person Living with HIV Infection
PLHs	People Living with HIV Infection

## CHAPTER 1

### INTRODUCTION

#### The Problem

As the population of people living with Human Immunodeficiency Virus (HIV) is increasing, so is their longevity as the result of medical advances (see Appendix A). This has led to an increase in requests for services. Unfortunately, this is not reflected in funding proposals (Millman 1998). Treatment advances, managed care, and welfare reform have led to increased dependence on community based services for which limited funds are available (Millman 1998). Services, when available, tend to be fragmented which may restrict people's access to adequate healthcare (Sherer and Goldberg 1994).

A further complication is that it is often assumed that individuals control their own health outcomes, including whether or not they contract HIV infection. People living with HIV infection are stigmatized because HIV is often associated with what many people consider to be deviant, immoral behavior (i.e. male to male sex and intravenous drug use). As a result, the consequences of such behavior are believed to be their responsibility. People frequently identify HIV infection as a disease that is easily preventable. It is also considered to be contagious, threatening, and undesirable, and is not clearly understood by the general public (Alonzo and Reynolds 1995). Stigma has been referred to as a characteristic which is considered to be shameful and undesirable to the extreme that it excludes the one possessing it from full social interaction (Goffman 1963).



When an individual is believed to be responsible for his or her stigma, the severity of it increases. Thus, there are those who are viewed as victims and those who are viewed as deserving of their stigmas. Preventing HIV infection is often viewed as being as easy as changing individual actions and avoiding risk behaviors.

It is this narrow line of thought that leads people to “blame the victim” (Singer 1994). People living with HIV infection are viewed as responsible for their demise because they engaged in high-risk behavior when it is presumed that they knew better. This point of view naively assumes that all individuals have equal access to education, healthcare, and income (Thomas and Quinn 1994). It is considered naive because people do not have equal opportunities to obtain these resources due to social forces such as poverty and discrimination. Access to healthcare requires economic resources. This, coupled with the fact that our healthcare system does not emphasize preventive care, has serious ramifications. Too little is done too late. The practice of discrimination which includes inaction or “looking the other way” in terms of targeting groups for prevention, research, and treatment efforts is not absent in American society.

People’s abilities to adopt suggested Acquired Immune Deficiency Syndrome (AIDS) prevention strategies should be considered. These abilities can be affected by sexual politics. For example, research has shown that inner city women have difficulty encouraging their male partners to wear condoms because they fear their partners will be angry with them for questioning their trustworthiness. Some women judged challenging their partners to be as

dangerous as practicing unsafe sex (Singer 1994).

According to Grob (1995), research indicates that emerging populations of people living with HIV infection must overcome distinct barriers to address their needs. These barriers include cultural differences in mores, transportation, family responsibilities, poverty, substance abuse, and homelessness (Grob 1995). Other barriers include being uninsured or underinsured; the lack of social support, both instrumental and emotional; the lack of medication; the absence of knowledgeable personnel, both medical and support; the absence of adequate services; the lack of community based support; and limited community understanding and acceptance. If people live in rural areas, costs in time in addition to money are likely to be incurred if there is inadequate community based support. There are also costs associated with human suffering, both on the parts of the person who is sick and their friends and family members who care about them.

The ability to meet most of these needs is contingent upon financial resources which are scarce, particularly among people living in poverty. Some of these needs are addressed to varying degrees by programs and services that are funded by federal sources such as Medicaid and the Ryan White Care Act. While these healthcare access issues are being addressed by policy makers and healthcare professionals, limited funding and fragmented services represent hindrances to this process. The lack of adequate support could be explained, in part, by recognizing that people living with HIV infection are often stigmatized by others in society, including political representatives who have power and who

have reputations for promoting their own agendas. For example, in response to requests for AIDS research funding, North Carolina Senator Jesse Helms claimed that AIDS would disappear if people would stop engaging in homosexual activity. In his view, engaging in this behavior is synonymous with playing Russian roulette (Kirkman 1998).

### Purpose of Study

It is important to understand the social experiences of people living with HIV infection (PLHs). Their experiences along with the facts regarding HIV infection should be shared with the public, other PLHs, and members of the medical profession, so they may be more informed to make decisions that reflect understanding rather than stigmatization. There is no cure for HIV infection. While there is continuous research on the virus itself, research also needs to focus on people who live with the virus in society. This is especially relevant because of advances in medicine (i.e. protease inhibitors) that have led to decreased AIDS mortality rates. People still have HIV infection, but they are living with it.

HIV infection is more than a physical disease if the stigma associated with it is considered. A disease refers to a biophysical phenomenon, whereas an illness refers to a social phenomenon. Diseases are part of the physical world, and illnesses are part of the social world (Conrad 1997). People have diseases, but they act out illnesses. Thus, illness is both a social role and a label. As such, any illness can be viewed as a reflection of cultural values and can vary from

society to society. Hence, there are social consequences associated with each label, including the label of HIV infection which is stigmatized. These consequences are a central focus of this research.

### Outline of Work

A central assumption of this research is that through the process of social interaction, meanings are created. Through this process, identities emerge and reemerge. Because HIV infection is a stigmatized illness, I argue that being labeled as such is a turning point in identity (Strauss 1959). Turning points in identity are “critical incidents” in personal careers when people realize that they are not the same as they once were. According to the paradigm of symbolic interactionism, people create reality. Therefore, they have the ability to manage the impressions they project to others, including those that tend to be stigmatized. I am interested in the stigma management techniques PLHs use to maintain awareness contexts and the corresponding consequences of these awareness contexts for social interaction and identity construction. Some of the social consequences of disclosure include understanding from others, discrimination by others, and poverty.

The situational approach to the study of social psychology will be used to guide this research project. In Chapter Two I will provide an overview of the Chicago school of symbolic interactionism as a conceptual framework. This review will not be comprehensive, as it is beyond the scope of this project. It will include a discussion of one of the approaches to the study of identity classified in

this tradition, dramaturgy. One of the central areas of study within this tradition is impression management, or the use of the dramaturgical skills individuals employ to control their impressions of themselves to others. An overview of the research regarding stigma as it pertains to HIV infection will be organized according to three groups of proponents: the profession of medicine, popular health moralists, and religious moralists.

PLHs will be interviewed regarding their social experiences. I will provide a thorough explanation of this qualitative data collection technique, data organization, and data analysis in Chapter 3. Chapters 4 and 5 will consist of the research findings and a discussion of the results, respectively.

## CHAPTER 2

### REVIEW OF THE LITERATURE

#### Sociological Social Psychology

Sociological social psychology has focused on processes related to self and identity development. Blumer (1969) emphasized that an individual can act toward his or her own self just as he or she does to others. Relying on Mead's interpretation of the self is a social object, Blumer explained:

"In declaring that the human being has a self, Mead has in mind chiefly that the human being can be the object of his own actions. He can act toward himself as he might act toward others. Each of us is familiar with actions of this sort in which the human being gets angry with himself, rebuffs himself, takes pride in himself, argues with himself, tries to bolster his own courage, tells himself that he should 'do this' or not 'do that,' sets goals for himself, makes compromises with himself, and plans what he is going to do" (cited in Charon 1989:72).

The self is a process and emerges and is defined and redefined through interaction with others. Thus, the process of the self is dependent on social definitions (Charon 1989).

Identity consists of the meanings imputed to an actor by the self and, it follows, by others (Gecas and Burke 1995). Identities are the names individuals refer to themselves as. They are the labels used by the others one interacts with, and they can change from situation to situation, according to whom one interacts with (Charon 1989). Identity has been described as what a person announces to others that he or she is; identities are meanings imputed to the self. Interaction reestablishes them during each encounter (Charon 1989).

According to Gecas and Burke (1995), one of the general social psychological perspectives regarding self and identity is the situational approach which focuses on the process of the self, including its emergence and sustenance in various social situations. This approach represents the Chicago school of symbolic interactionism. A central concept of this orientation is the process of the definition of the situation which suggests that social reality is not static, but is socially constructed. This applies to identity as well. Identity construction involves such interactional processes as negotiation, bargaining, and impression management.

#### Precursors to Symbolic Interactionism

The roots of symbolic interactionism can be traced to American pragmatists who, in general, viewed the mind as an adaptive, natural object and emphasized that interaction with the natural and social world is necessary for the emergence of the self. The most notable philosophers who contributed to this school of thought are James, Dewey, and Mead who was the most influential (Stryker 1990).

James viewed an individual's self esteem as changing from situation to situation while arguing that each person also has an enduring disposition. He asserted that individuals have various social selves which they show to different groups of people, as they care about others' opinions of them (Rosenberg 1990). James pointed out:

Many a youth who is demure enough before his parents and teachers, swears and swaggers like a pirate among his 'tough' young friends. We

do not show ourselves to our children as to our club companions, to our customers as to the laborers we employ, to our own masters and employers as to our intimate friends (cited in Rosenberg 1990:594).

Dewey recognized the relationship between the individual and society and viewed it as intimate. Each individual is born into a social world which consists of associations of people that existed before his or her arrival. He referred to habit and custom (collective habit) as personality organization and social organization, respectively. It is because of custom and habit that individuals can think and adapt to their environment. By thinking, people define objects in their social worlds in the context of action and rehearse potential lines of action. It is through this process that meaning emerges so they can adapt to their environment (Stryker 1990).

The ideas of the philosopher George Herbert Mead influenced the development of the theoretical framework of symbolic interactionism in sociology, and in particular the sociologist, Herbert Blumer. Mead's ideas are expressed in *Mind, Self, and Society* (1934) which is collection of his lecture notes taken by his students. The major areas of this work will be identified and explained.

Mead identified and explained the nature of mental processes and the mind. Intelligence is the capacity of humans to use significant symbols to mutually adapt to the acts of one another and other organisms. Reason is the capacity of humans to converse with themselves individually. Reflexive intelligence consists of three components. First, humans have the ability to temporarily delay their reactions to stimuli and thus have the ability to identify the possibility of different responses to situations. Second, humans can contemplate the possible results of these different



responses by carrying on conversations within themselves. And, third, humans can identify different stimuli and choose which one to react to. They can also choose how to react. The mind is a social phenomenon that Mead defined as the social process of conversing with oneself inwardly (Ritzer 1992).

The self, according to Mead, is the ability of humans to view themselves as subjects and as objects and is dependent on the social process of human communication. The processes of self (mental process) and mind (social process) are dialectic. In other words, in order for the self to emerge, the mind must be developed, but the development of the mind is dependent on the reflexive nature of the self. This "reflexive nature" is the ability of individuals to put themselves in the positions of others and act like others and actively converse with others while monitoring what is said and what will be said (Wallace and Wolf 1991). Mead explained the necessary social nature of the self as follows:

"How can an individual get outside of himself experientially in such a way as to become an object to himself?...[It is through] the process of social conduct or activity in which the given person or individual is implicated...The individual experiences himself as such, not directly, but only indirectly, from the particular standpoints of other individual members of the same social group...[he] becomes an object to himself just as other individuals are objects to him or in his experience...it is impossible to conceive of a self arising outside of social experience" (cited in Charon 1989:65).

The genesis of the self consists of three stages: preparatory stage, play stage, and game stage. The preparatory stage (or pre-play stage) occurs at approximately the age of two years, when children engage in meaningless acts (usually imitation and mimicking), meaningless because children are not capable of seeing themselves from the perspective of others. The play stage occurs in later

childhood. Children acquire the ability to put themselves in the positions of others. They can also act in these roles, although usually one or two at a time. At this stage, the self begins to form. In the game stage, there are several players in one game (like baseball). The individual must be able to anticipate what the others, in relationship to one another, will do in a particular situation. It is in this stage that the individual gains the ability to take the role of the generalized other which, according to Mead, enables the community to influence the conduct of its members (Wallace and Wolf 1991). Ultimately, to develop a self requires being a participating member of the community.

The "I" and the "me" are two phases inherent in the process of the self. The "I" is the creative and unpredictable response of an individual to others. The "me," on the other hand, is the conscious response of an individual to others. It is conscious because the individual acts based on the internalization of the generalized other. Proceeding the processes of both mind and self is the process of society which is ongoing and shapes the aforementioned processes. Society represents the generalized other that constitutes the "me" phase of the self. Society is "in" the individual. Through self-criticism, individuals being guided by the organized generalized other control themselves accordingly.

### Blumer and the Chicago School

Herbert Blumer's most significant and recognized contribution to sociology was helping to incorporate the ideas of George Herbert Mead in the development of his views on symbolic interactionism and its methodology (Shibutani 1970). The

three premises of symbolic interactionism according to Blumer (1969) are: people act toward things on the basis of what the things mean to them; the meanings of things arise from the social interaction a person has with people he or she associates with; and meanings are used and changed by people's interpretations as they deal with the things they encounter.

The central position of symbolic interactionism is that "the meanings that things have for human beings are central in their own right" (Blumer 1969:3). Meaning arises through the course of interaction between different people. The meaning of things for people comes from the ways in which others act toward one another regarding the things. The way other people act defines things for people. From the perspective of symbolic interactionism, meanings are social products because they are created from the actions of people in the process of interaction. When a person uses meaning in his or her actions, it is an interpretive process which has two steps. First, the actor interacts or communicates with himself or herself by deciding what things he or she is acting toward, or what things have meaning. Second, the actor "selects, checks, suspends, regroupes, and transforms the meanings in the light of the situation in which he is placed and the direction of his action" (Blumer 1969:5). Interpretation is the process in which meanings guide the actions an individual takes.

There are six basic ideas, or "root images" as Blumer (1969) called them, that symbolic interactionism is established on. The first is the nature of human society or human group life. Society exists in action; therefore it is necessary to view society and group life in terms of action. The second basic idea of symbolic interactionism is

the nature of social interaction. Blumer (1969) discussed Mead's ideas regarding this root image. Society is composed of people who interact with one another. This process of interaction "forms" human conduct. A person fits his or her own activities in some way to other people's actions. Mead's two levels of social interaction are "the conversation of gestures" and "the use of significant symbols." The conversation of gestures is when a person directly responds to someone's action without interpreting it. Blumer (1969) referred to this type of interaction as non-symbolic. The use of significant symbols, which Blumer (1969) referred to as symbolic interaction, is when one person responds to the action of another person after interpreting it. Of importance to Blumer (1969) was Mead's definition of symbolic interaction as "a presentation of gestures and a response to the meaning of those gestures" (Blumer 1969:9). The meaning of a gesture indicates what the person to whom the gesture is directed is supposed to do, what the person who is makes the gesture is planning to do, and what the joint action will be as a result of both of the acts. Blumer (1969) added that when people interact, they must take each other's roles, or take the standpoint of each other.

The third root image is the nature of objects. Blumer (1969) described objects as "anything that is pointed to or referred to" (10). Three types of objects are physical objects (i.e. trees), social objects (i.e. friends), and abstract objects (i.e. morals). What an object means to a person stems from the way other people with whom he interacts define them to him or her. Common objects have the same meaning for groups of individuals. The consequences associated with this are first, that the environment only includes the objects that a group of people recognizes. To

understand people's actions, one must distinguish their world of objects. Second, the meanings of objects are social creations. People's lives and actions change as their world of objects changes.

The fourth root image is the human being as an acting organism. According to Mead, by possessing a "self," one can be an object of his own action. A person acts toward himself and others based on the kind of object he is to himself "from the outside." Through role taking, people have to see themselves from the outside to become objects to themselves and can do this by putting themselves in the positions of others and acting toward themselves from these positions. These positions include the different roles of individuals, organized groups, and the abstract community or society. From Blumer's (1969) perspective, human beings are social because they engage in social interaction with themselves.

The fifth root image is the nature of human action. Human action involves taking into consideration various things and acting on the basis of how these things are interpreted. This equally applies to collectivity. Blumer (1969) said that such things could include wishes, wants, objectives, means for achievement, actions of others, anticipated actions of others, self-image, and the anticipated outcome of actions.

The sixth root image is the interlinkage of action. Joint action is the conduct of the individual acts of different participants as they are organized by society. In other words, the joint action of a group is the interlinkage of each participant's individual acts. Blumer (1969) discussed the implications of the interlinkage of joint action. Repetitive and stable action is when people share common and pre-

established meanings of what actions are expected of them. People guide their behavior by these meanings. "It is the social process in group life that creates and upholds the rules, not the rules that create and uphold group life" (Blumer 1969:19). The extended connection of actions refers to when individuals act based on the use of given sets of meanings that are specific to a localized process of social interaction (Blumer 1969:19). And, finally, joint action arises from previous actions.

### Goffman's Legacy: Dramaturgy

Goffman's work was also influential in the development of the situational approach. According to Brissett and Edgley (1990), dramaturgy is concerned with how people achieve meaning in their lives. Meaning is the consequence of interaction, not the antecedent, and has two components. First, meaning is the result of what human beings do. Second, relying on Mead's definition, meaning is one actor's response to another actor's gesture. Further, "meaning is a behavioral, socially emergent, problematic, variable, and in fact arbitrary, concoction of human interaction" (Brissett and Edgley 1990:3). In other words, meaning is coincidental to social interaction. People have the power and freedom to create their destiny in the dramaturgical view.

While Goffman expressed that identities are social fictions created by actors engaged in social processes of self-presentation, their consequences are real (Gecas and Burke 1995). Brissett and Edgley (1990) assert that identity is shaped by social interaction. People are what they do because it is not possible to separate the self from the act. People have multiple selves according to the

situation; this includes the people they interact with. For people to interact, it is necessary for them to know information about one another. When people act, they express themselves so others in that situation may get this information. In other words, the actor makes impressions of himself to others; it is a two-sided relationship. This is why the self is shaped by social interaction (Brissett and Edgley 1990). Hence, when a person “comes out” as having HIV or as being a homosexual, his or her interaction with others will change and as a result so will his or her identity (Nardi 1990).

Charmaz (1994) expressed that another concern of dramaturgy is the problematic features of an individual's actions. It is when a person's actions are questioned that the issue of motivation commences. Motives are explanations or accounts of past, not future, events. Having a diagnosis of HIV can be viewed as an act, as a form of conduct. People sometimes look for motives from those who are ill or from those who are close to them. Motives in the dramaturgical sense are part of the act. They come into question only when a line of action is interrupted, when a person challenges the acts of another (Brissett and Edgley 1990). Some people mistakenly believe that people have complete control over the disease and whether they contract it. Emphasis seems to be placed on how people become HIV-positive. This is clear upon reviewing the statistics available on HIV infection, which are maintained by the Centers for Disease Control (CDC). Information regarding social living conditions such as socioeconomic status is excluded. The prospect of HIV transmission is framed so that individuals (not including children) are responsible for themselves no matter what.

Goffman's contributions include considerable attention to dramaturgical matters such as how people stage self-presentations and how people deal with embarrassment and stigma (Gecas and Burke 1995). Stigma, in Goffman's view (1963), is a powerful social label which discredits and taints how individuals are viewed by others and, in turn, themselves. People who are stigmatized are discounted as a result of their undesirable attributes. Stigma is a characteristic which is considered to be shameful and undesirable to the extreme that it excludes the one possessing it from full social interaction. The person who is stigmatized is viewed as being what Goffman (1963) described as "not quite human." When an individual is viewed as being responsible for his or her stigma, the severity of it increases. Hence, there are those who are victims and those who deserve it.

People living with HIV infection (PLHs) are stigmatized because people associate HIV infection with deviant, immoral behavior, and as a result its consequences are their responsibility. Thus, it represents character flaws (Alonzo and Reynolds 1995). The disease is considered to be contagious, threatening, undesirable, and an anesthetic way to die. Further, HIV infection is not clearly understood by the general public, while at the same time health professionals do not view it positively (Alonzo and Reynolds 1995). An overview of the research regarding the stigmatization of PLHs by the profession of medicine, popular health moralists, and religious moralists will be examined in the next section.



## Societal Reaction to HIV Infection

The profession of medicine has a history of stigmatizing PLHs. A situation becomes a social problem only after it has been defined as a social problem (Spector and Kitsuse 1987). Similarly, in the profession of medicine, it is the physicians, not laymen, who define what constitutes illness and what conditions warrant their medical skills and research efforts. The public accepts this thereby ensuring that the profession of medicine has the power to create what is "real" (Freidson 1970; Freund and McGuire 1995).

According to Freidson (1970), the medical profession's definitions of illnesses and their degree of severity change over time. Sometimes present definitions contradict past definitions. Gay-Related Immune Deficiency (GRID) was not a research priority until it was acknowledged that the syndrome posed a threat to the health of heterosexuals. It was at this point that GRID was redefined to include heterosexuals and renamed Acquired Immune Deficiency Syndrome (AIDS) (Freund and McGuire 1995). Kayal (1993) offers an explanation of the medical profession's lack of interest in HIV research:

Unlike broader society, which felt fearful and apathetic toward AIDS, social or medical scientists were not interested in relevant AIDS research and accurate information on gay life-styles not only because of stigma, hatred, or ignorance but also because of unethical political considerations, the need to protect reputations, and moral self-righteousness (p. 37).

The stigma associated with being gay or being a prostitute is further exacerbated by being diagnosed with HIV infection. This can be referred to as being doubly stigmatized (Sandstrom 1990). Medical scientists did this when they did not consider GRID to be a priority. Caregivers may even view homosexuals and

intravenous drug users as self-centered and responsible for the spread of HIV infection (Fulton and Owen 1994). In Goffman's (1963) explanation of stigma he stated that "by definition of course, we believe the person with a stigma is not quite human" (p. 5). This is exemplified in the following description of one PLH regarding his experience in a hospital:

I was sleeping on a bed with no linens, in a room with no towels, no personal care stuff, no barf pan, nothing. Just me, on this bed, on a plastic sheet (Tewksbury & McGaughey 1997:59).

Fulton and Owen (1994) reported the results of one study which found that while 75% of caregivers believed that AIDS facilities would offer more adequate care than general hospitals, only 11% reported that they would work in these special units. During a presentation, Dr. Elisabeth Kubler-Ross suggested that a community in Virginia build an AIDS hospital for abandoned children. The middle-class audience opposed her proposal, and she was forced to end her presentation (Fulton and Owen 1994).

Popular health moralists are people who focus on causality and the "do's and don'ts" of healthy living. The notion of causality must be taken into account because HIV infection is viewed as the consequence of activities such as non-monogamous, male-to-male sex and intravenous drug use which are considered by many people to be immoral or illegal or both. HIV infection is transmitted most often by acts of penetration such as rectal intercourse or the injection of drugs. Quam (1990) posits that these acts of penetration can also be viewed as acts of violation. Rectal intercourse has been considered to be abnormal and unnatural. It is associated with rape in prisons. Illegal drug injection such as heroin causes people to become addicts and lose control of their lives. Americans seem to regard AIDS as

"something undeniably awful...that makes clear the dangers of self-indulgence" (Quam 1990:41). Fulton and Owen (1994) assert that babyboomers would attribute the AIDS epidemic to the "failure to produce proper hygienic measures with respect to both sex and drug use" (p. 387). Babyboomers also consider illness as controllable by individuals or as preventable or curable by medicine.

Seeking motives from PLHs suggests that there are other alternatives as evidenced by the health promotion and prevention movements which are perpetuated by the mass media. According to Albert's analysis, the media is inclined to emphasize the stigmatized status of individuals in high-risk groups whose lifestyles are considered to be deviant such as homosexual men and intravenous drug users (cited in Nardi 1990). This allows the public to discriminate between those who "brought the disease on themselves" and those who had nothing to do with their condition (Nardi 1990). These movements could also be referred to as "the dos and don'ts of healthy living." Edgley and Brissett (1990) refer to this as "health fascism" and explain that because AIDS is "[w]idely feared as a hazard to the human race, it becomes an excuse for Fascist calls..." (p. 261). This is because tenets of this political program seek to save people from HIV infection by attempting to prohibit what they also consider to be immoral behavior. They also charge that:

...to equate morality with health as a way of facilitating conformity to certain moral values is, at the same time, to obscure the very moral consequences of such conformity (p. 272).

AIDS is viewed by some individuals as a disease that a person brings on oneself as a result of a defect in character, poor judgment, and a "sick life-style." Nardi (1990) explains that "because of the confounding concepts of morality and medicine, the media reports AIDS using language that perpetuates the stigma

attached to it and to the people dying from it" (p. 159). Topics of such media reports include "the risk which children afflicted with AIDS pose to their schoolmates; the advertisement of condoms on television; [and] the distribution of free needles to drug addicts..." (Fulton and Owen 1994:387). Tom Brokaw hosted a television segment on AIDS and presented the vision of AIDS as "the gay man's disease" to the American public despite the fact that intravenous drug users, children, and heterosexuals had been shown to have the disease for over ten years (Fulton and Owen 1994). Over time, while HIV infection began to be associated with groups that society values such as children and heterosexuals, the stigma of the disease did not wane (Nardi 1990). In Albert's analysis of obituaries, AIDS was not cited as the cause of death (cited in Nardi 1990). Instead diseases such as pneumonia, meningitis, and others not prominent among young people were cited. As people learn to decode this language, they will attribute the causes of death to AIDS. Thus, stigmas are preserved (Nardi 1990).

If the beholder of the disease is thought to have participated in any behavior that violates the dominant Christian ideology, then the reason he or she has the disease is not justified. One might say he or she is getting what he or she asked for: punishment for sinful acts. He or she deserves it. This viewpoint "serves to separate the people of 'good' behavior from those of 'bad'" (Fulton and Owen 1994:394) and is supported by the following excerpt from the Old Testament:

If a man also lie with mankind, as he lieth with a woman, both of them have committed an abomination: they shall surely be put to death; their blood shall be upon them (Leviticus 20:13 as cited in Fulton and Owen 1994:385).

Conrad posits that illnesses that are stigmatized either produce deviant behavior such as in the case of mental illness or are a product of it such as in the

case of sexually transmitted diseases (cited in Alonzo and Reynolds 1995). People with stigmatized illnesses are often shunned or devalued and are thought to lack "moral character." It is in this vein that religion may strengthen stigma because God may be regarded as punishing PLHs for their immoral behaviors which led to their condition (Alonzo and Reynolds 1995). Kayal (1993) further explains this rationale:

Since religions committed to male privilege prohibit same-gender sex, the social distance and stigma that effectively "ghettoize" gay concerns are legitimated. In effect, gays, not being considered "real," normal ("natural") men, should die of AIDS because they are sinful "failures" (p. 80).

The hypocrisy of religious moralists can be seen if one considers that the sympathy and forgiveness that they contend to offer are not constant; they vary by the clergy leadership. Therefore, it might be necessary for people to seek the acceptance and support of a religious congregation (Alonzo and Reynolds 1995).

Some PLHs even perceive their condition and the suffering that accompanies it as punishment by God. One of the individuals interviewed in Sandstrom's (1990) study explains:

In the beginning, it [AIDS] triggered feelings that had to do with...well, I hesitate to say this but it was like I deserved this [illness]. This is exactly what I deserved! I've heard other gay men talk about the same thing like "God, we've tried to live such a decent life and we're being punished." We made that connection of somehow being punished...and even if we didn't come right out and say it was punishment or something, what we said or what I said was "Well, God's trying to tell us something here" (p. 276).

People are only justified if they are victims of the disease who did not participate in lines of action that would have a deadly disease as a consequence. For example, the infants of HIV positive mothers are viewed as innocent, helpless victims. A woman rejected her status as an "innocent HIV victim" explaining that just because she was not a homosexual male or an intravenous drug user does not

mean that she had never committed acts that are considered to be wrong such as premarital sex (Tewksbury and McGaughey 1997). Another PLH claims that "[y]ou can't single people out and say this is a victim...and these people are guilty...You don't do life that way...We're talking about death here" (Tewksbury and McGaughey 1997:57). However, people do this. Thus, there are those who are suffering the negative consequences of others' actions that they could not control, and there are those who are suffering the negative consequences of their own actions which they should have controlled.

Once it is known that an individual has HIV infection and the cause has been established, meanings could change and interactions could be suspended. This is apparent upon examining the consequences of bearing the double stigma of being homosexual and HIV positive. One PLH explained:

The nurses are scared of me; the doctors wear masks and sometimes gloves. Even the priest doesn't seem too anxious to shake my hand. What the hell is this? I'm not a leper. Do they want to lock me up and shoot me? I've got no family, no friends. Where do I go? What do I do? God, this is horrible! Is He punishing me? The only thing I got going for me is that I'm not dying—at least, not yet (Kleinman as cited in Freund and McGuire 1995:165).

Interactions could also continue, but it may not be favorable to the PLH, even if he or she provided a justification. As discussed previously, the meanings imputed to HIV infection are not usually favorable. PLHs are stigmatized regardless of why they have it. It is because of the nature of the disease; it is not curable (Tewksbury and McGaughey 1997). People may not want to associate with PLHs because they are afraid that the virus is contagious through interactions such as kissing or hugging (Sandstrom 1990). They may also be apprehensive about being stigmatized by others who fear them as being a possible source of contagion as a result of being

close to PLHs (Sandstrom 1990). This is also known as courtesy stigma (Goffman 1963). The fear of contagion has been called "the most salient feature of stigmatizing responses to PLHs" (Tewksbury and McGaughey 1997:52). Tewksbury and McGaughey (1997) refer to the stigmatization of PLHs as a metaphorical vaccine. Society acts toward PLHs instead of the virus because it is incurable at this time.

According to Tewksbury and McGaughey (1997), some PLHs compare themselves to rape victims in that they believe others view them as having asked for their condition. One of the respondents in their study said:

I think the world sees me as this terrible, promiscuous, sex-hungry, drug-using slime of a person. I don't think society or the world sees me as just someone who had a bad break (p. 55).

PLHs can also be compared to incarcerated rapists. Consider the following excerpt from Brissett and Edgley (1990):

Once again we see that the difference between one's audience accepting one's motives and not doing so has consequences ranging from mild disapproval to maximum-security incarceration, depending on the perceived severity of the conduct in question (p. 206).

PLHs face the same dramaturgical task with similar consequences, metaphorically speaking. However, everyone with a diagnosis of AIDS gets the death penalty. It is different than the gas chamber, lethal injection, or the electric chair in that the physical demise is not as quick.

### Turning Points in Identity

It is clear that to live as a person with HIV infection is to live as a person who is stigmatized by others. The moment at which a person is labeled with HIV infection

represents an important turning point in identity. According to Strauss (1959), a turning point in identity is the moment when the person transforms into something he or she was not before. This shift in identity also leads to irreversible changes in perceptions of everything in his or her social world, including the self and others. In other words, the turning point is a vantagepoint which is used to evaluate themselves in the past and the future from this new status. Thus, turning points are “critical incidents” in personal careers when people realize that they are not the same as they once were. In the case of HIV infection, the irreversibility is compounded because it is a stigmatized disease and it is incurable at this time.

Turning points are usually accompanied by “misalignment” (Strauss 1959). People are surprised, shocked, anxious, or tense. They engage in self-questioning. It is also common for people to want to try out the new self so that exciting and fearful conceptions can be validated. This identity transformation process is both “socialized” and “socializing” even though evaluations take place within the individual. In other words, incidents that lead to the revision of personal identities are likely to be experienced by others who will also revise their personal identities.

It is apparent that people living with HIV infection are often stigmatized by others. Hence, being diagnosed as having HIV infection can be seen as a turning point in identity. From the standpoint of symbolic interactionism, people create reality. They have the ability to manage the impressions they project to others; this includes managing stigma. What makes the study of HIV infection as a social phenomenon so challenging is that it is not possible to look at someone and know he or she is HIV-positive. To impart HIV-related stigma, it is necessary to know the



information or to suspect it. PLHs can exercise some control over this in their interactions with others. Glaser and Strauss' (1965) awareness context theory will be used to explain the possibilities for social interaction and the related consequences.

### Awareness Context Theory

Glaser and Strauss (1965) developed awareness context theory which consists of four awareness contexts. An awareness context is what people know about the definition of the situation. Awareness context theory provides a framework within which impression management techniques can be further understood. It will be explained in the context of one person in the situation having a diagnosis of HIV infection. Relationships can be characterized according to four awareness contexts: open awareness, closed awareness, suspicion awareness, and mutual pretense. Social interaction proceeds based on the awareness context of any given situation.

Open awareness refers to the situation in which both people are aware that one has HIV infection, and they interact based on this information. For example, a PLH may practice safe sex with his or her partner to prevent the transmission of HIV infection. In contrast, closed awareness refers to a situation in which a person knows he or she has HIV infection, but the other person does not. This could be beneficial to a PLH in that he or she can avoid being stigmatized by others.

Suspicion awareness refers to a situation in which a person knows he or she has HIV infection, and the other person suspects it. The PLH may or may not know that he or she is suspected of being HIV-positive. This is referred to as open and

closed suspicion awareness, respectively. When someone questions visible symptoms of HIV infection such as lesions (i.e. What happened to your face?), it would be considered closed suspicion awareness. An example of open suspicion awareness is when a person goes to the doctor to get treatment. When he or she informs the physician of various symptoms, he or she might be asked if he or she is HIV-positive or if he or she engages in any of the risk behaviors associated with it. In this case, an HIV test would be the only way to know for sure.

Finally, there is the awareness context of mutual pretense. This refers to the situation in which both people know that one has HIV infection, but they act as if he or she does not. Interaction rules do not permit discussing that the person has HIV infection or anything related to it. If the subject does come up, the context must return to mutual pretense.

Glaser and Strauss (1965) suggested that awareness contexts apply to all situations of social interaction in general, not just to interactions centered around one who is dying. They encouraged the study of other substantive areas so that a general theory could be developed because the study of such variations is part of the process of theory development. They recommended that any study of social interaction should have a data analysis plan that reflects consideration of the variable awareness.

### Stigma Management and Identity Construction

People act to maintain awareness contexts. They use the dramaturgical skills of impression management. Lincoln and Guba (1985) compared reality to quantum

mechanics in their consideration of “popping the qwiff.” This can be used to illustrate the non-deterministic nature of social interaction and its impact on identity construction. By popping qwiffs, people create reality; reality is not a given. By not popping qwiffs, there is only potential for different realities. PLHs create reality which results in meaning and identity construction when they reveal or conceal their diagnosis. This is facilitated through the dramaturgical practice of impression management skills known specifically as stigma management techniques. Two strategies commonly used to manage HIV-related stigma are information control and embracement (Tewksbury and McGaughey 1997). When an individual utilizes the information control strategy, he or she uses the techniques of passing, covering, isolation, and insulation to restrict the visibility of his or her health status (Tewksbury and McGaughey 1997; Sandstrom 1990). These stigma-management techniques will be described and discussed in terms of their relationship to the awareness contexts.

Passing refers to not revealing one's diagnosis. This is usually done in the early stages of HIV infection when symptoms are not apparent. When a person uses the stigma management technique passing, the situation can be characterized as a closed awareness context. Sometimes PLHs do not reveal their real diagnosis and instead tell others they have other conditions such as leukemia or cancer to explain the visible symptoms of the disease. This dramaturgical skill is known as covering. In Sandstrom's (1990) research, this technique was utilized more frequently by people in their relations with others who did not know they were gay. The PLH who uses the stigma management technique covering to conceal his or her

diagnosis is able to maintain closed or suspicion awareness contexts. PLHs resort to isolation when they want to avoid expressions such as fear and social devaluation from others that could arise in interaction if people recognized that they had HIV infection by visual cues such as lesions. They withdraw from mostly all social interaction. This could also help them maintain either closed or suspicion awareness contexts. Insulation is when individuals restrict interaction to a limited number of people, usually those who are trusted and with whom they can be open regarding their diagnosis (Sandstrom 1990). The situation in which the stigma management technique insulation is used allows for the contexts of mutual pretense or open awareness.

When individuals use the embracement strategy to manage stigma, they assume their HIV identity. In other words, they accept their identity as a PLH. Examples of embracement are participation in support groups and referring to oneself as "a person with HIV" instead of as "a victim of HIV" (Tewksbury and McGaughey 1997). A person who embraces his or her HIV identity may also become an activist for certain causes such as privacy rights for PLHs. People who use the embracement stigma management strategy are in open awareness.

### Framework Summary

This research will serve as a theoretical and empirical contribution to the study of the processes of self and identity. It will be guided by the social psychological perspective referred to as the situational approach, otherwise known as the Chicago school of symbolic interactionism. An attempt will be made to

integrate the core theoretical concepts which are the emphasis of this research and to provide empirical evidence to support this integration. These concepts include stigma, turning points in identity, impression management, and awareness contexts.

Previous research supports the contention that PLHs are stigmatized by members of society. Thus, being diagnosed with HIV infection can be regarded as a turning point in identity. Just as people are creative and have control over their destiny, they can manage the impressions of themselves they project to others. They can present themselves so as to manage the stigma of HIV infection. It is not possible to know that a person is HIV-positive by looking at him or her. To experience HIV-related stigma, a person must be known or suspected to have HIV infection. Awareness context theory contributes to an understanding of this. Stigma management techniques can be used to maintain awareness contexts which have corresponding consequences for social interaction and, in turn, identity construction. In short, this project will focus on people's accounts of their interactional experiences regarding living with HIV infection. Their accounts of their interpretations of their interactions with others will be examined, in addition to how these interactions shape identity.

The following research propositions were derived from my conceptual framework in conjunction with the review of the literature regarding people's accounts of living with HIV infection.

1. PLHs are stigmatized by others.
2. Being diagnosed with HIV infection is a turning point in identity.
3. As creative beings, PLHs act to maintain certain awareness contexts.

4. PLHs practice stigma management techniques.
5. Social interaction proceeds according to each awareness context. In other words, there are social consequences associated with each awareness context.
6. Social interaction and its consequences (meaning) shape each individual's HIV-identity.

The following general research questions were derived from the research propositions previously articulated.

1. What revisions in identity does receiving a diagnosis of HIV infection engender?
2. What concerns do PLHs have regarding maintaining social interaction with others?
3. How do PLHs use stigma management techniques to preserve social interaction with others?
4. What are the consequences of revealing a diagnosis of HIV infection on social interaction?
5. Do PLHs interactions with others center on their HIV diagnosis?

These questions guided my research activities which are discussed in detail in the next chapter. They will be addressed systematically in Chapter 5.

## CHAPTER 3

### METHODOLOGY

The Chicago school of symbolic interactionism advocates the implementation of naturalistic inquiry to examine research questions (Gecas and Burke 1995). This research project is a qualitative study of people living with HIV infection. Twenty-five unstructured, in-depth interviews were conducted to obtain empirical evidence. To answer the research questions posed, the interactional experiences of PLHs expressed in their own words are analyzed. No hypotheses were tested. This data collection method and the data analysis are discussed in detail in the following paragraphs, including strengths and limitations.

#### Qualitative Interviewing

Qualitative interviews are ideal because they allow researchers to engage in interpretive understanding, to collect data that is characterized by descriptive richness, and to analyze data inductively. The main goal of this method of field research is to learn about everyday social life in some social setting from the perspectives of the people engaged in it (Cahill, Fine, and Grant 1995). It is appropriate for me to use field research methodology for this project because its roots in sociology were established along with the Chicago school of social psychology, symbolic interactionism, the paradigm used to guide this research (Cahill, Fine, and Grant 1995).

Among the most prominent sociologists whose scholarship contributed to the development of symbolic interactionism are Weber, Cooley, Thomas, and Blumer. Weber stressed the concept of *verstehen* in his definition of sociology:

“Sociology is a science which attempts the interpretive understanding of social action in order thereby to arrive at a causal explanation of its course and effects. In ‘action’ is included all human behavior when and insofar as the acting individual attaches a subjective meaning to it. Action in this sense may be either overt or purely inward or subjective; it may consist of positive intervention in a situation, or of deliberately refraining from such intervention or passively acquiescing in the situation. Action is social insofar as, by virtue of the subjective meaning attached to it by the acting individuals (or individuals) it takes account of the behavior of others and is thereby oriented in its course” (cited in Wallace and Wolf 1991:238).

Translated, *verstehen* means interpretive understanding or subjective meaning.

His emphasis on these areas contributed to the development of symbolic interactionism (Wallace and Wolf 1991).

Cooley insisted that sociologists should employ the process of “sympathetic introspection.” This means being sympathetic to imagine things the way others do. Through this method, social facts can be discovered about society and individuals, as one cannot exist without the other. Cooley recognized that the self could not exist without others (Stryker 1990).

W. I. Thomas emphasized that subjective as well as objective facts must be considered when studying social life. While objective facts are situations which individuals act in, subjective facts are characterized by the definitions of the situation that guide people’s actions. Consideration of the subjective facts of social life is crucial to sociological understanding because, as Thomas pointed out, if a situation is defined as real, it is real in its consequences (Stryker 1990).



According to Blumer (1969), methodology concerns the principles that direct the "process of studying the obdurate character of the given empirical world" (23). The implications of this are threefold. First, methodology comprises scientific inquiry as a whole, not just a single aspect of it. Blumer (1969) discussed the important parts of scientific inquiry. The utilization of a pre-existing representation of the empirical world being studied and the recognition and assessment of the premises of this representation is necessary. Inquiry should begin with questions regarding the empirical world. These questions should lead to the statement of problems. One also has to decide what and how data will be collected and what relationships and associations there are between the data, once gathered. The findings must also be interpreted. The use of concepts is central because they are the basis of scientific inquiry. These parts of inquiry should be carried out so that respect for the empirical world being studied is maintained.

Second, each part of the scientific quest as well as the complete scientific act, itself, has to fit the obdurate character of the empirical world under study. Blumer (1969) emphasized that empirical validity is best confirmed by going directly to the empirical social world, not by adhering to the rules of the scientific method.

Third, the empirical world being studied provides the answers to questions, not scientific inquiry. This is possible through what Blumer (1969) called exploration and inspection because "the empirical social world is the world of everyday experience...<and> the life of a human society consists of the action and experience of people as they meet the situations that arise in their respective worlds" (35). Through exploration, or the exploratory study of human group life, researchers can

become more familiar with spheres of social life that are not familiar to them at the beginning. The research at the start has a broad focus, but becomes clearer as the study progresses. Inspection, or the direct, focused examination of the empirical social world, should also be a part of analysis. Blumer (1969) described inspection as "flexible, imaginative, creative, and free to take new directions,... and is not tied down to a fixed mode of approach and procedure" (p. 44-45). The methodological implications of symbolic interactionism are that both individually and collectively, people act on the basis of the meanings that objects have to them.

The data collected from field research methods has been charged with being "glorified journalism," as it is nothing more than mere description. As a result, it does not contribute to theory development or understanding and its results are not generalizable (Cahill, Fine, and Grant 1995). These criticisms reflect a lack of understanding of field methods, including the advantages. For example, it can assist quantitative researchers in the development of surveys meant to measure areas of social life they are unfamiliar with. Critics fail to recognize that not all theoretical frameworks view social acts as deterministic. With this assumption in mind, utilizing qualitative methods allows researchers to follow Blumer's (1969) advice on how sociologists should conduct research. Blumer (1969) summed up the methodological orientation of symbolic interactionism as defined by him very clearly when he said:

"The task of scientific study is to lift the veils that cover the area of group life that one proposes to study. The veils are not lifted by substituting, in whatever degree, preformed images for firsthand knowledge. The veils are lifted by getting close to the area and by digging deep into it through careful study. Schemes of methodology that do not encourage or allow this betray

the cardinal principle of respecting the nature of one's empirical world" (p. 39).

Interviews are "special interactional encounters" (Denzin 1970). A key feature of these encounters was articulated by Benney and Hughes (1956). That is, both interviewers and respondents are experts in the interviewing process. Interviewers must be the experts on asking the questions, and respondents are the experts on answering the questions. The best defense an interviewer can have is being aware that things can go wrong, anticipating that they will, and being prepared to correct the problems to ensure that the interview is successful (Denzin 1970). Interviewers must establish rapport with respondents in order to obtain data that can be classified as thick and descriptive. One requirement is that interviewers must not be uneasy or anxious about asking personal questions; it may make the respondents feel uncomfortable with answering the questions (Smith 1991; Banaka 1971).

As respondents are encouraged to answer questions freely in their own words, the flexibility of the interviewer is crucial to his or her success. It is possible that more questions will emerge during the process of interviewing. It is up to the interviewer to keep the direction of the interviews focused on the subject of interest (Judd, Smith, and Kidder 1991). Unstructured interviewing techniques enable researchers to ask questions regarding different time periods according to the information the respondent shares (Erlandson et al. 1993). Another advantage is that interviewers can ask questions to clarify the responses expressed by study participants.

## Selection of Participants

For the present study, representatives of HIV/AIDS support organizations were asked to distribute announcements of this study to PLHs (see Appendix B). PLHs who were interested in participating were instructed to contact me in one of three ways: by telephone, e-mail, or postal mail. To secure more participants, I did not limit this study to the local area. I established a toll-free telephone number so that potential participants could call me at my expense rather than their own. I relied on the snowball method to secure more interviews. Interviews were arranged in two ways. In 9 cases, individuals contacted me via telephone, and in 2 cases individuals contacted me via e-mail. We agreed on convenient appointment times for face-to-face or telephone interviews. In 5 cases, it was not financially feasible to travel, so telephone interviews were conducted. These individuals expressed the desire to participate, so I accommodated them. In 14 instances, 2 informants made face-to-face appointment arrangements for me and notified me. They introduced me personally to each referral. One of the informants also escorted me to most of the HIV/AIDS support organizations in his city of residence. There were 3 no shows and 2 cancellations during the data collection process. Appointments were not rescheduled with these individuals. A total of 25 interviews were completed over an 8-month period.

## Ethical Considerations

The subject matter of HIV infection is a sensitive one because of the stigma attached to an HIV diagnosis. Rapport was established because I made

the respondents feel comfortable and certain that I would maintain the confidentiality of their responses. Informed consent was obtained from the participants (see Appendix C). To protect the privacy of the respondents, fictitious names are used in the analysis and discussion of the data. Only adults aged eighteen years and older were interviewed. This project was approved by the Oklahoma State University Institutional Review Board (see Appendix D). Upon the completion of this project, I will share my results with the individuals who shared information about their lives with me, if they are interested.

### Data Collection

To ensure that interviewees expressed themselves freely, it was imperative to lessen their fears of disapproval, admonition, or dispute. This was accomplished by reminding them that their responses were confidential and that their participation was voluntary throughout the course of the interviews (Judd, Smith, and Kidder 1991). This was especially important for PLHs who may have experienced fatigue during the course of the interviews. Participants were encouraged to express themselves in a way that was meaningful to them (Judd, Smith, Kidder 1991).

The majority of the interviews were the anticipated length of between one and two hours each. While there was a sequence of questions, they served as a guide (see Appendix E). Therefore, the interviews followed a non-standardized format without eliciting normative responses from the interviewees. This interviewing technique allowed respondents to articulate their definitions of the

situation (Dexter 1970; Lincoln and Guba 1985; Erlandson et al. 1993). This method was chosen because PLHs' interpretations of their social experiences are the focus of the study. Confining their answers to specific categories would have been inappropriate. The interview questions were not derived from any specific source, but instead are a reflection of the central research questions of this project. At the end of each interview, each respondent was invited to suggest additional questions related to the subject of interest, the social experience of living with HIV-infection. If suggestions were made, they were asked to answer their own questions. This was done to allow participants to be an active part of this research project. Each subsequent interview included suggested questions if they were pertinent to this study. Field notes were written including responses to the questions and relevant observations related to their dialogue (i.e. angry tone, laughter, crying, etc.).

### Description of Participants

Three females and 22 males aged 29 to 50 years were interviewed. The average age was 40 years old. Most were white. Seven of the participants had a combined total of 20 children. Over half of the respondents had post-secondary education, including some college, associate's and bachelor's degree, and postgraduate education. Half of the people interviewed identified themselves as being single, never married. Others were widowed, divorced, separated, married, and had partners. Eight of the participants lived in institutional settings, 5 lived alone, and 12 lived with someone, including family members, roommates,

partners, or companions. The majority of people were receiving disability benefits (15). Six people worked full-time, 1 person was searching for employment, and 2 people were neither working nor looking for work.

The majority of the interviewees (16) reported that their income did not meet their needs. The people interviewed had known of their HIV status from less than one year to 19 years. In other words, they were diagnosed from 1979 to 1998. The exposure categories were male-to-male sex (13), male-to-male sex and IV drug user (1), IV drug user (3), and heterosexual contact (5). Three individuals did not disclose this information.

### Limitations

Because of the flexibility of in-depth interviewing, the data collected by using this technique has low reliability. For this reason, the responses of the interviewees can be viewed as incomparable. This is because the questions and answers are not worded and ordered the same for each interview. The questionnaire was used more as a guide or checklist (Judd, Smith, and Kidder 1991). Another limitation is that I did not actually observe any of the interactions the respondents referred to during the interviews. The data consists of accounts of interactions as participants described them during the interviewing process. As this study is exploratory in nature, the results have limited generalizability to the population of people living with HIV infection.

## Data Organization and Analysis

The data I collected assisted me in answering the general research questions that guided this project. It consists of 25 individuals' expressions of their interpretations of their social experiences related to living with HIV infection. The general topics that each person was asked to discuss included 1) disclosure of diagnosis 2) worries related to having HIV infection 3) being open about HIV status with others 4) death and dying 5) healthcare experiences 6) organized support. After each interview was conducted, field notes were reviewed. Permission was granted by all participants for follow-up interviews if clarification was necessary or if further questions emerged relevant to this project. One follow-up interview was conducted. I kept an accurate log of interview dates and times, including follow-up interactions. The field notes (data) from each interview were typed including relevant observations regarding responses (i.e. crying while discussing a certain topic).

The data are organized as it pertains to interview questions and topics. One-sentence summaries of the responses to each question were written. These sentences reflected the main points the participants articulated for each question asked. As the process continued, the summary data were reclassified into different or emergent categories. This process, known as "emergent category designation," enabled me to organize the data in conjunction with my conceptual framework (Erlandson et al. 1993). It is for this reason that this is "one of many possible constructions of reality" (Erlandson et al. 1993:118; Lincoln and Guba 1985). In other words, if someone else examined this data utilizing a different



framework, emphasis would be placed on different themes. The categories were then regrouped into themes. These themes are used to answer the research questions. Examples of themes are cited and discussed in the remaining chapters of this dissertation.

## CHAPTER 4

### BECOMING A SURVIVOR OF HIV INFECTION

The results of this research are presented in four parts. Part one, "Disease Related Turning Points," addresses the beginning of the process of becoming a survivor of HIV infection. Two turning points in identity that were experienced by PLHs included receiving a diagnosis of HIV infection and becoming a patient with HIV infection. In this section I describe these processes. Part two, "Misalignment and Stigma," concentrates on the social processes that accompany the turning point of becoming a person with HIV infection. These processes center around the anxiety and tension related to interacting with others as a person who has a stigmatized illness. Part three, "Awareness Contexts" focuses on the impression management techniques PLHs use to conceal their HIV status and the consequences of revealing it to others. Some of these consequences precipitate other turning points in identity such as when relationships end or emerge. Part four, "Becoming a Survivor," addresses the revision in identity that occurs when PLHs come to see themselves as survivors of the disease. Certain processes facilitated this turning point. These are support group participation, outliving other PLHs, redefining HIV infection as a chronic, manageable condition, and deciding to live with the disease.

## Part One: Disease-Related Turning Points

In part one examples are given of how people were given the news of their HIV infection. Healthcare experiences as a patient with HIV infection are also discussed. Thus, two turning points addressed in this section are becoming a person diagnosed with HIV infection and becoming a patient with HIV infection.

### Disclosure: Becoming a Person Diagnosed with HIV Infection

The accounts of the people included in this study illustrate the overall multifaceted and diverse process of becoming a survivor of HIV infection. Disclosure of their diagnosis by healthcare professionals marked the beginning of this process. The way this information was communicated to them was a central issue. For some it was not done in a supportive or informative way. Although people agreed or made requests to be tested for HIV infection, until the results of such tests were disclosed, the *qwiff* had not been popped. In other words, the reality of having HIV infection had not been created until PLHs were told of their diagnosis by an authorized professional. The ways the *qwiff* was popped and the associated consequences are central dramaturgical issues of this research.

The disclosure of the news that one has HIV infection represents what Strauss (1959) referred to as a turning point in identity. At this moment the person transforms into something he or she was not before. This shift in identity leads to irreversible changes in perceptions of everything in his or her social world, including the self and others. In the case of HIV infection, the irreversibility is compounded because the disease is incurable. Further, it is a stigmatized

disease. The turning point is a vantagepoint which is used by people to evaluate themselves in the past and the future from this new status. Thus, turning points are “critical incidents” in personal careers when people realize that they aren’t the same as they once were.

The delivery of bad news in the context of the healthcare setting is a multifaceted issue. Central concerns include deciding who should give the bad news (doctors, nurses, or counselors) and how (abruptly; by making patients and families guess; etc.) and where (on the telephone; in the waiting room in the presence of strangers; etc.) bad news should be disclosed to patients and families. People living with HIV infection described how their diagnosis was disclosed to them. While the people interviewed had diverse experiences, three styles of disclosure emerged from the data analysis: the unsupportive approach, the compassionate approach, and the informative approach. It is recognized that these are generalizations and that there is much diversity in how bad news was imparted. While the responses reflect reconstructions of their memories of a past event, the disclosure of HIV infection represents an important turning point in each person’s identity. Examples of each of these three approaches will be cited.

#### The Unsupportive Approach

Being told that one is HIV positive in an unsupportive way is marked by the lack of compassion, support, and information on the part of the bearer of the news. The diagnosis is given as part of the agreed upon services to be rendered by the healthcare provider or counselor. One PLH explained how she was

brought into open awareness about her diagnosis a few months after she was tested:

I found out in 1996. An M.D. gave me the news. I was there for an office visit for something else. "We tested you in August and you tested positive." They told me about a coordinating organization and that's all.

She was not given much support. This was also the case for another respondent:

I found out that I have HIV in 1990. My T-cell count was high. They did not refer me anywhere. I should have jumped in and said that I need medications. I immediately went in denial. The people at the clinic told me. I didn't know the names of the people. I went and talked to a male doctor about t-cells. He said that no medications were needed. I didn't say anything about it.

For one PLH being told was a matter of routine practice. The patient's ability to comprehend the information was not taken into account.

I found out this year (1998). The doctor told me at the hospital. I was incoherent. All I remember is him telling me I was HIV positive. I didn't care whether I lived or died right before my diagnosis. I was staying at a homeless shelter. I lost a month and a half. I can't remember.

A few PLHs were given the news of their HIV infection on the telephone.

One PLH explained:

I found out in 1994, and I've been here (facility) since. They told me over the phone. It isn't right. They aren't supposed to do that. A nurse from the hospital—I guess—it was a woman that told me. It could have been a damn secretary. I flipped out.

Another respondent revealed that he was not even the one on the telephone; it was his lover impersonating him:

The doctor told me over the telephone in 1987. I went to the doctor because I wasn't feeling well. He suggested that I get tested. He told me over the phone when I called. My lover actually called and said he was me. He just said that I was positive. I wasn't given any counseling. My lover died in 1988.

In these cases disclosing that a person has a stigmatized illness in an unsupportive way meant not showing compassion or trying to educate PLHs. This style of giving bad news also made the obligation to maintain confidentiality more difficult, as exhibited in the telephone disclosures.

### The Compassionate Approach

The compassionate way of being told one is HIV positive is marked by empathy. Unlike the unsupportive way, time and patience did not seem to be scarce resources. The bearer of the news sometimes presents himself or herself as sad as one PLH explained. She was the first person her doctor had ever given a diagnosis of HIV infection to:

The doctor told me that I have HIV in 1993. When I applied for supplemental life insurance, I had to get tested. I applied because I wasn't feeling well. I thought it was cancer. It was for \$100,000. I didn't tell my husband. The insurance company wanted my doctor's name. The doctor's office called. I knew it was something strange because they wanted me to come in that day. He said, "There's no easy way to tell you this..." I cried. He cried. It was his first time. He referred me to another doctor, and I got started on medications.

One doctor took the time to explain as he led up to disclosure. The respondent explained:

The doctor told me compassionately in 1996. I was sick. I constantly had colds and sinus infections. I got tested. He asked me leading questions. We stair-stepped our way to the diagnosis.

A young PLH described the way her family doctor told her of her HIV status as compassionate as well.

My family doctor told me in 1996. I went to a clinic and was diagnosed with shingles. He thought it was odd for someone my age to have that and CMV (cytomegalovirus). He had diagnosed his brother with AIDS and he wanted to test me. I knew when he asked me to come into the office that

he was going to tell me. He was very compassionate. He knew my parents and had known me for a while. He referred me to another doctor who specializes in HIV/AIDS treatment.

According to the following account, the doctor went so far as to have another PLH visit his patient to answer the questions he could not. The respondent said:

A doctor told me while I was in the hospital in 1986. I said that I wanted to be tested. I had a broken foot. I asked out of the blue. I expected it to come back not positive. He was very concerned and matter-of-fact. He told me in an empathetic way. He had a PLH come visit me while I was in the hospital.

The respondents who described how the news of their HIV status was given to them as compassionate did not have any grievances about such encounters.

### The Informative Approach

The informative way of bearing bad news is marked by explaining what it means to have HIV infection. The news is disclosed in person. The bearer sends a message that emphasizes hope. The focus of this approach is educating the PLH about what can be done. Those who were trained specifically to disclose HIV test results utilized the informative way. The respondents shared their stories of being told the news of their HIV infection. One PLH explained his experience at an anonymous testing site:

I found out four months ago (1998). It was recent—thank goodness it was early. I got tested at an anonymous testing site. You were given a number, and it was anonymous. They don't tell anybody anything. I had to call for an appointment for the results—I had to go in. The people there told me my t-cell count and my viral load. They explained things to me.

Another PLH described how he became aware of his HIV status as a result of donating blood:

I found out in 1987. I was in the southwest. Eight months after I was discharged from prison the first time, my lover and I had gone to the fertility clinic to donate sperm. While we were there, they announced the need for blood donation. I wanted to give to the community. A couple of weeks later I received a letter telling me to come to the blood bank. The counselor told me I was HIV positive. I didn't think anything of it. He told me about precautions and that I needed to notify people I shared needles with and partners. I did.

According to one respondent, the HIV counselor not only gave him the news, but also educated him:

I found out in 1992. I got tested at the health department. I was married. We were thinking about having a baby. After watching a *60 Minutes* special about HIV/AIDS, we decided to get tested the next day. I was positive and she wasn't. I knew nothing about it at the time. The HIV counselor gave me a lot of information.

Another PLH who was homeless described his nurse as professional when she disclosed his HIV status to him:

In 1995 a nurse at the Salvation Army told me after she tested me that I needed to come back the next day for the results. I was homeless at the time. I knew before she told me. I had training in HIV before that. She was professional when she told me. I knew anyway. It sounds dumb, but people know because of the symptoms.

The informative way of telling people that they have HIV infection allows for educating PLHs, as well as letting them know the next steps they need to take in the process.

A few cases did not fit into this classification of disclosure styles. In one case the physician used a forecasting technique so that the recipient of the bad news could figure it out for himself (Maynard 1996). Thus, when the doctor did get around to telling him he had HIV infection, the patient already knew. The physician was relieved from the duty to disclose the news. The respondent explained:



In 1994, my regular doctor at that time left me in an exam room for 4 hours. He couldn't tell me. He told me so later. He explained that he could treat me, but he was inexperienced with treating HIV/AIDS. He would just consult books. He recommended another doctor because he thought I would get better care. I had already figured it out by the time he got there. I had a cold a month for four months. They were all different. The last time he thought it was PCP (pneumocystis carinii pneumonia).

One of the PLHs had a unique experience compared to other respondents. He had not been diagnosed with HIV infection or AIDS, but with GRID in 1979 before it was accepted that heterosexuals also contracted and transmitted the disease. He explained:

I was diagnosed with GRID in 1979 when I was living in California. GRID was my first diagnosis. No one believed that I wasn't gay. I told them I pitied them. At first I never understood what was going on because I was too interested in getting my drugs. I've been living with this disease for about nineteen years. The doctor told me my immune system was infected and that I would probably die in a year. I had the same doctor for fourteen years. I've had PCP twice.

These accounts suggest that there is much diversity in how bad news is disclosed. Regardless of which style is utilized, once the person received the label of HIV infection, he or she went through a turning point in identity. Further, the type of disclosure did not prevent the anxiety and tension that accompanies revisions in identity. This is presented in part two. Being labeled as PLHs marked the beginning of their encounters with healthcare professionals as a special kind of patient. This turning point signaled another new identity: becoming a patient with HIV infection. This turning point will be examined in the next section.

## Healthcare Experiences: Becoming a Patient with HIV Infection

Being diagnosed with HIV infection means that one must become a patient with HIV infection. While there is no cure for HIV infection, there are life-sustaining treatments available. It is also necessary to measure t-cells and viral loads on a regular basis to monitor the course of the disease and modify treatment regimens accordingly. Because there is frequent contact with healthcare professionals, it was important for PLHs to describe their healthcare experiences. They had diverse experiences as patients that they described as both negative and positive. This is relevant because it is through interaction with others that identities emerge. For example, negative interactional experiences led a few PLHs to feel powerless, as having no control over their healthcare. This is a crucial issue considering that treatment regimens prescribed for PLHs are usually stringent. Their lives depend on compliance. It is difficult to determine whether the negative encounters with healthcare providers resulted from operating within bureaucratic guidelines or from stigmatization of HIV infection.

The participants suggested that some healthcare professionals could improve their interpersonal skills with patients and have a better attitude toward them. One PLH explained an encounter with a physician whom he described as inconsiderate and ignorant:

It is so disappointing that healthcare providers can be some of the most inconsiderate and ignorant people there are. I would challenge any physician in a debate over HIV. They think they know everything, and they don't. A doctor asked me if I had AIDS because I was taking AZT. I told him, "No, I'm positive." He said it was the same difference because I'm

going to die from it anyway. I was only there for a physical for my job. I told him I was not there to discuss HIV.

According to one respondent, healthcare professionals are not involved enough, and it shows in their attitude:

I haven't had any positive experiences with my healthcare providers since being diagnosed with HIV. They could stand to be more personally involved and act like they really give a shit. They could be logical. They expect that you should know what is wrong with you instead of them telling you what is wrong.

Another PLH said his doctor was negative:

The health department doctor was egotistical and sarcastic and negative. I had to get re-tested. He lectured to me on why I got it and about my lifestyle. He had a negative outlook.

Some PLHs expressed dissatisfaction with how their healthcare providers communicated with them during the course of their treatment and about their treatment regimens. This included the lack of communication, as well as the dismissal of patient input. One PLH explained how he was excluded from decisions regarding his treatment:

It took 6 months to be put on HIV medications. My doctor wouldn't listen to me. He thought he knew it all. He wasn't compassionate. He was smug about the whole thing. He only treated me for the illnesses that came up. He treated the symptoms, not the cause. After a while, I changed doctors. He wasn't an HIV specialist.

Another PLH was dissatisfied because of his doctor's lack of communication about and knowledge of treatment options:

The doctors are in it so they can get money. I don't like my doctor now. She won't sit down and talk to me. She doesn't know the answers to my questions. I think she's an intern. I know more about the medications than she does. She wants to know why I won't take certain medications. I am resistant. I was taking 90 pills a day at one time. It was pointless. I was sick all of the time. The doctor is learning from me. I am patient and stay calm.

A mother described her situation as a pregnant woman which was unique because her child had to accompany her to her doctor visits. He was not old enough to attend school. She explained:

Some healthcare workers don't know how to talk to you. They aren't delicate. When I was pregnant the doctor asked me a bunch of questions about how I became positive in front of my son. I didn't appreciate it. He was curious because he had never treated anyone with HIV.

The following respondent believed he was not receiving appropriate healthcare because his doctor spent too little time with him and did not administer pain management.

The doctor I have now is worthless. If I had transportation, I would go somewhere else. He's a quack. He hasn't seen me for a month. He just writes prescriptions and that's it. He was supposed to put me on a patch (morphine, codeine, etc) for pain, but he didn't.

One PLH discussed the consequences of receiving inadequate care while he was a prison inmate:

I didn't get the medications like I was supposed to when I was in prison. I have seizures now. I am resistant to AIDS medications now because I wasn't given medications the way I should have been. I use a walker now. I take pain medications now. Medicaid will pay for only 3 medications a month, but I need 7.

Whether it is because of scarce financial resources, the unwillingness of others to treat them, or the failure of others to recognize alternative treatments, many PLHs were faced with limited healthcare options. This contributes to the feeling of some people that they had no control over their healthcare. They were powerless. Some PLHs reported that they were refused medical treatment. One PLH could not find a dentist that was willing to provide care to PLHs.

Dentists don't want to provide care. I feel more comfortable that they know I have HIV just in case.

Another PLH said that his healthcare provider refused to treat him because he lacked the ability to pay.

The other doctor told my doctor that I needed some tests run and he said he couldn't because I'm poor. I got switched over to another healthcare provider. My doctor was a good doctor, but if you don't have the money, he doesn't want you as a patient.

Another respondent reported similar treatment:

The private physician that I was seeing left the office. That is when they decided to close my case because I owed money. Now I have to apply for Ryan White financial assistance. The DHS caseworker has not called me back. I called last month. I have tried to contact them a couple of times. I don't know if we keep missing each other. I get my medications through a special program. They come in the mail.

In the following account, a PLH explained that he, too, was turned away by the doctor he preferred to take his case. He described what it is like to rely on public assistance.

It has been hell. I couldn't afford to see the doctor I wanted. I had to go to the clinic. All I saw there were students. I couldn't receive dental benefits. I had no opportunity to choose what doctor I wanted to see. I applied for Ryan White benefits. Ryan White is a good thing. It does help people, but you don't get to choose doctors. You are only allowed limited services. You don't get to establish personal rapport with a doctor, which I think is very important. Instead you see a different doctor every time. When I see one doctor it makes me feel like I have more control over my healthcare. It makes me feel valuable and equal with other human beings.

The treatment of HIV infection is expensive, even if just considering the medications alone. According to PLHs, it is difficult to afford all of the medications that are prescribed. Doctors do not take this into account when designing treatment regimens. One PLH discussed this issue:

My HIV and pain evaluation doctors are good. I get mad when they write me more prescriptions and I can't afford all of them. They cost \$1200-1400 per month, cash value. I pay about \$250 per month out of pocket. This doesn't include the \$265 per month prescription, marinol, which I don't

get. It is pot in a pill. It makes you eat—it gives you the munchies. I smoke pot when I need to get the munchies. It's cheaper, and you can have it delivered. When I started chemotherapy, I weighed 155 pounds. When I finished I weighed 186. The pot took away the nausea and made me eat.

Another limitation faced by PLHs was the failure of healthcare providers to recognize alternative treatment regimens. One respondent said:

I'm going to a nutritionist next month. The healthcare industry doesn't take into consideration nutrition, holistic, alternative, vitamin therapy, even as supplements. The doctor told me to take a multivitamin and didn't give me any details. Some doctors just want you to take HIV medications and that is it. I feel like they want me to be on a drug study or they don't want me in their office.

One of the respondents who was unsatisfied with his healthcare described what his ideal doctor-patient relationship would be. He was looking for a doctor to take his case at the time of the interview.

I am still looking for a doctor that I feel comfortable with, a doctor that has answers. The doctor I'm looking for is well educated about HIV/AIDS, medications, and related complications. I want a friend, not just a doctor. He/she is an information giver and has time for me—not just 10 minutes. All my last doctor could do was find things to bill insurance for. I want quality care and to be treated as a quality human being. I want to know that this doctor is dedicated to the treatment of HIV/AIDS.

While these accounts overwhelmingly support that PLHs had negative experiences with their healthcare providers, the majority of PLHs also reported positive healthcare experiences. These positive interactional experiences also shaped the respondents' HIV identity formation. Being a patient with HIV infection was not necessarily defined as something bad. Positive healthcare experiences noted included being given satisfactory medical treatment such as appropriate pain management. For example, one PLH claimed:

My doctor is wonderful. He's concerned about my viral load and T cell count. He gives me pain medications.

One PLH attributed his life to his excellent medical treatment.

I think I've been treated with the most excellent care. I'm still alive. I thought I had 5 years max. It is not time yet. They have all been good. I maintain a doctor-patient relationship where I let the doctor treat me. I don't have M.D. behind my name. Some people think they should be treated the way they think. They will tell the doctor he is wrong.

Other healthcare experiences that were described as positive were being given good news.

I was given the news that my t-cell count is up and my viral load is undetectable. I was told that the antibiotics I am taking are effective. I was told that I don't have cancer. I was relieved to get out of the hospital.

For some PLHs, being addressed by healthcare professionals with a caring attitude was noteworthy. One PLH explained his relationship with his doctor:

I love my doctor. We have a doctor-patient relationship and a friend-friend relationship. I go to his house for cookouts and we go water-skiing. He will get on me about compliance. He tells me he gets on me about it because he loves and cares for me. Occasionally I'll miss a dose of my medications. This isn't good because it is easy to build resistance to the drugs.

Another respondent described how caring his nurse was to him:

When I went to the hospital, my nurse was really nice to me. She did everything. Some nurses are hesitant to be around AIDS patients. She was the opposite. She would always check on me and went out of her way to make sure I was comfortable.

Some patients liked the way their physicians explained everything to them and allowed them to take part in their own treatment decisions. For example, these respondents discussed how they were included in decisions regarding their treatment regimens.

I have 2 primary physicians. Both are experts and have been good to work with. We work together. They don't just dictate to me. They know that I am educated and that I know what my options are. They know what I want out of life and the quality of life I want. Some medications require a strict schedule. If that doesn't fit into my life, we discuss other options. I've seen treatments fail because people weren't ready to start a stringent regimen. Non-compliance does more harm than good.

My HIV specialist is outgoing, friendly, and positive. I am involved with my care. I make the decisions. He gives me information. He doesn't look down one straight, narrow path. He gives me time to think about decisions. He will discuss and help me with decisions.

Another PLH stated:

My doctors and nurses have positive attitudes. They explain what and why they are doing what they do. They have a positive approach.

The following PLH explained that his doctor takes as much time as needed to spend with his patients:

He answers any of my questions. He takes the time that is needed if I need it. He never gives me the impression that I'm bothering him. He is reassuring. A lot of times he is running so far behind because he does take the time to spend with people.

In this section, PLHs' expressions of their interactional experiences as patients with HIV infection were presented. This is a revision in identity that results from being labeled with HIV infection. It should be recognized that not everyone who receives this label undergoes this revision. Access to healthcare is a prerequisite. All of the people interviewed for this study had access to some healthcare, although many were not given choices. Accompanying these revisions in identity is the process of misalignment. PLHs engage in self-questioning about their anxieties and tensions related to having an incurable, stigmatized disease. This is discussed in the next section.



## Part Two: Misalignment and Stigma

In part one, I argued that the style of disclosure did not appear to lessen the anxiety and tension that accompany a turning point in identity. This anxiety and tension is referred to as misalignment (Strauss 1959). In part two, misalignment will be discussed in terms of its relationship to interacting with others as a person with the stigmatized illness of HIV infection.

### The Qwiff Has Been Popped: Misalignment

The people interviewed were aware of HIV infection prior to their diagnosis, but some were not educated about it. This lack of knowledge or misinformation contributed to people's anxieties related to having HIV infection. Turning points in identity are usually accompanied by "misalignment" (Strauss 1959). This refers to when people are surprised, shocked, anxious, or tense. They engage in self-questioning. Participants were asked to recall their initial worries after being diagnosed with HIV infection in order to understand their anxieties and tensions. This is important because living with HIV infection is more than living with a physical disease. PLHs must also contend with the social consequences of having a stigmatized illness. The most common worry they expressed was dying. Many people thought that having HIV infection was a death sentence. For one PLH, this perception resulted from being uneducated about the disease. He explained:

I didn't know anyone who had AIDS. I thought that's it. I'm going to die. I deal with it now. You have to. You have no choice. You can make yourself miserable and be depressed.

The following respondent said that his biggest fear was a long, slow death process:

It took me a while to figure out what my greatest fear was. I wasn't afraid of being busted, HIV, my family, or killing myself. My greatest fear was a long, slow death process.

Another PLH believed that he had no future:

All I could think about was that I was going to die and that I had no future. I called the person I thought infected me to let him know. We were together for 2 years and we had just broken up a few weeks earlier.

Some PLHs who were not hopeful about their prognosis made plans for the future related to their impending deaths. The following respondent made funeral arrangements:

When I first found out there was only one approved drug, AZT. Things weren't so bright. People were dropping like flies. I made funeral arrangements. I planned the whole service and picked out all the merchandise. I took out a policy for the amount. I could stretch the payments over 20 years—no health questions were asked. I'm still paying. I changed policies so I can pay it off sooner. I didn't think that would happen.

A respondent was worried about a long, painful death and decided to update his will:

I didn't know a lot about HIV. I thought I would die. Initially I fell into a deep depression, and I updated my will. I feared a lingering, tormented physical death with great anguish. I feared dying an ugly death. I have overcome this now because I receive excellent preventive healthcare.

Similarly, the following PLH prepared his finances:

I was worried about a little of everything--dying. I thought I had 6 months to live. I sat at home the first 4 or 5 months. I isolated myself. I did a will and got my finances straight. Then I started volunteering. That saved me. Otherwise I would have probably wasted away.

Another PLH also isolated himself in the beginning:

I just knew I was going to die. I didn't want to be around my nieces, nephews, mother, or anyone. I isolated myself. I quit work. I went back after I got over myself (to the same job).

The following respondent began HIV/AIDS support organizations to cope with his diagnosis of an incurable disease:

I worried that I would die within 2 weeks. At that time, in 1986, they weren't so sure about things. I learned as much as I could and started some organizations to help me overcome my worries. I practiced functional denial. I know I have a problem, but I won't deal with it directly. I learn what I need to, but it won't consume all of my life. Now I have accepted it. I have come to terms with it. I watched my two best friends die.

Other worries expressed by PLHs included telling others and the potential consequences related to disclosure. Such consequences included hurting family members, being discriminated against, and being rejected. One respondent was concerned about telling not only her family, but also a man she had been intimate with. She explained:

My worries were telling my family—my children and parents. I was intimate with a man from November to January. We had no safe sex. I had to tell him. We weren't seeing each other at the time. I called him right away. He didn't believe me so he called the doctor's office and they confirmed it. It was unethical and illegal for them to do that.

Another PLH discussed how he felt guilty for hurting his family:

I worried about hurting my family—putting my mom in a position to bury a child. I am really tight with my brothers and sisters. I felt like I disappointed them. I made the major screw-up. I felt guilty because I knew it would hurt my family and they would have to pay consequences. I didn't have a good chance of surviving because of both the cancer and HIV.

Being discriminated against by potential employers as a result of misinformation about HIV infection was a major concern of the following PLH:

I know I'll have problems getting a job—stigma. The workplace doesn't understand. They don't know that you can't get it from shaking hands. I wish there was more education about HIV. People still haven't gotten the idea. You can't catch it by shaking hands. People think HIV is just a homosexual thing. This is still the mentality. They think that just because you have AIDS you're gay. That's not true. It will take a while.

Being rejected sexually was difficult for the following respondent who described himself as lonely:

I am lonely. It hurts. I probably will never get in another relationship. Nobody wants me. I didn't deserve this. I need a relationship with a woman. I've had no sex since I found out. I also have to tell the woman that I have the disease. I haven't met anyone yet. I can only talk to 1 nurse about it. I take Prozac, too—it's a crazy pill. I don't talk to others about this disease. We talk about other stuff.

Another PLH had similar concerns about her sexuality initially:

I have a virus that can kill. I lost a big part of myself—I lost my sexuality. People would say, "Well, maybe you'll meet someone." Most people aren't prepared to lose their sexuality until their eighties. It is painful. It hurt so much. I finally became comfortable with myself. I redefined my sexuality. I redefined being a woman. What is part of other women is part of me. I put it in God's hands. Maybe I can serve God better like this. I realized how much I have to live for. In reality life with a man is difficult. Even if I wasn't HIV positive, it would still be difficult to find a relationship. It is difficult to blend two lives. Sexuality must happen within that blend. To bring a relationship into my life would make things difficult. It could be disruptive.

One PLH explained that he was no longer worried about the consequences of disclosure of his HIV status. His declining health was his major concern at the time of the interview.

I had to become o.k. with who I was before I could be open. When I wasn't, I had a lot of concerns about how I would be treated. I learned to face my fears. I have very few concerns now. Now I am worried about how my family and friends will deal with my declining health. I want to help them through that.

Some PLHs were concerned about becoming sick and not being able to support themselves and honor their responsibilities. Having to ask for assistance from others was difficult for them. These PLHs explained their concerns:

My biggest worries were taking care of my responsibilities. My wife passed away in 1993. My mom asked me what I was going to do. She asked me if I was going to work in the town she lived in. I could feel changes because of my illness. I got tired and my appetite weakened. I said, "Mama, I really don't know what I am going to do. What if I live with you?"

I don't even remember coming here (facility). Initially, I didn't care. I was so frustrated. I didn't want to ask for help. I didn't feel good. I didn't know what was going on. I was going to start my own business before I got sick. I had a new pick-up truck, but I had to turn it in.

I worried about when I would show actual illnesses, when I would show the signs of actually being sick. I haven't overcome my worries. You can't ever overcome that.

Healthcare can be expensive in the face of any chronic disease. Being uninsured or underinsured when one is dependent on life-sustaining medications is a serious issue for many PLHs. While there are drug assistance programs, their resources are limited. Thus, receiving appropriate healthcare is a central concern, as articulated by PLHs in the following accounts:

To be honest, I have been so educated about HIV that it didn't really create worries when I found out about my diagnosis. I was just concerned about getting appropriate care. Medicaid only allows 3 medications a month. But, there are other resources. The gentleman I moved here with had AIDS. I quit my job to take care of him during the last year and a half of his life. Taking care of him, I learned to deal with it. I learned about resources. I'm healthy and educated. I'll be happy to make it to 65.

I was worried about my wife. They told me she had to tell me her results. When I told her, she went limp. All life left her. We were scared. We didn't have any health insurance. We started to educate ourselves. That was the key to accepting it.

I was worried about getting medications and about my count and stuff like that. I was mainly worried about my health. Getting off the street has helped me overcome my worries.

A few PLHs said that in the beginning of their illness, they weren't bothered by the news of their HIV infection. They were more concerned about maintaining their recreational drug habits than treating HIV infection as they explained in the following instances:

At first it didn't bother me. I never understood what was going on. I was too interested in getting my heroin.

At the time I was heavy into drugs and alcohol. I didn't give a shit. I didn't try to help myself. It went on until I was diagnosed with full-blown AIDS. Then I started to turn around. I still did drugs and alcohol. I started AZT. I decided it was time to quit. I have been speed-free two and a half years now.

A couple of PLHs worried that they would infect or had infected their loved ones. One respondent said:

I was scared I would infect my family. My mom wouldn't let me not be around her. I didn't feel comfortable with her around me. I was afraid I would infect her.

Another PLH stated:

I worried that I wasn't going to be there for my son and that my son and my husband would have it. They were both tested and they were negative.

The following PLH was worried about infecting his partner:

My partner told me right away that he would stand behind me the whole way. Deep down I wondered if he would and if I should put him through this. I thought the disease would progress faster. I was worried about passing it on to him, and it happened. I didn't take the necessary precautions. He said that he knew what he was doing and didn't take the necessary precautions either. He told me not to blame myself.

Several of the people interviewed for this study said that they had contemplated or attempted suicide. It was difficult for them to accept a disease

that was incurable and often associated with a long, painful dying process. One PLH did not want to think about her HIV status and described her drinking habits as a subtle suicide.

When they found pre-cancerous cells in my vagina, I decided to live with HIV. At first it was like a subtle suicide. Back then I was in denial. I thought I would drink myself to death.

Another PLH had a similar outlook:

I started abusing cocaine. I decided that if I put cocaine into water and injected it into my veins, I could die faster. I couldn't kill myself because the insurance would not pay my beneficiary...I entered a rehabilitation center after a while. After a couple of weeks, I decided I needed a few extra xanax and sleeping pills to help me rest. I overdosed. No one visited me, and it was unacceptable. I was trying to sleep through it. I didn't want to kill myself.

Other PLHs attempted suicide via more direct ways such as threatening to jump off a building or bridge, overdosing, or driving recklessly. One PLH who still considered suicide to be an option explained:

I've tried to kill myself three times. I was going to jump off a building twice. I went to a crisis center. I still think about it. I will kill myself if I get so helpless that I have to wear diapers. [He is crying.] My life is doomed now. They've got me on crazy pills. I don't know what to do. I take 6,250 milligrams of pills a day—20 pills a day. I'm undetectable now (viral load). That is good. But the side effects are messing with me. I've been going to church to get the devil out of my head. It drives me crazy sometimes.

A PLH who had hope for a cure said:

There's no cure. I had a joint and was going to jump off a bridge. I was ready to dive, but then I thought they might find the cure when I'm halfway down. I'd be halfway from being dead and alive.

Another respondent stated that he did not commit suicide because of his children:

A few years ago, I thought about killing myself. It was so unbearable. Now I just pray. Now I won't kill myself. I don't want my kids to remember something like that. I have attempted suicide. I took a gram of heroin and lived.

The following PLH thought that he was going to die anyway because he had PCP. He explained:

I started drinking heavily. I attempted suicide. I was going to crash my car. I was diagnosed with PCP. Everyone I knew with that died. What stopped me from killing myself was the thought of my mother.

It is evident upon examining the accounts of PLHs that the turning point of being diagnosed with HIV infection was accompanied by misalignment. Their feelings of anxiety and tension related to the diagnosis were sometimes attributed to the stigma of HIV infection. Because of the central importance of the concept of stigma to this study, it will be addressed in the next section in terms of PLHs' interactional experiences with others.

#### Stigma: Concerns Regarding Interaction

The participants of this study confirmed that HIV infection is a stigmatized illness. People were asked if they knew how they contracted HIV infection. Most people knew how it was transmitted to them. Some people could pinpoint it to a particular person or even a particular encounter. Of significance were PLHs' reports that it was not uncommon for others to want to know their exposure categories. This information was important so that distinctions could be made regarding guilt and innocence in some cases. Not only is HIV infection stigmatized, but so are most of the exposure categories. One PLH explained that people want to know how he was exposed to HIV infection:

I don't really know how I contracted HIV. Maybe it was from shooting needles. Most people don't ask, but they want to. Everybody is a little nosy. Some friends and some acquaintances have asked, "How did that come about?"



PLHs viewed such inquiries as attempts to make judgments regarding their innocence or guilt. According to one respondent, others seemed to express relief about how she was exposed to HIV infection.

I know how I contracted HIV. It always is a question asked, but it's not important. Most people seem happier that I'm not a junky and got it from unprotected sex. People ask because I would be the last person they would have suspected. I think they want to believe it was some strange thing that happened. It wasn't just like everyone else. I was married for 15 years, and I had two children. I trusted the man I was with during the divorce. I wasn't as worldly as I thought. It wasn't something that happened to heterosexual women in my age group—non-drug users.

A PLH who was imprisoned discussed how he was further punished for being promiscuous.

It could have been all the risks. I used IV drugs, I was a hustler, and I didn't have safe sex in prison. I was also raped. I was very promiscuous. I was in solitary confinement. I was segregated because I admitted to my sexual activity—that I was gay and had sex. They were afraid I would spread the disease. I had no good time credits during that time. [He showed me Department of Corrections letters to confirm all of this. One stated that he "is considered to be promiscuous."]

The following PLHs explained how they were judged as being guilty and deserving of their HIV status. One PLH explained how frustrating this was for him:

I contracted HIV infection through male-to-male sex. People, especially those who aren't educated, seem to emphasize this. They want to know how you got it so they can judge you. Did you get it innocently or did you deserve it? I am a speaker, and I make presentations about what it is like to live with HIV. Schools want someone who is not gay, not an IV drug user. I tell them, "Good luck!" It frustrates me that their minds are so closed. It makes prevention efforts more difficult. I pity their ignorance. I get angry because I know what works in prevention. They can't see past their own moral viewpoints.

Another respondent said:

I guess I contracted HIV through sex. My mother emphasized this. She said if it wasn't for my lifestyle, I wouldn't have this. I think she believes it is a punishment. The homosexual lifestyle is so wrong to her.

One PLH explained that his family wanted to know how he was exposed to HIV infection so they could blame someone for doing this to him:

I don't know when, but I know how I contracted HIV—through sex. I didn't do drugs. People ask (family) who gave it to me. I tell them that I've got it, so who cares. It wasn't intentional. It is one of the hardest questions for families to get over. It is so hard to tell unless you have been with just one person your whole life.

Respondents discussed whom they had been open with about their HIV status. Several of the participants were open with almost everyone at the time of the interview. However, most people concealed their diagnosis at some point during their illness because of the stigma associated with HIV infection or concerns about understanding from others. Many of the PLHs were aware of how others stigmatized them. Most were concerned about maintaining social interaction with others. One PLH said that he doesn't parade his HIV status where he is employed:

I don't parade it. I don't tell my employer because that would be an opportunity for misconceptions and shoptalk among those who are misinformed about HIV.

There appeared to be fear of contagion on the part of others, as indicated in the following accounts:

I have told my mother and youngest sister that I have HIV, mostly just family. My wife's parents also know. I haven't been intimate since 1992. I don't want to get involved with anybody. A lot of people frown on this disease. Even if they say they don't, a lot of people gossip. Some people change the story from the way you tell it. They'll have you dead and buried in two weeks. They shy away from you. Anything that's not good, people stay away from. It's like having to drink castor oil—no one wants it.

I told all of my friends. Some of them are scared to get close to me. I explained to them how to get it. They are scared they'll get it by touching me. I have a video that I give to my friends that explains HIV. This helped.

I tell everyone. I don't care. Silence=death. If they don't want to be around me, fine. I've never had anyone ostracize me. In the penitentiary (maximum-security prison), they made me shower last and fed me last. I was in my cell 23 hours a day. I didn't go to the yard because people fought there. Other cellmates didn't like the idea of showering after someone with HIV. They were uneducated. They fed me last, but I got double servings.

Courtesy stigma was also a fear of others as expressed in the following account:

I didn't tell anyone for 2 weeks, then I told my best friend. He promised he would take care of me no matter what. He said he would even buy a bigger house. But when I decided to go public about it, he stopped. He dropped out. I did an interview on the 5:00 news, so I told everyone then.

Another PLH said:

My close friends and my family know. They don't understand it and they reject it. My gay friends understand what I go through. In 1993, my mom had cancer. She died. When I got there, my family asked me to leave town. No one wanted me around. They thought that I would hurt them. They didn't want the stigma attached to their name—gay and HIV. They wanted me to leave for my safety. They were afraid I would start blabbing about being HIV positive and gay if I got to drinking. They didn't want someone to hurt me.

One PLH was not selective in who she told of her HIV status. It didn't take long before she realized the consequences of such openness.

At first I told everybody until I noticed that some people weren't quite receptive to it. People distanced themselves from me. They stopped returning my calls.

Another PLH also told everyone about his HIV status, but the consequences were quite different for him as a gay male.

I have been open with everybody. I couldn't live with myself if I did something with someone and didn't tell him or her. It is nothing to be

ashamed of. I didn't ask for it. I thought I would never get a date. It worked to my advantage because people respected that I was honest.

Some PLHs perceived that they were viewed as not good or as sinners by others. This supports the view that some people are deserving of HIV infection which increases the severity of the stigma associated with it. This is consistent with the religious moralist accounts presented in the previous discussion on the societal reaction to HIV infection.

I found out in June. By September I still hadn't told my family. I was visiting my mother. We were in Wal-Mart. Some people spoke to her and she said they had a daughter who died of AIDS. She said if people didn't sin, they wouldn't die of AIDS. I told her she should be careful about how she judges people and that she never knows when this will come back in her face. I didn't say anything else until January.

This PLH explained that when he disclosed his HIV to his mother, it was a "triple whammy." Not only did he tell her that he was HIV positive, but he also told her that he was gay and getting divorced from his wife. In the following excerpt, he describes what happened.

I told my youngest brother the day before I told my mom. I asked him to check on her. I set up a meeting with a minister, a lady whose son died of AIDS, my aunt, my mother, and me. I told my mother at this meeting at the church. She cried. She wanted to know how. I told her it was transmitted through having unprotected sex with men. She was puzzled. I told her I was gay. She said, "but you're married." I told her I was getting divorced. It was a triple whammy. She cried.

In this section, the discussion centered on the stigma associated with HIV infection. This was made apparent in PLHs' accounts of how others focused on exposure categories after being brought into open awareness by PLHs.

Participants also discussed how others stigmatized them after revealing their HIV

status. Awareness contexts will be addressed in the next section in terms of impression management and consequences.

### Part Three: Awareness Contexts

Awareness contexts refer to what is known about the definition of the situation (Glaser and Strauss 1965). Thus, the primary significance of awareness contexts lies in their consequences for social interaction. By maintaining closed awareness contexts, or actively keeping people in the dark about HIV status, interaction with others can be preserved. How this is accomplished by PLHs will be addressed in this section. Attention will also be given to the consequences of bringing others into open awareness regarding HIV status in order to validate fearful conceptions related to this revision in identity. Finally, HIV status as the focus of interaction will be examined.

#### Maintaining Closed Awareness Contexts: Concealing HIV Status

While some people informed everyone about their HIV status, others were selective about who they told. To protect themselves and others, PLHs maintained closed awareness contexts regarding their HIV status. They described how they concealed their HIV status using various impression management techniques known specifically as stigma management techniques. The most common impression management technique was passing or simply not telling others. In many cases this was made easy because there were no indications that they were sick, such as visible symptoms or excess doctor visits. This was explained in the following accounts:

To conceal my diagnosis, I just didn't talk about it. I grew up in a home where my dad was a minister and a child and wife abuser. I learned at a young age how to suck it up and put on a happy face and pretend like everything was ok when it wasn't.

I just don't mention it. No one has questioned me about it. I've had a few jobs and I didn't say anything.

It wasn't brought up. There were no physical signs. I didn't see any reason to tell anyone else.

The following PLH explained how he concealed his HIV status from his partner's parents:

Most people can't look at me and tell I have HIV infection. I look like I have my shit together. I don't, but I look like I do. I am concealing my condition from my partner's parents. He does not have HIV infection. We made this decision together to protect them from unnecessary worry. They don't ask, and I don't tell.

In some cases, the participants explained that they concealed their HIV status by telling others they had something else wrong with them. This technique is known as covering. They did this to protect themselves and others. One mother living with HIV infection stated:

We just don't tell. My son (5.5 years) knows I am sick. He knows it is something in my blood, but not really what it is and what could happen. I probably won't tell him for a few more years. It is for his own good. He might talk about it at school, and I don't want them to treat him differently. Maybe the kids wouldn't, but the adults would. They wouldn't want their kids to be around him. Or the kids might say, "you're mommy's got something, and she's going to die."

Another respondent said:

My landlord doesn't know. I told him I have cancer. Some landlords don't want to serve people living with AIDS.

Some PLHs used the insulation technique. They limited the number of people they told to those that they trusted. One respondent said:

Trust is important. I don't wear a t-shirt that says I've got AIDS. All of my hometown knows, I'm sure, because people talk. It's nobody's business.

Another PLH explained:

To conceal my diagnosis, I just didn't tell anyone. I didn't have to take medications because they weren't available. I only went to the doctor every 6 months. No one knew except the people I chose to tell. This was very few people at first. I didn't tell because I was afraid of how others would react—discrimination, prejudice, and rejection. I was afraid of disappointing my parents.

Other PLHs limited the number of people they told to those that they thought would understand, as the following respondents explained:

I wouldn't want to tell anyone that I have HIV until I was sure about the person understanding. I wouldn't be sexually active with them.

My HIV status is not relevant. Those who have found out have no difficulty. I seek out people who are educated.

PLHs also reported isolating themselves when they initially learned of their diagnosis of HIV infection. PLHs expressed this in these accounts:

I sat at home the first 4 or 5 months. I isolated myself. I did a will and got my finances straight.

I didn't want to be around my nieces, nephews, mother, or anyone. I isolated myself. I quit work.

### Open Awareness: The Consequences of Revealing "I'm a PLH"

It is common for people who have reached a turning point in identity to want to fulfill "the need to try out the new self, to explore and validate the new and often exciting or fearful conceptions" (Strauss 1959: 93). A key feature of bringing others into an open awareness context is that once a person has avowed his or her new identity to others, there is no turning back. One can not

know the consequences of disclosure until the qwiff has been popped.

Participants were asked to discuss the consequences of revealing their HIV status to others. Most people described both negative and positive experiences.

Among the negative consequences was losing relationships with friends and family members. This was described by a PLH in the following instance:

Two of my friends stopped their relationships with me. I was surprised and hurt. They never called.

One respondent had a similar experience with his family:

HIV cut me off from my family. That hurt. I'm alone. They handled that I was gay. It was the HIV. They were afraid of it. We were a close family—we gave each other hugs and kisses. My aunts, uncles, sisters, and brothers-in-law didn't want me around their kids. Two of my sisters wouldn't come see me.

Another PLH also noticed that he lost friends as well after informing them of his HIV status:

Most of my friends have been accepting, but not overwhelmingly. It hurt. Every time I would say it, it hurt me to realize it. People have backed away, but I don't know why.

The following PLH explained how almost everyone in his life discontinued his or her relationships with him because he came out as being gay and having HIV infection.

I got divorced, lost my kids, and lost my career. Old friends dropped me. I didn't know there could be such hateful people in my church. It is a church with a double standard. I gave years of my life to this church by volunteering, supporting others, and staying in contact with people. When I experienced the worst time in my life, not one person contacted me. I was totally abandoned by most of my family as well. I literally cried myself to sleep most nights.

He continued:



I am supposed to have my younger son every other weekend. I never see him. They are embarrassed of their gay father. In their Pentecostal world, it is a sin. My oldest son is away at school. I saw him for one and a half hours at Christmas. I called him at school because he didn't say good-bye to me before he left town. He told me that I was an evil sinner on the path to hell and that I would never see my grandchildren. They don't try to understand.

One respondent said that he was told he was deserving of HIV infection because he is gay.

I lost some of my friends and most of my family. They didn't want me coming around to visit with their kids around. We were never close anyway. My little brother has HIV, too. My family will have nothing to do with us. My mother believes we have AIDS because of our lifestyle—because we are gay. My mother was afraid to go in the swimming pool with me. I also have really strong friendships too. You find out who your friends are. It weeds everybody out that you don't need around.

Some PLHs were feared by friends, family members, and members of their communities. A PLH explained how this was made apparent to him:

If I would go to the grocery store, they would lock me out. No one understood it well. When I was diagnosed with GRID, no one believed that I wasn't gay. I told people I pitied them. Things have come a long way.

One respondent said his brother was protecting his family by not associating with him:

I told one of my older brothers. At first he accepted me, then he decided he didn't want to deal with it. He told my mom to tell me not to come by anymore. I confronted him. He said he had to protect his family because the government could be hiding something. After a couple of years, he came to his senses. He is accepting of me now.

Another PLH believed that several students dropped a class he was enrolled in because they were afraid they could contract HIV infection by merely associating with him:

I told the students in a class I was taking. We had 50 students, but the class dropped by 15. They thought they could get it by associating with

me. They told the instructor. The instructor knew in advance that I was going to bring it up.

PLHs also experienced rejection as a result of disclosure of their HIV status. This was not limited to family members and friends. One respondent asked his father for financial assistance, but he was not supportive as a result of his son's sexual orientation.

I called my Dad in 1992 because I needed help with buying medications. He said, "Let your peter-puffer friends take care of you." I told my dad about my HIV status a couple of months after my diagnosis. I didn't tell him right away because he didn't like the idea that I was gay.

Another PLH lost his job and believed his dismissal was related to his HIV status.

When I told my employer, I was fired in 2 weeks—the day I signed up for medical leave. The laws in this state won't help. They didn't say it was because of HIV. I was sick and run down. I experienced rapid weight loss. I was told things like "You're not working out." "Your enthusiasm isn't there." "You're not using a high energy voice." "You're always sick." "Your attendance isn't good." I was a car rental representative. I took reservations.

The consequences related to bringing others into open awareness were not limited to negative experiences. People's positive experiences included receiving support from family members and friends. This is evident upon examining these accounts of PLHs. A respondent described his experience with his sister:

People have been more supportive than anything else. My youngest sister had to get on me. I cried when they took me to the VA hospital. I feel like I'm in the way. I'm going to take up too much of her time. She said, "We won't forget you. I'll never forget my big brother." It made me feel better about coming here (facility). I am learning about medications, and being here makes it easier to deal with the side effects.

One PLH was concerned about revealing his HIV status to a conservative friend:

I was surprised. Everyone said they accepted it fine and didn't act otherwise. I told one friend last. I didn't want to lose his friendship. He and his wife are very conservative. They have ended up being the most supportive.

Another PLH stated:

There have been no negative consequences. There has only been worry and fear on part of my mother, my family, and my employer about me dying and being sick. The support from my family and employer was great.

The following PLH did not expect people to be supportive, but they were:

I find that I'm more accepted. I haven't had any incidents. I expected that I would. I don't believe in keeping secrets because they can kill you. If people have something on you, they will try to hold it against you or blackmail you. You out yourself. My family has been extremely supportive.

For some PLHs, bringing their families into open awareness made their relationships better. Respondents described how being open has brought their families closer in the following accounts. A respondent explained:

Having HIV has brought my family closer. I don't have trouble calling my sister if I need to talk. They come here once a week to see me. My family has been positive. I've gotten closer to them. Some are bigots (a few of my uncles), but my immediate family has been supportive. They were jerks before they found out (uncles). We talk and visit more. Before we seldom talked or visited.

Another PLH had a similar experience:

It has brought my family and me closer. We were distant at one time. They are supportive; they call and check on me. We get together. They help me with laundry and cleaning supplies.

One individual discussed how being open with others showed them that there is hope for people with HIV infection. He encourages others to get tested.

I get a lot of guys to get tested. Everyone I date gets tested. They can see that I am healthy and that the drugs work. Sex is more creative. I try to do it safely.

The positive and negative consequences identified by PLHs could also be seen as turning points in identity. This is because once the information has been revealed to others, there is no turning back. It is not possible for the interaction to be classified as a closed awareness context again. The consequences of bringing others into open awareness contexts are critical to identity formation. Because identity is shaped through social interaction with others, when interactions are suspended or relationships end or change, identity necessarily changes as well.

#### HIV: The Focus of Interaction

Participants were asked if their HIV status was the main focus of their encounters with others. For some PLHs, it was not always the focus of interaction. They tried to maintain awareness contexts of mutual pretense. PLHs explained how this is possible in the following accounts. A PLH said that it is not the focus of interaction because he does not advertise it:

I don't advertise it. If someone likes me, it will be for who I am, not what I've got.

Another PLH explained that he does a lot more than live with HIV infection:

To those who know it is not relevant. It is not awkward if something comes on television about it. We have our own lives. I have far too many other things I do like collecting records and antiques and going to auctions.

For one PLH, family members only bring up his HIV infection to make sure he can engage in activities with them:

I do so many other things around home. It is the focus sometimes, but it is not always the topic. Other family members treat me like I'm normal. They may ask me how I feel, but then I'll go places with them.

The following respondent said that it is easier for him to go on if he does not emphasize his HIV status:

We don't talk about it that much. I don't really want to. It makes it easier to go on if you don't dwell on it. Just go on with your life like you normally would.

Another PLH also de-emphasizes her HIV status:

I try to minimize the disease. I downplay it when I'm with my family. It's not me. It's something I have. I am a lot more than HIV positive.

For other PLHs, it was the focus of interaction because they interact with other PLHs or they volunteer or educate others. Maintaining awareness contexts of mutual pretense was made difficult in these situations. For example, when they interact with other PLHs, it is not uncommon to exchange information about living with HIV infection. One PLH stated:

HIV is something we have in common. We will talk about our illnesses, medications, side effects, treatments, and how we feel on a daily basis. I find out a little more all the time. It is something I've got to live with.

Another respondent explained:

I do think the focus of my interaction with others is my HIV status. In this facility with everyone being positive it is the main topic. People talk about medications and complications. Outside the facility, they'll ask about my health, and I'll downplay it. So many of them are not knowledgeable about the disease. I have to explain everything. Some things they don't need to know.

Being an HIV educator or volunteer requires one to emphasize it. For one PLH it was a career choice.

It is because it is what I have chosen to do with my career. For some it is not. It is not the only part of who I am. The majority of the time it is, but it is by choice.

Another PLH emphasized it so that he could educate others.

After my first television interview, other stations and newspapers wanted to talk to me. I was approached about doing an HIV special on a major cable network. It aired for 2 years. I am just really open about it. I used to do a lot of public speaking at schools and churches. I still do sometimes. I do one-on-one education. My friend told me to be careful. I thought this is a small town and that's a big city problem. I became infected. I was warned. I didn't think I needed to be warned. I would look at them and think they look healthy. The media always found the skinniest, sickest person they could find to portray the disease. Consequently, naïve people fell for it and wound up in this situation.

Some people reported that HIV infection was the focus when they or someone close to them was sick.

If someone is sick, we'll talk about being sick. It is the focus because I interact with other HIV-infected persons for the most part.

My family always brings it up, but it's not my focus. It is a big part of it. There's always something there to remind us of it. My legs are weak.

I don't think that the fact that I have HIV is the focus all the time. Sometimes I do, but it's not a regular feeling. I tell my sister that it's how I'm feeling, not because of them.

Other PLHs explained that it was the focus when they were first diagnosed, but it ceased once their health was restored.

It is not the focus anymore. At first (first year) we only talked about new drugs and side effects, but not really other than that. The first year, getting back to being healthy was the focus. Learning about it and what could be done was the focus.

It is not the focus at all now. Maybe the first year it was. Everybody checked on me. Once my t-cells climbed and my viral load went down and I started looking and feeling healthy, they stopped.

One PLH explained that HIV infection and her health are always the topics of conversation, and this frustrated her.

HIV has weakened me in their eyes. I'm less strong than before, physically and mentally. All the bad they think outweighs what's left. Conversations always revolve about my health and "the sky is blue" and "yes, it's HIV blue."

Taking medications was a frustrating daily ritual that made it difficult to forget about HIV infection:

I have to put forth effort toward not talking about or dealing with HIV. I take medications three times a day and injections three times a week. I go to the doctor every two weeks. I have to set aside time to not deal with someone who needs me. I have to plan my days and weeks around medications, even social activities. I can't go out and party on Friday nights. I can't go out of town without planning.

One PLH intentionally makes it the focus of interaction because although he is healthy now, there is no guarantee that he will stay that way. He makes sure the subject is not avoided.

My partner and I talk about it sometimes, but he doesn't like to talk about it. He definitely knows what could happen. He has cried about it. He's fully aware of it. I try to help him and not to let him forget. Sometimes I push him to talk about it. When he is talking about our future, I make sure he considers all the possibilities in decision-making. I am not always negative. I have lots of hope. I try to make sure he knows that, too.

The following respondent explained that his HIV status is the focus of interaction in sexual and romantic encounters:

When I meet someone new, it is the elephant in the room. I am forced to have that awkward moment and drop the bomb and wait for their news. When they tell me they are positive, it is a little easier. Most people don't like to date outside their serostatus. It is a big jump for those who are negative. I wonder if I want to date this person and put them at risk of getting it. They could get sick and die. It takes away half of the issue when they are positive, too.

It is clear that awareness contexts are not static, but are ever-changing from interaction to interaction. Awareness context theory highlights the processual, not structural, nature of social interaction. PLHs were able to maintain awareness contexts by using the dramaturgical skills of impression management. Until they revealed their HIV status to others, it was not possible

for them to know what the consequences of open awareness were. The consequences defined by PLHs were not always grim. Understanding social interaction from this perspective makes apparent the diversity of how people respond to others from their vantagepoint as PLHs.

#### Part Four: Becoming a Survivor

Another revision in identity or turning point occurs when a person who has been diagnosed as having HIV infection comes to see himself or herself as a survivor of HIV infection. According to the respondents, the processes of support group participation, outliving other PLHs, redefining HIV as a chronic, manageable condition rather than as a death sentence, and deciding to live with the disease facilitated this revision.

##### Identity Transformation: Support Group Participation

The identity transformation process is both “socialized” and “socializing” even though evaluations take place within the individual (Strauss 1959). In other words, incidents that lead to the revision of personal identities are likely to be experienced by others who will also revise their personal identities. Many people reported participating in support groups at some time since being diagnosed with HIV infection. For some, it was comforting to know that others are living with HIV infection and are able to survive. Much discussion revolved around sharing common experiences and how they handled similar problems. A PLH described how participating in a support group helped her:



I participate in a women's support group. There are so few women here. Talking about the ways we acquired HIV and the ways we are handling it helps.

Another respondent explained his experiences with support groups:

I have participated in the past. It helped me know that I wasn't the only one going through this and that I could handle it. I facilitate one now. It doesn't do that much for me now. I've built a support network beyond that.

One PLH stated that the support group was a good source of ideas for solutions to problems:

I was involved. We mostly talked about sex, old dates, and old tricks. You left feeling better because some people have it worse. You hear other ideas on how they handled problems.

Some people hope or find that the support group is a good information resource.

I go to a support group three days a week. It is o.k. The first day we discussed wrestling. It was disappointing. I expected it to be informational. I thought we would talk about medical updates and stuff that is beneficial.

I've been to them in California and it helped. Everyone thinks it is a death sentence. It is not a death sentence. It is especially good for people when they first find out. Support groups are a good source of information.

However, as one respondent pointed out, the benefits of participating in support groups are limited as a result of the repetitiveness of the meetings.

I participated in support groups at first. Then a lot of new people came in and all the information got repeated. It didn't benefit me anymore. I have my own support system now. It helped answer a lot of my questions. I think it is really important for someone just finding out to go, but they have a limited amount of effectiveness.

One individual participates in a support group to help educate others because he has been living with HIV infection for a while.

At first, I needed support and education. Now I'm the old person in the group. Now people look to me for information. It makes me feel good. I worked with a guy who found out he was positive. He knew I was. He

approached me and his doctor hadn't educated him. He asked me about viral load and what qualifies as AIDS. I had to be the bearer of bad news. His t-cell count was low and his viral load was high. I told him, "You're there." He's now on disability, and he's dealing with it. I can't believe his doctor didn't tell him.

There were some PLHs who did not find participating in support groups to be beneficial to them. One PLH said that it took too much energy to go to support group meetings.

I don't feel up to it. I use that as a crutch sometimes. It would take a lot out of me.

Another PLH explained that interacting with other PLHs and volunteering is enough for him. He doesn't need a support group.

My support comes from being with others who have it. I volunteer. It gives me something to do with my time so I don't sit around depressed.

In a few cases, PLHs viewed participating in the support group as being potentially harmful to them.

It doesn't interest me. I went to a group meeting one time. Everyone was crying and feeling sorry for themselves. It was just a pity party. I just wanted to find out what it was like. I didn't like it.

I have participated in the past. It depressed me. People were repeating their stories over and over. It wasn't going to help me get better. I started an informal support group for myself—my friends and family. I shared with them.

Most PLHs had participated in support groups, albeit to varying degrees, at some time. For many PLHs doing so was an indication to them that others shared similar experiences. This suggests that others who are diagnosed with HIV infection revise their personal identities. Thus, the process of revision is facilitated through interacting with others. It is not necessary to participate in

support groups for these revision processes to occur. However, social interaction is.

### The Reality of Outliving Other PLHs

Most of the people interviewed are or have been friends, spouses, or partners with other PLHs. They have outlived others and watched them die. They were asked to discuss what this meant to them and how they dealt with it. Some PLHs made the decision to distance themselves from others. They don't get close or too involved because they don't want to lose someone they care about again. The following respondents explained:

You've got to be careful who you choose as friends. They could be gone tomorrow. You don't want to get too involved because you've always got that in the back of your mind. My best friend...I watched him die. There was nothing they could do for him. I don't get too close now.

I have lost over 12 people in one year. In October I took a chance with another lover. The week he moved in, he went to the hospital and died. I've outlived all of my friends. I have had a few lovers since 1988, but I was used to being independent. When I met him, I decided to try it, but he died. I won't do that again. I don't want to go through it again—to love someone. I don't have it in me.

Participants also described outliving other PLHs as a difficult experience that saddened them. It was not uncommon for PLHs to have experienced the loss of several friends to HIV infection. The following account illustrates this:

I like to do woodwork. I built a shelf for a patient here, but she died 2 weeks after she asked me to. I've seen 20 people die. It tears me up every time. You can see it in their faces when it is time. I have to be by myself and cry. She didn't even get to see the box I built for her. It was the last gift she gave her mother.

One respondent explained the difficulty she experienced:

It changes how you feel about death. I'm not colder; I can deal with it so much better now. It is hard to lose friends. I was wasting and my friend was. I came out and he didn't. I believe it's your fight and your spirit.

Another PLH discussed the ways he coped with losing his friends to AIDS:

The church I go to—25% of the people there are HIV positive. That in itself is a big support. Since the beginning, we have lost 50-60 people to AIDS in 5 years. I do well most of the time with everything. Every time there is a death and I know about it, reality sinks in. I go through depression. When it is someone I'm close to, it makes it harder. I cry about it, I talk about it in the support group, and I have certain close friends I can talk to and my minister.

A few PLHs used their experiences of outliving others as inspiration for their own lives. For some this meant being open about who they were.

A lot of us living with HIV are friends with others with HIV. We see a lot of them die. There is a lot of grief—personal and for others. I have lost many friends with HIV, men and women. I still lean on them for strength because I know what they had to go through. They inspired me to be public about who I was. I learned a lot. One friend and I had issues we had not settled. That death was extremely hard for me. It made me realize not to wait too long.

He explained further that he learned from these experiences:

It was a gift to be there to help in that time of someone's life. It wasn't easy, but I have no regrets. It helped teach me about life, learning what is really important, family and friends. One of the most important things we leave behind is the memory of how we treated others. It is hard to put it into words. You may be doing physical work as far as care, but they give you lessons about yourself. You can deal with this if it comes your time.  
(10)

For others it meant taking care of themselves.

Quite a few people I know have died—50 or 60 in 4 or 5 years. In the last year or two there haven't been that many. There are a few that I expect to go before long. It depends on how close the friend was. I'm pretty well numb to it now. I quit going to funerals. There were too many of them. I take care of myself better now than I ever have. I know my body better now than ever. If something doesn't feel right I find out what it is and what it could lead to.

For one respondent, the deaths of others inspired him to fight until there is a cure:

When I broke up with my last lover of 8 years, I went to find old friends. Over half of them were dead. I went to one friend's house to see him one last time. He was skin and bones, his eyes were swollen shut, and he had lesions on his skin. I laid and cuddled with him for a couple of hours. He died the next day. We were close friends. It was hard, and it still is. It was last year. So many have died. I just cried and let it out and said a prayer. I will be here until the cure is here.

For one PLH, the deaths of his friends inspired him to continue organizing

HIV/AIDS support activities.

At first I was angry, frustrated, and had survivor's guilt. It hurt a hell of a lot. I resolved the feelings by going to therapy and forcing myself to get back out there. I got back to working with AIDS issues and allowing myself to be hurt and vulnerable. I was always there for them. I quit counting the number of deaths at 28.

Several PLHs saw the deaths of others as an indication of what the future would eventually be like for them. According to one respondent:

I have helped care for people in the last stages of their illness. It was hard because it was like looking into a mirror or a crystal ball about what my life would be like.

Another respondent discussed how two of his friends died. One friend had a healthy lifestyle, but he died anyway:

I just lost a couple of friends this summer. Bill let it happen to himself because he didn't take care of himself. He suffered with wasting syndrome—KS (Kaposi's Sarcoma). He was diagnosed a couple of years ago. He didn't tell anyone. He wouldn't go for his chemotherapy treatments because it made him miss work, and he didn't want them to know. Jack was a health nut. He didn't let anyone know. He worked out. 9 months later he was dead. It makes me think what he did was useless, so why should I? He was a health fanatic. He was the first of our inner circle of friends to die. Probably 4 or 5 more have died since.

A PLH stated that he does not want to think about his own dying process because he does not want to be sick:

Seeing others die doesn't make me think about myself. I don't want to see myself like that right now. I'd be crying all the time. I don't want KS. I don't want to be like that.

Other PLHs described how seeing others die makes them see their own futures:

It scares me. It could be me next year or next week. It makes me face the reality of what could be. I grieve. I accept it. I don't dwell on it. I don't try to live in the pain of seeing someone die.

It gets hard because you start thinking of your own mortality. We try to get together and talk about it and remember the good things. I wonder if I'll be here to see my kids graduate or get married or get to grow old with my husband like other people.

I have outlived most of my friends. It hurts each time one dies. It is scary because I know I will go through something similar. I hope I have the courage to fight until the end.

### It's not a Death Sentence Anymore

Many of the participants said that in the beginning they thought they were going to die. They were under the impression that having HIV infection was a death sentence. Advances in medicine have led to decreased AIDS mortality rates. PLHs were asked if they saw themselves as living or as dying with HIV infection. The majority said that they are living or learning to live with it now as opposed to dying of the disease. Getting medications is the key to living according to some PLHs.

I look at life a little different now. As long as I can get drugs to keep me alive and get help.... It's too hard to do on your own—like retired people who can't. Sometimes when you get on disability, they'll give it to you until you die. I could work and make \$9,000 a year. I want to work when my feet get better.

I am living with it. I live day to day like any other person. I take my medications and I eat right. I would like to have the American dream, but that is out of reach now. I'm not dying with this disease. I'm living.

Many PLHs said that at first they prepared to die. However, now they must prepare for a long life. Issues such as retirement, career choices, and maintaining healthy lifestyles are major concerns. This respondent planned for the future while keeping in mind potential obstacles:

Early on I was preparing to die. I don't see that now. I see myself as living. I plan for the future, but I keep in mind the possibilities. My retirement fund may need to be used for medical bills.

Another PLH discussed his concerns regarding retirement, his career, and health insurance policy benefits. He never thought any of this would be an issue:

When I found out I was waiting and planning to die. But things are changing. Medications are being developed and are working. Now I'm planning to live. I have to think about retirement. I would have never thought of that before. It has been a difficult transformation. Now I think, is my job what I really want to do for the rest of my life? Now I want to find a career. Drugs are expensive. My health insurance policy is for \$1,000,000 maximum lifetime. My drugs are \$3,500 per month. This doesn't include doctor appointments and lab work. I don't want to spend it too quickly.

A respondent explained that because of advances in medicine, he had to worry about health maladies other than HIV infection:

I am living. I've had it for so long. My attitude has changed about it. It is manageable. At first I thought there was nothing I could do. The protease inhibitors made a big difference. My t-cell count is 500 now. A lot has changed. Before they told me to eat what I want. Now I have to watch my cholesterol. Now we're living longer. It would be a shame to have a heart attack now.

The following respondent talked about how support from his family helped him prepare to live again.

I am not dying. I'm as healthy as you and anybody else. I just take a lot of medications. It is hard to get out of pity parties. I have a positive attitude because of prayer, family, and faith. My sisters and mom gave me emotional support. I had to prepare to live again. I had to also get comfortable with death. I am living. The first year to year and a half I was

dying. When I was diagnosed with PCP, I thought it was over. I've learned how much people cared for me. They were by my side when I needed them. I know my needs will be met.

One PLH equated HIV infection as being just another of life's challenges that must be dealt with:

I ran into a friend in the doctor's office who had just found out he had HIV infection. He was freaking out. That moment is hard. I told him to remember that it is not a death sentence. He has to take better care of himself and monitor his health more than someone his age normally does. It is all about challenges and rising to them. These are the cards you were dealt. You have to play them.

A few PLHs explained that how they feel changes from day to day.

Sometimes they feel like they are dying, but it does not dominate them.

According to one account:

I am living with HIV now. When I was first diagnosed, it was like I was unaware of it. Some days I think I am dying, especially when I take anti-viral medications. The side effects are worse than HIV itself. 80% of the time I am living. 20% of the time I am dying. It depends on how I feel that day. I have not had an opportunistic infection or an AIDS related illness. The virus is eating my t-cells. The way I have lived—it is no wonder I am alive. I didn't take care of myself. I guess I was stronger than I thought.

Another PLH also described how his feelings vary from day to day:

I am living. I'm really comfortable now. I stopped feeling sorry for myself. I have control. It's not a death sentence. I used to tell myself I wouldn't see 30. Now I have made a choice to live and not to die. I feel like I'll live until I'm 80 just like anyone else. I don't always feel that way. Some days I'm really discouraged. If I get bad test results or if a friend dies or if I don't feel good or if other things like family problems happen, I get discouraged.

Not every PLH embraced his or her HIV identity. One respondent could not cope with his HIV status.

Sometimes I'm afraid to go to sleep at night. I'll stay up all night. [He is crying.] I used to not smoke as much. My nerves are so bad. I used to be an artist.



One long-term survivor believed he was dying at the time of the interview and explained how he was dealing with it.

I am dying now. I can't fight off infections. I lay in bed a lot. I don't have strength. The winter is coming, and I figure I'll be dead before it is over. Being a Christian, it doesn't bother me. I pray that I'll be around for my kids. I deal with it. My kids are where my strength is. I talk to my dad when it is bothering me or to my friend when I get scared. I tell my kids I am dying and that I'm going to heaven. I had a videotape made for them. I talk about life, respect, giving, good vs. evil, and the good and bad consequences of decisions. I talk to them about drugs, alcohol, and gangs. I talk to them about the good parts of my life. Clippings of events of my life are cut into the tape. I know something I said will help my kids. My advice will help them in the future.

### Living with HIV Infection

Surviving HIV infection and deciding to live with it is another turning point in identity that is distinct from being diagnosed with it. Whether one sees himself or herself as living or dying does not dismiss the fact that he or she is surviving, as one PLH explained. However, most of the people who participated in this study saw themselves as living. People have lost things and gained things as a result of living with HIV infection. They recognize that they have changed, but it is not necessarily for the worst. For some PLHs, becoming a survivor of HIV infection has meant not feeling well.

I'm still me. I'm still the person I was before. I'm getting dementia. I'm still me. It made me sick. It didn't turn me into an alien. *I live with it—it's **my** disease. They don't have to live with it—I do.*

I don't know how long I've had this. I have neuropathy in my legs. It attacks the weakest part of my body, all of my joints. It's getting in my brain—dementia. One can't eat, walk, or talk. It makes you go crazy. I don't want to live like that.

For others it meant becoming dependent on others.

I'm let down because I promised my mother that I would take care of her, then I got sick. It makes me real depressed. I can't forget it because I promised her.

I hate depending on my family. My dad buys cigarettes for me. There are organizations that help, but they don't do enough to let people know.

Being limited in what one can do was also problematic as illustrated in this account:

Not being able to work bothers me the most. It made me feel good. I can't do the work I was trained to do now. I made a lot of money. Work was so rewarding because the problems I solved were always different. I have no routine. I have to plan and reserve my energy. I can only go to school in the morning. Being limited in what I can do is hard. I have to cancel a lot of things. I can't play basketball. There have been times that morphine won't kill the pain.

Another PLH discussed how he missed his independence:

It sucks. I feel separated from society. I can't be as much a part of it as I want to be. I can't dance or stay up late. I have no energy to go. I have no interest to go. I could continue on and on. Living here gets old. It is the same thing day in and day out. I have to get my legs stronger so I can move into my apartment. It would give me the freedom to fix my own meals. I miss my independence. I feel like I'm being treated like a kid sometimes because I am limited to what I can do for myself. Sometimes it is how I am dressed by others. Sometimes it is like I am being talked down to.

Financial limitations were also problematic for PLHs as indicated in this account:

The biggest down for me is not being able to afford to live the way I would like. Just trying to make it is hard. The last week of the month is the worst. I stress over not being able to afford my medications. I have had to sell prescription medications (xanax) to pay a bill or to eat.

One PLH explained that it was troublesome that he could not live one day without being reminded of his HIV status.

Sometimes I get sick of it—of taking 20 pills in the morning, 10 during the day, and 20 in the evening. It's just a reminder. I can't go through one day without thinking about HIV. There's no escape.

Becoming a survivor of HIV infection has also meant having hope and faith, being able to express oneself, and appreciating more about life. This is evident in the following accounts. Seeing HIV infection as a manageable condition helped this PLH have hope that he had a long life ahead of him.

Living with HIV is a major part of my life. Protease inhibitors are doing a lot. I thought there would be no way to wipe out HIV. I don't believe this now. I have no negative thoughts about now or in the future. I'm me again. It is like someone with cancer or liver or lung disease. HIV is no different. There is the possibility it will destroy your life, but pursue what you need and you'll be o.k. I fully intend to live for a while and to be happy. I know this sounds optimistic, but that is the only way to live your life.

One respondent said that although he resents depending on others for assistance, he is happy that his religious faith has been strengthened.

It has changed me religiously. I've become much stronger in my faith. I have to rely on people. I've learned to even though I feel I'm using them. I have to do it. Sometimes I resent it because I used to do it for myself. Now I'm very limited.

It was not uncommon for PLHs to explain how they appreciate their lives much more after coming to accept their HIV status. According to one respondent:

I am more open. I am able to express my thoughts to others. I have weeded out friends. I don't put up with everyday crap from people anymore. I don't let people take advantage of me anymore like I used to. I get mad at people who complain all the time. It gets on my nerves when people don't take advantage of what they have. I appreciate things more. I have always worked my whole life. I'm not as strong as I was, but I still would like to work full time. I am not used to being this broke. My monthly income is what I used to make in a week.

A PLH explained how having an incurable disease influenced how he experienced his life:

I value life more and the things around me. I notice more. I appreciate other people and what they have done for me. Life is more clear, keener. I don't just work, eat, and sleep. Just knowing that you could die at any time makes a difference. You might feel great today, but tomorrow you

could get pneumonia, and they might say they can't do anything for you. I have seen it happen.

Another respondent said:

It has made me appreciate everything so much more. I never had to think about having a positive attitude. Bitter does nothing but kill you. I don't want self-pity. Nobody wants to hear wining.

Becoming a survivor of HIV infection taught the following PLH about life and empowered him:

It has made me a better person and taught me a lot. I know how to care for the body and health and how to help other people. I pray and read spiritual books. Everybody is like "big virus, little me." I am like, "Big me, little virus." I am empowered. I have to control the disease physically, but I can't let it control me.

One respondent compared having HIV infection to other life transitions:

I'm living with HIV infection, so it is part of my life. Ten years ago it wasn't part of my life. You could associate it with having a child and how it changes your life politically and financially. It changes how you care for yourself. It could be like losing a limb. If you lose your legs, it doesn't mean you're dead. It means you lose your legs, and you have to deal with that.

Four processes, as discussed in this section, facilitated the turning point of becoming a survivor of HIV infection. These were support group participation, outliving other PLHs, redefining HIV infection as a chronic condition, and living with the disease. It should be recognized that other processes could be involved that were not articulated by the respondents. To assume this revision in identity did not require that all four processes occur in any specific order. The first process, participating in support groups, showed that this transformation is socialized and socializing. This means that others share similar experiences as PLHs and that through interacting with others, the revision in identity progresses.

The second process presented was outliving other PLHs and the various ways respondents handled it. The third process described was redefining HIV infection as a chronic and manageable disease as opposed to a death sentence. The dramaturgical consequences of this are significant because although both living and dying are forms of conduct, they are distinct. Preparing for a long life is quite different than preparing for death in the near future. The fourth process PLHs discussed was deciding that they are living with HIV infection, not dying. They explained this in terms of how they lived with HIV infection and what it meant in terms of consequences.

In this chapter, the illness experiences of PLHs were examined. Their accounts suggest that there is an overall process of becoming a survivor of HIV infection. It is clear that it was a diverse process for all of the participants. However, there were recurrent themes expressed in their accounts. Throughout the process of becoming survivor of HIV infection, PLHs experienced turning points in identity. Such revisions were accompanied by the dramaturgical activities of impression management which were used to maintain awareness contexts and the related consequences. In the next chapter, I will discuss these results in terms of the general research questions posed in chapter 2 and the practical implications of this study.

## CHAPTER 5

### CONCLUSIONS

This research is a theoretical and empirical contribution to the study of identity. Major social psychological concepts were integrated to better understand the social process of living with HIV infection. These concepts were turning points in identity, stigma, the dramaturgical skills of impression management, and awareness contexts. The integration of these theoretical concepts allowed me to develop a more comprehensive understanding of the complex processes involved in how people construct HIV identities. These complexities were made apparent in the accounts of the research participants. The examination of these accounts through the lens of this conceptual integration was a useful way to understand the interactional experiences of PLHs and the related consequences for identity construction.

Awareness context theory provides a framework to examine the dramaturgy of social interaction and its consequences for people living with HIV infection. Such consequences included the various experiences of HIV-related turning points in identity. A key feature of awareness contexts is that they are characteristics of social interaction that can be maintained by one or more actors. PLHs recognized the stigma associated with HIV infection and engaged in the dramaturgical skills of impression management to maintain awareness contexts. Thus, the interactional experiences of PLHs were shaped by awareness contexts in terms of their consequences. The results of this study are also a contribution to the existing

literature regarding living with HIV infection. This body of literature should be consulted by anyone who is directly involved with PLHs, as well as those who make policy decisions that affect their lives.

In-depth interviews were conducted with PLHs to gain an understanding of the social processes that contribute to the development of HIV identity after being labeled as a person with HIV infection. Five general research questions guided this project, which were represented by the specific questions that participants were asked. By interpreting PLHs' answers to these questions, I was able to understand the overall process of becoming a survivor of HIV infection. While everyone had diverse experiences, there were recurrent themes suggested in the data, as presented in the previous chapter. As this qualitative research was exploratory, no hypotheses were tested.

### Discussion of Research Questions

Being labeled as a PLH was an important turning point in identity for the respondents. Characteristics of HIV infection that make it salient are the stigma associated with the disease and its incurability. According to Strauss (1959), turning points in identity are accompanied by misalignment. PLHs expressed their initial anxieties after learning that they had HIV infection. Many PLHs were afraid that they would die soon after being diagnosed; some feared a long, painful death. Several people considered suicide to be a potential solution to living with the disease. One PLH still considered suicide to be an option at the time of the interview. A few PLHs expressed that they were worried about becoming dependent on others. Others

were concerned about telling people about their HIV status and the related consequences.

Receiving a diagnosis of HIV infection signaled another turning point in identity, becoming a patient with HIV infection. The results of a classic study that focused on socialization for medicine, *Boys in White*, indicate that while in medical school, students learn to distance, or detach themselves from the human body, disease, and death (Becker et al. 1961). They must dissect the cadavers which lay people tend to treat with reverence. They also realize that because they will repeatedly face the pain, dying, and death of their patients, they should not become emotionally involved with their patients. Such a detachment may inhibit one's ability to be empathetic, not only in terms of giving bad news, but also in terms of treating patients. A lack of empathy on the part of healthcare professionals was perceived by some of the PLHs.

A final turning point in identity that was revealed by the respondents was seeing oneself as a survivor of HIV infection. Certain circumstances and redefinitions facilitated this revision in identity. These included participating in support groups, outliving other PLHs, redefining HIV infection as a chronic and manageable condition, and deciding to live with the disease. This meant living with the advantages and disadvantages associated with having HIV infection.

The participants' accounts confirmed that others stigmatized them because they had HIV infection. Some PLHs were doubly stigmatized if they belonged to certain risk groups (i.e. male to male sex). Most respondents reported that they



concealed their HIV status at some point because they were concerned about maintaining relationships.

According to dramaturgy, people create reality. They project images of themselves unto others by both revealing and concealing information about themselves. The dramaturgical skills of impression management facilitate this process. PLHs described the ways they concealed their HIV status from others. Practicing these stigma management techniques enabled them to maintain closed awareness contexts. Passing, or not telling, was made easier because there were no obvious symptoms. One can not simply look at a person and tell that he or she has HIV infection. Covering was also a technique used to control information, although it was used less frequently than passing among the PLHs who participated in this research. The insulation technique was used by PLHs to protect themselves from unfavorable reactions from others. They only told a select group of people that were trusted and understanding. A couple of PLHs reported that they isolated themselves when they initially learned of their HIV diagnosis. However, this was only for a short period of time. These findings are consistent with previous research on stigma management among PLHs (Sandstrom 1990; Tewksbury and McGaughey 1997).

PLHs discussed bringing others into open awareness contexts and the consequences of revealing their HIV status. These consequences also represent a turning point in identity for PLHs. Relationships ended, were strengthened, and emerged as a result of disclosure. Since it is through social interaction that identities are formed, when interactions were suspended, changed, or emerged, identities

changed accordingly. PLHs also maintained awareness contexts of mutual pretense so that the focus of their interactions with others was not HIV infection. For some respondents this awareness context was out of reach because they interacted with other PLHs regularly, volunteered, or educated others about HIV infection.

By answering the research questions posed, I was able to understand the overall process of becoming a survivor of HIV infection. It is important to note that none of the concepts explored can be understood outside the context of social interaction. A turning point in identity is established through interaction with others. Stigma is a social label and must be imparted by others. People perform the dramaturgical skills of impression management to maintain their definitions of the situation. In short, these processes can not exist in the absence of social interaction.

### Practical Implications

The accounts of disclosure that were given by people living with HIV infection represent a shift from closed or suspicion awareness contexts to the context of open awareness. For most, a diagnosis of HIV infection could be classified as bad news. However, by being truthful, healthcare professionals can be supportive and give patients the information they need to live a healthy life. By communicating with patients, multidisciplinary teams can develop healthcare regimens that reflect the biopsychosocial needs and limitations of patients on an individual basis. It appears that for this ideal to be realized, those who disclose need to learn how to give bad news in a compassionate, informative way. This should be taken seriously and practiced by all who are in the business of disclosure in the healthcare setting. It is

apparent from the PLHs' accounts that the people who disclosed their HIV diagnoses to them need to work harder to accomplish this. There were too many examples of the unsupportive approach. Confidentiality was not maintained in some instances. This suggests that the bearers of the news were not acting virtuously. More emphasis should be placed on the appropriate ways to disclose bad news in the healthcare setting. If the disclosure of an HIV diagnosis does not comply with ethical standards and the law, severe sanctions should be imposed. Confidentiality must not be taken lightly.

Many physicians are afraid to give patients the bad news that they are going to die, and few of them think their skills in this area are adequate. Although this is common, medical schools are still hesitant to spend too much time teaching their students the clinical skill of imparting bad news (Lancet 1993; Fallowfield 1993). Newly qualified physicians are inexperienced and frequently must deal with communicating the bad news in critical situations such as in emergency rooms (Lancet 1993; Fallowfield 1993). However, it has been suggested that empathy, an art of medicine, can be acquired by all doctors (Lancet 1993).

While there has been an increase in the amount of education healthcare professionals receive regarding death and dying, it usually occurs during the first two years of medical school through lectures. However, during the clinical years, little training is given in this area (Rappaport and Witzke 1993). Rappaport and Witzke (1993) found that of 106 medical students in their third year of clerkship, all of them had experienced caring for a terminally ill patient. However, 41% of the students had never witnessed an attending physician talk with a terminally ill patient, and 35% had

never been told by an attending physician how to interact with a terminally ill patient. They also reported that more than half of the medical students in their study thought they were not adequately prepared to interact and cope with terminally ill patients. Almost all of the students thought that education on death and dying during the clinical years was a good idea.

Fallowfield (1993) posited that communicating bad news in an insensitive manner can be troubling to both the person who gives it as well as the person who receives it. Because of inadequate clinical training in communication skills, most physicians are not able to give the bad news in an appropriate manner. This should be remedied, according to Fallowfield (1993), and can be if doctors learn to empathize with the recipients of bad news, learn to overcome the fears associated with giving the bad news such as feelings of blame and failure, and learn to cope with the recipient's reactions to the bad news.

### Limitations

This study was exploratory and has limited generalizability to the population of people living with HIV infection. However, the results are considered to be a contribution to the body of literature that emphasizes identity construction among PLHs. Taken together, this body of research provides useful information regarding the lives of PLHs that should not be disregarded. The people interviewed were predominantly male. Only three females volunteered to participate. Future research inquiries should target this minority group. The conceptual framework utilized in the current research project would be beneficial in understanding the social experiences

of women living with HIV infection and the unique circumstances of their lives. Another future research inquiry involves a group of people that were not considered in the current research project. A few of the PLHs revealed that they had partners who did not have HIV infection. It would be interesting to examine the concepts addressed in this research from the perspectives of partners who are not infected, but are affected directly by HIV because their partners have it.

In conclusion, what it is like to live with a stigmatized illness can only be articulated by those who have them. The practice of empathy can help others make informed decisions about their own actions when dealing with PLHs or HIV/AIDS issues from the interactional level to the organizational level (i.e. public policy).

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## APPENDIX A: BACKGROUND

It is widely accepted that the human immunodeficiency virus (HIV) is the virus which infects blood cells that regulate the immune system. It also infects cells in the nervous system, colon, and blood vessels. The virus is transmitted by semen, blood, vaginal and cervical secretions, and breast milk (American College Health Association 1996). The exposure categories identified by the Centers for Disease Control (CDC) include men who have sex with men, injecting drug use, men who have sex with men and inject drugs, heterosexual contact, transfusion recipient, hemophilia, and other/not identified. HIV infection refers to all stages of this disease including the last stage, Acquired Immunodeficiency Syndrome (AIDS). AIDS is "the clinical state resulting from prolonged infection with HIV. It is usually characterized by poorly treatable opportunistic infections and malignancies appearing in the setting of profoundly decreased immunity" (Frumkin and Leonard 1997:189).

While HIV infection was once portrayed as the disease of gay men, it has come to be known as a disease that is prevalent among ethnic minorities, women, the poor, and children (Hunter and Rubenstein 1992). AIDS cases among young women from July 1997 to June 1998 were 52% among 13-19 year olds and 38% among 20-24 year olds. Of the newly diagnosed HIV cases from July 1997 to June 1998 among people aged 13 to 19 years in the United States, 65% were females. Among people aged 20 to 24 years, 44% were reported to be women (Centers for Disease Control 1998). Perhaps this phenomenon could be referred to as the "feminization of HIV infection."

Minorities disproportionately represent people living with HIV infection. Of 69,151 people living with AIDS in the United States in 1996, 42% were black and 19% were Hispanic. Together these two ethnic groups disproportionately accounted for 61% of the AIDS cases, as they only comprised close to an estimated 24% of the total United States population (Centers for Disease Control 1998). This is exacerbated among women with approximately 78% of women's AIDS cases in 1996 being among blacks and Hispanics (Centers for Disease Control 1998). Most of the children living with HIV infection acquired it perinatally. Approximately 20% of people living with AIDS are younger than eighteen years of age (Williamson 1994). Over 80% of children whose mothers have or will die of HIV infection are African American or Latina (Williamson 1994). Black and Latina women living with HIV infection or at risk for the disease are more likely to live in inner city neighborhoods which are characterized by violence, unemployment, joblessness, substandard housing, and the absence of adequate healthcare (Williamson 1994). The results of a study of HIV infection in New York City indicate that the highest prevalence of AIDS occurred in inner city neighborhoods primarily inhabited by poor, ethnic minorities (Singer 1994).

It is not surprising that homelessness is a growing problem among people living with HIV infection. It has been estimated that between 20 and 30% of the people who are homeless in New York City have HIV infection, or about 13,000 people. The majority of the homeless people living in New York City are minorities (King 1992). Similarly, in 1989, it was estimated that 20% of the homeless Dallas population was living with HIV infection (King 1992).

## APPENDIX B: ANNOUNCEMENT OF STUDY

### *HIV/AIDS Research Project*

**Researcher:** Deborah White, Department of Sociology, Oklahoma State University

**Proposed Study:** The Symbolic Meanings of Living and Dying with HIV Disease

I am conducting a study of people living with HIV disease aged eighteen years and older. As a participant in this research project, you will be asked to complete an interview that will last between one and two hours. Questions will be asked regarding social interaction with others such as family members, health care professionals, and friends. The purpose of the study is to learn more about the social experiences related to living with HIV disease. Your responses will be kept confidential. Neither your name, nor any other type of personal identification, will be linked to this study.

You may volunteer to participate in this study if you are 18 years of age or older and have tested positive for HIV disease. Please contact Deborah White in one of the following ways with a message that states only your name and a way to reach you. It is not necessary to tell anyone except Deborah White or Dr. Lee Maril that you wish to participate in this study. You will be contacted by Deborah White to schedule a confidential interview.

Phone: 800-817-8228 access code 02 or 405-744-6105

E-mail: [wadwhite@aol.com](mailto:wadwhite@aol.com)

Address: Department of Sociology, Oklahoma State University,  
006 Classroom Building, Stillwater, OK 74078

## APPENDIX C: INFORMED CONSENT FORM

The Symbolic Meanings of Living and Dying with HIV Disease  
Deborah Ann White, M.A. and Robert Lee Maril, Ph.D.  
Oklahoma State University  
Department of Sociology  
405-744-6105

I have been asked to participate in a research project by Deborah White and Dr. Lee Maril of the Department of Sociology at Oklahoma State University. The purpose of this study is to gain an understanding of the social experiences of people living with HIV disease. As a participant of this research project, I will be asked to complete an interview that is expected to last between one and two hours. I will be asked to answer questions regarding my social experiences with others such as partners, family members, friends, health care professionals, coworkers, employers, support groups, and religious organizations.

I understand that no one will be able to connect my name or any other type of personal identification with the information I provide during the interview. The information that I furnish will remain confidential. I understand that I am not likely to derive any direct, personal benefit from participating in this research. However, the information I share may help others, including health care professionals, employers, and others, understand the social aspects of living with HIV disease. When the research project is completed, I may obtain a written report by contacting the principal investigator.

I understand that participation is voluntary, that there is no penalty for refusal to participate, and that I am free to withdraw my consent and participation in this project at any time without penalty after notifying the project director. I may contact Deborah White by telephone at 405-744-6105. I may also contact Gay Clarkson, the IRB Executive Secretary at 305 Whitehurst, Oklahoma State University, Stillwater, OK 74078; telephone 405-744-5700.

I have read and fully understand the consent form. I understand that it will be filed apart from the interview notes. I sign my name freely and voluntarily. A copy has been given to me.

Date: \_\_\_\_\_ Time: \_\_\_\_\_ Signature: \_\_\_\_\_

I certify that I have personally explained all elements of this form to the subject or his/her representative before requesting the subject or his/her representative to sign it.

Signed: \_\_\_\_\_  
Project Director or Her Authorized Representative

APPENDIX D: IRB APPROVAL

OKLAHOMA STATE UNIVERSITY  
INSTITUTIONAL REVIEW BOARD  
HUMAN SUBJECTS REVIEW

Date: 07-06-98

IRB #:AS-98-071

Proposal Title: THE SYMBOLIC MEANINGS OF LIVING AND DYING WITH HIV DISEASE

Principal Investigator(s): Robert Lee Maril, Deborah Ann White

Reviewed and Processed as: Expedited

Approval Status Recommended by Reviewer(s): Approved

ALL APPROVALS MAY BE SUBJECT TO REVIEW BY FULL INSTITUTIONAL REVIEW BOARD AT NEXT MEETING, AS WELL AS ARE SUBJECT TO MONITORING AT ANY TIME DURING THE APPROVAL PERIOD.

APPROVAL STATUS PERIOD VALID FOR DATA COLLECTION FOR A ONE CALENDAR YEAR PERIOD AFTER WHICH A CONTINUATION OR RENEWAL REQUEST IS REQUIRED TO BE SUBMITTED FOR BOARD APPROVAL.

ANY MODIFICATIONS TO APPROVED PROJECT MUST ALSO BE SUBMITTED FOR APPROVAL.

---

Comments, Modifications/Conditions for Approval or Disapproval are as follows:

Signature: 

Date: July 10, 1998

Interim Chair of Institutional Review Board  
and Vice President for Research

cc: Deborah Ann White

## APPENDIX E: QUESTIONNAIRE

HIV Disease Questionnaire  
Deborah White, M.A. and Dr. Robert Lee Maril  
1998-1999  
Department of Sociology  
Oklahoma State University

Fictitious Name: \_\_\_\_\_

1. What is your sex?

- 1 Male      2 Female

2. What is your race?

- 1 African American                      4 Hispanic  
2 Caucasian                                5 Asian  
3 Native American                        6 Other \_\_\_\_\_

3. How old were you on your last birthday? \_\_\_\_\_

4. How much education have you completed?

- 1 Less than 8<sup>th</sup> grade  
2 Some high school  
3 High school diploma or GED  
4 Some college  
5 Trade, business, or community college complete  
6 4-year degree complete  
7 Post graduate education

5. What is your marital status?

- 1 Single, never married                5 Widowed  
2 Married                                    6 Living with someone  
3 Separated                                7 Other \_\_\_\_\_  
4 Divorced

6. How many children do you have? \_\_\_\_\_

7. Who lives with you? (nobody, children, spouse, etc.) \_\_\_\_\_

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8. What is your employment status?
- |   |                    |
|---|--------------------|
| 1 Working full time (30 or more hours a week)   | 5 Retired          |
| 2 Working part time (less than 30 hours a week) | 6 Not able to work |
| 3 Not working and not looking for work          | 7 Other _____      |
| 4 Not working but looking for work              |                    |
9. What is your income before taxes? \_\_\_\_\_ Does this meet your needs?
10. What is your religious affiliation? \_\_\_\_\_
11. When did you learn that you have HIV disease? (time frame)
12. How was the news given to you?
13. What were your worries? Have you overcome them? How?
14. Who have you been open with regarding your diagnosis?
15. What have the consequences of revealing your diagnosis been? (positive/negative)
16. What concerns do you have regarding maintaining favorable relationships with others?
17. Do you socialize as much as you did before your HIV diagnosis?
18. Do you think your HIV status is the focus of your interaction with others? How?
19. Do you participate in any support groups?  
If no, why?  
If yes, what does this do for you?
20. Have you had any negative experiences with your healthcare providers since being diagnosed with HIV disease? If yes, please describe.
21. Have you had any positive experiences with your healthcare providers since being diagnosed with HIV disease? If yes, please describe.
22. Have you sought support from any religious organizations/churches?  
If no, why?  
If yes, what happened? Please describe both positive and negative experiences.



23. Do you know how you contracted HIV disease?
24. What advice would you give to others about how to help someone who has HIV disease?
25. Is there anything else that you would like to tell me regarding living with HIV disease?

Z

VITA

Deborah Ann White

Candidate for the Degree of

Doctor of Philosophy

Thesis: TURNING POINTS IN IDENTITY: BECOMING A SURVIVOR OF HIV INFECTION

Major Field: Sociology

Biographical:

Education: Graduated from Louisa County High School, Mineral, Virginia in June 1987; received Bachelor of Science degree in sociology from Longwood College, Farmville, Virginia in May 1991; received Master of Arts degree in sociology from East Carolina University, Greenville, North Carolina in May 1995. Completed the requirements for the Doctor of Philosophy degree in sociology at Oklahoma State University, Stillwater, Oklahoma in May 1999.

Experience: Teaching Assistant at East Carolina University from 1993-1995; Interviewer for the Developmental Disabilities Quality Assurance Project at Oklahoma State University from 1995-1997; Teaching Assistant and Teaching Associate at Oklahoma State University from 1997-1999.

Professional Memberships: Alpha Kappa Delta; Phi Kappa Phi; American Sociological Association; Mid-South Sociological Association; Midwest Sociological Society.