To the Graduate Council:

I am submitting herewith a thesis written by Susan M.K. McCallister entitled "Kindred Spirits: Social Support of HIV-Positive Individuals." I have examined the final copy of this thesis for form and content and recommend that it be accepted in partial fulfillment of the requirements for the degree of Master's, with a major in Nursing.

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KINDRED SPIRITS

SOCIAL SUPPORT OF HIV-POSITIVE INDIVIDUALS

A Thesis

Presented for the

Master of Science in Nursing

Degree

The University of Tennessee, Knoxville

Susan M. K. McCallister

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"When I Heard the Learn'd Astronomer"

When I heard the learn'd astronomer,
When the proofs, the figures, were ranged in columns
before me,
When I was shown the charts and diagrams, to add,
divide, and measure them,
When I sitting heard the astronomer where he lectured
with much applause in the lecture-room,
How soon unaccountable I became tired and sick,
Till rising and gliding out I wander'd off by myself,
In the mystical moist night-air, and from time to time,
Look'd up in perfect silence at the stars.

---Walt Whitman

(Van Doren, 1945/1982, p. 214).

Dedicated,

with gratitude and respect,

to this study's Stars.

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identify emerging themes.

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Most importantly, I express my gratitude to the participants of this study, who generously shared their wisdoms about life with me. Each of you has been a guiding star. I hope that by telling your stories we will help to end ignorance about people with HIV.

ABSTRACT

The purpose of this study was to discover more about the experiences of HIV-positive individuals with regard to their social support networks and the types of caring they are offered. An open-ended interview format was chosen to provide depth and richness from the personal accounts of fourteen HIV-positive men and women. Transcripts and field notes were analyzed, using standard qualitative methodologies, to reveal themes and patterns.

Study participants reported a variety of supportive behaviors offered to them, which were thematized into fourteen categories of emotional, informational, attitudinal, and practical forms of support. Positive and negative examples were noted for each theme. Phases of adjustment to the illness, common sources of support, unmet support needs, and strategies for coping with the illness were also thematized according to prevalent patterns.

Implications of the study for nursing practice and social change are discussed.

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CHAPTER ONE

INTRODUCTION

STATEMENT OF THE PROBLEM

Acquired immunodeficiency syndrome (AIDS) results from the infection of human T helper cells, and possibly other cells, with a retrovirus called human immunodeficiency virus (HIV) (Fauci, 1988). After an average of eight years of incubation (Curran et al., 1988), the weakened immune system begins to succumb to opportunistic diseases such as Pneumocystis carinii pneumonia, Kaposi's sarcoma, and tuberculosis. As of May 1991, a total of 179,136 cases of AIDS have been reported to the United States' Centers for Disease Control; 1,244 of these were reported within the state of Tennessee (Centers for Disease Control, 1991).

Partly because AIDS was first concentrated within already stigmatized groups such as homosexuals and intravenous drug users, and partly because of its initially unknown mechanisms of transmission combined with its poor prognosis, AIDS became the subject of

public hysteria and prejudice. Metaphors of plague, battle, alien invasion, punishment, and holocaust have been associated with the syndrome (Kramer, 1989; Ross, 1989; Sontag, 1989). Infection with HIV confers a stigmatized status, and produces a constellation of psychosocial concerns unique to this illness.

Persons who are HIV-seropositive, or who have progressed to a diagnosis of AIDS, experience unique concerns and needs for support. This qualitative study explores the forms of support received by HIV-positive men and women who are associated with a Knoxville AIDS service organization. The study also identifies caring behaviors which are considered helpful, and describes psychological, social, and spiritual needs.

This research is significant because most prior studies have drawn subjects from metropolitan areas much larger than Knoxville. Public awareness and specialized support systems are expected to be less developed in communities, such as Knoxville, which have relatively few HIV-infected persons. Although social support has been shown to increase psychological and physical well-being, the effectiveness of specific supportive behaviors is not well described. Results of

this study will assist health care providers, counselors, and community support organizations in developing strategies to help HIV-seropositive persons adjust and cope.

CONCEPTUAL FRAMEWORK

HIV disease is linked with a unique set of psychosocial concerns. The person with HIV infection must confront societal stigma, changing social relationships, an uncertain course of physical decline, and the probability of early death. Because of their underlying commonality of experience, particularly with regard to the reaction of the community at large, HIV-positive persons may be considered a subculture.

Madeleine Leininger (1985a), a nurse-anthropologist, has developed a conceptual model based on the differences and similarities of caring behaviors across various cultures. She states that expressions of caring communicate different meanings depending on their cultural contexts. Nurses, says Leininger, must be aware of the lifeways of their clients in order to provide care which is relevant and effective.

Leininger's Sunrise Model (Figure 1) has been used to study and categorize meanings and mechanisms of

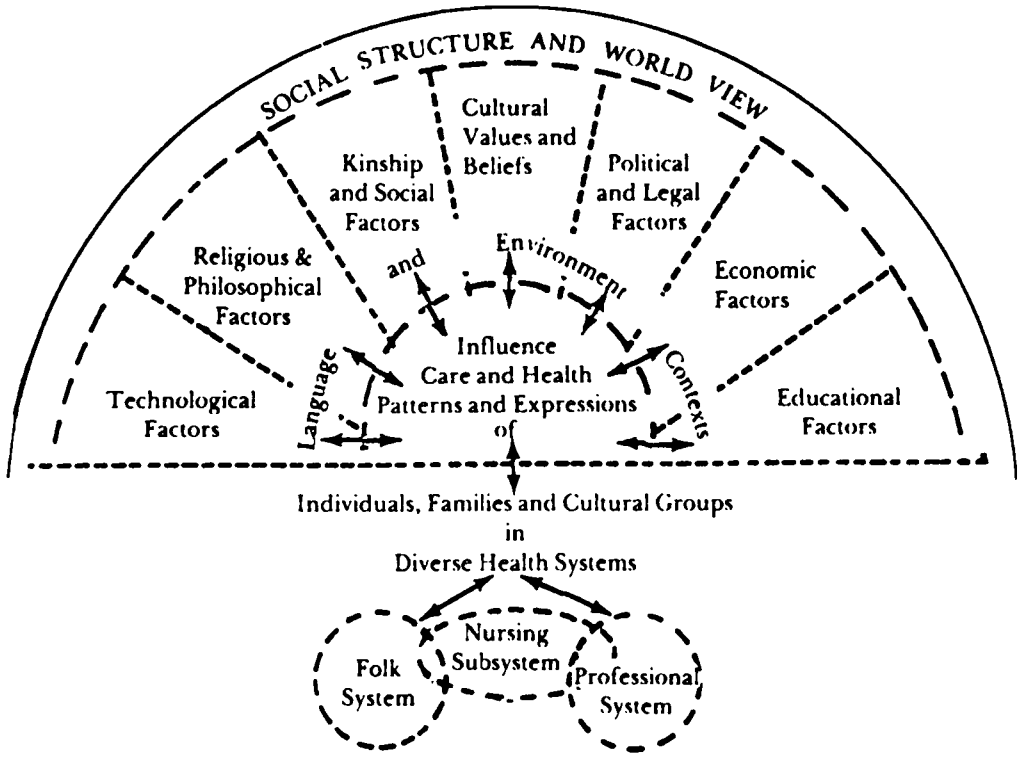


Figure 1. Leininger's Sunrise Model

caring in many diverse cultures. Leininger's (1985b) research regarding rural southerners made it possible to identify major themes of caring and social support. Black southerners, for example, valued expressions of presence (visiting persons who were sick) and touching. Knowing valued expressions, it was possible for Leininger to explore the "fit" between types of care important to the villagers and types of care offered by townfolk or professional caregivers. Villagers were

often reluctant to visit a large nearby hospital because the professional staff seemed distant and unavailable to them. Culture-specific and appropriate care could be offered the villagers by incorporating expressions of presence and touch into standard nursing care. By learning about the perceptions of those receiving care, supportive actions can be expressed in a manner which is meaningful to the recipient.

RESEARCH QUESTIONS

1. What are the relationships of HIV-positive individuals to their important support persons?
2. How is caring expressed to persons who are HIV-positive by persons in their support network?
3. What unmet needs for support are expressed by HIV-positive individuals?
4. What values or spiritual strengths contribute to coping with the experience of HIV infection?

DEFINITION OF TERMS

Caring consists of "actions to assist, support, or facilitate another individual or group with evident or anticipated needs to ameliorate or improve a human condition or lifeway" (Leininger, 1985a, p. 209).

Persons who are HIV-positive are persons who have tested seropositive for antibodies to HIV according to diagnostic laboratory tests. They may or may not be diagnosed with AIDS.

Support network is a web of social contacts who contribute to the individual's psychological integrity by expressing caring behaviors. A network may include a spouse or other partner(s), friends, family, colleagues, professional caregivers, and other caregivers such as members of a church or community agency.

Needs for support or caring are physical, emotional, social, or spiritual yearnings identified by the individual which he or she perceives could be alleviated through the expression of caring behaviors by another person or persons.

Spirituality is an individual's experience of or search for meaning, relatedness, integration, and transcendence.

Confirming messages are verbal or nonverbal communications which enhance the recipient's sense of self-worth, interpersonal connectedness, and well-being.

Disconfirming messages are verbal or nonverbal messages which communicate rejection, distancing, stigma, or lack of personal worth.

ASSUMPTIONS

1. Caring is a process common to all humans, but the expressions, patterns, and meanings of caring vary from culture to culture.
2. Caring behaviors valued by the recipient are influenced by the individual's cultural background, personality and developmental characteristics, and the situation provoking needs for care.
3. HIV-seropositive individuals encounter similar stressors and obstacles in interacting with society which produce support needs unique to this illness.
4. For behaviors to effectively communicate caring, they must be perceived as caring by the recipient.
5. Research can be conducted as a process of "caring attention" which enhances relationships and clarifies and confirms personal worth (Bateson, 1991).
6. "The research strategy you choose shapes the world of the people you do research on" (Bateson, 1991). My assumption and my hope is that this qualitative research approach will help shape the world to be a

less stigmatizing and less alienating place for persons with HIV infection, through a more sensitive understanding of their experiences.

LIMITATIONS

This study has been conducted with a small sample of fourteen men and women within a southern Appalachian community. The fourteen individuals cannot be presumed representative of typical HIV-positive persons within this region, and particularly may not be representative of those who are not affiliated with a community support agency in any way. Likewise the experience of persons within this community may not be generalizable to persons in other geographic regions and cultural settings. Universal issues among persons living with HIV, however, may be reflected in the experiences reported by study participants.

SUMMARY

Treatment for persons with HIV disease has been complicated by public perception of the illness not simply as a disease process, but as part of a matrix of stigma, unreasonable fear of contagion, and prejudice against persons in traditionally "high risk" groups such as male homosexuals or intravenous drug users.

Even among health care providers, whose ethics uphold equal provision of care, prejudice and lack of understanding have compromised the offering of care.

Research is needed to describe the experiences of men and women with HIV infection, their reactions to their illness and to their care providers. Data derived from such study can lead to the development of more effective interventions for helping HIV-positive individuals cope with changes in their lives. This information is expected to be useful for community organizers, health care providers, and health educators. In cities such as Knoxville, where awareness of the reality of AIDS is still in its early stages, information about the experiences of persons who are HIV-positive can allay misperceptions and increase the human understanding which leads to compassionate care.

CHAPTER TWO

REVIEW OF THE LITERATURE

This chapter provides an overview of concepts which are central to the study. The first section of the chapter introduces a philosophical framework for considering individuals within their complex social surroundings. The second section compares theoretical definitions of social support. Part three establishes the importance of social support to maintenance of health and well-being. The final section describes research specific to HIV disease, with special attention to concepts of stigma, psychosocial well-being, and spirituality.

CONCEPTUAL CONTEXT OF THE STUDY

Two fundamental concepts structure the inquiry of this nursing study. The first is holism; the second, culture. The nursing profession in recent years has embraced the concept of holism as a way of affirming what nurses intuitively practiced all along. Where physicians traditionally focused on healing of the

physical self, nurses, in part because of their close contact with patients and families, have learned to see whole people with complex needs for care.

Within a holistic perspective, physical curing is not the bottom line. Patients are instead encouraged to develop an optimal wellness by enjoying the most fulfilling life possible within their limitations. Healing is viewed as an integrative process that involves psychological well-being, social interrelatedness, maintenance of physical health, and a sense of life's spiritual meaning (Carson, 1989). Holistic caring offered by the nurse encompasses myriad aspects of the whole person, and involves processes that, unlike medications, are difficult to quantify.

Comaroff (1978) writes that the "holistic focus of anthropology" (p. 249) functions to clarify different levels of cultural information. In this sense, an anthropologist's approach to culture parallels the holistic nursing approach to the individual. Within the context of culture, therapeutic actions can be identified as a relationship of both symbolic and utilitarian functions. Ideas concerning health, including the prevailing Western paradigm of

rationality and scientific results, fit into a philosophical and moral matrix inseparable from a particular culture. The field of anthropology has traditionally incorporated concepts and research methods which emphasize holistic relationships. The field of nursing has more recently discovered the value of a holistic approach to research in exploring patients' experiences.

The concept of culture becomes a bridge connecting our holistic view of the individual with an understanding of that person's social roles. Cultural values shape the meanings communicated by various actions within the social network. These shared values define the relevance of information, attach meaning to ritual activity, weigh the interrelationship between physical and spiritual well-being, and indicate methods for managing the tensions of uncertainty. Caring actions carry meanings which are generally cohesive with cultural definitions and values. The caregiver's actions are more likely to be beneficial if they reflect an awareness of the recipient's culturally influenced beliefs and values (Leininger, 1985b).

Cultural systems shift and change. Culturally

defined meanings shift over time, and vary within diverse social settings such as family or work, public or private places, or among different groups of friends. Urbanization and mobility have reduced reliance on extended families for support, have lessened the availability of a circle of long-term friends, and have, in general, "atomized" the individual (Pilisuk & Froland, 1978). In order to fulfill human needs for support and affiliation in a time of change, individuals must try their skills at adaptation. A person's level of skill and creativity in adapting to gather sources of support has profound effects on health and, indeed, survival.

CONCEPTS OF SOCIAL SUPPORT

This section of the chapter introduces the concept of social support as an exchange of information and as a flow of aid occurring in the context of human relationships. Social support is considered with regard to reciprocity issues and developmental theory. Finally, a model of types of support represented within research literature is reviewed, with attention given to the benefits of qualitative research methods.

Definitions of Social Support

Sidney Cobb (1976) emphasizes the moderating effect of social support as it "facilitates coping with crisis and adaptation to change" (p. 302). His definition of social support highlights its character as a transmission of information. This information, according to Cobb, takes three major forms depending on the meaning perceived by the recipient. Especially in intimate relationships, support may carry the meaning, "You are loved and cared for." In more public situations, support may extend the message, "You are valued, and worthy of my respect." A third form of support involves the message, "You belong" as a member of a network of mutual obligation and sharing of necessary knowledge. The concept of social support as a process of communicating messages is fundamental to the theoretical framework of the present study.

Cobb (1976) is careful to exclude from his definition of social support the offering of material goods and services. According to his definition, social support is an exchange of information which facilitates independent functioning, unlike material support, which tends to encourage dependency. Despite

Cobb's characterization, however, most people do perceive needed material aid as supportive, and aid is a commonly used form of symbolic communication.

House (1981) defines social support as composed of four different types of aid. 1) **Emotional support**, which is generally perceived to be the most important aspect, is the extension of trust, empathy, concern, and love. A second form of support involves 2) **instrumental behaviors**, such as the offering of money or practical services to assist the individual. 3) **Informational support** gives persons knowledge, or awareness of resources, which they can use to cope more effectively with problems. 4) **Appraisal support** involves information leading to a social comparison, as when another person relates their experience of a similar situation. House's system of classification lacks depth because it focuses on behaviors without considering meanings communicated to the recipient.

House (1981), a sociologist, calls attention to the nature of social support as a flow between persons: "Giving or receiving social support usually involves expectations of reciprocity. Thus flows of social support occur primarily in the context of relatively

stable social relationships" (p. 29).

Attempts to improve the quality of social support, according to House (1981), should involve an understanding of individual personality factors, characteristics of relationships, and social or cultural conditions which foster or impede the exchange of support. Oftentimes professionals cannot control the presence or absence of support persons, but can influence existing relationships to be more effectively supportive. Research into interpersonal issues surrounding support is necessary to guide professional attempts to improve supportive relationships.

Issues of Relationship and Development

Tilden and Galyen (1987) argue that social support is not a panacea: "social interactions are neither free, nor always benevolent" (p. 9). If social relationships are viewed as reciprocal, the costs of their maintenance must be considered. Many times persons who serve as sources of support also act as sources of conflict, worry, or inequity. Potential negative consequences of social support identified by Tilden and Galyen include loss of privacy, reduction of independence, and obligation of reciprocity.

Observations of social support must not overlook the possibility of these unwelcome effects.

Ellison (1987) uses developmental models to describe changing needs for support over the human lifespan. She asserts that humans evolve through stages which emphasize needs for social inclusion, stability, and closely connected relationships versus needs for independence, change, and loose-knit social networks. Negative aspects of support, according to Ellison, may derive from the provision of support in a developmentally inappropriate style. A common example of this problem is overprotection of a person who would prefer to maintain independence.

Integration of Social Support Constructs

Social support is a broad concept, difficult to operationalize. Barrera (1986) has attempted to clarify notions of support by drawing distinctions between three components commonly represented in research literature. 1) **Social embeddedness** is that concept of social support which contrasts with alienation and isolation. 2) **Perceived social support** focuses on individuals' perceptions of their degree of support from others in terms of availability and

adequacy. A last conceptualization of support describes 3) **enacted supportive behaviors**, forms of support actually received, usually recorded by the recipient retrospectively.

Each of the three constructs of social support, when applied, tends to neglect important areas of consideration. Measurement of social embeddedness involves the quantification of social ties, but has not allowed insight into the usefulness of specific relationships. Reports of perceived social support may be influenced by other variables such as psychological distress. Information about enacted support generally lacks usefulness because it fails to explain the meaning of behaviors to the care recipient. Each of these problem areas may be compounded by the narrowness of focus common to many quantitative research methods.

Barrera (1986) suggests that researchers choose between various social support concepts those that relate most closely to their research questions. Thus he advocates narrowing a study's inquiry to one component of social support. A preferable research approach is to consider social support globally and holistically, incorporating Barrera's three aspects of

social support as well as the natural array of associated factors. This approach resolves the problems outlined in the previous paragraph. Qualitative exploration of support is likely to discern the relative importance of different care providers, uncover confounding variables such as degree of well-being, and describe the perceived meanings of supportive actions.

Social support has been described as a communication exchange which occurs within the context of human relationships. Research involving social support has emphasized the identification of support persons, the perceived availability of support, and behaviors demonstrating support. Qualitative research methods, because of their broad scope and in-depth nature, are likely to reveal issues surrounding supportive actions, such as reciprocity, psychosocial development, relationship conflicts, and culturally defined meanings.

RELATIONSHIP OF SUPPORT TO HEALTH AND WELL-BEING

This section reviews literature establishing the importance of stress as a contributor to illness, and the role of social support in buffering harmful effects

of stress. A model developed by Norbeck relates the concepts of stress, social support, and health outcomes. Barrera's models describe multidirectional relationships between social support and stress or distress.

Relationship of Stress to Illness

Epidemiologist John Cassel (1976) outlines the familiar model of host, environment, and agent linked in the process of disease causation. Many disease-causing agents are ubiquitously present in the environment. The resistance of the host therefore becomes the major determinant of illness. Physiologic stress, exhibited through complex neurologic and endocrinologic processes, appears to predispose the body to illness, although it is not directly etiologic. A variety of disease outcomes is produced in response to harmful levels of stress.

Effects of Social Support on Stress and Health

Perception of stress is dependent on the meaning of events to the individual experiencing them. Thus one can reasonably assert that coping skills or supportive relationships may buffer the physiologic effects of stress. Cassel (1976) offers a

comprehensive review of research literature to support this assertion, and Cobb (1976) likewise reports the moderating effects of social support on stress, as found in studies across the life span.

Social support has been seen to moderate stress; social support may also lessen the effects of illness. Cobb (1976) enthusiastically affirms the importance of social support as protection and aid to recovery from an array of physical and psychological illnesses. Research has suggested that social support, along with stress reduction and positive cognitions, can lead to better therapeutic outcomes in AIDS, including higher T cell counts (Lovejoy & Sisson, 1989). The latter researchers incorporate fascinating new findings related to communication between the neurological and immune systems, as part of a budding holistic field called psychoneuroimmunology.

House (1981) proposes three strategies for preventing deleterious health outcomes which result from stress. The first level of intervention directly **reduces** the level of stress adversely affecting health. For example, persons might remove themselves from stressful situations or plan adequate time to complete

activities. A second strategy **compensates** for adverse effects by providing positive balance to support health and well-being. Positive input includes healthful lifestyle practices such as exercising to relieve physical tension or eating an appropriate diet. House's third method **buffers** the impact of stress on health, by providing cheerful respite or contributing to a less malevolent interpretation of events.

Interestingly, House's (1981) latter two strategies do not reduce the exposure of the organism to stress, but do reduce the negative effects of that stress. House states that social support acts primarily as a buffer factor, though it may also contribute to stress reduction and compensation through positive health habits.

Model of Social Support, Stress, and Health

Norbeck (1988) reviews contributions of nurses to the study of social support through instrument development and fifty-three descriptive and intervention studies. She provides an admittedly oversimplified conceptual model (Figure 2) which describes the relationships between social support, stress, and health outcomes.

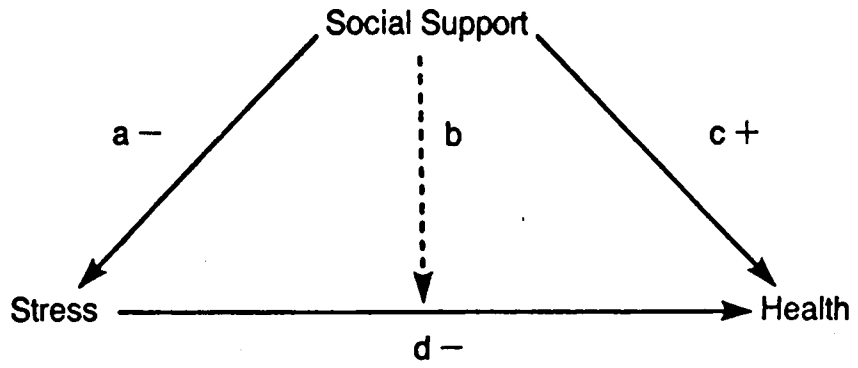


Figure 2. Norbeck's Model of Social Support

In Norbeck's (1988) model, stress tends to predispose the organism to poor health outcomes (arrow a). Social support, as previously described, ameliorates the effects of stress on health (arrow b). Support also directly affects both stress and health (arrows c and d). Norbeck states that relationships between variables may be bidirectional, and may involve other influencing factors.

Models of Social Support and Stress

Barrera (1986) complicates our picture of social support by detailing its diverse roles in relationship to stress and distress. He offers research data to support each linkage. Barrera's first model (Figure 3) hypothesizes a positive correlation between social support and stress. In this instance, the individual's support system is mobilized in response to adversity.



Figure 3. Stress activates the support network.

The second model (Figure 4) describes a negative relationship between stress and social support. This may occur by two mechanisms: 1) Either social support prevents the occurrence or perception of stressful events, or 2) stress deteriorates the social network (Barrera, 1986).

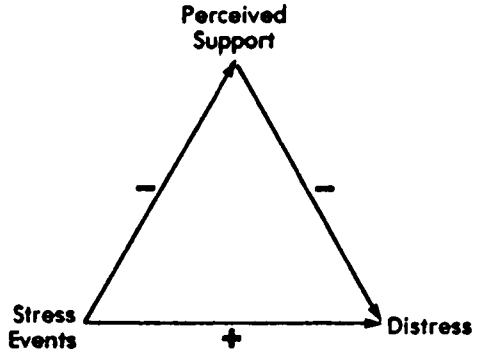


Figure 4. 1) Support lessens perceived stress.
2) Stress lessens available support.

Findings supporting Barrera's (1986) third model (Figure 5), in which increased social support is associated with distress, may reflect help-seeking behavior in the presence of illness.

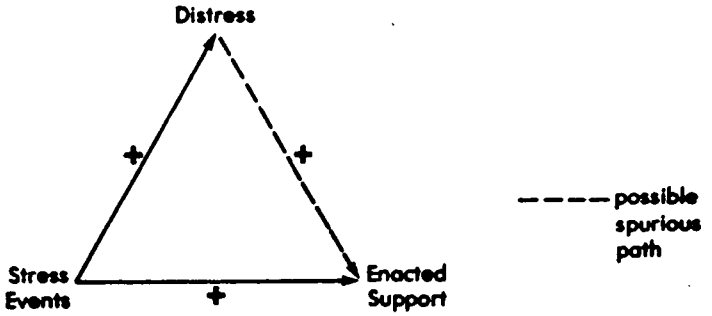


Figure 5. Help-seeking behavior may increase support.

The fourth model (Figure 6), which asserts the inverse relationship of social support and distress, is well supported by research literature (Barrera, 1986). These findings reflect the common view that support buffers distress. An alternate direction of causality should be considered, however: Distress may directly erode support, or factors predisposing persons to distress (such as poor social skills or psychiatric illness) may also hinder the ability to obtain support.

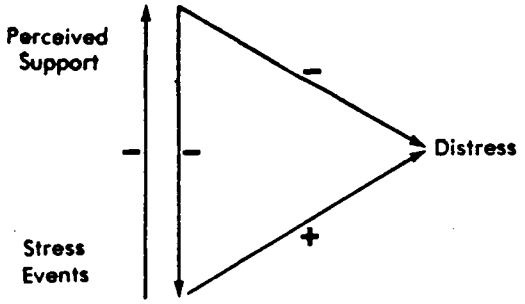


Figure 6. 1) Support buffers distress.
2) Distress erodes support.

The models presented here, and an abundance of research literature, confirm the linkages of social support, stress, and health. Nevertheless, social support is too complex an issue to be easily reducible to a few dots and arrows in a diagram. Social support interacts with myriad variables in a holistic and multifaceted way. Above all, the effects of social support depend on its communicated meanings to persons receiving care.

SOCIAL SUPPORT AND HIV-POSITIVE INDIVIDUALS

Looking beyond issues of disease and curing, a holistic perspective cultivates connections between body, mind, and spirit. Instead of putting all our eggs in the "physical outcomes" basket, a holistic approach allows us to consider the meaning of a human life and of a person's journey over time as a social, cognitive, and spiritual being. Instead of focusing on losses, framed in terms of T cell counts or degrees of fever, we can address our attention to the incredible accomplishments of individuals in embodying the beliefs they value, integrating their lives in the presence of great concerns, and finding a sense of community, growth, and transcendence.

This section of the review of literature considers issues and research important to the experiences of HIV-positive individuals. Empowerment, stigma theory, psychosocial changes, and spirituality contribute to a picture of possibilities for growth and integration.

Empowerment

Empowerment, argues nurse educator Denise Ribble (1989), is a key role for nurses working with those affected by HIV. Support by other persons with HIV infection may also foster empowerment, defined as the decision to control and direct one's own choices. Long-term AIDS survivor Michael Callen (1990), in a series of interviews with other long-term survivors, disputes the concept of inevitable death, and advocates for empowered decision-making regarding treatment options. In light of different personal approaches to illness, Callen exhorts: "AIDS can either be viewed as a sign to begin dying or as a challenge to begin living" (p. 191).

Adelman (1989), in a review of literature, reports that persons faced with traumatic events attempt to understand the meaning of the crisis, reestablish a sense of order and control, and bolster their self-

esteem. Social support is a key resource during these processes. Validation, active listening, emotional support, and self comparison with other persons with AIDS have been identified as useful forms of help. Adelman remarks that the perception of support by the person with AIDS is more important than the way support is given. This statement justifies further attention to the meanings supportive actions communicate.

Cline's (1989) review of the literature reaffirms the importance of social support to positive health outcomes, but cautions against disconfirming communications. Stigma and fear of terminally ill persons may lead to disconfirmation through distancing and avoidance. In particular, persons with AIDS may feel pressured to deny their concerns, and to express constant optimism. Bereaved care providers of those with AIDS may also receive disconfirming messages due to their association with multiple stigmas, including societal fears of illness and death.

Confirming communications convey an acceptance of a person's identity and individuality (Cline, 1989). Positive social support communicates messages which negate impressions derived from a stigmatizing

environment. Confirming communications empower because they promote a sense of the self as unique, valuable, and worthy of well-being. Clearly social support assists the process of adjusting to serious and stigmatizing illness, but the specific caring messages perceived to be supportive have not been identified.

Stigma

Erving Goffman's (1963) classic work on stigma relates the concept to the ability of an individual to interact socially with others. Stigma implies that a person has been categorized as different, as bearing a tainted identity. Stigmatized persons tend to incorporate such attitudes, and to reflect discredit in an internalized self-blame. Goffman described changes in social role that result from the experience of stigma, including social alienation and lowered self-esteem. He also noted that stigmatization is socially contagious, so that family or care providers of discredited individuals also suffer the results of fear and stigma.

Herek and Glunt (1988) discuss four sources of stigma important in the context of AIDS. The first is the stigma of disease, particularly when the illness is

transmissible and scientifically not well understood. Second is the association of AIDS with death, which confronts members of society with the reality, usually avoided, that all human life is terminal. The stigma of AIDS also interacts with already existing stigmas against homosexuality, intravenous drug use, multiple sexual partners, and Black and Hispanic cultural origins. Hemophiliacs and children with AIDS are frequently labeled "innocent victims," a phrase that cannot fail to imply that someone else is guilty.

Herek and Glunt (1988) explain that the anxiety associated with AIDS has fostered a "hypervigilant" style of decision-making (p. 888) in the arena of AIDS-related issues and policies. Early recommendations by media and political figures for quarantine, tattooing, and mandatory HIV testing of those in stigmatized "high risk" groups increased the distinction between "us" and "them," and failed to recognize long-term effects of such attitudes on civil liberties and general public health education.

Hypervigilance has often resulted from misreading by the lay public of scientific statements (Herek and Glunt, 1988). Such statements probabilistically report

"extremely unlikely" means of transmission, rather than "impossible" means. Lay persons unfamiliar with such phrasing may conclude that cautious avoidance of HIV-positive individuals in school or work settings can reduce personal risk. Because of differences in assumptions and language used by the scientific and lay communities, lack of knowledge may occur even among persons who have attempted to become informed of safe practices regarding HIV. Hypervigilance is a form of misunderstanding which promotes distancing and isolation, and exacerbates the experience of stigma.

Bennett (1990) conducted an interesting qualitative study of the perceptions of ten homosexual men with AIDS. The participants were white, relatively well-educated, and lived in the New Orleans area. Bennett's subjects reported themes of rejection and protection in response to their experience of stigma. Themes which conveyed rejection were coolness or avoidance (at times subtly expressed), an obvious staring or "eek!" reaction (p. 147), and an internal fear of being cut off, ostracized, or quarantined.

People with AIDS also developed sources of protection against stigma (Bennett, 1990). Significant

protective roles were played by lovers, friends, and families who offered unconditional acceptance, affection, visits and letters, material support, and help in gathering information about alternative treatments.

Psychological protective mechanisms identified by Bennett (1990) included anger at the negative reactions of others, angry refusal to be labeled a victim, social shyness as a way of avoiding rejection, concealment of outward signs of sickness, and gambling to beat mortality odds. The men in the study compared themselves with other people with AIDS, and generally expressed a sense of good fortune, of feeling lucky and relatively healthy.

Bennett's (1990) qualitative study yields much fruitful understanding of the experiences of people with AIDS, and calls for more inquiry into the protective roles of coping skills and social support. The study suffers from its narrow demographic focus on white, well-educated, urban gay males. Inclusion of women in the study would have provided much needed information about their experiences.

Psychosocial Concerns

Several studies have addressed psychosocial concerns of persons with HIV infection in response to pervasive stigma and life-threatening illness. In two quantitative studies, measures were used to explore alienation, self-esteem, mood states, and social support. A qualitative study examined the experiences of people with AIDS through in-depth interviews. Finally, a review of literature demonstrates the relevance of developmental theory to psychosocial tasks of young adults with AIDS.

Korniewicz, O'Brien, and Larson (1990) studied self-concept, self-esteem, alienation, and social functioning. Sixty-three Baltimore-area subjects participated in the study; three-fourths were male and two-thirds were white. The subjects were categorized into four groups based on stages of the disease process. Subjects who were HIV-positive and asymptomatic scored significantly higher on scales measuring alienation and powerlessness than those in later stages of illness. This finding suggests that persons find ways of coping with the illness before reaching later stages. In addition, females and blacks

were more likely to experience alienation. These differences may be due to a greater lack of social supports and acceptance for those outside the homosexual male community. No significant differences were found between the four disease stage groups in self-concept, self-esteem, or social functioning. These findings suggest a need for further exploration of coping and adjustment throughout the course of the illness. Clarification of the differences in support reported by females and blacks is also needed. The study was limited by sample size, which was not large enough to permit the use of powerful statistics, or to exclude the effects of differences in educational backgrounds or other extraneous variables. Over a third of the overall sample was composed of a group of "at-risk" individuals not known to be HIV-positive.

Donlou, Wolcott, Gottlieb, and Landsverk (1985) used a battery of quantitative psychological instruments to study self-esteem, mood state, and social support in a group of 21 gay and bisexual men with AIDS or AIDS-related complex (ARC). All but one of the subjects were Caucasian. The researchers noted a positive association between self-esteem and a lover

or spouse as a major source of support. Thus intimate relationships seem to be an important factor in psychological health. Persons who relied primarily on professional care providers had lower self-esteem scores, possibly meaning that these individuals had no other support available. Persons with AIDS were most likely to ask for help from a close friend, although doctors, professional counselors, mothers and other family members also ranked highly. This study indicates a need for more complete understanding of the links between social support and well-being, and particularly to describe the relationship of physical and psychological distress. The sample was not statistically large enough to allow accurate testing of hypotheses regarding physical illness and mood states.

Weiss (1988) conducted a series of in-depth interviews with three Boston-area men with AIDS, two gay males and one former intravenous drug user. Weiss reports that persons with AIDS are likely to experience an upsurge in attachment emotions, and a greater need for reassurance of acceptance from family and friends. The men in the study described a great sense of loss when unable to continue their employment, which had

provided a source of identity and feelings of self-worth. The men reported forming new friendships more slowly as a result of diminished energy, changing priorities, and fears regarding disclosure. The person with AIDS may find himself in a dependent and non-reciprocal relationship to parents and friends; this may cause strains regarding boundaries and autonomy that are reminiscent of adolescence. Weiss noted that attitudes of hopefulness and of facing AIDS as a challenge tended to lead to a higher quality of life. This study shows the wealth of information which can be obtained using qualitative methods.

Borden (1989) reviewed developmental tasks of early adulthood and suggested that the young person with AIDS is in the paradoxical position of developing a sense of self-identity and purpose, while reflecting on the self in preparation for dying. For many individuals this process entails the relinquishing of cherished goals and plans. Unfortunately the paper fails to describe the developmental conflicts of middle-aged and older persons confronted with HIV disease.

Spirituality

One of the most important psychosocial needs suggested for the AIDS patient is the need to find meaning in living and dying (Belcher, Dettmore, & Holzemer, 1989; Fortunato, 1987; Kubler-Ross, 1987). The diagnosis of AIDS often leads to spiritual crisis, feelings of loss of control, and a loss of confidence in the self (Weiss, 1988). Three studies of hope, spiritual well-being, and social support will be presented, following a literature review on issues regarding death.

Mayer's (1989) review of literature suggests that coping with suffering and fear of death is easier when a sense of meaning and connectedness with others is present. Spirituality may provide a sense of hopefulness, unity with others, and transcendence. The spiritual dimension also tends to integrate life experiences, psychosocial concerns, and physical existence. Human fears of death, which include fears of the unknown, of suffering and pain, and of life left unlived, occur at a deep level within the psyche, leading to subconscious avoidance behaviors. Mayer advocates a new paradigm of death, which emphasizes

self-awareness and awareness of the oneness all humans have with each other.

A group of researchers (Carson, Soeken, Shanty, & Terry, 1990) studied hope and spiritual well-being in a group of 65 HIV-positive males associated with a major medical research center. The participants were primarily homosexual or bisexual; seven were intravenous drug users. Overall, the subjects appeared to be hopeful and optimistic, based on responses to the Beck Hopelessness Scale. Men diagnosed with AIDS were significantly more hopeful than those diagnosed with ARC, again suggesting resolution of distress as the disease progresses.

The study found hope to be closely linked with spiritual well-being (Carson, Soeken, Shanty, & Terry, 1990). The aspect of spiritual well-being which involves life satisfaction and purpose in life seemed more important to the expression of hope than was religious well-being, which is based on one's relationship to God. Particularly because of the reluctance of churches to embrace stigmatized groups, the successful spiritual adjustment of these individuals is remarkable. These findings suggest an

integration of life's meaning and direction during the disease process. The findings also lend credence to the holistic notion that wellness as personal integrity can be realized even when physical health is poor. Nevertheless, the data gathered through two quantitative scales are sketchy and superficial. The study unfortunately does little to increase our understanding of the ways one's values and outlook on life affect coping with catastrophic illness.

Rabkin, Williams, Neugebauer, Remien, and Goetz (1990) studied hope, social support, and symptoms of depression and physical illness in a sample of 124 HIV-positive and 84 HIV-negative homosexual men. The researchers found a generally high level of hope using the Beck Hopelessness Scale. Hope was found to be associated with higher levels of social support and lower levels of depressive symptoms. Hope was not related to the number of symptoms of HIV-related illness. This study, like the previous study, enlists participants who are male and predominately white, homosexual, and well-educated. Although the research addresses the importance of social support to hope, no information is derived regarding the benefit of

specific supportive messages.

Belcher, Dettmore, and Holzemer (1989) conducted 35 interviews with people with AIDS, along with a review of literature, to focus on issues of spirituality and social support. The presence of social support, the researchers determined, may cause spirituality to flourish or decline, depending upon the nature of the relationships. Persons with AIDS tended to define their spirituality in terms of a sense of connectedness with others, and of a sense of transcendence, peace, and protection. Respondents reported differing attitudes toward religion and specific belief systems, with some considering these important and others feeling they were contrary to spirituality. Spiritual activities identified by the participants ranged from traditional church-going to meditation, prayer, visualization, involvement in the arts, and service to others. All the respondents perceived a change in their spiritual perspective since the time of diagnosis, often referring to an increased intensity of experience. The researchers provide scant information about their participants and methodology.

Care Providers

Persons with HIV disease are met with a variety of challenges to social and spiritual growth. The role of support persons in assisting with these tasks is well documented, but not completely understood. Lack of support of psychosocial and spiritual needs results in great costs, both in diminished quality of life and in greater dependence on overloaded health care and institutional systems. Although exploring the experiences of care providers is beyond the scope of the present study, sensitivity to issues caregivers face helps us understand their relationships with HIV-positive individuals. Two articles reviewed here describe stresses encountered by caregivers.

Providers of social support may suffer from similar perceptions of stigma, isolation, and unspeakable bereavement as persons with AIDS. Pearlin, Semple, and Turner (1988) interviewed San Francisco area caregivers of AIDS patients about their sources of stress. The participants in this study were members of the homosexual male community, and were friends and lovers of the persons receiving care. Their stress primarily derived from three sources: physical demands

of caregiving, identification with the patient as a mirror of personal vulnerability, and role conflict between caregiving and other responsibilities. Coping skills and social support networks, both formal and informal, were noted as resources which ameliorate caregivers' stresses.

Flaskerud (1988) described stresses experienced by nurses caring for people with AIDS. Discomfort or lack of experience in relating to intravenous drug users, homosexuals, and members of minority ethnic groups is a frequent problem. In addition, many health care providers confront their own fears of death when young patients are critically ill. Finally, the intense physical and emotional needs of the patient, combined with the traditional medical goal of achieving "cure," tax the emotional reserves of the nurse.

SUMMARY

Social support occurs as a process of communication between human beings. It occurs within a cultural context which lends meaning to behaviors and verbal messages. The perceived meaning of care and need for care by the recipient determine the efficacy of supportive gestures.

The most important function of social support in the context of HIV-related disease is empowerment of the individual. The person is a holistic network of physical, emotional, intellectual, and spiritual dimensions, all of which are valuable. New challenges and developmental tasks result from the complex experience of HIV infection. Successful negotiation of these waters tends to facilitate physical well-being. Resolution of spiritual and psychosocial dilemmas can be considered great victories, even if physical health declines. The role of nurses and other care providers is to support each person's unique evolution.

Many advances have been made in the understanding of social support and its impact on well-being. Our image of the experiences of women, Blacks, and people living outside major metropolitan areas who are affected by HIV remains inadequate due to lack of research. The behaviors of support persons have been superficially described, but little is known about the perceived meanings of care to its recipients. The conflicts that HIV-positive men and women experience in their relationships with others are also relatively new ground for discovery. The purpose of the present study

is to contribute to knowledge about these areas of concern.

CHAPTER THREE

METHODOLOGY

In chapter three I explain the methodology used in this descriptive, qualitative study. The first chapter sections describe the participants of the study and the measures used to protect their identities. The interviewing and data collection procedures are then explained. Finally, an overview is given of the process of data analysis.

DESCRIPTION OF PARTICIPANTS

Fourteen men and women agreed to take part in this study. The volunteers were affiliated with a.i.d.s. Response Knoxville, a community support agency, as members of support groups or participants in other services. All the individuals lived within the general Knoxville area and all were diagnosed as HIV-positive, at varying levels of disease progression.

Potential participants were identified by Dr. Charles Rees, director of a.i.d.s. Response Knoxville, and approached by him to be in the study. No one who

was contacted declined to participate. An effort was made to choose persons who would represent a broad variety of experiences and social backgrounds.

PROTECTION OF PARTICIPANTS' PRIVACY

Potential volunteers were first contacted by Dr. Charles Rees, who explained the purpose of the study and asked them for their participation. After individuals agreed to participate, an interview time and place were arranged. Volunteers were not required to give their names, phone numbers, or other identifying information to the researcher.

Dr. Rees gave participants consent forms and information sheets explaining the purpose of the study and methods for assuring their anonymity (Appendix A). A second copy of the written consent form was signed, sealed in a brown envelope, and stored in a locked cabinet by Dr. Rees. During the interviews a verbal consent form was read and participants voiced their understanding and agreement to take part in the study (Appendix A). In this way the researcher had no record of participants' names. Pseudonyms were used to identify all audiotapes and other data.

Interviews were audiotaped to provide a verbatim

record of the interviews, preserving much of the flavor conveyed by pauses, inflection, and emotional tone. Tapes were transcribed by Susan McCallister personally, and stored in a locked filing cabinet. The tapes will be securely stored for seven years to provide a record of the accuracy of the data. Participants were given the option to have their tapes erased immediately after transcription. Two women chose this option.

Access to taped and transcribed data was limited to the researcher and advisory committee members. Transcripts were altered to obscure identifying information, and names of people mentioned in the interview were replaced with pseudonyms. Participants were given a phone number and address to contact the researcher if they have further questions or concerns.

INSTRUMENTS

Participants were requested to a) complete a written demographic questionnaire, and b) respond to open-ended questions on their reaction and the reactions of their care providers to their illness (Appendix B). Each interview was audiotaped and generally lasted thirty to forty-five minutes. Brief field notes were kept which recorded nonverbal cues,

seating arrangements, and contextual information.

Members of Dr. Kathleen deMarrais' Qualitative Research Support Group read both the demographic questionnaire and the interview protocol during preparation for data collection. The tools were revised for sense and clarity. The first two interviews were considered pilot interviews, but no revisions in the protocol were made at that point.

Mishler's (1986) critique of standard interviewing practices served as a guide to an alternative approach based on "jointly constructed discourse" (p. ix). Mishler identifies four propositions of his methodology: "(1) interviews are speech events; (2) the discourse of interviews is constructed jointly by interviewers and respondents; (3) analysis and interpretation are based on a theory of discourse and meaning; (4) the meanings of questions and answers are contextually grounded" (p. ix). Interviews were conducted in a relaxed and conversational style, and an effort was made to construct questions in a wording and context that would be meaningful to individual participants.

The interviewing process was founded on Bateson's

(1991) concept of qualitative research as "caring attention," as a process of mutuality and exchange. I hoped that the participants would benefit from, and be empowered by, the process of reflecting on and clarifying the meaning of their experiences.

PROCEDURE

After agreeing to take part in the study, volunteers arranged a time and interview location agreeable to them. Most of the interviews were conducted in the participants' homes; three interviews took place at the a.i.d.s. Response Knoxville offices.

At the start of each meeting, I explained the purpose of the study, reviewed the information sheet, and answered any questions a participant might have. The demographic form was then completed, and the participants were asked to choose a pseudonym to identify their data. The tape recorder was turned on and the verbal consent form was read. Participants voiced their willingness to volunteer for the study. The interview began, and concluded with the participants' agreement that they did not wish to add more. The tape recorder was then turned off. After each interview a period of time was given to express

feelings or reactions as needed.

DATA ANALYSIS

Data were analyzed following the methods of inductive content analysis (deMarrais, class notes, 1990; Goetz & LeCompte, 1984; Mishler, 1986; Spradley, 1979). The inductive method, in its simplest sense, begins with a mental immersion of the researcher in the data, which process allows themes and patterns to suggest themselves out of the observation of particular instances. The final step is a return to the data for confirmation of identified themes.

My data analysis started during the data collection phase, as I reflected on themes that seemed to be mentioned by several people, or by one person in a way that linked the efforts of care providers. I kept a list of these themes I observed in order to make my thinking explicit to myself.

The working list of themes and my knowledge of research and theoretical literature continued to shape my interest in the subject. As the research moved closer to data analysis, I began to feel that my research questions were not specific enough. In addition, I had initially focused much more heavily on

behaviors, as does Madeleine Leininger, rather than communicated meanings, which I believe to be of greater interest and potential usefulness. In the manner of Harry Wolcott (1990), I refined my research questions to clearly target topics of greatest interest.

Within the context of asking specific questions of the data, I sorted and shuffled quotes and examples on pieces of paper until patterns emerged. This was a process of identifying several general themes which can describe the common threads of specific experiences.

Spradley's (1979) highly methodical analysis examines semantic relationships and constructs taxonomies. His approach is stifling in its attention to detail, but is interesting in its use of analysis at varying levels of meaning. My approach parallels Spradley's methods in that I looked at a variety of levels of meaning: caring behaviors, then general themes expressed by those behaviors, and later, values important to care recipients.

In preparation for writing up my findings, I collected specific examples which typify the themes I discovered. This return to the data allowed for confirmation of patterns I intuitively felt were

present. For the reader, descriptions of specific events clarify the meanings of themes, and provide a context for understanding.

This chapter has explained the methods I undertook to develop the study. In the next chapter I will describe what I discovered from the participants' reports of their experiences.

CHAPTER FOUR

FINDINGS

The purpose of the present study is to learn more about the ways HIV-positive individuals relate with the people in their support networks. In this chapter I will thematize the expressions of caring conveyed to the study participants, noting patterns of communication which support (confirm) or interfere with (disconfirm) the individual's sense of self-worth and well-being. Needs for support, as identified by the participants, will be catalogued. Finally, I will consider values and spiritual strengths reported as helpful in coping with the experience of HIV infection. Findings of the study will be presented following a description of the study participants as a group.

DESCRIPTION OF PARTICIPANTS

In this chapter section I describe the participants in terms of demographic variables, and then give an overview of their responses to their illnesses. Although much of the data given here is

based on the group as a whole, readers should keep in mind the importance of each participant's unique and individual perspective. Pseudonyms are used when referring to participants and their support persons.

Demographic Information

Participants in this study were affiliated with a.i.d.s. Response Knoxville, a community support organization which serves approximately one hundred clients. The group of study volunteers does not precisely represent the demographic prevalence of HIV infection in the Knoxville community or among clients of the organization. Nevertheless, the participants do reflect the diversity of age, gender, and social backgrounds among people with HIV.

Gender, age, and race

The group of study volunteers was composed of nine men and five women. Twelve participants were white; two were black women. The participants ranged in age from 23 to 46, with 34 being both the average and median age.

Length of time in Knoxville

The average length of time participants had lived in Knoxville was 8.4 years, with a range from 2 months

to 42 years. About a third (5/14) of the participants moved to Knoxville after the onset of their illness. Several were moving home after travels elsewhere; others moved from smaller East Tennessee towns to Knoxville because of special services and medical care available here. Four of the participants had grown up in the Knoxville area. All but one person were native southerners. Half of the participants were employed and established in supportive networks within the Knoxville community before the onset of their illness.

Educational backgrounds

Participants ranged in their educational background from eight years of schooling to graduate degrees. The most frequently reported (5 of the 14 participants) category was vocational training or one to three years of college. Two participants had earned baccalaureate degrees, and three had received graduate level education.

Occupational backgrounds

Participants had worked in occupations ranging from food preparation to hair styling and from acting to child care. Five of the fourteen had worked in health care fields, two as providers in fields which

require graduate level preparation. Two participants were college students. Only three interviewees were presently employed outside the home, although two others were considering a return to work or school. Two women mentioned the needs of their HIV-positive children for care as a deterrent to returning to work.

Family and household composition

Study participants generally lived either with a partner or spouse and children, or alone (6 of the 14). Seven of the men did not have partners, although one of these had lost through death his male partner of seven years, and three others expressed the wish for a mate. One man was in a heterosexual marriage of 2.5 years, and one man was in a homosexual marriage of 5.5 years. One single man still finishing college lived with his parents for financial reasons. Three women were married (range 3 to 13 years), and the remaining two women had lovers of two to three years. All of the women and the one heterosexual man had children, the average number being 2.3. Of a total fourteen children, only three were known to be HIV-positive. One of these had died when he was about six months old. As of May 1991, 15 cases of full-blown AIDS among

Tennessee children aged twelve and under have been reported (Centers for Disease Control, 1991).

Modes of transmission

The participants reflected the predominant modes of HIV transmission, through sexual exposure or in association with intravenous (IV) drug use. None of the participants was aware of exposure through blood transfusion, treatment for hemophilia, or occupational accident. Seven of the participants were exposed through homosexual relationships. Another man had the combined risks of homosexual behavior and IV drug use. The one heterosexual man reported exposure to a female IV drug user who was known to be HIV-positive. One of the women was exposed through heterosexual contact to someone not in a known risk group. Two women discovered after exposure that a male partner had been an IV drug user. The remaining two women had multiple risks of IV drug use themselves, as well as known exposure to male partners in high risk groups.

Length of time of diagnosis

Three of the participants were HIV positive and asymptomatic. Four described themselves as having had some symptoms. The remaining seven had received an

AIDS diagnosis, generally after a bout of pneumonia.

Participants who were HIV-positive without an AIDS diagnosis had known about their status an average of twenty months, with a range from seven months to two years and nine months. One man diagnosed with AIDS for four years had been diagnosed as HIV-positive eight years ago. The average length of time participants had been diagnosed with AIDS was two years, ranging from six months to four years. Five of the study participants qualify as long-term survivors of the illness, having survived more than eighteen months since their diagnosis (Callen, 1990).

Participants' Responses to Their Illnesses

The experiences of individuals in coping with their illnesses is vitally important to understanding the responses of support persons. Therefore accounts of their thoughts and feelings at different phases of response are presented in the accompanying chart (see Figure 6). Note that the boundaries between phases of adjustment are fluid, not sharp. Despite good coping skills and a secure support network, a person may again experience previously resolved feelings of fear, anger, and sadness when confronted with physical changes.

Phase One: Initial Reactions

"devastated" "petrified" "shocked"
"the initial shock" "panic"

"I started freaking out." (Marilynn)

"It's horrible, it's really a horrible feeling. You know that? You're HIV positive." (Bette)

"I was pregnant and I had a lot of guilt and concern about my baby." (Susan)

"In some ways it was a relief to finally know what was going on with my health." (Sandra)

"It sort of went both ways--a relief and a slap in the face." (Toby)

"When I was in the hospital, it was so long before they found out, that I was kind of glad they finally said, 'We know this is something.' So that we could get started on doing something about it. That gave me a lot of relief." (Lisa)

"I had already made up my mind that I was not going to let it freak me out. I was not going to go into some panic and go off and sit somewhere and wait to die." (Scott)

"I didn't panic or anything. I was like, 'Oh well! Nothing I can do about it now.'" (Ronald)

"Well, it was no surprise because I was already so ill and I was aware of my lifestyle." (Andrew)

Figure 7. Participants' Responses to Illness

(Note: All names are pseudonyms.)

Phase Two: Emotional Adjustments

"In the initial months, I was just a real basket case. ... I probably for six months stood at my back door and cried." (Sandra)

"It was kind of scary and I was worried, and then I started worrying about my children." (George)

"The whole fatality of it ... blew me away!" (Andrew)

"I never was angry. I never was mad. I never went around and 'Why me?' because I kind of felt that some of the lifestyle and behavioral aspects did put me at risk." (Steve)

"I would smoke like eighteen joints [a day]. As soon as I would come down I would get high. ... I just wanted to wash it away, forget about it. It didn't work." (Marilynn)

"I had plans for the future. Now there's nothing." (Bette)

"I began making plans to die. Imminently. ... And then I got better and realized I was going to be around to live a while longer. And then I got back to that." (Steve)

"I was in shock and just kind of numb. I kind of went through a dream-like stage for almost, oh gosh, about 9 months. And then I got real angry and pissed, and I just got angry at this disease!

I still go through moments that I'm just angry with it. But I don't stay angry. I'm not going to let anger rule my life. I'm not going to let this disease rule my life any more than I have to." (Bill)

Figure 7. (Continued)

Phase Three: Reordering of Life

"It's getting easier to live with." (George)

"I almost like my life again." (Sandra)

"[I began] to see my illness as like diabetes, a chronic illness." (Joseph)

"It's on your mind every day, if only because you have to take those damned pills every day. It gets better all the time, but I'd be lying if I say that I don't have my days." (Scott)

"Seems like things get put into perspective a little bit, over what kinds of things are important and what kinds of things you ought to just let go of." (Sandra)

"I'm dealing with it. I know it's there. But I just don't think about it." (Marilynn)

"People have told me this countless times that they can't <u>believe</u> my mental outlook is so good, and this and that. And I used to be embarrassed and I used to get irritated and then I said, 'Well, maybe it's <u>true</u>.'" (Andrew)

"It's changed everything I look at: the way I eat, the way I keep myself, the way I view people, the way I view relationships. It's, in a word, honesty, believe it or not." (Rusty)

"I see myself handling whatever comes along." (Steve)

"Instead of spending my time worrying about who gave it to me, where I got it, I just take it from where it's at now and deal with it." (Scott)

"There's a lot of good despite the illness that has come of it." (Toby)

Figure 7. (Continued)

"When I first came to terms with this disease I decided, if anything good can come out of this, and anybody else can be helped, they're going to be." (Rusty)

"[I came] to the realization that the relationships that you have with those people who are closest to you are really what's important." (Sandra)

"I imagine if I didn't have my children I would probably just give up, turn it in. I want to live for my children." (Bette)

Phase Four: Thinking about Sick Days and Dying

"When I get overtired and I'm not feeling well it's easy to be depressed." (Sandra)

"Days I get sick I'm real weepy: 'Oh, I'm sick and I don't like it.'" (Marilynn)

"I have a desire to do things, and you can't do things that you want to do. I can find myself getting angry at times." (Toby)

"I want it over one way or the other. ... I mean, I don't want to die, but I don't want to be sick all the time." (Marilynn)

"Sometimes [the future] looks dim." (Susan)

"I'm real fearful about what's going to happen down the road. It's bad enough that I'm going to get real sick. I think my bigger fear is that I'm going to get very stupid." (Sandra)

"I just refuse. I just don't think about it. I'd much rather think about what I'm going to do when I go skating tomorrow." (Scott)

Figure 7. (Continued)

"As I said, I wasn't fearful initially. I'm not fearful now. ... And I'm not fearful of death." (Steve)

"I think life is wonderful. And I don't think dying is any more than just changing perspectives. I believe that life continues forever, my life." (Toby)

"I might not feel hot. I feel very close to Jesus." (Bette)

"Sometimes God, I just feel like He reaches you however He can. And illness is one way of reaching you." (Lisa)

"I think overall I'm pretty optimistic. I don't think I'm gonna survive." (Sandra)

"Some days I feel like I'm gonna live forever and some days I want to pull it over my head. But the reality usually is that I don't have a date for my death, but then, no one else does. So I can't really look at it any differently than if I were involved in a normal life, a life without this problem." (Andrew)

"I refuse to give up. I'll fight to the bitter end." (Ronald)

"Strength is one thing, but reality is another." (Scott)

"I feel a loss ... in knowing I can't live my life as much as I want to live it." (Toby)

"You really appreciate life much more. And I think you start noticing little things like the flowers in bloom, that otherwise you'd just pass it by and not know it. These past three years, as far as I'm concerned, have been a gift from God that I'm alive. Because by statistics I should have already died." (Bill)

Figure 7. (Continued)

Participants responded very individually to the knowledge of their HIV status, but several general patterns can been seen. Many felt an **initial reaction** of shock or panic, sometimes mixed with relief. Some persons who anticipated the diagnosis had prepared themselves for potential bad news.

The period of several months after diagnosis was generally a time of **emotional adjustments**, with responses ranging from anger and sadness to attempts at avoidance. Self-imposed social isolation, or its opposite, wide disclosure, were not uncommon.

After a period of time, many of the participants were able to achieve a **reordering of their lives** to accommodate the illness. They established coping techniques which improved their enjoyment of life. Nevertheless, participants still had to deal with the ongoing nature of their illness by **thinking about sick days and dying.** Even for very strong-spirited people, coping with exhausting limitations and days of flu-like malaise can be at times a real struggle.

RELATIONSHIPS WITH SUPPORT PERSONS

This chapter section answers the research question: **What are the relationships of HIV-positive**

individuals to their important support persons? In this section I will discuss categories of people who are frequent sources of support. I begin by describing two qualities that influence the degrees of support provided by various persons within a support network.

Qualities Which Influence Supportiveness

Participants in the study were asked questions about who their most supportive people were, who was most helpful, who they could rely on for support. Most listed a few names, others gave a ranking of the top three or four, and a few answered more generally, "my family and friends."

Supportiveness appeared to exist as a continuum, with some people playing consistent major roles, and others helping out at varying levels. Two factors influenced support persons' positions along this continuum: 1) the degree of interpersonal closeness between the support person and the HIV-positive individual, and 2) the degree of ability of the helping person to be supportive. The two qualities have additive effects, so that a person ranking highly along both dimensions is likely to be highly valued as a source of support (Figure 8).

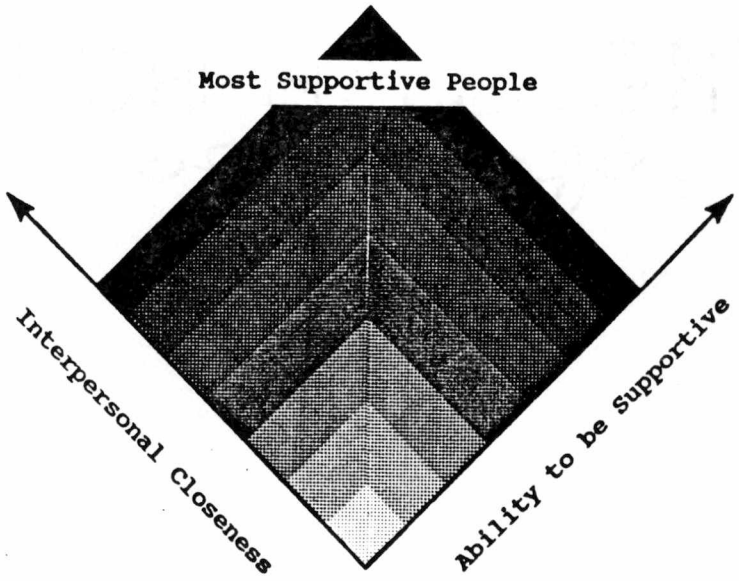


Figure 8. Most supportive persons tend to have high supportive ability and a closeness to the individual.

Interpersonal closeness is a quality which derives from feelings of intimacy, understanding, and shared history. This quality is a basis for adequate support to occur in the emotional realm. Family and friends are most likely to rank highly in interpersonal closeness, and thus are frequent "most supportive people."

Ability to be supportive is the second factor which influences which people are most supportive. Personality differences largely account for variations in supportive ability. Persons also may be influenced by their life stresses and responsibilities, level of psychological well-being, degree of understanding about

HIV disease, and history of relationship with the individual being supported. Family and friends vary widely in their ability to be supportive, but most do a reasonably good job. When they do not, volunteer or professional care providers, some of whom are effective support persons by temperament or training, can rise to greater levels of importance.

Susan Brooks (a pseudonym) is an example of someone who found much of her support outside her network of friends and family. She listed as her most supportive people the majority of the social workers she knew, the gay men she had met, her volunteer buddy from a.i.d.s. Response Knoxville (aRK), and a group of HIV-positive people.

Susan had interpersonal closeness with most of these persons because they were compassionate enough to understand her disease, or were HIV-positive themselves. She did not have the level of commitment or shared history with them that she might have had with family members. Her family members, however, were impaired in their ability to be supportive by a lack of knowledge about the way the disease is transmitted, judgemental attitudes about Susan's former lifestyle,

and their own fear and denial. Susan's most supportive people appear more highly valued in both interpersonal closeness and supportive ability than her own family members.

Frequent Sources of Support

I will describe several categories of people who provide support to HIV-positive individuals. Not all were noted as most important sources of support, but all were frequently mentioned as providing some degree of assistance and encouragement. For each type of relationship I will describe common patterns or examples of support.

Family members

Family members were among the most frequently listed and most valued sources of support. Parents, especially mothers, were commonly mentioned as playing a central supportive role. Sisters also were highly supportive people, and were notably more likely to earn "most supportive" status than brothers, and notably less likely than brothers to be described in a negative light. Other family members, including a cousin, two nephews, and both official and unofficial in-laws merited high mention.

During our interview, Steve, a former health professional, remarked upon a pattern he had noticed among families of support group members:

> I find in my experience that people tend to continue to be what they were to begin with. ... If you are from a loving, supportive family, they probably will continue to be. If they're not, more than likely [the illness] is not going to <u>suddenly</u> change the dynamics of those relationships.

His perception, when applied to the families described by the study participants, was quite accurate.

Families tended to continue with the same styles of response as before the illness: Families that never discussed touchy subjects discussed the illness as little as possible. Families that were only marginally supportive to begin with did not tend to become more trustworthy or involved. Lisa, one of the African-Americans in the study, described the almost overwhelming degree of support she received from her large family. They filled her hospital room during a conference with her doctors. What does Lisa say about her family's style of response? "They've always been

like that. ... I didn't think this would be any different."

Qualities that make families special are the long history of relationships, the blood bond of commitment, and the often unconditional acceptance of family members. Sandra describes the supportive response of two members of her family: "At least in my situation--I know this is not true for everyone--you discover that your parents love you no matter what." Bette explains why her cousin is her most supportive person: "My lover's mind could change. He could find himself somebody else. But I don't think my cousin's going to leave me. He seems to be there. No matter what." The unquestioned expectation of support within many families made abandonment, in the few cases where it happened, all the more devastating.

Children

Children were not a significant source of support in the usual way of looking at things. The majority of the children, whose average age was about six years, were too young to understand a serious illness. None of the parents had yet told their young children about their diagnosis. Due to normal developmental needs,

the children demanded attention, care, and worry; yet their presence was universally described as a positive factor.

Bette Davis, a quietly regal African-American woman, chose a pseudonym appropriate to describe her beautiful large eyes. Here Bette talks about the attitude toward survival she has as a mother: "I want to live for my children. I want to see them get big enough to take care of themselves." George Brown, the only father in the study, and the oldest participant as well, conducted most of his interview with his 17 month old daughter happily snuggled in his lap. Looking down at her, he said, "Wasn't for this girl here, I wouldn't live long anyway. She's partly what keeps me alive."

George tells a story about the loving support of his toddler-aged daughter. She cannot realize the seriousness of his condition, but conveys her playful and affectionate concern for him. One night George's wife asked him to rest in his daughter's bed until the little girl fell asleep. During the night, he moved into the living room and slept on the couch. Early the next morning his daughter woke him up running through the house looking for her daddy. Expressions of love

and caring are an important form of emotional support.

Partners

Lovers and spouses of the participants fulfilled a challenging role in coping each day with immense changes in the physical and emotional well-being of their partners. Often these support persons were seen going through their own struggles, wondering about their own health and that of their children, passing through phases of denial and blame, trying to figure out whether they could handle what the future might bring. Sometimes to the amazement of HIV-positive or more ill spouses, most partners did stay, and most were described as very important sources of support.

George, who moved to Knoxville with his family from a small East Tennesee town, tells this story about his marriage:

> When I first found out it caught me as a surprise. I'd been worrying so much about my wife and babies I even tried to run my wife off. I tried to run her away. Thought it might be better on her if she'd just up and leave, took the babies with her, and went back to her mother. She said no, she wasn't going nowhere. She said I'd be dead and in

the grave before she did that. She was going to stay here and see that I was took care of.

Bill, an attractive man wearing a gold band on his right hand, was a successful health professional before the onset of his illness. He describes the commitment between him and his life-long partner Marshall: "We've had rough times probably due to this disease, but hell, we argued before the disease too. It all boils down to: We're committed to one another and we love one another, so we'll be there for one another."

Friends

The category of friends also contains many highly supportive people. Friends rival family members in importance as a source of support. Friendships tended to foster a sense of reciprocity and fair exchange. In this way friends maintained a healthy level of interdependence, and contributed to the sense of life continuing normally. Long-term friends were especially valued in terms of security. Other HIV-positive persons were valued as friends because of their special bond of understanding and empathy.

Scott, an energetic and likable man in his late twenties, now juggles college coursework and a full-

time job. The period of time after his diagnosis was made more difficult for him because of changes in his support system. Most of his friends, perhaps overwhelmed by fears about their own well-being or their abilities as caregivers, became alienated rather than supportive. Scott went on to develop a close circle of new friends, in part bonded by their shared illness, in which he finds a high level of trust and empathy. Here he offers his advice to others whose friends let them down:

> If you have people around you who are alienating you, don't take it personally. ... There's a lot of people in the world and there's always somebody out there who's not going to understand. There's always somebody out there who <u>will</u>. You may have to <u>look</u> a little harder and in a few places you normally would not look, but I promise you it's there.

Joseph, a native Knoxvillian with a clever wit, a fascinating collection of books, and a penchant for football, describes his long-term friendships:

> I'm lucky to have a lot of really close friends. Well, I say lucky, but I've worked very hard at

> maintaining those friendships. I know I've made friendships that are "friends for life." ... I don't think my friends know what they're getting into, but I know they'll be there for me.

AIDS support organizations

Many people experience a contraction of their support networks at some point after their HIV-positive diagnosis. If individuals stop working, they lose contact with work-related friends and associates. They may choose not reveal their illness to any but their most trusted friends and family members. AIDS support organizations are an important avenue for revitalizing the support network and making new and highly empathic friends.

Volunteer and community support for people with HIV disease occurs at a variety of levels. Some people mentioned the support of organizations in providing financial and practical support, housing or medication. Others mentioned key individuals within support organizations or in the gay community. Two of the more organized forms of social support are the support groups for HIV-positive persons and the volunteer buddy program. For several people, the services of an AIDS

support organization were among the most valuable support received.

One of the differences between volunteer care providers and professional care providers is that the volunteers seemed to more easily step over the line into being truly friends. Rusty, a spirited man in his late twenties, is the longest-surviving long-term survivor in this study. His apartment is filled with items to promote healing: green plants on the windowsills, medicinal herbs simmering in a pot on the radiator, a head of garlic hung above his bed, a collection of crystals stored in a Pringles potato chip cannister, and a rich collection of his own poetry. Rusty went through several buddies before he found one who truly suits his personality: "The support I get from my buddy Rosie Day is tremendous. We go out on picnics; we go to movies together. She is one of my best friends."

Support groups met with mixed reviews, but were an important way of making friendships that continued outside the regular meetings. Often the groups provided a haven during the first months of adjustment to the illness. Sandra, a highly nurturing woman, has

always led her life with a great deal of purpose and discipline. She was forced to end her much-loved career after the onset of her illness. Here Sandra describes the support of the group during this difficult time:

> I know the other people in the group thought, "Who is this maniac woman?!" In the initial months, I was just a real basket case. I didn't have any place to vent a lot of my anger and a lot of my fears. That was a place I found that I could go in there, and I could cry, I could say anything, and I was going to be accepted. [It helped that] there were other people who had a lot of the same feelings that I had. It became and still is a real safe place to vent some of those feelings that I think need to be expressed.

Several people did not feel comfortable with support groups and chose not to attend them. Scott, for example, prefers to cope with his illness by leading an active life and finding support from "people who have the disease who are handling it well." After attending a few support groups, he says, "I'd just as soon <u>not</u> sit around with a bunch of people who

constantly talk about death and dying and that old 'Poor Me' syndrome which I just hate." Within most AIDS support organizations are a choice of avenues of support to meet the needs and coping styles of a variety of individuals.

Professional care providers

Providers such as nurses, doctors, social workers, and counselors were mentioned by almost everyone. Many described the roles of physicians and nurses in creating a positive or negative outlook at the time of their diagnosis. Several participants developed over time a strong sense of teamwork with their medical care providers. Experiences within the medical arena were not universally positive, however, as will be further described in the next chapter section.

Counselors and social workers were very helpful in providing a nonjudgemental ear for persons dealing with initial diagnoses or difficulties with drug and alcohol use. Some professional care providers were quite skilled at offering support and empathy, and relationships with the participants occasionally became more like friendships over time. Nevertheless, professionals are bounded by their roles, time

constraints, and responsibilities to other clients. Professional care providers do not tend to become central support figures unless family or peer support is virtually unavailable.

Church and ministerial support persons

Several persons mentioned the support offered by churches or church members. George noted that a church deacon, who had helped his family with practical and financial needs, was one of his most supportive people. Marilynn appreciated the positive focus of church teachings and the structure of frequent meetings within her church. The majority of the participants remarked upon changes in their spiritual feelings, whether or not this involved an organized church support system.

A few people noted the role of ministers in providing for their spiritual and ritual needs, as well as being present as a known source of support if insufficient help was available. Ministers, because of their less intense level of interpersonal closeness with participants, did not tend to become major sources of support.

People who don't know about the illness

A few people obviously derived important aspects

of their support from people who did not know about the illness. One man was living with his parents but had chosen not to reveal his HIV-positive diagnosis to them. Several women were active in their churches but had not told the majority of the church members. The decision against disclosure did not necessarily seem troubling to the participants, especially when compared with their fears regarding candor. Nevertheless, people who did not know about the illness were unavailable for most forms of emotional and attitudinal support.

Summary

In this chapter section I have examined the roles of key persons in providing support for HIV-positive individuals. Participants reported that their most supportive people were often family members, partners, friends, or members of AIDS support organizations. Other care providers played supplementary and often quite specific roles in offering needed forms of support. The people who were most supportive appeared to be those who combined an interpersonal closeness to their care recipient with a high ability to be supportive.

MESSAGES CONVEYED BY SUPPORT

In this chapter section I will address the second research question: **How is caring expressed to persons who are HIV-positive by persons in their support network?** In answer to this question I will thematize the expressions of caring conveyed to study participants. Each theme will be justified by stories and quotations which are typical of the positive and negative expressions of that category of support. Examples will be given of communication patterns which support (**confirm**) and interfere with (**disconfirm**) an individual's sense of self-worth and well-being. Figure 9 summarizes the major themes of caring, each of which will be examined in turn.

Emotional Support

Probably the most significant major type of support offered to HIV-positive individuals is emotional support. This form of support encompasses shared trust, open communication, expressions of empathy and love, presence and involvement, and honoring of commitments. Many of the demonstrations of emotional support were made by close friends and family members, but other sympathetic individuals within the

EMOTIONAL SUPPORT

- Trust
- Communication
- Empathy
- Presence
- Commitment

INFORMATIONAL SUPPORT

- Giving Information
- Becoming Well-Informed
- Offering Professional Competence

ATTITUDINAL SUPPORT

- Strength
- Acceptance
- Connectedness
- Normalcy

PRACTICAL SUPPORT

- Assisting with Daily Needs
- Fostering Independence

Figure 9. Major themes involving communication of support

network are also capable of communicating such themes.

Trust

Assurances of preserved trust appeared as an important form of support to several participants. Messages of trust are conveyed in positive expressions. Negative interactions demonstrate trust's opposites: breaches of confidentiality, broken promises, lies, and ulterior motives. Bette's doctors, in a positive example, conveyed a message of trust by respecting her confidentiality. When her baby was in the hospital quite ill with HIV disease, his doctors promised to keep news of his death out of the newspapers in order to protect her other children.

Breaches of trust were often a particularly painful type of disconfirming message, or message which upsets someone's feelings of individual integrity and esteem. Marilynn's mother broke her trust by promising to come visit and never showing up. Scott experienced a breach of confidentiality when friends went behind his back to tell a new friend he was dating about his HIV status, instead of allowing him to reveal that fact in his own timing and manner.

Rusty was subject to an unusual situation

involving a compromise of trust. His mother, a nurse, is remarkably supportive and attentive to him during his illnesses. This is a form of support he needs and accepts. Rusty realizes, however, that his mother acts in part out of ulterior motives: She hopes to gain access to his prescription narcotic drugs.

Communication

Openness to communication seemed to be one of the more universal themes of supportiveness. Communication of feelings and reactions to the illness were especially important. The message contained within this theme is "I care about how you are feeling." The converse side of this theme is noncommunication, making the disease and feelings about it an off-limits subject.

Joseph reports that his best friend Peter was very helpful to him, especially soon after his diagnosis: "My friend Peter is one [of my most supportive people] because I can call him up any time and just talk about whatever's bothering me." Susan explains what is special about her most supportive people: "They just let me talk, and they listen. I can express my feelings, and just talk about whatever's bothering me.

That's helped me a lot."

Sandra remarked upon her appreciation of the support group for HIV-positive persons as a place to vent her anger and fears. She describes a similar gratitude for the communication her husband tolerantly accepted, as well as for his commitment to her:

> When I first was diagnosed I had just an enormous amount of anger, and I took a great deal of it out on my husband. It's like I almost waited for him to come home so I would have someone to yell at. And I'm lucky that he put up with it until I passed through that phase.
>
> I think you take out a lot of your anger on those people that you love and you know love you, because they're a safe person to vent all that on. ... If they have any commitment to you at all they're not going to walk out, and I think you know that. You can take that kind of anger out on them and they'll accept it because of who they are.

Rusty conveys a slightly different definition of open communication. After a bout of HIV-related meningitis, his neurologist tried fifteen or twenty

trials of medications, physical therapy, and other treatments. Finally, she admitted, "Frankly, I don't know what to do." Rusty was not upset by this, but instead, was grateful for her candor. Her honesty, to him, communicated respect and a desire to include him in the treatment decisions, thus confirming his importance in the scheme of things.

During the interviews, several participants reported examples of people in their support networks who did not discuss the illness. In families where noncommunication is the norm, this was not necessarily perceived as negative. Overall, noncommunication did not seem to be so much an overtly disconfirming gesture as it was a lack of positive expression. Sometimes participants then wondered what their support people really thought and felt. Here Lisa refers to her husband: "He doesn't hardly talk about it, so you don't really know. He still seems the same to me, but I find it hard to believe that he doesn't think about it."

Marilynn, an angelic woman in her early twenties, spends most of her time in Bible study and caring for her preschool aged daughter. She comes from a family

which has never been very supportive, and instead much of her support comes from members of her church. Marilynn has several friends from church who know about her diagnosis and are supportive with practical needs and in helping her to keep a positive attitude, but as far as communication, "We don't talk about it." Because her illness has been an off-limits subject, Marilynn has rarely felt the relief that comes from being able to express her thoughts and feelings. In addition, the silence of her friends about this subject is an unconscious demonstration of fear, stigma, and verbal isolation.

Empathy

Empathy is a theme which encompasses sharing of emotions, demonstrations of concern as well as love. Probably the single most common key word I heard from participants, other than "support" itself, was "understanding." Understanding conveys empathy with a person's situation and feelings, a nonjudgemental attitude, and genuine caring for that person's well-being. During moments of empathy, a high level of interpersonal closeness was often achieved, even between people who hardly knew each other.

Soft-spoken Bette describes the emotional reaction of her sister when Bette told her about the illness: "She was very hurt. Very. We both hurt over it together." In this loving response, Bette's sister allowed herself to share Bette's pain. Bill tells the story of his partner Marshall's response to Bill's initial hospitalization and their awareness of the probable diagnosis. "That was one of the few times I've seen Marshall cry," Bill says, and they cried together despite the fact that as men, they had been trained from childhood not to.

Sometimes empathy is achieved in interactions with people who are not members of the circle of loved ones. Bill, a former health professional, describes the doctor who first discussed the likelihood of an AIDS diagnosis:

> She came in and I just asked, "Do you think this is pneumocystis pneumonia?" She said, "Well, from your x-ray it could be. We'll have to do a bronchoscopy." And she requested an HIV test on me to get this confirmed. But she was very, very loving. Great doctor. Really cared. She was straightforward and I'm the kind of patient--I

want to know.

Bill's doctor not only was straightforward in communicating the facts about his condition, she was not afraid to let her concern and empathy show. To open one's heart is often the greatest gift one can give.

Bette is a beautifully strong woman who in recent years had made a lot of decisions to improve her life. Several years ago she quit using IV drugs, moved away from her old friends and boyfriend who used IV drugs, and met a new lover who has been very supportive. They decided to have a baby together, but after he was born, he was often sickly, and eventually ended up in the intensive care unit. Some of the people at the hospital were very supportive; the chaplain was present every day to pray for her baby. When the little boy died, Bette was not the only one there crying. The nurses also cried, and held him and kissed him. Bette says, "I didn't <u>know</u> these people," emphasizing their great empathy despite the fact that they were essentially strangers.

The opposite of empathy is callousness, or a failure to respond in an understanding manner. In a

few examples, health care workers were callous about the physical or emotional pain they caused. One of Bill's doctors, for instance, performed a bronchoscopy on him without anesthesia. It took four or five people to hold him down on the table during the procedure.

Family members are also capable of responses which are without empathy. Ronald Reagan is a lean, blond-haired man in his mid-twenties who chose his pseudonym to protest moralistic and militaristic politicians. He had lived with his life-long partner Dan for seven years, and devotedly cared for him while he was sick so that he could die at home. Ronald's family did not approve of their relationship, and were not always very understanding:

> When Dan died I called home and my stepmother got on the phone and I told her Dan had just died. And you know, when you tell somebody something like that, they should say, "Well, I'm sorry to hear that. You need to come home now." Instead I got, "That's life. It happens." [I felt like] saying, "You bitch!" He just died in my arms and she's all about "Life happens." I don't think I've ever been so mad in my life as I was then!

The response from Bill's family was a little different. His father and brother were initially very upset, angry, and antagonistic towards Marshall. Bill's father, at least, later became very supportive and even apologized for his earlier lack of understanding. Bill explains, "My family pulled through, and I don't want to make it sound bad. But when they're hit with this news, it's not always very pleasant. They have to get their anger out and all this stuff too." Bill demonstrates a reciprocal empathy for his family's distress in coping with their own emotional reactions.

Presence

Presence is a form of support which includes companionship, demonstrations of affection, and a willingness to be involved. It is a form of commitment occurring in the present tense: "They're there for me." Physical isolation and refusal to get involved are the most notable opposites of presence.

This theme was invoked time and again with statements like this one from Bette about her lover, "It just feels good to have somebody there for you." For others, presence was conveyed by small gestures of

involvement and friendship. Scott explains how his friends show their support:

> They'll ask you how you're doing. "How are you feeling today? How are you doing?" Or they'll give you hugs when you see them. And to me, it's the smaller things that can add up to the most, really. People don't seem to realize [the worth of] just a phone call, something that takes a person two minutes to make out of a whole day. To say, "Hey! how're you doing? How's it going?" That can do a lot for you.

George appreciates the change in his wife's mother and sisters in coming by to see how he's getting along: "Before they found out I was sick, they didn't hardly come around. ... Now that they know I'm sick they come often." Lisa's family showed a supportive presence, as was mentioned earlier, when they came as a group to meet with her doctors. Bette's hospital chaplain was not able to do much for her baby in terms of curing, but he was present every single day to offer his prayers. Rusty appreciates his cat for being a cheerful source of companionship and continual presence, particularly when he is not well enough to

venture from his apartment.

Physical isolation and refusal to get involved form the opposite of presence. These actions overlap with other themes. When Scott went through an episode of flu-like illness, he needed help with his daily needs, such as buying and preparing food. All but one friend were unavailable or busy. This example shows an unwillingness to be present and involved, in addition to a stigmatizing isolation and a lack of support for daily needs.

Joseph experienced a situation in which a physician was hesitant to become involved with his illness. He had waited a long, worried, and drunk weekend until his doctor would be back in the office to read his HIV test results. On Tuesday morning, Joseph kept his appointment and was put in a back office where he waited 45 minutes for the doctor to arrive. After the doctor gave Joseph his HIV-positive diagnosis, he expressed his unwillingness to treat an opportunistic skin infection because of his (erroneous) belief that it would not heal. This story conveys the lack of support demonstrated by both the physical isolation of Joseph, and the doctor's hesitancy to become involved

in his diagnosis and treatment. An additional theme is present as well, the issue of professional competence.

Commitment

Presence and commitment are very similar qualities. What distinguishes them is the messages conveyed about the expected duration of involvement. Presence hints at commitment, but occurs in the present tense. Commitment sends the message, "They'll be there for me always, no matter what." In the sections which described the support of friends and family members, several examples were given of this type of support.

Bette went through a period of time after her diagnosis when she questioned the commitment of her lover of three years: "At first it seemed like, I thought everybody'd turn away from me. I was actually pushing them away from me, you know? He refused to budge." Commitment brings a wonderful sense of security and acceptance.

The opposite of commitment is abandonment. Several study participants had met with this type of response. Scott noticed a dramatic change in his circle of friends after he revealed his diagnosis:

I hated that I tried to tell them. They just went

every direction. And when it came time to ask for help, there was nobody to be found. It's kind of hard to figure that out. ... To me, I guess, I really learned what alienation is about.

Marilynn experienced a very upsetting interaction with her father when he responded to his suspicion of her diagnosis with both abandonment and an unwillingness to communicate: "My pop told me when I was sick,...he just said, if I turned out positive, that I'm not welcome home anymore. ... So I don't go home, so he knows."

Summary

Themes of emotional support, and failure to support, have been presented here. Trust, open communication, empathy, presence, and commitment convey important messages of concern and positive regard. Examples have been presented of very moving and loving gestures by support persons, as well as tragic instances of people who, for whatever reasons, were unable to respond with compassion.

Informational Support

Informational support was not mentioned by the participants nearly as often as emotional support, but

still made a contribution to their overall health and well-being. Themes of informational support considered here are providing information, becoming well-informed, and demonstrating professional knowledge and competence.

Giving information

Providing information was a significant type of support offered by professional care providers, AIDS support organizations, and other HIV-positive individuals. Ronald describes the supportiveness of the hospice nurses who came to visit his ailing lover Dan:

> He had nurses come around the clock and so I got information from them. I was his caregiver, and they would bring me pamphlets on what to do, and how to expect certain things, and how to manage certain things, and how to handle it when it happened. So that really helped out a lot.

At the time Marilynn first found out she was HIV-positive, her doctor told her over the phone that she could expect to live three months to a year. Marilynn's spirits were lifted enormously when she called a local physician, Dr. Shepherd, to ask him how

long she could live with an HIV-positive diagnosis. He informed her that the life expectancy was an average of ten years, with good hope for longer, as new medications are becoming available.

Bill gives an example of failure to inform, or restriction on the spread of information, as a dangerous lack of support. He maintains that researchers had some knowledge about the way HIV is transmitted by the early 1980's. Although the public was told early on to avoid multiple sexual partners, not until later did information about using latex condoms and avoiding anal sex become widely available. Lack of candor in the media about "embarrassing" topics has led to the unnecessary loss of many lives.

Becoming well-informed

When friends and family go to the effort to become well-informed about HIV disease, its course and transmission, this is a form of support. For some people, becoming well-informed is something they do even before they know of someone who is HIV-positive. For others, the fact of knowing someone creates a need to know more about the disease.

Andrew, a former actor who returned to Tennessee

to be near his parents, describes the supportiveness of his family and friends:

> People that I know seem to have made a real effort to educate themselves about this. So that I'll feel comfortable. So that they won't do something that's stupid, just because they don't know that it's okay to do. ... It's crazy, but they don't treat me like anything is wrong.

Sandra explains one of the things her father has done to support her, "My father's done a great deal of reading and trying to come up with new ideas that maybe will make me feel a little better."

Andrew's family is generally well-educated, but they still experienced some not at all unusual difficulties when his sister turned out to be misinformed about HIV transmission. She was afraid at first to let Andrew's nephews come to visit him. Luckily, his sister's husband and some of Andrew's friends were more well-informed, so they helped her to become aware of the necessary issues. Other families have not been so open to new information.

One of Marilynn's former friends broke her confidentiality by telling other friends about her

diagnosis. To add insult to injury, the friend didn't realize what she was telling them, as Marilynn reports: "She didn't tell them I was HIV-positive. She told them I had AIDS. And I think there's a big difference there."

Offering professional competence

Demonstration of professional knowledge and competence was another valuable form of support mentioned by the participants. Sometimes what they appreciated was just the awareness that their medical teams were providing excellent care.

Toby, a gently spiritual and positive-thinking man, came to Knoxville because of his career and decided to stay here after the onset of his illness. Here he states his appreciation for Dr. Shepherd and his other care providers:

> I do believe that the medical care is some of the best here in Knoxville. Despite the fact that this is considered a small city compared to Atlanta, the people here, aRK as an organization, the medical community, to me are on top of it.

Andrew expresses similar sentiments: "I trust my doctors, I trust the nurses at the hospital, and I know

I'm getting the best possible care I can get. Anywhere. At this point. ... You're in good hands."

Problems arose with several of the participants whose doctors were not well-informed about HIV disease, or did not demonstrate adequate professional competence. Marilynn's doctor, as mentioned earlier, found out Marilynn had HIV and thought she would be dead within a year. Bill's initial doctor referred him to an allergist who completely missed an obvious sign of immune deficiency. Despite seeing Bill's oral candida, he blamed everything on a faddish yeast problem. Bill's next clue as to what was wrong was a nearly fatal episode of pneumocystis pneumonia.

Bette tells a funny story about a phlebotomist whose hands were shaking so much that he could not draw her blood. After he practically ran down the hall out her room, the next phlebotomist was more well-informed:

> That man was a bundle of nerves. And I know he didn't mean to be, but he was really, actually terrified. And then he passed by another lady who was coming in who knew me already. And he told her, "Watch out! You don't want to catch that!" But she came in, she was laughing. She said, "He

needs to get out of the field if he doesn't know what he's doing."

Summary

Having information and sharing information are important forms of support. Information leads to more expert care, and reduces the likehood of unnecessary isolation. As Rusty says, "Knowledge takes away fear."

Attitudinal Support

Positive attitudes are believed by many to afford a degree of protection against illness. Caregivers bolster positive attitudes when they convey a spirit of strength and optimism, acceptance, or relating without stigma. In this chapter section I examine four types of attitudinal support, offering for each theme examples which confirm and disconfirm feelings of personal worth and well-being.

Strength

The function of support persons as a source of strength was one of the most important supportive roles. Support persons encouraged attitudes of survival when they communicated strength, optimism, humor, and forbearance. Often the theme of strength was combined with a message of commitment to the person

in need.

"My father especially has been a great source of strength," says Sandra. Joseph explains why his mother is his most supportive person: "Just because of her attitude that no matter what happens, we can handle it." Rusty expresses the importance of the strength conveyed by his circle of support persons: "I've got plenty of good people around me, I really do. I could not have made it without them."

Many examples were given of the use of humor to improve spirits. When Lisa was first in the hospital trying to discover what illness she had, her sister-in-law Karen called each day, and they laughed about the possibility of her having AIDS. Remember the story about Bette's two phlebotomists. The second one, through her laughter, turned what could have been a depressing experience of stigma and isolation into a very funny situation.

Support groups have been a source of (sometimes morbid) humor and cameraderie for many people. Among other things, they are a place to discuss the good common sense of Imelda Marcos in having her dead husband preserved on ice, so that he can still attend

his own birthday parties. Joseph relates another one: "I thought about this last night. I'll have to tell them this one at group when they ask me how I'm doing. I haven't gotten any sympathy fucks yet out of this!"

Andrew talks about the importance of his support people in keeping him going:

> Those people are there to sort of prop you up! You know, when you can't prop any longer. Joan Rivers has a joke about propping. She says, you talk about having a date, and you know he's dead, but we'll prop him and bring him. "Bring him along, bring him along! He's dead, we'll prop him, and bring him along!"
>
> That's the way it is sometimes. You're like, "No more, no more of this!" Getting up in the morning and taking those pills. Sometimes it's just...[pause]. Then, it could be worse. And that's what all my people are there for. It sounds like some kind of conglomerate, "My People," but all my friends and family. They prop me up. They do.

Support persons fail to be a source of strength when they convey hopeless messages. Susan was visited

by a social worker who hoped she would surrender custody of her child:

> Her attitude is wrong about a lot of things. She's very negative. Because she's a projectionist: She says things like, "You know you'll be getting weak soon." I don't know that! It just makes me feel bad.

Andrew describes differences between the type of care provided in the hospital in 1990 compared to the way it was in 1987. This example recalls several themes, issues of empathy, presence, and competence as well as attitudes:

> They genuinely care. And that care has changed in the past 2 1/2 years. ... Their attitudes, their educational level is higher. They're not afraid of us any more. It's not this whole feeling of isolation any more from these people, and that really helps. ... Because when you're sick and you're down and you're out, you don't need someone being rude to you or callous or uncaring. That's the way they were the first time I got ill. And it was very difficult.
>
> They were afraid of you, and they isolated

> you physically from everybody else, and they treated you, they treated me, like they didn't want or need to be dealing with me, that I was probably going to die soon anyway and what was the point.

Some support persons, instead of being sources of strength, foster reciprocal concern and worry on the part of the HIV-positive individual. Being concerned about how caregivers will respond or deal with the illness is at times a great source of strain. Another excerpt from my interview with Andrew:

> It was hard at first because I felt like I was carrying the emotional load of all my friends and family too. I figured that I'm dealing with this, but I also have to make them believe that everything's okay too.

Lisa describes the protective attitude she and her family had toward some of its members, who initially handled her illness with more difficulty. They decided not to reveal her diagnosis to this particular brother until she was home from the hospital:

> He's not used to anybody being sick around him. He'd never been in the hospital or anything. He

> came up there and he saw me getting oxygen. And saw me with a thing [IV] in my vein, and he's like, "She's dying! She's dying!"

Scott is hesitant to tell his brothers and sisters that he is HIV-positive: "If they need to throw a fit, they're going to do it away from me. Because I don't need the stress." Andrew is reluctant to renew friendships with some people who don't yet know his diagnosis:

> The first two years of this were very, very stressful and emotional, with everyone trying to get their bearings on it at all. I just didn't want to go through it any more. I've gone beyond all that beginning stuff you go through, and I didn't want to deal with that any more.

Acceptance

Acceptance is an attitude held by the caregiver that conveys respect and affirmation of a person's individuality. Disconfirming communications within the theme of acceptance involve blame and judgement.

Bette describes her surprise at the understanding attitude of her lover as he came to terms with her diagnosis: "He's accepted it. Love will make you

accept a lot of things. ... He's been willing to deal with it. And that really changed my mind about people with HIV problems. Just his attitude."

Joseph is grateful that his doctor was able to accept him as a new patient:

> Dr. Shepherd is such a pleasant, compassionate person. I'm sure some of the things he hears are so far from his experience of what he will ever do in his life. You tell him something, and it seems like his jaw would drop or something, but he doesn't show anything. He's just like, "Okay." He must be thinking, "How do these people get themselves into such situations?" but his attitude is that people are people and it's okay. He has a very understanding manner.

Bill's father, described as a "macho" man and an ex-Marine, was never comfortable with the issue of homosexuality. This incident occurred soon after Bill's diagnosis:

> Then he said, "Well, I guess you're sorry about being gay now," or some tacky remark like, "You've brought this on yourself." Later on we hashed it all out and he apologized. But his initial

reaction was not very good.

Susan experienced difficulty for a while with her boyfriend's blaming attitudes:

> He used to sling in my face about how I used to live. I guess that's how I got sick. ... He used to hurt [my feelings] too much. I used to cry a lot. ... It was true, as far as my lifestyle. Still, I didn't need to hear it all the time.

Connectedness

The theme of connectedness is about supporting and affirming connections to and between care providers. For some families, connectedness happens when good communication and family harmony are preserved. For other families, acceptance of the partners of their gay sons or brothers is an important step. Fostering connections between people is an important role for health care workers, as well as a worthy societal goal.

The story has been told about Lisa, one of nine sisters and brothers, whose family filled her hospital room because they heard about plans for a conference with her doctors. One of Lisa's nurses had asked if she and her husband would like to meet with the physicians to discuss her illness. Seeing that Lisa

was receptive, the nurse invited her other family members as well. The meeting turned out to be an important moment for Lisa's family to express their solidarity.

While Bill was in the hospital with his initial episode of pneumonia, his lover Marshall was heartbroken that he had to leave for work each day. After some negotiations, Marshall's employer agreed to give him two months off with pay so that he could care for Bill.

Ronald Reagan had been with his partner Dan from the time they were teenagers until Dan's death about a year before our interview. Ronald told me about the roles of many people in supporting his relationship with Dan, and in negating it. The hospice nurses and Dan's mother were important sources of affirmation during Dan's illness. Even now, Dan's mother sends plane tickets twice a year for him to visit her, and mails him monthly checks from Dan's life insurance money. Ronald's own mother initially blamed his illness on Dan, but after being angrily rebuked, she has not brought up that viewpoint again. At one point Ronald was told by a psychiatrist that to resolve his

grief over Dan, he "would just have to push him out of my mind." Not only was this an example of forcing a inappropriate coping style, it failed to address Ronald's desire to lovingly honor Dan's memory.

Lisa mentioned the supportiveness of her sisters in reassuring her that her husband would not leave her, and he didn't. Bill's father, partly by temperament, expresses a little less faith in relationships. Worse yet was the response of Bill's brother:

> My brother and I had a big blow out in the hospital and he threatened to beat up Marshall. It was an ugly scene. And he never came back, and basically ... the only time I see him is at family get-togethers.

Normalcy

The attitude of normalcy is a way of relating to the HIV-positive person without stigma, and without expecting him or her to be confined to the role of sick person. Disconfirming attitudes which are associated with stigmatization overlap with other themes, such as isolation, abandonment, and lack of information.

Almost everyone described some supportive friends or family members who helped maintain a sense of life

as normal, despite the pervasive stigma within general society. Toby used to charm his friends and co-workers with homemade cheesecake and other cheerful treats. When he revealed his HIV-positive diagnosis, everyone responded with support and encouragement: "I think people responded to me because they knew me. ... My friends have helped me by continuing to live their lives, and helping me to live mine as normally as possible."

When asked what things his friends did to be supportive, Joseph responded: "Nothing--just accept me and let me be normal. Around my friends I don't have to worry about my beeper going off for my AZT. I just feel comfortable and accepted." Joseph also tells the story of a friendly competition between him and two brothers he knows who have heart disease. Each of them is determined to outlive the others. This attitude defines Joseph's illness as no less normal than other common diseases of people in their forties.

Andrew appreciates the efforts of his support persons to treat him as somebody normal, rather than as somebody sick:

I think one of the biggest things is that they

> don't treat me like anything is wrong. People don't treat me delicately. There's no physical difference between what it is now and what it would have been, say, 10 years ago.

Many examples have already been given of actions which conveyed attitudes of stigma. Stigma can occur in response to prejudices about homosexuality or IV drug use, because of fear of contagion and mortality, or in avoidance of the stigma of association. Scott describes the dramatic change in his former friends, most of whom were themselves gay men at risk for HIV disease: "When you were around them and they didn't know about the diagnosis, everybody was just hunky-dory. But all of a sudden you're diagnosed with having the AIDS virus. It's kind of like a whole other world starts."

Sandra discusses the stigma associated with the ways HIV is transmitted:

> I got it from having sex with somebody that was infected. I so much wish I could say I got it from my dentist! But that's not the case.
>
> I know of at least one person who I've told who automatically assumed that I must have gotten

> it through a blood transfusion of some kind. And I thought--that was kind of nice. At least they didn't assume that I got it through using IV drugs or because I was a slut.
>
> I think that's a real hard thing self-esteem-wise to try to overcome, because the stigma of being a slut is associated with having this. I have never considered myself to be that way and I still don't. But it's hard to not let other people's perceptions affect you in a negative way.

Almost all the participants changed their lives significantly from normal to accommodate the secrecy needed to avoid societal stigma. This concern was most evident in the reports of mothers with young children. Bette, a mother of four, explains her situation:

> If [knowledge of my HIV status] were out there, and a lot of people <u>knew</u> that are afraid of it, I would probably be in a different position than I'm in. I am aware, and I know the precautions I have to take. I haven't told people, like my neighbors, nobody, none of them. ... And I'll never tell them. Because my kids would be in

jeopardy.

Summary

Attitudinal support can occur in as general a manner as fair representation and acceptance in the media, or it may be as personal and intimate as that conveyed by a loving parent. Attitudes which confirm personal worth include strength, acceptance, affirmation of connections to loved ones, and continuation of life as normal.

Practical Support

Practical support occurs on two levels and thus is represented by two themes. The first is attention to daily needs, making sure persons have the support they need for a comfortable existence. The second is fostering independent living, helping persons to remain autonomous and free to make choices about their lives. Inappropriate types of support are those which are either inadequate or overdone. Practical support was almost universally mentioned and appeared to be a vital form of assistance.

Assisting with daily needs

When considering support, individual differences in its definition become apparent. A practical person

like George describes mostly practical assistance: someone giving his daughter five dollars, taking his wife to the doctor, buying a bag of diapers for the baby, helping him to get a phone. Andrew describes a great deal of support he receives in terms of attitudes and emotions. Still, he argues that practical support is significant: "All those things really are a form of support because they're supporting my daily needs, not just my emotional needs."

Support of daily needs sometimes means caring for persons when they are sick and unable to care for themselves. One supportive minister even brought communion to Bill at his home, and performed a healing rite in his hospital room. Support for healing also occurs in the form of encouragement of self-care, such as that offered by Lisa's husband:

> At work he calls me up at night to see if I took my medicine: "Did you take your medicine?" I say, "Yeah. I'll see you when you get in." He says, "Okay, bye." It's like he took the time out to do that.

Daily needs are supported when caregivers are available to help when needed, like George's wife:

"She was going to stay here and see that I was took care of." Bette's lover is another who helps with whatever practical needs he perceives: "Just anything I need. At all. He's just at my beck and call." Andrew describes his perception of the different levels of support made available by his different caregivers:

> I know pretty well where everyone stands and what I can and cannot ask for from each particular person. They have had the time to establish themselves where they want to be, what they <u>can</u> do, what their limits are as far as support.

Some participants mentioned difficulties with support persons who were unavailable when support was needed. This might happen because of a lack of supportive abilities and motivations, the burden of other roles, or a failure to perceive the need for help. In some cases, study participants were able to accept and understand these hindrances to support, as Steve did in this story about his mother:

> Mother's husband has been very, very ill...and she's just had her hands full with him. She really has had to focus all of her attention there. ... She's been pretty distant about [some]

things. I think that's partly just self-preservation.

At times participants felt uncomfortable with shifting family roles. Sandra has fulfilled the family's caretaker role since before she and her husband Mark were married. She occasionally wishes that she could be pampered more: "I think that sometimes he overestimates my abilities. ... I feel that he expects that I should be doing more than I'm really capable of doing sometimes." Bill describes a similar problem that occurred when he was too sick to do his house chores:

> If you don't vacuum about every other day, there are globs of dog hair everywhere. There was dust everywhere. [Marshall] would do the laundry and he'd cook some and wash the dishes and that was it. See, that was my job in a way. And he didn't want to realize the fact that I can't do as much as I used to.

Fostering independence

Practical support helps people during times when they are sick, in the hopes that their condition will improve. It tides people over, but should not create a

lasting or increased dependency. In most cases, HIV-positive individuals were eager to care for themselves and preserve their independent living. One form of support is that which fosters this goal.

Sandra describes the efforts of a close friend to help her maintain her lifestyle with her husband and young daughter: "My girlfriend just came up and cooked a ton of stuff and put it in the freezer so that those days when I don't feel very well I can pull something out that's already prepared." Her friend helped with Sandra's practical need for dinner on the table in a way that preserved daily choices and contributions.

Ronald is appreciative of the financial support he received, which allowed him to keep the autonomy he has established as a young adult:

> aRK's probably been the most supportive, because they've fixed me up and gotten me in this apartment. It was very handy. ... As long as I can live by myself, I want to live by myself. As long as I can do for myself, I'm going to do. I don't want to be living with somebody that tries to tell me what time I have to be home.

Ronald is happy to avoid the controlling messages he

expects if he is forced to move home to his mother.

Marilynn has a similar difficulty with a helpful older friend who plays a supportive but motherly role: "She's all right, but she tells me what to do. ... I mean, she gives me all this advice." In contrast, Marilynn's volunteer buddy respects her autonomy: "She gives me her opinions, but she's always my friend even if we disagree about my religion. Which is nice to know."

Toby expresses, in a beautiful passage, the graceful way in which he has accepted a certain loss of autonomy:

> I have such a desire to do things for myself. This is a new situation for me to be in a situation where people do help me, willingly, and there are times when I do literally have to ask for help. That's very difficult for me. ... Sometimes as I'm experiencing it, as a newness, it can be uncomfortable, but no, it's not negative. I always knew that no matter what someone was doing, whether I <u>personally</u> was comfortable with it, that it was coming to me by way of love and goodness.

One of the important aspects of autonomy is the freedom to make choices. Making choices about medical treatments was one way that participants kept a degree of control over their lives. One of the first doctors Scott visited disagreed with him about his treatment approach. Scott found a new doctor, and "let her know the way I feel." She agreed to start him on AZT therapy early in the course of his illness.

Bill has worked out several deals with his physician, Dr. Shepherd. He reports, "If you just passively let the medical people walk all over you, they will. They don't care if they hurt you." Dr. Shepherd has been very supportive and agreeable to Bill's decisions about what procedures he is willing to endure, and what comfort measures he demands be provided. For Bill, this teamwork restores some of the control he has lost through having a serious illness.

Caregivers compromise independence when they are overnurturing or push inappropriate coping styles. While Bette and her baby were in the hospital, they were assigned to an overeager nursery nurse. This woman kept trying to engage Bette in a conversation about her illness, in a genuinely concerned manner.

Bette had just learned of her diagnosis, was worried enough, and didn't feel ready to talk about it. She started avoiding the nursery, requesting that the baby be brought out to her: "And I'll be damned if she didn't find me. She came from over there! To my room, honey."

Andrew is a naturally gregarious person with many friends. He has had to develop ways of preserving his privacy, by taking the phone off the hook or not telling people when he goes into the hospital, so that he can get some rest. Andrew notices:

> When I'm feeling the worst, everyone wants to do the most. And I don't want anyone around me. ... If I'm in the hospital sometimes the phone will just ring and ring and ring. ... And I know that everyone is concerned. I'm very grateful for all of that. But when you're in the hospital, you're there because you're sick. Sometimes I can't deal with all the attention.

Summary

Practical support is perhaps the most important form of support in ensuring the physical well-being of many HIV-positive individuals. Through themes of daily

assistance and maintenance of independence, support is given to alleviate financial needs, needs for physical care, and needs for psychological integrity. These two themes are employed to describe a hopeful balance between offering enough practical support to address needs, and allowing enough autonomy to preserve an individual's chosen way of life.

Summary

This chapter section has been filled with descriptions of fourteen themes of support loosely organized into four major categories: emotional support, informational support, attitudinal support, and practical support. These themes were derived from descriptions of interactions between the study participants and their caregivers. Often stories called to mind more than one theme, so that a support person communicated empathy, presence, and support of daily needs all in the same gesture. Among the positive attributes of support are its occurrence on so many different levels, its ability to be expressed by a variety of people, and its adaptability to change when present within honest and communicative relationships.

UNMET NEEDS FOR SUPPORT

This chapter section contains my response to the research question: **What unmet needs for support are expressed by HIV-positive individuals?** Despite quite a few stories about difficulties with support persons, the participants expressed surprisingly few needs for support which failed to be met. Participants generally answered questions about needs in highly concrete terms. Their responses held a disappointing lack of richness with regard to emotional and attitudinal needs. In fact, the most common reply to my asking, "What's missing," was "Nothing." My favorite response, however, and perhaps the most sensible, was "A cure."

Unmet needs for practical assistance were described during several interviews, even if they were not explicitly mentioned when I asked about needs. Lisa explained her difficulty in finding safe **child care** for her HIV-positive son so that she could work outside the home. Andrew wishes he could get his prescription **medications by home delivery**, instead of hassling with bus schedules and a hike. Scott related his previous difficulty in procuring **food** when he was sick. Bill would really like to be able **to remain at**

home as long as possible before going into the hospital. Sandra recognizes that her husband will need some **help caring for her** if her condition declines. Susan also expressed her fears about the availability of **care if she becomes sick.**

Several people mentioned a need for **money.** Susan wanted a **telephone.** Two wanted more available **transportation.** George described his difficulty in getting to the doctor by bus when he is sick. Andrew wanted more mobility to visit friends who are not nearby. Two participant's families were very much impaired by their lack of understanding about HIV transmission, although **information** was not explicitly noted by these persons to be a need.

Emotional support is the final major category of unmet needs. Two men described their sincere hope to find **a mate**, as Scott says, "It would be nice to have someone to come home to, watch TV with, go out and do things." Rusty expressed a wish for more **companionship**, since he is often unable to leave his apartment. He also feels a lack of **support when people die**; fourteen people he knows have died this year. Toby misses his **friends from work.** Susan hopes she and

her daughter will **not be separated.** Sandra wishes more **support** were available **for her husband** and other partners of people who are HIV-positive.

A problem mentioned by almost everyone, but rarely clarified into an explicit need, is the lack of freedom to disclose HIV disease publicly without serious repercussions. Susan requests an **end to societal stigma** when she hopes: "That it won't be feared like it is now."

VALUES AND SPIRITUAL STRENGTHS HELPFUL TO COPING

This chapter section addresses the final research question: **What values or spiritual strengths contribute to coping with the experience of HIV infection?** Most study participants reported that they were doing well in coping with the illness, and that their coping strategies had improved over time. In this chapter section I present the major strategies voiced by individuals, organized into categories of values, attitudes, and actions (Figure 10).

Long-term survivors figure prominently in this section on strengths. They tended to be more outspoken than most about attitudes and coping mechanisms they have developed to improve their chances of survival.

VALUES

Becoming Closer to God

Becoming a More Loving Person

ATTITUDES

Taking It One Day at a Time

Thinking Positively

Counting Your Good Fortunes

ACTIONS

Finding Enjoyable Activities

Having Will and Determination

Helping with Your Own Healing

Figure 10. Values and spiritual strengths reported as helpful to coping

Five of the study participants (Rusty, Andrew, Bill, Steve, and Sandra) qualify as long-term survivors, having lived longer than the average of eighteen months after diagnosis with AIDS (Callen, 1990). Several other respondents expressed strengths characteristic of long-term survivors, though their illnesses now are at an earlier stage.

Values

Participants frequently reported experiencing a shift in values, a change in their perceptions of what is most important in life. Although not everyone noted such a change, those who did reported that their relationships with God and with the important people in their lives had taken a more central role.

Becoming closer to God

Some people experience their connection to the divine as a very personal relationship with God. This connection can be strengthened in times of adversity. Bette describes the changes in her spiritual life since the onset of her illness:

> I'm so close to Jesus. That's one thing it's done. Before, I'd go to church, and might not go back for two or three months. Now I'm up and

ready every Sunday. I might not feel hot. I feel very close to Jesus. I know Him. Now more than ever.

Lisa has also made a commitment since she became ill to attend church more regularly. She describes a conversation she had with her husband one day about her relatively sudden change of focus:

We were talking about it one day and he said, "It is so funny that when people get sick and they're thinking about dying, they call on God."

And I said, "Well, to me that's what He's there for." ... I just feel like He reaches you however He can. And illness is one way of reaching you.

After his diagnosis, Bill attended a year of classes in preparation for his confirmation as an official member of his church. His spirituality has been a source of great comfort:

I know there's life after death. I know God's up there, and if in His infinite wisdom I have to suffer some, I guess I'll have to suffer some.

It's comforting to know that. I mean, I just don't believe it, I know that there is an

afterlife. It takes a lot of the fear of death away from you.

Rusty also offers God a central role in his life, although he does not claim membership to any denomination. Rusty describes himself as having "understandings" with God which strengthen him:

> I keep looking at God, and I keep saying, "How much more can I take?" But I always keep in mind that God never puts more on you than you can handle. So I look at God and I say, "Well obviously, I'm one of the strongest people on the face of this earth."

Ronald does not place a high value on church attendance or religious exercises, but he does consider his private spiritual convictions important:

> I've done a lot of wrongdoings in my time, but as long as I know who's in my heart I know where I'm going when I do die. You don't have to go to church every day just to prove that you're going to heaven. Going to church is not going to get you into heaven. So I'm not that worried about dying.

Susan is another person who voices the importance of

her private faith in God: "He seems closer to me now. He's helped me through a lot, through prayer. And giving me the support people, leading me to them."

Becoming a more loving person

Many of the people in this study described a change in their daily activities, having less energy to devote to school or career ambitions. Some found their relationships with support persons, especially family and friends, to be taking a more central role. Sandra talked very candidly about her realization of this shift in values:

> The relationships that you have with those people who are closest to you are really what's important. I value relationships much more than future expectations of success or monetary gain or social status or any of that. I think that if you can strip away all of those things, that there are some really good, genuinely good, loving people out there. Maybe everybody has the ability to be that way, but there's just a lot of other garbage that gets in the way of people showing that.

Toby also speaks of his greater focus on relationships and becoming a more loving person:

> I have seen a lot of outpouring of love, not only in my own life, and my own thoughts have changed in many ways and my lifestyle has changed to be more loving. There's a lot of good despite the illness that has come of it. ... Someone once said that life is love in motion and only when we move towards each other in love are we fully alive. That's what I believe life is all about is living and loving.

One of the ways participants demonstrated an increased emphasis on caring for others was through volunteering to help others. Several people voiced their hope that their participation in my interviews, or other interviews they had done for the press, would be helpful and increase awareness among other people. Others mentioned a willingness to help in caring for other HIV-positive individuals. Rusty even conducted rounds in a local hospital to visit other people with AIDS, an altruistic activity that he also believes helps keep him alive:

> I know I'm not going to die from it because I am able to get my message across. I am able to express myself. I am able to show other people

> what I've been through, what I'm going through, by the way I write down my poetry. I can help other people. And as long as you're helping other people, God's got a use for you. If you're able to help other people then God says, "Why don't I keep this one around for a while? He can do some good."

Attitudes

Quite a few participants discussed the difficulty of living with the awareness of their serious illness. Most developed realistically hopeful ways of thinking to prevent them from becoming overwhelmed by negative possibilities, sorrow, and hopelessness. Although no one was immune to difficult days, the positive attitudes most worked to maintain helped to make such times as rare as possible.

Taking it one day at a time

Several interviewees mentioned their philosophy of dealing with the illness one day at a time. By focusing on the present, they were able to diminish disabling fears and worries. Sandra voices her version of this theme: "You just have to take things one day at a time. You can't worry about what's going to

happen six months from now or a year from now."

Scott says he would be scared to death if he started thinking about dying all the time:

> I don't think ahead about what I could get and what I'm going to look like when I get there. I just go a day at a time. I do my medication. And keep a good positive attitude every day on a daily basis. Sense of humor all the time. Just deal with it that way. I <u>strongly</u> advise that for anybody.

Andrew discusses what he has learned in over three years of being diagnosed with AIDS:

> I'm not afraid to watch a part on the TV about people with AIDS or read articles about it, because I don't assume anymore that that's going to be me or that that is me. I know that each individual reacts and deals with this differently. ... I can't look at someone I know with AIDS and say, "Okay, I'm going to go through this because they went through it six months ago." That doesn't make sense, because not only is it not true, you'll just sit there and worry about it. When is it going to happen to you? ... So that has

> helped as far as looking ahead or looking down the road. I just take each situation as it comes.

Thinking positively

Thinking positively was one of the most often mentioned themes related to effective coping. Some of the participants were careful to place positive thinking within the context of realism, however, as did Sandra: "Overall, I'm pretty optimistic. I don't think I'm going to survive. I think I'm going to die from this."

Andrew believes positive thinking helps him stay healthy, but he is not convinced that it will cure him:

> I really believe, and I probably didn't until this happened to me, but I really believe in the power of positive thinking. I believe in the ability each one of us has to take control of ourselves physically to help out. I'm not saying that we can erase cancer or things like that using our mind. I don't know about that. But I know that keeping my stress down and my attitude positive keeps me well, or weller.

Marilynn reports that she keeps herself concentrating on positive things by reading and

studying Bible scriptures. Scott keeps an attitude of continuing to learn about life. Sandra describes her methods for keeping a positive perspective:

> I've never been a very religious person, but I find that to have spiritual messages and affirmations and to think about those things at least once a day is helpful to me. I have a little book of daily meditations and I find that really helpful to keep myself in a positive frame of mind.

Andrew reports that he has ignored and then surpassed statistical predictions about how long he will live: "I have my problems like everybody else, but I haven't packed any bags yet. Because things could get a lot worse. And you cannot live like that. You can't live with this ominous outlook. Nobody can."

Counting your good fortunes

Finding things for which to be thankful is perhaps a natural extension of positive thinking. Despite sickness and difficulty, most people were thankful to be as healthy as they were, thankful to have the support they did, thankful that they were luckier than some. Scott describes his gratitude to be alive:

"People who are not ill take for granted what you see as precious. You see it in a totally different light." Bill also notes that in having a serious illness, "you really appreciate life much more."

Some people compared themselves with other people with HIV and found reason to be thankful. Sandra says she discovered, "There's a whole lot of people out there that are much worse off than I am." Steve admits:

> I've tried to remain aware of the fact that my situation may not be very typical. ... I just don't think that I've needed a lot of the support that might be needed by people who don't know day to day where they're going to be able to stay, or find food, or things like that.

"I'm very fortunate," says Bill, "because there are people with this disease who don't have anyone." "I just feel so fortunate," says Toby, "that my good comes from so many sources." "I'm more fortunate," says Sandra,

> in that the whole time I was growing up I always had, let's say, a double dose of self-esteem. So when I found out I was sick with this disease my

self-esteem greatly diminished, but I had so much of it that it wasn't possible to diminish it all the way. So I still feel pretty good about myself.

Actions

Participants frequently mentioned the positive effects of their efforts to stay busy with enjoyable activities and actions to improve their health. Strong positive attitudes underlie the decision to remain involved in life as much as possible. In recounting the actions they have made to promote good coping, participants voiced the desire to live life to the fullest.

Finding enjoyable activities

One of the most important methods of coping with the illness mentioned by the participants was staying involved in worthwhile activities. Not only did they benefit from the feeling of being productive individuals, the joy they derived from doing things they enjoyed gave them more zest for life.

Scott made some big changes in his life after his diagnosis, including a commitment to finish his college education. Here he shares the philosophy he lives by,

one of staying active and involved:

> You've got to make something good out of your life. Don't look for all the bad spots and situations you can be in, how depressed you can be. Find good things and fun things to do. Find something you can appreciate and just keep right on going with it. That will make your life a lot easier. And I think you'll enjoy your life a lot longer if you do that, instead of just constantly worrying all the time.

Sandra felt a great loss at not being able to continue her career after her diagnosis with AIDS almost two years ago. Her life has improved as she has found new directions in which to focus her energies:

> I've gotten another activity that I'm involved with. It's something that I can do on my own time when I feel like it and it's given me a little bit of direction. ... I was really miserable for quite a while because I didn't feel like I was being productive. I guess the old American work ethic really stuck with me: I felt that in order to be a worthy individual I needed to be productive, I needed to be doing something. Other than taking

care of the house and taking care of a child. ...

I was at group one night and I told somebody that now that I can see I'm doing something with this and I might be successful at it, I almost like my life again. That was a big part of being happy was to be able to do something productive.

Rusty has been active during his illness with many efforts aimed at increasing awareness and acceptance of both homosexuals and people with AIDS. He feels his sense of direction has helped his survival:

It's a greedy way of looking at it, but with the time I've got left, I'm going to make as much productive use out of it as I can. That's like with doing the lectures, that's like with helping people out, getting laws changed if they need to be, helping to integrate society. I've got a lot of dreams, a lot of things I'm going for. I think that's one of the things that keeps me going is my dreams. And being able to see those dreams come into reality. ... That is saying that I'm making a difference. I want to make a difference.

Several individuals spoke of an increased directedness with their activities, of deciding no

longer to waste time doing things they don't want to do. Joseph expresses this sentiment when he says, "I guess I've gotten more selfish about things. If there's something I don't want to do now, then I'm less likely to do it. Yardwork, for example." Andrew discusses his reasoning behind staying away from certain activities: "In a situation like this, sometimes you have to put yourself first. And you have to try to avoid negative situations." Bill describes his efforts to maintain a sense of control over his activities, whether by negotiating with his doctors about his treatment, or working out a budget with Marshall so that each has his own spending money.

Other individuals mentioned their desire to stay fully involved in life, or as Toby says, "The meaning for me, first of all, is that I believe we're here to live life to the fullest." Ronald reiterates this notion when he vows, "I'm going to do what I want to do as long as I can. And I don't care who likes it. That's the only way to be I think." Bill reports that after the onset of his illness he decided not to put off doing things he had long wanted to do, such as taking a trip or redecorating the house.

Having will and determination

Another way participants cope with their illness is by maintaining a spirit of will and determination. Although this theme sounds as if it should be categorized with other attitudes, it was so often combined with expressions of effort, "working on it," "dealing with it," that I believe it belongs in the category of actions.

Andrew feels he has a very strong will to live, and believes his spirit of survival has kept him going:

> Really, some days I'm on top of it and some days, every little ache and pain, I'm gonna be dead tomorrow. Those are the days when you really have to work hard to get yourself out of it. Because it's a lot easier to be sad than it is to be happy. It's a lot less work. ...
>
> You hear stories of AIDS patients who live for ten years or more. You have to say, "Why not me?" And do everything you can to make that you.

Scott discusses his adjustment to the fact that he is HIV-positive, and his determination to make the most of the situation:

> I just accepted it as a part of my life. I mean

> you really don't have a choice, considering the virus and what it does. You can either handle it or it will handle you. There's no two ways about it. ... I think that with a lot of mind control, a lot of will and determination, you can just about do anything. If the chances are so great that you're inevitably going to die, do it in a graceful way. Do it with some strength. Because I really think if you put up a fight you're going to get something back out of it.

Rusty shares his viewpoint, which includes an emphasis on being honest with himself:

> Well, I'm glad I'm a Virgo because I can deal with things. I can look at them logically and decide on a course of action, instead of being afraid and trying to hide from it. You have to deal with it. If you don't deal with it, you die.

Several others also expressed a will to live and determination to fight to improve their chances of survival. Steve speaks with simplicity and modesty: "I see myself handling whatever comes along." Toby expresses the decisiveness of his desire to live: "I do believe that as I try to maintain an idea of a focus

on what I truly want that my life around me will change. And I've seen it happen. So I'm very hopeful." Ronald voices his determination in metaphors of battle: "I'm not going to lie around and die. There's no sense in giving up. I refuse to give up. I'll fight to the bitter end."

Helping with your own healing

A number of people had developed strategies to reduce the likelihood of illness, or to ease their recovery from periodic exacerbations. Often what was expressed was their attitude of being involved as a full partner in medical treatment, rapidly seeking help for problems and participating in reasonable self-care activities. Participants also mentioned avoidance of stress and negativity, getting plenty of rest and good food, exercising within their abilities, and being aware but not overconcerned about the risks of things they really want to do.

Andrew discusses his desire to know as much about his condition and treatment plan as possible:

> Medically I think it's real important to understand as much as you can and your doctor can explain to you. If you don't understand what's

going on with your body, then you can't help your body heal itself.

Joseph has a much different attitude about his body since the onset of his illness. Before he was sick, he felt comfortable waiting for his body to heal itself of minor wounds or infectious illnesses. In contrast, "Now if I have a problem I get it taken care of right away. I'll go to the doctor and get some antibiotics."

Several of the participants, including Scott, described actions they take to maximize their health, such as "good exercise and good eating habits and trying to think positively." Rusty's techniques include arranging his environment to be cheerful and focused on his healing: "I've put growth around me, the plants, and I put herbs around me, and it's just--I'm trying to make everything as positive as possible. That's all anybody can do."

Sandra realizes that her need to rest and take care of her body will sometimes clash with her desire to be involved in her favorite activities:

The days that I feel well I get out and I do things that I want to do, and the days that I

> don't I lie around. The days that I don't feel well are really kind of hard because I feel guilty about lying around and not doing anything. Even though I know that I've got to limit my activity or else the next day I'm going to be worse than I was. It's hard if you're used to being an active person to not do anything.

Susan has adjusted her lifestyle and activities since her diagnosis. Although she is not feeling particularly unwell, she wants to take better care of herself: "I've settled down a whole lot. A whole lot: Drugs, my wild lifestyle. I wanted to go go go go. My complete outlook on things [has changed]."

A few people also mentioned the usefulness of avoidance or denial when dealing with particularly difficult periods of adjustment. Although this technique might be detrimental if it were used to the exclusion of more constructive methods, it should not be overlooked as a valid coping response. Ronald describes his reaction to his partner Dan's death, after seven years together and many months in which Ronald cared for Dan at home:

> I couldn't believe that he died. ... I knew it

> happened, but I didn't want to believe it. So I hadn't gotten to drink anything in six weeks and I had a gallon of rum under my kitchen sink and several two-liters of Coke, and when he died the first thing I did was to make me a very strong drink. And I got drunk! And I think that's what really helped me pull through. If I hadn't had that I probably wouldn't have made it.
>
> But I left while the hearse was taking him away. When they came in the hearse to get him, I left. I didn't want to see them take him.

Marilynn initially coped with the shock of her diagnosis by smoking marijuana every day. Although she no longer uses drugs, she still tries to keep her mind off her illness. Marilynn says, "I'm dealing with it; I know it's there. But I just don't think about it." Avoiding negative thoughts, Marilynn instead focuses on positive activities such as Bible study: "I guess it's my cop out now. But it's a good one. It makes me happy. It's better than drugs."

Andrew uses several techniques to get himself out of bad moods, including working on his attitude, moving to a different environment, and getting out and doing

things. One of his occasional methods is to take a prescribed medication at bedtime to reduce his feelings of anxiety:

> I will admit sometimes I will take a pill and go to sleep. But I'll wake up and everything will be fine. The advantage to that is that it will relax me enough mentally and physically that I can start thinking about things that maybe have been so scary, and so sad. I think that's fine when I'm in the hospital for an extended period. ... They help just take the edge off being there. ... It's nice to have the option when you're stressed out.

Andrew also remarks that he is cautious about the use of pain medications, fearing that they can detract from a person's will to live.

Summary

In this chapter section I have described the efforts of HIV-positive individuals to cope with their illnesses in order to live longer and more happily. The voices of five long-term survivors have been heard often, as well as accounts by those who have developed useful values and strengths for survival while still at early stages of the illness.

This chapter has included my responses to the four major research questions of the study. I have drawn heavily from the stories, descriptions, and reflections of the study participants to form an image of both the variety and the commonality of their experiences. While maintaining the anonymity of the participants, I have hoped to convey the richness and depth, the honor and determination, behind their struggles.

CHAPTER FIVE

DISCUSSION AND IMPLICATIONS

The purpose of this study has been to explore the experiences of people who are HIV-positive, with special interest in the types of support they receive from the people in their support networks. In this final chapter I summarize what has been learned with regard to each of the four guiding research questions. Implications of the study, which are discussed following the summary of findings, include applications of the findings to clinical nursing practice, social change, and further research efforts.

SUMMARY OF FINDINGS

What are the relationships of HIV-positive individuals to their important support persons?

The study participants drew much of their support from family members, lovers or spouses, and close friends. Volunteer and professional care providers played contributory, though usually not central, roles.

Female support persons, including mothers,

sisters, and female friends and care providers, were more commonly ranked as highly supportive than their male counterparts. This finding correlates with those of Donlou, Wolcott, Gottlieb, and Landsverk (1985) who found that mothers and sisters were more frequent sources of support than fathers or brothers.

Donlou et al. (1985) also found a relationship between low self-esteem and professional care providers being key sources of support. Although I did not measure self-esteem specifically, I observed a similar pattern related to sources of support and the integrity of family systems. Family members and friends tended to supercede professional providers as the most important sources of support unless the former were overwhelmingly lacking in supportive abilities or inclinations.

How is caring expressed to persons who are HIV-positive by persons in their support network?

I categorized the expressions of caring into fourteen themes, which fall into major divisions of emotional, informational, attitudinal, and practical support. I chose to encourage participants to develop their own definitions of support, so that they

described types of support they felt were important. Although Cobb (1976) reports that practical assistance should not be considered as social support, for example, most of the participants considered this to be a significant style of support.

Participants also clearly stated the importance of support occuring within the context of relationships. They voiced their joys at the ongoing commitments of family and friendship ties, their desires to avoid burdening their care providers, and their struggles to maintain comfortable levels of autonomy and mutual friendship. These descriptions of the dynamics of support mesh well with the categorizations of several theorists: House (1981) described support as a flow of exchange within relationships. Tilden and Galyon (1987) explained the reciprocal costs of support, including loss of autonomy and concern for caregivers. Finally, Ellison (1987) outlined developmental needs, such as desires for autonomy or emotional security, which affect perceptions of supportiveness.

Overall, the thematic arrangement of types of support coincides well with Cobb's (1976) definition of support as a process of communication. Although each

type of support was represented by behavioral components, study participants perceived messages within the actions which confirmed their feelings of personal worth, of being loved, respected, and included.

What unmet needs for support are expressed by HIV-positive individuals?

This research question was the most difficult to answer, perhaps because participants seemed reluctant to voice their unmet needs, or voiced them mostly in pragmatic terms. Alternately, participants may have responded to activate their support networks in order to obtain the emotional support they need, as theorist Barrera (1986) predicts.

Some of the unmet needs of HIV-positive individuals, such as those for companionship, can be in part explained by the effects of stigma. Others, such as needs for money or transportation, reflect the devastating economic impact of any long-term illness.

What values or spiritual strengths contribute to coping with the experience of HIV infection?

The expressions of strengths for survival were particularly interesting in the context of ongoing

research into qualities shared by long-term survivors (Callen, 1990). Participants' descriptions of phases of adjustment to the illness, as well as the eventual development of successful coping methods, uphold the tentative findings of earlier researchers who observed an increase in hopefulness and a decrease in alienation and powerlessness during later stages of the illness (Carson, Soeken, Shanty, & Terry, 1990; Korniewicz, O'Brien, and Larson,1990)

Specific coping strategies identified in this study have been mentioned in recent reports of qualitative research. Weiss (1988) noted that a sense of hopefulness and an approach toward the illness as a challenge tended to improve quality of life. Bennett (1990) described attitudes held by her respondents, including angry refusal to assume the role of victim, and the belief that, "I'm fortunate."

APPLICATIONS TO NURSING PRACTICE

The professional practice of nursing is inseparable from social change activity. When caring for patients, educating clients and their families, and promoting self-care activities, nurses communicate ways of thinking about our bodies, our beliefs in personal

worth, our relationships with family and friends, and our feelings about the transience of health. Nursing practice must be approached as a ceaseless effort at empowerment, in which clients are offered the vision of their potential health, autonomy, and satisfying relationships with others.

This research study has confirmed the important role of nurses as direct sources of support and as catalysts for supportive interactions within available social networks. Guidelines for improving the abilities of nurses, families and friends, and members of general society to be supportive are presented in this chapter section.

Although I believe that the ability to act compassionately begins within each individual, depending on his or her inclination to self-awareness and empathy, nursing education also plays a formative role. In the compressed attempts of educators to impart the necessary technical knowledge and ability, personal development is easily overlooked. Nursing students need the opportunity to become aware of their own values, personality styles, and cultural beliefs. Nurses must develop, as part of our professional

culture, a greater appreciation of the variety and value of the cultural backgrounds of our clients. We must begin to question hardened prejudices and assumptions, often subtly perpetuated by the language we use. People who take nonprescription drugs, for example, are automatically labeled with the pejorative term "abuser." Understanding begins with respect for people whose challenges and resources we do not share.

The themes of support presented in the previous chapter highlight several areas of support which easily become points of emphasis in nursing practice. One such area is support of coping behaviors which the client already uses with some success. If a client copes with an initial diagnosis by temporarily avoiding the issue and choosing not to discuss it, this should be viewed a valid defense against strong feelings. Although some coping mechanisms appear more "healthy" than others, nurses must refrain from the impulse to judge, and allow the individual's choice and prior abilities to suggest what is most appropriate.

Nurses have a responsibility to support the autonomy of clients, and to encourage their involvement in treatment plans. Health care providers should

accustom themselves to asking for permission and agreement about treatments, regardless of the setting in which they work. No adult should be forcibly held down on a table for any procedure! Nurses can also assist in the development of businesses, such as home health care services, which support the desire of many chronically ill people to live more independently. Child care resources are also needed for HIV-positive youngsters, so that their parents may continue to lead more normal lives.

Nurses are important catalysts for the effectiveness of family and friendship networks. As House (1981) explains, nurses may not be able to find family and friends for everyone, but they can sometimes help existing support people to do their job better. Helping to develop communication skills, providing information to alleviate unnecessary fears, and continuing to offer ill people respect and independence are valuable ways that nurses help support persons understand their roles.

The networks of family and friends sometimes need some encouragement from nurses, so that redirected anger and miscommunication do not lead to harmful

divisiveness. In particular, nurses can respect the role of homosexual partners, who generally lack legal rights, in interactions with clients' families of birth. Mary Catherine Bateson and Richard Goldsby (1988) exhort the value of stable relationships as a source of benefit to society. As can be seen from this study, committed relationships are a frequent context for the expression of supportive gestures. Therefore, encouraging the stability and legitimacy of homosexual relationships is a worthwhile societal goal. Bateson and Goldsby argue:

> We cannot expect those with homosexual preferences to fit into social expectations of sustained relationships unless we treat gay and lesbian relationships as equivalent in value to heterosexual relationships. Marriage is hard enough to maintain in a society that approves of it and values it. This would mean finding ways to register and celebrate new commitments, permitting gay couples to adopt, preventing discrimination in housing, and treating same-sex companions as legal spouses. (p. 129-130).

Nurses may find that many clients can be helped to

empower themselves in their relationships and life choices. As a worldwide phenomenon, women often have difficulty asserting their control over sexual and reproductive choices. Women are physiologically more vulnerable to sexually transmitted diseases than men, but may need a nurse's encouragement before they insist upon the use of condoms. When nurses meet with clients, especially in outpatient settings, they have the opportunity to encourage self-direction toward useful goals. People in underprivileged communities, especially women, will occasionally benefit from the nurse's belief in realistic aspirations other than early sexual activity and intravenous drug use. As much as possible, nurses must foster real social change to expand opportunities for those in cultures of poverty, addictive drug use, and prostitution.

In every setting, nurses can work toward social changes, such as increasing the supportive skills of males, who have not traditionally been socialized to feel comfortable about these abilities. When nurses encourage the involvement of new fathers in the processes of pregnancy and delivery, or help men to lovingly care for their ailing parents, this attention

contributes to a slow unfolding of social change.

Nurses must become strong advocates for persons with HIV infection to continue to lead active and productive lives over the long course of the illness. Advocacy for the involvement of HIV-positive individuals in their chosen careers, including the safe practice of nursing, research, and medicine, is a vital endeavor.

Finally, nurses are active facilitators for the spread of information and new ways of looking at things. Because of their frequent contact with clients and families, nurses are able to promote the awareness of sexual health and choices, including preventive measures such as the use of condoms. Nurses are well positioned to combat social attitudes of stigma, alienation, and hopelessness about HIV infection. An important new role for nurses is to encourage a wider audience for the voices of people with HIV disease who are surviving with endurance and enjoyment of life. They are a source of hope.

RECOMMENDATIONS FOR FURTHER STUDY

One thing I hope this study has made vividly clear is that people with HIV infection are persons of

remarkable depth, dignity, and worth. In the earlier days of the AIDS epidemic, conservative politicians sometimes publicly expressed the opinion that AIDS was a convenient way of getting rid of stigmatized groups like homosexuals and intravenous drug users, implying that a cure should not be sought too quickly. On the contrary, the life of every person in this study is precious. A cure cannot be found quickly enough.

In the absence of a cure, we need to know more about helping people who are HIV-positive to live their lives longer, more productively, and more enjoyably. Future studies might evaluate changing societal awareness of HIV disease, and interventions leading to greater understanding. Interval studies of social support which take into account the changing demographics of the illness will be important in shaping the responses of professional and community care providers to changing needs. Studies of long-term survivors may give us information which will help make almost everyone a long-term survivor.

CONCLUSION

This research study has focused on the responses of HIV-positive individuals and their care providers to

a serious, life-threatening illness. Although much of what has be found may also be true for persons struggling with a diagnosis of cancer, diabetes, or heart disease, HIV disease is distinguished by its association with stigma. As Bateson and Goldsby (1988) remark: "Anyone with an HIV infection is really afflicted by three diseases--HIV itself, personal fear, and the fear felt by others" (p. 111).

Perhaps the most beneficial supportive action we can make is movement away from unquestioned fear, and towards understanding, realistic hope, and sustained affection. All members of society, whether or not they know someone with HIV, can offer the support of working to reduce every form of societal stigma and alienation. Free of fear, people are generally able to respond to HIV infection as they would to any other illness, with consideration and compassion.

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APPENDICES

Information Sheet

I invite you to participate in a study I am doing which will explore people's reactions to illness and the support they receive from people who care about them. This research, which is being done through the College of Nursing at the University of Tennessee, will be the basis for my master's thesis.

If you agree to participate in my study, you will be asked to complete a brief demographic questionnaire and then respond to a series of oral discussion-style questions. You will also be required to sign a consent form, which is attached, stating that you understand the conditions of the study. I hope that you will benefit from the process of reflecting on and responding to the research questions. I do not anticipate any risk to you as a participant of the study. I hope that the findings of this study will lead to better attention to people's needs for support.

Your responses will be held in confidence by myself and my advisory committee members (Dr. Sandra Thomas, Dr. Kathleen deMarrais, Dr. Betsy Overton, Ms. Ginger Evans). Your signed consent form will be placed in a sealed envelope which will be stored by Dr. Charles Rees. You do not have to tell me your real name. I ask you to make up a name (pseudonym) of your choice which will be used to identify any information you give. Our conversation will need to be audiotaped for accuracy, but I will be primarily working from written transcriptions of the tapes. These tapes will be stored for seven years, unless you request otherwise, to provide a record of the accuracy of the data. I will ask you to verbally repeat your consent at the start of our interview, since I will not see your written consent form. All transcripts and tapes will be kept in a locked filing cabinet in my home. When I write up my findings it will not be possible for readers to identify an individual by quotations or responses.

Participation in this study is entirely voluntary. You may withdraw from participation or refuse to answer specific questions at any time without any penalty. During our conversation I will be asking you about various types of support you receive and needs you may have. As a researcher I will not be able to help you with those needs, but I can refer you to professional caregivers at your request. I would be happy for you to contact me at any time if you have further questions about the project or your participation in it.

Susan McCallister
College of Nursing

Participation Consent Form

I understand that the purpose of this study is to learn about the types of support or caring that are important to people when experiencing an illness.

I understand that all my responses are confidential. Pseudonyms will be used to identify all data, such as the completed questionnaire and transcripts of our audiotaped discussion.

I understand that my participation in the study is completely voluntary. I may withdraw from participation or refuse to answer specific questions at any time without penalty. Potential risks (such as loss of privacy) have been minimized by the design of the study. The benefits to me are in the process of reflecting on and responding to the research questions, and in contributing to knowledge about people's needs for support.

I have read the information sheet supplied by the researcher. I understand how, where, and how long taped and transcribed responses will be stored, as well as who will have access to them.

I understand that I am free to contact the researcher at any time if I have any further questions about the project or my participation in it.

Signature_____

Date_____

Verbal Consent Form

The purpose of this study is to learn about the types of support or caring that are important to people who are HIV-positive.

All your responses are confidential. Pseudonyms will be used to identify all data, such as the completed questionnaire and transcripts of our audiotaped discussion.

Your participation in the study is completely voluntary. You may withdraw from participation or refuse to answer specific questions at any time without penalty. Potential risks (such as loss of privacy) have been minimized by the design of the study. The benefits to you are in the process of reflecting on and responding to the research questions, and in contributing to knowledge about PWA's [persons with AIDS] needs for support.

Have you read the information sheet I gave you?
[Participant will respond yes or no.]

Do you understand how, where, and how long taped and transcribed responses will be stored, and who will have access to them?
[Participant will respond yes or no.]

It is customary to securely store raw data, including audiotapes, for seven years. Is this okay with you?
[Participant will respond yes or no. A different time period may be negotiated.]

You are free to contact me at any time if you have any further questions about the project or your participation in it. You are also free to review your own tapes if you would like. Do you have any questions now?
[Participant will respond yes or no.]

Do you agree to be in the study?
[Participant will respond yes or no.]

Demographic Questionnaire

Please fill in your responses in the space provided. Feel free to make additional comments.

1. What is your age?
2. What is your sex?
3. How long have you lived in Knoxville?
4. Describe the number of people in your household and their relationship to you.

5. Do you have children?

   If yes, please list their ages.

6. Describe your educational background, including fields of study.
7. What is your occupation?
8. What is your current health status?

   A. Actual AIDS diagnosis

   B. HIV+ / some symptoms

   C. HIV+ / no symptoms

9. How long have you known about your diagnosis?
10. Do you have a lover, partner, or spouse?

    If yes, how long have you been together?

Interview Protocol

1. Tell me about when you first found out about your illness. What was going on, and how were you feeling about it?
2. Who did you talk to about it? What was their response?
3. Can you think of a time when someone had a negative reaction?
4. Do you feel that the way you got the virus has made a difference?
5. Who have turned out to be the most supportive people? What do they do to show their support?
6. Can you recall a time when someone was trying to be helpful or supportive, but it came across as being negative to you?
7. What needs do you have that you have trouble getting met? What's missing?
8. Now that some time has gone by, how do you see yourself coping with all this?
9. What is your outlook on life or your feeling about the meaning of life now?

VITA

Susan McCallister graduated from the University of North Carolina at Greensboro in 1985 with a baccalaureate degree, majoring in religious studies and minoring in dance. After several years of travel, adventures, and major and minor mishaps, she enrolled in the Master of Science in Nursing program at the University of Tennessee at Knoxville, from which she graduated in August 1991.

For a year and a half Ms. McCallister has volunteered with a.i.d.s. Response Knoxville as a buddy to a woman with a delightful sense of honesty and wit. Ms. McCallister is currently employed as a family nurse practitioner in the prenatal clinic of the Knox County Health Department, where she works part-time so that she may also pursue her interests in music, dance, and the meanings of life.