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Origins and development of exceptional responses to AIDS : implications for research and education.

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ORIGINS AND DEVELOPMENT OF EXCEPTIONAL RESPONSES TO AIDS: IMPLICATIONS FOR RESEARCH AND EDUCATION

A Dissertation Presented

by

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DEDICATION

To my Mom and Dad:

whole-hearted.

whole-loving,

wholesome people.

I was raised and bathed in the warmth of their love. They bring honor, respect and excellence into being. I present them with this flower of thanks...

my share is theirs.

I love you Mom and Dad.

ACKNOWLEDGEMENTS

I wish to acknowledge, praise and thank God for granting me the power to see this project to a reasonably graceful conclusion.

The most important people in helping this process, were my wife and children: they ran the family while I ran the computer. Their knowledge and experience of "surviving a challenge" has grown. Their love and support provided me a nest, a foundation.

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Al Winder rallied to my call for help ... and generously provided me his time, his experience and his intelligence. Thank-you.

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Many other friends buoyed me: they never doubted my ability or my resolve. The like me the way I am: Thanks Pat, Greg, Jeff, Bette, and Karen and the Olsten staff.

A warm acknowledgement and thanks to the AIDS-counselors, especially to Judy Fine. She single-handedly comprised at least 50% of both experimental groups, and also patiently accepted and nurtured me beyond my first-interview naivete.

Finally a special thanks and offer of love and prayer to the AIDS-survivors, for whom, and with whom this project is offered.

ABSTRACT

ORIGINS AND DEVELOPMENT

OF EXCEPTIONAL RESPONSES TO AIDS:

IMPLICATIONS FOR

RESEARCH AND EDUCATION

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Worldwide, people are contracting and dying from AIDS at a devastating rate: in varying degrees, fear and desperation has affected every segment of society. AIDS demands action. Successful AIDS action requires the finest physiological, biochemical and psycho-social coordination ever demanded by any other human crisis. To date, this finesse has not been fully achieved. There are some exceptional long-term AIDS-survivors (LTASs), however, who seem to be defying the odds. They live at least three years beyond diagnosis, significantly longer than the 70% of people with AIDS (PWAs) who die within two years after diagnosis (Douglas & Pinsky, 1987; Frumkin & Leonard, 1987; Runck, 1986).

In a qualitative, human inquiry study involving individual interviews and group processes, four LTASs and four AIDS-counselors, independently and collectively developed theories of survival: the origins, development

and manifestation of exceptionality in long-term survival of AIDS. The findings for this group of survivors follow:

Their most distinguishing characteristics appear to be the determined, self-realized and abundant psycho-social styles recognized in survivors of other life crises. In this sample, some of their coping skills were reportedly developed in challenging or compromising situations that occurred before-HIV-diagnosis. In those situations, they usually adapted by changing their response, rather than by trying to change the typically unyielding or rigid circumstances that they faced.

In developing exceptionality in response to AIDS, these LTASs seemed to progress through these steps: Shock, Choosing To Live, Owning Up, Going For It, Respecting Reality, and Empowerment. Concomitant with their progression were: a significantly felt need to experience "more" in life; feelings of urgency with respect to time; and the presence of people who influenced the development of coping or survival skills.

Exceptionality in long-term survival of AIDS seems to be a daily process of choosing to live, and a progressive empowering of self and others: choosing to acknowledge, accept and fully present self in an internally and externally consistent way. The implications for research and education and the potential benefits for society at large seem evident: One can love, support, provide information and hope, and accept and empower people for whom they are, and for what they choose.

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CHAPTER 1

THE PROBLEM

AIDS is invariably fatal: approximately fifty percent of people with AIDS [PWAs] die within the first year, and seventy to eighty percent expire before two years have passed (Douglas & Pinsky, 1987; Frumkin & Leonard, 1987; Runck, 1986). A relative few long-term AIDS survivors [LTASs] live more than three years beyond diagnosis. Recent research suggests that an "exceptional" coping style is one factor in their survival. Their exceptionality profile is essentially the same as that of people with cancer who beat long odds, and of others who triumph over a variety of tragedies.

Many investigators are attempting to understand why some PWAs survive much longer than others. Based on research findings as presented in the literature, two basic assumptions are taken as "givens:"

(1) Psycho-social variables play an important role in survival; and

(2) There are certain psycho-social variables which seem to be outstanding in terms of fostering survival.

Virtually no research that addressed the issue of how the exceptional survival skills of long-term AIDS survivors develops was found. The purpose of this descriptive multiple case study was to identify the possible origins of

LTASs' exceptional responses. The goal of this dissertation, therefore, was:

To generate tentative conlusions about the common origins of the development of effective survival skills in LTASs.

The following are this study's key terms and their operational definitions:

AIDS is an acronym for "Acquired Immune Deficiency Syndrome," a human disease process first formally identified and classified in 1981 by the federal Center for Disease Control [CDC].

As classified by the CDC, long-term AIDS survivors are PWAs who have survived at least three years following initial diagnosis of full-blown AIDS.

Critical transformation points are major turning points in life which serve to refocus, add meaning to, or otherwise transform individual world view.

Personal style refers to a characteristic way of viewing the world, a cognitive conceptualization by which meaning and order is individually imposed onto a person's relationship with their environment.

Coping styles and/or survival skills signifies patterns of thoughts, actions, feelings, attitudes, values and beliefs that are effective in compensating for, managing, and triumphing over the stresses and strains of life. Common to long-term survivors of AIDS, cancers, and other life-threatening crises are "exceptionality" coping styles.

Teachable or learnable exceptionality responses refer to those responses in exceptionality coping styles which teachers or counselors can teach - and PWAs can learn - in order to facilitate longevity and/or healing.

AIDS continues to spread across the globe at an exponential rate. In 1979, the United States recorded 11 cases of AIDS (Douglas & Pinsky, 1987); an Associated Press release on January 9, 1989[1] reports that as of December 14, 1988, the World Health Organization [WHO] records 80,538 cases in the United States alone, and estimates more than 350,000 world wide. In that same release Dr. Jonathan Mann, director of the WHO's global program on AIDS, predicts that "during 1989 and 1990, more than 400,000 new cases are expected to occur [worldwide], with another 600,000 anticipated in the following three years."

Although no cure has been found, there may be lessons to learn from the LTASs. They currently number nearly two thousand, and represent approximately fifteen percent of all PWAs (Gavzer, 1988). If characteristic LTAS coping styles can be identified, and appear to be learned at any point in life, the spectrum of possible therapeutic and/or educational applications broadens. Education may be a vehicle for increasing the probability of extended longevity and improved quality of life of people with AIDS.

---

[1] AIDS cases near 133,000. (1989, January, 9). Associated Press: Berkshire Eagle, Pittsfield, MA., p. C5.

The underlying hope for this study was to gain insight in the process of helping people choose health, life and abundance. Therapists, parents and leaders in general could benefit from this information.

CHAPTER 2

LITERATURE REVIEW

This chapter is organized in the same order as these chapter goals are listed:

(1) To present an overall picture of the AIDS epidemic, the people affected and their responses.

(2) To provide a review of current treatment approaches.

(3) To introduce and explain related research philosophy and relevant findings.

(4) To provide theoretical perspectives relevant to the study.

2.1 AIDS: What is it?

AIDS is actually the final stage in a progression of medically compromised conditions that occur as a result of infection by the Human Immunodeficiency Virus [HIV]. Although the virus can lay dormant for significant periods of time, it eventually causes a generalized rash of symptoms (e.g. prolonged fevers, severe weight loss, persistent diarrhea, skin rash, persistent cough, shortness of breath: Gong, 1985). Ultimately, however, the virus severely damages and depletes certain immune system cells, thereby leaving HIV-infected people susceptible to opportunistic infections: diseases which are usually routinely encountered and successfully combatted by

normally functioning immune systems. The existence of opportunistic infections or cancers is the key factor in differentiating a diagnosis of AIDS vs. the less medically compromising HIV-related syndromes which precede it.

Although a public opinion poll might indicate otherwise, the Institute of Medicine's National Academy of Sciences classifies the AIDS virus "fragile." The AIDS virus is very unhardy outside of the environment within which it thrives: the human body, especially in blood and semen (Institute of Medicine, 1986). The blood/semen major routes of transmission of infection set up two predominant risk-categories in the United States: (1) Male bisexual and homosexual individuals (especially those who are receptive partners in unprotected anal intercourse); and (2) IV drug abusers who share needles. Their vulnerability was accentuated by two other complicating factors: (1) the infectious but typically asymptomatic incubation period between viral infection and onset of AIDS-related symptoms has been reported to vary anywhere between six months up to nine years among PWA (Bohm, 1987; Douglas & Pinsky, 1987; Koop, 1987); and (2) some individuals have multiple sex and/or needle-sharing partners (Bohm, 1987; Flaskerud, 1987; Flavin & Frances, 1987; Gafoor, 1988; Koop, 1987; Piot, 1988). Without being aware of their own HIV-positive status, very mobile individuals unwittingly passed on the infection to others who did similarly. Although to a lesser degree, this

continues to happen today (Flavin & Francis, 1987; Morokoff, Holmes, & Silvia-Weisse, 1987; Piot, Plummer, Mhalu, Lamboray, Chin, & Mann, 1988). The result is a geometric progression which has created a world-wide epidemic. Although the majority of diagnosed individuals still come from those two subgroups, the problem has reached to virtually every portion of the population (Douglas & Pinsky, 1987; Gong, 1985; Koop, 1987; Langone, 1988).

2.2 Psycho-Social Effects.

Although the AIDS-virus is not age discriminatory, it has been contracted predominantly by men aged twenty to fifty years (Gong, 1985). Preparing for death at any age may be difficult; at such a young age, it may be especially traumatic. Nichols (1987) categorizes the basic adjustment to the "multiple crises and repeated stresses" of AIDS as a "catastrophic reaction." He describes AIDS as a stress and chaos-inducing disease which provokes "situational distress": i.e. "occurring when stress is so great that everybody who is exposed to it has a reaction, and the reaction tends to be similar in everyone." Many researchers have documented a plethora of negative reactions, thoughts and feelings experienced by people with AIDS: fear; anxiety; denial; uncertainty; isolation; guilt; shame; lowered self esteem; sadness; helplessness; hopelessness; fear of contagiousness,

disfigurement and loss of bodily control; panic; intense nervousness or irritability; feelings of desertion by family, friends, lovers and God; preoccupation with illness or physical symptoms; increased use of drugs (including alcohol); insomnia; lack of concentration; loss of function at work or home; inability to enjoy social or sexual life; thoughts of suicide; and avoidance of needed medical care (Bohm, 1987; Durham & Hatcher, 1984; Flavin & Frances, 1987; Haney, 1988; Lomax and Sandler, 1988; Morin, Charles & Maylor, 1984; Nichols & Ostrow, 1984; Perry & Tross, 1984; Price, Omizo & Hammett, 1986; Thompson, 1987).

Nichols (1987) summarizes the above-described "catastrophic-type" reaction as follows:

(1) Crisis;

(2) transition; and

(3) resolution or deficiency state.

> The crisis, especially the initial crisis, is characterized by denial where the patient is almost nonchalant. ...
>
> The transitional state is a terribly disruptive state .... The patient experiences a series of alternating emotions: anger, fear, terror, depression, and suicidal thoughts.
>
> [Nichols characterizes resolution of transition as] "acceptance," ...[or] "supported denial." Here the patients achieve a state where

they are able to function again .... Patients no longer deny their illness. They know they have AIDS, they know their time is limited, they know what their losses are. What they accept is that they are still alive. ... [however], this stage does not last very long because ... there is always a new crisis .... As the disease progresses, the sense of loss becomes overwhelming.

Lomax & Sandler (1988) use slightly different terminology to provide a concise summary of the above.

Table 2.1 Lomax & Sadler's (1988) Characterization of Stages of Living with AIDS.

Stage	characterized by:
Initial Diagnosis	Emotional crisis.
Stabilization	Adjustment and reframing.
Deterioration	Loss of hope; arising of death and dying issues.
Termination	Anger, denial and withdrawal; or, acceptance.

As reported, AIDS strikes heavily among homosexuals and IV drug abusers, groups which have already been stigmatized by society (Flavin & Frances, 1987; Haney, 1988; Kubler-Ross, 1987; Nichols & Ostrow, 1984; Thompson, 1987). Patrick Haney, a PWA who has died since his writing, described a "them and us" response from society:

The "them and us" mentality is a way of thinking about AIDS that encourages people to think it's not

> a problem they need to worry about, because AIDS primarily affects them. Most of us know who "them" are: gay men, drug abusers, hemophiliacs, Haitians, blacks, Hispanics, women, prostitutes, and some children. (Haney, 1988, p. 251)

Families and relatives of people with AIDS are also subject to strong reactions (Flaskerud, 1987; Flavin & Frances, 1987). They too may need help in coping with the news and the course of the illness experienced by their son or daughter, friend, lover or spouse. For some, the news of the diagnosis could conceivably be doubly shocking if they are also learning for the first time about the others' homosexuality or illegal drug abuse.

Although rarely found reported in the literature, some people with AIDS turn their AIDS situation from crisis to apparent fullness: e.g. increased awareness of joy and opportunity in life; growing awareness of and increased ability to effectively respond to personal and interpersonal needs; greater capacity to empathize and to unconditionally give and receive love (Adams, 1988; Gavzer, 1988; Haney, 1988; Solomon, Temoshok, O'Leary & Zich, 1988). These seem to be ideal treatment goals that could lead to some exceptional ends: e.g. improved quality of life; increased longevity; and peace in dying.

2.3 Treatment Approaches.

Since 1981, scores of therapeutic interventions have failed to significantly alter the ultimate death sentence imposed by AIDS (Douglas & Pinsky, 1987; Gong, 1985; Langone, 1988). A survey of literature reveals that to date, the bulk of therapeutic interventions offered to people with AIDS can be categorized as follows:

(1) medical treatment of generalized symptoms;

(2) bolstering the immune system (Bohm, 1987; Langone, 1988);

(3) developing a vaccine (Frumkin & Leonard, 1987; Gong, 1985; Koop, 1987; Langone, 1988);

(4) disease-process education and prevention (Price et al., 1986);

(5) support in coping with the multitude of psychosocial issues, including death-and-dying (Flavin & Frances, 1987; Lomax & Sandler, 1988; Kubler-Ross, 1982, 1987; Parker, 1988; Price et al., 1986).

The rapid rate of spread of such a fatally disarming disease has shaped our responses: understandably, they have been patchy, symptomatic and reactionary. The scientific and medical communities have focused upon, but not yet achieved eradication and cure for a new disease and a new virus; the public health system has attempted to inform, raise consciousness regarding moral issues and prevent further spread of disease in the midst of shock,

denial and despair; and the helping professions have been confronted with the task of helping PWAs die peacefully.

Today, nearly ten years later, a picture of the whole may be starting to fall together. A "biopsychosocial" (Temoshok, 1988) model of the pathogenesis of AIDS is evolving. Engels (1960) first described a multifactorial model of disease, which accounts for the "interaction of genetic, biological (specific and nonspecific), emotional (state and trait), behavioral, situational ("stress"), and cultural factors in the pathogenesis of all diseases" (Temoshok, 1988). Regarding future directions, then, work on fortification of the immune system and development of a vaccine will remain an important priority, and communities will continue to need prevention and risk-factor education and updating. In their therapeutic interventions, however, the helping professions have already begun a shift in emphasis from assisting PWAs in peacefully dying with AIDS, to facilitating their abundantly living with AIDS. They are accomplishing this by placing greater focus on the emotional, behavioral and situational circumstances of PWAs: as a result, more emphasis is being placed on longevity of life, vs. prolongation of death: a "healing unto life and death" as Steven Levine (1982) states.

Aimed at gaining insight to the achievement of those ends, two questions are being asked:

(1) What influences the transition from asymptomatic HIV-positive status, to symptomology?"

(2) Once symptoms are present, what influences the progression of the disease?

Co-factors are secondary variables or influences which seem to positively or negatively affect the presentation, progression or alleviation of disease symptoms. Co-factors under consideration with AIDS include: abuse of illegal drugs; repeated exposure to virus; history of sexually transmitted diseases; anal-receptive sexual activity; psychological stress (Bohm, 1987); hardiness (Maddi, & Kobasa, 1984); history of immunosuppression; life goals; coping measures; social support (Langone, 1988); perceived stress; self-efficacy; locus of control; anxiety, depression; personality, etc. (Szapocznik, Millon & Eisdorfer, 1987). These and others are being acknowledged for their potential roles in immunological response to the AIDS virus.

In 1964, Solomon & Moos coined the term "psychoimmunology: psychological influences (experience, stress, emotions, traits, and coping) on immune function and on the onset and course of immunologically resisted or mediated diseases" (Solomon, 1987). The study of co-factors and their effects on health, wellness, and response to illness has become the central theme of the larger and developing multidisciplinary field of Psychoneuroimmunology [PNI].

2.3.1 Co-factors and Psychoneuroimmunology.

PNI is a study of the links between the central nervous system [CNS] and the immune system, and of the psychosocial factors which influence the overall interaction between the two. In AIDS: the Facts, Langone (1988) provides insight for understanding the field of PNI:

> For years, scientists have known that the vital immunological organs and tissues are joined with nerve fibers that originate in the brain, and that if they destroyed or stimulated portions of an experimental animal's brain, they could boost its ability to fight infection, or suppress it. They also know that various brain chemicals can force immune cells to multiply, and that brain-secreted hormones can also affect the way the body fights disease. ...
>
> All this is evidence ... that the mind, indeed, is involved in manipulating our immunological defense system, and that the immune system can be turned on and off, in a sense, at will, or unwittingly (pp. 166-167).

In 1985, one of the major pioneers in the field of PNI, George Solomon, created "14 'hypotheses' or corollaries based on the thesis that the immune system and the central nervous system are intimately linked." His current list numbers thirty-one: two of them are especially aligned both with AIDS and with this dissertation topic:

(1) Enduring coping style and personality factors (so-called "trait" characteristics) should influence the susceptibility of an individual's immune system to alteration by exogenous events, including reactions to events.

(2) Emotional upset and distress (so-called "state" characteristics) should alter the incidence, severity, and/or course of diseases that are immunologically resisted (infectious and neoplastic diseases) or are associated with aberrant immunologic function (allergies, autoimmune diseases). (Solomon, 1987, p. 629)

More generally stated, Solomon hypothesizes that enduring personality climate ("trait") interacts with the more volatile emotional weather ("state"), and directly influences the body's capacity to encounter dis-ease. Expanding on this perspective, Coates, Temoshok, & Mandel (1984) suggested "four heuristic models of causation that might shed light on the immunosuppression observed in AIDS:"

(1) The first suggests that stress is linked to immunosuppression, which is linked to a predisposition to immunologically related diseases.

(2) The second model links psychosocial factors to immunosuppression and a predisposition toward immunologically related diseases. ... [that] suggests a broader range of psychosocial

factors, besides stress, that might potentially affect the immune system - including depression, life satisfaction, and hopelessness (Kaplan, in press).

(3) The third model is derived from important experimental work by Ader and Cohen (1975, 1982) and suggests that conditioned learning is linked to immunologically related diseases.

(4) Our preferred model combines features of the first three. Thus, psychosocial factors, including personality variables and transient states, partially influence susceptibility to environmental stressors. Genetic and environmental factors would also influence susceptibility to stress. Thus, we propose that it is the <u>interaction</u> of genetic, environmental, and psychosocial factors that may, at various times, protect the organism, predispose the organism to disease onset, or influence the course of disease once contracted (p. 1311).

AIDS is an immune deficiency disease. Co-factors that negatively affect the immune system are anathema to HIV-compromised people. Still lacking a vaccine and/or substantial pharmacological immune support, any factor which might fortify the immune system is a blessing, a chance to improve health, longevity and survival. If Coates, Temoshok & Mandel (1984) are correct, the

interaction of genetic predisposition, environmental factors AND psychosocial factors determine progression of the disease. Genes are realistically beyond modification, and environmental factors are relatively fixed at the common AIDS-susceptibility age. The most accessible component of the model seems to be psychosocial factors. According to Temoshok (1988, p. 187), "perhaps the most prevalent but least understood of the environmental modulators of human immunocompetence are behavioral or psychosocial factors." For the purpose of this dissertation and hopefully for the overall viability of life for people with AIDS, the psychosocial co-factors to be directly examined are those which appear to be most characteristic of long-term AIDS survivors [LTASs]. Psychosocial co-factors found to be characteristic of exceptional responders to cancer and other major life crises will also be considered in this review of literature, and will be acknowledged in the eventual formation of tentative conclusions.

2.4 AIDS-Survivor Research.

"There is a growing population of long-term AIDS survivors who are alive and well three, four, and even five years after an AIDS diagnosis" (Temoshok, 1988, p. 194). Regarding their relatively robust response to AIDS, Dr. Ann M. Hardy, (a CDC epidemiologist who tracks LTASs), asks: "Could the key really be a "life-style-psychosocial

type of thing - a positive attitude and emotional support?" (Coleman, 1989).

Of the AIDS research literature reviewed, only four studies have at least partially addressed this question. All are longitudinal studies currently in-progress. Three of the studies draw from the same data pool - (1) Solomon & Temoshok, 1987, or Temoshok, 1988; (2) Solomon et al., 1988; and (3) Temoshok, 1988 - and all statistics derived from the studies to date are presented as early indications or trends (L. Temoshok, personal communication, February 7, 1989). Temoshok, Solomon & Stites (1987) is the fourth of the studies which will be presented in sequence:

2.4.1 UCSF-BAP Longitudinal Study.

By definition, direct and concurrent analysis of survivor vs. deceased groups is impossible. In an attempt to counteract this limitation, the University of California San Francisco's Biopsychosocial AIDS Project [UCSF-BAP] is completing retrospective analysis of data collected in a longitudinal psychosocial study of men with AIDS and ARC (UCSF-BAP; Temoshok, 1983). Designed to explore the possible relationship between psychosocial factors and subsequent health outcomes, self-report scales were administered within 2 to 8 weeks of an AIDS or ARC diagnosis. The psychosocial self-report scales include: Total dysphoria ("as assessed by standard self-report measures of anxiety, mood state, and hopelessness");

Taylor anxiety; Beck hopelessness; Profile of Mood Scales [POMS] confusion; POMS depression-dejection; POMS fatigue-inertia; POMS tension-anxiety; POMS vigor-activity; POMS anger-hostility; Kobasa's "Hardiness" Scale; Kobasa's "Control," "Commitment" and "Challenge" Subscales; Type of help sought: emotionally-sustaining vs. problem-solving; Marlowe-Crowne Social Desirability Scale.

Approximately three years after data-gathering began at the UCSF-BAF, retrospective comparisons are being made between psychosocial variables of long-term survivors versus those of subsequently deceased PWAs (Solomon & Temoshok, 1987; Temoshok, 1988). Given the distinct medical differences between AIDS vs. ARC populations (opportunistic infection vs. no opportunistic infection), the investigators differentiated between those two groupings for intra-group survivor vs. deceased study. Upon further consideration, however, the investigators decided that further differentiation within the AIDS population was necessary: Because it is not yet understood why some PWAs seem to be more susceptible to one or the other of the two major opportunistic infections, they created three separate experimental groups:

1. AIDS subjects with Pneumocystis Carinii Pneumonia[2], (AIDS-PCP; n=21).

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[2] Pneumocystis Carinii is the most common opportunistic infection in PWA: it is a pneumonia that affects over 60% of people with AIDS and which has an expected mortality rate from 30 to 50 percent for each episode (Gong, 1985).

2. AIDS subjects with Kaposi's sarcoma[3]. (AIDS-Kaposi, n=28).

3. ARC subjects (n=53).

In a comparison of psychosocial variables of the survivor vs. deceased subgroups within each population, there were significant differences identified within two of the groups:

2.4.1.1 AIDS-PCP, Group #1: Significant Differences Found.

In the AIDS-PCP Group #1, Kobasa's "control" subscale was found to significantly differ between the survivor vs. deceased groups: M=60.0 in the deceased group, M=65.0 in the survivor group; $t=1.99$, $p<.05$, two-tailed. Citing Kobasa (1979), the experimenters at UCSF-BAF hypothesize that "people low in 'control' tend to feel powerless when faced with overwhelming stimuli." They suggest that "low control" coping styles provide "little or no buffering of the distresses, and health is negatively affected" (Kobasa, Maddi, & Courington, 1980; Kobasa, Maddi, & Kahn, 1982). This is consistent with the passivity, helplessness and hopelessness cited in the AIDS and Cancer summary-of-

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[3] Kaposi's sarcoma is the second most common opportunistic infliction: it is a treatable but previously rare cancer of the skin which affects approximately 33% of people with AIDS (Gong, 1985).

research findings presented in the "(-)Control and Resolve" section of Table 2.2, pp. 34-36.

Another significant difference was identified in the AIDS-PCP Group #1: "Frequency problem-solving help was sought (as assessed by social-support scale, Zich & Temoshok, 1986): M=8.7 in the deceased group; M=11.0 in the survivor group; t=2.56, p<.02, two-tailed)" (Solomon & Temoshok, 1987, p. 295).

The results were interpreted in this manner: Fawzy, & Wolcott (in press, as cited by Solomon & Temoshok, 1987) found that AIDS patients experienced less anxiety and depression when utilizing problem-solving vs. emotionally-sustaining support. This is consistent with the problem-solving style depicted in both the AIDS and in the Cancer "(+)Control and Resolve" section of TABLE 2.2.

2.4.1.2 ARC, Group #3: Significant Differences Found.

Social desirability refers to the tendency to say, act and do those things which will be pleasing to others (in contrast with being more inner directed). For the ARC Group #3, the Marlowe-Crowne Social Desirability Scale yielded significant differences: "M=12.9 in the deceased group, M=8.9 in the survivor group; p<.009, two-tailed" (no t-value given).

The UCSF-BAF researchers drew close parallels between the high social desirability scores in the deceased group and: (1) the findings of negative effects of "Type C"

cancer-prone coping style (Morris, 1980; Temoshok, 1988; Temoshok & Fox, 1984; Temoshok & Heller, 1981; Temoshok et al., 1985); and (2) "autoimmune personality" patterns[4] (Solomon, 1981, 1987). The social desirability scores of the "deceased" subgroup are also consistent with "looking to others for validation or worth" as listed in the "(-) Life Meaning" section of Table 2.2.

A second significant survivor-deceased group difference was noted in ARC Group #3: "The anger-hostility subscale on the Profile of Mood States Scale (M=4.2 for the deceased group, M=7.1 for the survivor group; p=.05, two-tailed" (no t-value given).

As an explanation, UCSF-BAF and Solomon & Temoshok (1987) suggest that "anger-hostility is equated with the beneficial effects of a fighting spirit upon cancer outcome (Greer, et al., 1979; Pettingale, 1984)." The (+) column of the "Confidence" section of Table 2.2 clearly depicts both exceptional AIDS and Cancer survivors as "spirited fighters."

The third and final deceased-survivor significant difference identified in the ARC Group #3 was discerned using Kobasa's (1979) "commitment" subscale "(M=56.4 for the deceased group, M=53.3 for the survivor group; p<.03, two-tailed" (no t-value given) (Solomon & Temoshok, 1987, p. 295). Neither the UCSF-BAF researchers, nor I can offer

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[4] Type C and other immuno-suppression-prone styles will be more fully presented in the related cancer review section which follows these AIDS-study reviews.

an explanation for the seemingly conflicting "commitment" subscale finding. This is contradictory to the summary findings of the "grit and resolve" of both AIDS and Cancer exceptional survivors as listed in "(+)Control and Resolve" of Table 2.2.

2.4.1.3 AIDS-KAPOSI, Group #2: Significant Differences Found.

In AIDS-KAPOSI Group #2, no significant differences were identified: neither the investigators nor I can provide a clear explanation for this finding (L. Temoshok, personal communication, February 7, 1989). Early in the study, a "two to eight week" delay between initial diagnosis and data-gathering may have affected the data; however, this seems to be a problem which would have affected all groups equally. In and of itself, the time differential probably doesn't account for Group #2's lack of significant differences. Another potential clue to the Group #2 discrepancy may be this: Kaposi's sarcoma is contracted more frequently but not exclusively by homosexual men (Goedert, Biggar, Melbye, Mann, Wilson, Gait, Grossman, DiGioia, Sanchez, Weiss, & Blattner, 1987), and Pneumocystis Carinii Pneumonia more frequently by IV drug abusers (CDC news release, May 2, 1983, as reported in Shilts, 1987). This is an intergroup differentiation, but speculation based solely on this information seems presumptuous and unscientific. Nonetheless, a

discriminating look at intergroup data gathered in this dissertation may be warranted.

In a critique of their own study, the UCSF-BAP investigators cited other limitations: "small sample size; group differences in average length of time involved in study at time of follow-up; several univariate tests for different groups leaving little room for comparison among groups." Although they advise "extreme caution in interpreting these results," they do offer their findings as "preliminary results ... to engage other researchers in posing hypotheses about the possible relationships of psychosocial variables to outcome in AIDS."

2.4.2 Solomon et al. (1988). LTAS Study in Progress.

In a separate report, Solomon et al. (1988) present a "pilot work, background studies, hypotheses, and methods" of their LTAS study-in-progress. Derived from (1) pilot interviews with LTASs, (2) initial findings as described in the previous study (Solomon & Temoshok, 1987, or Temoshok, 1988), and (3) "studies from the related areas of psychosocial oncology, behavioral medicine, and psychoimmunology," they have created a hypothetical "AIDS Survivors" profile. The profile is partitioned into three categories: (1) "Hardiness" and health; (2) Social support; and (3) Psychosocial Factors.

2.4.2.1 Hardiness and Health Hypotheses.

Their "hypotheses for the 'AIDS survivors' study" related to "HARDINESS" AND HEALTH are:

-Perceiving the treating physician as a collaborator, and not interacting in a passive-compliant (nor defiant) mode.

-Having a sense of personal responsibility for one's health, and a sense that one can influence health outcomes.

-Having a commitment to life in terms of "unfinished business," unmet goals, or as yet unfulfilled experiences and wishes.

-Having a sense of meaningfulness and purpose in life.

-Finding new meaning as a result of the disease itself.

-A prior mastered experience with a life-threatening illness or very serious life event.

-Engaging in physical fitness or exercise programs.

2.4.2.2 Social Support Hypotheses.

Their "hypotheses for the 'AIDS survivors' study" related to SOCIAL SUPPORT are:

-Deriving useful information from and supportive contact with a person with AIDS shortly following diagnosis.

-Being altruistically involved with other patients.

2.4.2.3 Psychosocial Factors.

Their "hypotheses for the 'AIDS survivors' study" related to PSYCHOSOCIAL FACTORS are:

-Acceptance of the reality of the diagnosis of AIDS in conjunction with refusal to perceive the condition as a death sentence, or at least an imminent one.

-A personalized means of active coping that is believed to have beneficial health effects.

-Altered lifestyle to accommodate disease in an adaptive manner.

With the realization that the above presentation is a set of preliminary findings and hypotheses, the investigators again advise the use of caution in any interpretations made; however, the distinct similarity shared by the above with statistically significant findings in "exceptional cancer survivor" studies supports the accuracy and validity of both.

2.4.3 UCSF-BAP Immunologic Measures and Psychosocial Variables.

Drawing information from the same group of subjects utilized in the two studies presented above, the UCSF-BAP correlated objective immunologic measures with psychosocial variables (Temoshok, 1988). Blood samples were drawn from newly diagnosed AIDS and ARC subjects within two weeks of psychosocial assessments (which were conducted between two

and eight weeks of the initial AIDS diagnosis). The key finding was that "overall dysphoric affect ... - reflective of relative failure of psychological defenses and/or coping - was positively correlated with total white blood cell count" (Temoshok, 1988, pp. 188-189): i.e. the greater the dysphoria, the more severely compromised was the total white blood cell count. The white blood cells are directly involved in the body's protective immune response.

2.4.4 Temoshok, Solomon, & Stiles, 1967: Immunological and Psychological Measures and Survival Time.

The fourth and final related AIDS investigation found, is a study-in-progress. It is designed to correlate immunological and psychosocial measures with survival time. Temoshok, Solomon & Stites (1987) are conducting an ongoing "study ... concerned with the interactions among psychosocial, immunologic, and psychophysiologic parameters in persons with AIDS who have varying durations of time since diagnosis, and who will probably have varying times of survival." The three experimental groups are:

Group #1: PWAs who had been diagnosed for less than one year (mean = 8 months), (n = 5).

Group #2: PWAs who had been diagnosed between one and two years ago (mean=19.9 months), (n=8).

Group #3: PWAs who had been diagnosed more than three years ago (mean= 42.4 months), (n = 5).

Samples for laboratory blood analyses are drawn "prior to an initial psychosocial interview, as well as prior to 6 weekly interviews addressing recent emotional experiences and related coping patterns." Objective immunological analyses conducted on the samples include: Total lymphocytes, Total white blood cells, Total T cells, B cells, Natural Killer cells, T Helper cells, Cytotoxic suppressor cells, large granular lymphocytes, T Suppressor cells, T cytotoxic ("T-killer") cells, and virucidal cells. Although an explanation of the various laboratory tests is beyond the scope of this dissertation, it can be said that these are indices of immune system efficiency.

Psychosocial measures are also administered:

- at initial interview: "trait" measures of psychological "hardiness," social support, and optimism; demographics;
- weekly: perceived stresses and positive experiences;
- daily: moods, health-promoting activities, and well-being.

The researchers indicate that because the study is in its early phases, and because the sample sizes are so small, clear differentiation among the groups is not yet possible; however, by considering all subjects across all groups as one population, they have found correlations between certain of the immunological and psychosocial measures:

(1) Directly correlated with absolute numbers of T-helper-inducer cells (important in combatting disease):

(a). at $p < .01$: -less POMS tension-anxiety.

(b). at $p < .05$: -less POMS depression-dejection.

-less POMS fatigue-inertia.

-less POMS anger-hostility.

-less stress from sickness.

(2) Directly correlated with absolute numbers of cytotoxic cells (important in combatting disease):

(a). at $p < .01$: -less stress from sickness.

(b). at $p < .05$: -less stress other than sickness.

-not doing unwanted favors,.

-less POMS tension-anxiety.

-less POMS fatigue-inertia.

(3) Directly correlated with absolute numbers of suppressor cells (important in combatting disease):

(a). at $p < .05$: -more fitness and regular exercise.

-not doing unwanted favors.

-withdrawing to "nurture" the self.

-less POMS fatigue-inertia.

(4) Directly correlated with absolute numbers of natural killer cells (important in combatting disease):

(a). at $p < .05$: -withdrawing to "nurture" the self.

-less preoccupation with AIDS.

-less POMS fatigue-inertia.

Although this work can not yet be specifically considered "long-term survivor" research, the findings suggest future findings. Even though the results are considered preliminary and suggestive by the investigators, they are a second and independent presentation of objective laboratory findings directly associating enhanced immunological function with certain exceptional survivor characteristics documented in these and other studies. The investigators hope that "as our sample matures, we will be able to test more directly whether these same psychosocial factors are also associated with length of survival."

Regarding the four AIDS-related studies presented above, common themes suggest a characteristic exceptional survivor profile. This profile will be presented in a summary-comparison of long-term and short-term survivors of AIDS vs. Cancer characteristics in TABLE 2.2 (page 33).

2.5 Cancer-Survivor Research.

As previously indicated, no other AIDS-related "exceptionality" studies were discovered in a review of the literature; however, because immune system function is

such a critical factor in both AIDS and Cancer, the following cancer-related studies are here included.

As cited by Solomon & Temoshok (1987), "Solomon's (in press) notion of an 'immunosuppression-prone' personality shares common features with a "Type C" coping pattern suggested to be predictive of more unfavorable cancer prognosis and possibly to cancer susceptibility (Benjamin, 1987; Morris, 1982; Pelletier, 1977; Temoshok & Fox, 1984; Temoshok & Heller, 1981)." Temoshok & Heller (1981) first developed the notion of the Type C Individual: "... passive, appeasing, helpless, other-focused, and unexpressive of emotion, particularly anger" (Temoshok, 1988), with "lack of emotional expression [hypothesized to comprise] ... the pathological core of the type C style (Temoshok et al., 1985). Temoshok & Heller (1981) describe Type C as the "polar opposite" of the popularly described high-pressured, over-achieving "Type A" behavior style [aggressive, impatient, self-involved, and hostile (Temohok, 1988)], and "different from" the Type B behavior pattern. In a hypothetical arrangement, they align the three constructs along a continuum, ranging from the predominance of Type A, to a moderate Type B, to the predominance of Type C characteristics.

Temoshok & Heller's (1981) immunosuppressing Type C pattern, and Solomon et al.'s (1988) immuno-augmenting "exceptionality" pattern are closely aligned with the findings of investigators in their work with behavioral

factors and the progression or prognosis of cancer. (Benjamin, 1987; Cousins, 1983; Cullen, 1982; Derogatis, Abeloff, & Melisaratos, 1979; Holland & Mastrovito, 1980; Greer, Morris & Pettingale, 1979; Justice, 1988; Levy, Herberman, Maluish, Schlien, & Lippman, 1985; Locke, 1987; Maddi & Kobasa, 1984; Pettingale, 1984; Rogentine, Boyd, Bunney, Doherty, Fox, Rosenblatt, & Van Kammen, 1979; Satariano & Eckert, 1983; Schmale, Cherry, Morrow, & Henrick, 1983; Segal, 1986; Shekelle, Raynar, Ostfield, Garron, Bieliauskas, Lie, Maliza, & Paul, 1981; Siegel, 1986; Simonton & Simonton, 1975; Temoshok & Fox, 1984; Temoshok, Heller, Sagebiel, Blois, Sweet, DiClemente, & Gold, 1985). Although some of the information presented by a few of the above cited is based more on clinical impression than straight empirical science (e.g. Dr. Bernie Siegel's Love, Medicine & Miracles), there is consensus of observation and opinion. In reality, the many common characteristics identified by the AIDS and Cancer survivor-studies could be considered: (1) causal factors; (2) consequences of living longer; and/or (3) false positive information. The frequency of similar findings, however, strongly suggests a valid profile.

As a means of condensing the cancer survivor research findings with the previously presented AIDS findings, Table 2.2 (page 33) summarizes, compares and contrasts the most frequently agreed upon findings of the authors cited in this literature review. It is presented in this form

not only to condense the cancer survivor studies, but also to highlight the nearly parallel AIDS and Cancer survivor findings. It also contrasts the characteristics of long-term vs. short-term survivors. The categories are adapted from Segal, (1986), and Kobasa, (1980; Kobasa, Maddi & Courington, 1980; Kobasa, Maddi & Kahn, 1982): Communication; Confidence; Control; Challenge; Support; and Life Meaning.

Table 2.2 Summary of Research Findings on Characteristics of People with AIDS vs. People with Cancer: Long-Term Survivors (+) vs. Short-Term Survivors (-).

Category	
Characteristics: AIDS	Characteristics: CANCER
COMMUNICATION	
(+)	(+)
Tuned in to own psychological and physical needs; Talk openly about their illness.	Opening to self and others: making the choice of honestly identifying, acknowledging and expressing inner beliefs, feelings and needs.
(-)	(-)
Depressed.	Failing to acknowledge and/or express beliefs, needs and emotions, especially hostility or anger.
CONFIDENCE	
(+)	(+)
Fighting spirit; Refuse to be helpless/hopeless. Belief in ability to positively influence health outcomes. Personalized coping style believed to be beneficial. History of previously mastered life-threatening illness/crisis.	Positive self beliefs. Positive expectations in life. Unprejudiced.

Continued next page.

(Table 2.2, continued)

Category	Characteristics: AIDS	Characteristics: CANCER
CONFIDENCE		
	(-) Feel powerless when faced with overwhelming stimuli.	(-) Negative self beliefs. Recrimination and negative self absorption and pity. Unassertive. Perceive self as powerless: hopeless or help-less in influencing internal or external circumstances.
CONTROL		
	(+) Assertive. Accept reality but choose not to see it as of death sentence. Able to and does take care of own physical and psychological needs. See physician as collaborator. Willing to make life-style changes to accommodate demands of the disease. Seeking out help: usually problem-solving vs. emotionally-sustaining support. Active physical fitness program.	(+) Accepting responsibility for self. Taking charge personal life situations with determination and persistence. Oriented to present. Shed blame.
	(-) Prone to seek emotionally-sustaining vs. problem-solving support. Compliant with wishes of others / conformity. Focused on illness. Slow to respond.	(-) Seeing misfortunes as punishment for past "bad behavior." Frequently absorbed in past or future worries. Conforming. Appeasing. Self sacrifice.
CHALLENGE		
	(+) Commitment to yet unfulfilled life goals, experiences and wishes. Take personal responsibility for one's health.	(+) Self-motivation to achieve personal goals. Working to master the environment. Grit and resolve.
	(-) Passive. Anxious.	(-) Passive. Appeasing.

Continued next page.

(Table 2.2, continued)

Category	Characteristics: AIDS	Characteristics: CANCER
SUPPORT		
	(+)	(+)
	Altruistically involved other persons with AIDS. Receiving useful information and support from other PWAs shortly after diagnosis. Willing to nurture self.	Accepting, loving and with caring for self and showing acceptance and compassion towards others. Giving and receiving unconditional love. Supportive ties and/or partnerships.
	(-)	(-)
	Seeking approval of others. Self sacrifice.	Blocking caring responses to self or others. Conditional relationships. Isolation. Self sacrifice. Focused on others.
LIFE MEANING		
	(+)	(+)
	Choose not to see diagnosis as death sentence. Sense of purpose and meaningfulness in life. Finding new life meaning as a result of the disease itself. Peace.	Internally conferred meaning. Ability to give a purpose to pain and trials. Devotion to higher cause. Inner sense of personal worth. Overall goal:
	(-)	(-)
	(Not directly specified.)	Accepting meaning from external sources. Looking to others for validation or worth.

This information is not presented to suggest that certain people deserve or intend to be ill or are responsible for getting well. Many factors, including genetic predisposition, come into play with health and illness. All things equal, however, those people who tend to possess the characteristics in the (+) sections of TABLE 2.2 seem to do exceptionally well in overcoming illness.

2.6 Developing "Exceptionality".

The gestalt of LTASs is a group profile that may only partially portray each individual of the group. Also, rather than a static profile, it may represent predominant vs. permanent characteristics or style. Indeed, the experience of love, health and/or wellness may be the result of having chosen exceptionality "frequently enough" (or soon enough) over the course of their lives. In whatever configuration it actually occurs or evolves, it can be safely said that "exceptionality" is one option in life which may help people to recover from dis-ease.

PNI researchers and others have empirically substantiated the immunological and physiological health-benefit-indicators of "exceptionality." It seems, however, that characteristics alone are the majority of "what is known" about the concept of "exceptionality" (TABLE 2.2). In a thorough search of the literature, the researcher found no one focusing upon the question of just how exceptionality develops. Over the long term? Short term? Adult acquisition? Are there patterns of development? Are there critical incidents or transformation points common among long-term survivors in their development of an exceptional style?

In 1954, Jean Piaget described development as a life-long process of assimilation and accommodation. As environmental stimuli become sufficiently discordant with the current meaning-making system (i.e. cannot be

assimilated), the resultant subject-object disequilibrium provokes the development of a new way of viewing the world (accommodation): movement towards an "evolutionary truce" (Kegan, 1982, p. 44). If exceptional survivor characteristics are acquired only as a result of life-long growth and maturation, then for those lacking them later in life, attempts to acquire these characteristics could prove to be frustrating and fruitless. Robert Kegan, however, states that "personality development occurs in the context of interactions between the organism and the environment, rather than through the internal processes of maturation alone" (Kegan, 1982, p. 7). If this is so, then given the desire, motivation and willingness to risk and encounter fear, and given appropriate environmental stimuli and support, development of an "exceptional" coping style could be possible - and productive - for anyone. Implicit in the Piaget and Kegan theoretical perspectives, however, is the understanding that accommodation could be impossible if the stimuli are perceived as overwhelming or too discordant. It does seem likely, then, that successful accommodation to, and long-term survival of AIDS would be increasingly more likely given a premorbid coping style which is relatively closely aligned with the LTAS coping styles presented in Table 2.2.

Without a formal data base, however, these suppositions must be considered speculative. With no related literature or research available, basing even tentative conclusions

solely on speculation seems patently inappropriate. Understanding the common origins and circumstances of the development of exceptionality, however, is vital to the effective educational and therapeutic application of the concept.

2.7 Dissertation Goal.

The goal of this dissertation was:

(1) To generate tentative conclusions about the common origins of - and circumstances surrounding - the development of exceptionality in LTASs.

The method designed to achieve this goal is described in the following chapter.

CHAPTER 3

METHODOLOGY

This chapter will present the rationale for and the methods by which this dissertation's goals were attempted to be achieved. The chapter sections are:

-Samples.

-Instruments.

-Research design.

-Data collection/editing.

-Data analysis.

3.1 Samples.

Long-term AIDS survivors were the population of major interest in this study. In conformity to the CDC's definition, this study's original definition of "long-term" survivor, was a PWA three years beyond initial AIDS diagnosis. Although the average time beyond diagnosis for this study's LTAS-group members was four years, one of the survivors was only two and one-half years beyond his diagnosis of AIDS. Given the significant difficulty realized in trying to comprise even a group of four long-term survivors, the investigator (and advisors) decided to scale down the original definition of three years. Two and one-half years is significantly greater than the life expectancy of a very large majority of PWAs: approximately fifty percent of PWAs die within the first year, and

seventy to eighty percent die before two years have passed (Douglas & Pinsky, 1987; Frumkin & Leonard, 1987; Runck, 1986). As will be presented in Chapter 4, ("Results"), the data collected was categorically symmetrical and consistent within the survivor group.

Although no age restriction was planned, the survivors' ages ranged between thirty and forty-five, well within the expected range: AIDS has been contracted primarily by men between the ages of twenty and fifty (Gong, 1985).

The investigator had hoped to gather two groups of three to six LTASs. In a qualitative study involving individual interviews followed by a group process, it was the group phase of this methodology that made gathering subjects especially difficult. The group meeting essentially required that the LTASs of each group would live within a reasonably tight geographical location. Within the entire United States, a total population of LTASs is approximately two thousand. Finding one or two northeastern United States communities with three-to-six LTASs who were willing and able to participate in the research was not reasonably possible for the investigator. Given limited resources and time, concessions had to be made.

The sparse number of available LTASs, and the geographical requirement for groupings, virtually mandated that sampling be non-random. In an attempt to gather groups of volunteer LTASs, AIDS-resource centers, hospitals

and individual AIDS-counselors were contacted by phone, by letter and in-person. Ultimately, two survivors were discovered within western Massachusetts (one 3-year survivor, and one 2 1/2-year survivor). They were not only willing to be interviewed, but willing and able to attend a group meeting. One 3 1/2-year survivor was found in central Connecticut. He was unable to tolerate a long ambulance ride to the group meeting, but was willing and able to be interviewed in his home. A fourth survivor (7 year beyond AIDS diagnosis) was located in New York City. He was willing to participate in the study via telephone only. This sample size, however, seemed sufficient for a study designed to generate vs. test hypotheses, especially given the use of a second experimental group comprised of AIDS-counselors.

The survivor group was comprised of: two gay men, one person with hemophilia (male), and one former IV drug abuser (female). The proportions were very similar to that found in the general population: the two largest subgroups within the general AIDS population are homosexual men (69%) and IV drug abusers (24%) (Douglas & Pinsky, 1987). The decision to consider LTASs a homogeneous group is discussed in the "Limitations" section of Chapter 5.

Professionally trained counselors (Master's degree level and beyond) who had at least one year's full or part-time experience with PWAs, comprised the <u>second experimental group</u>. I planned to gather two groups of

three to six counselors, hopefully from the same geographical locations as the LTAS groups. Ideally, both the survivor groups and the counselor-groups were to be subject to separate but similar research processes: individual interviews followed by a "within-group" group process. As with the survivor group, the group process phase reasonably required that the AIDS-counselors live within a relatively tight geographical range. In attempting to form the counselor-groups, the investigator encountered these roadblocks: (1) Many professionally trained counselors work with PWAs through federal or state-assisted programs. Because of confidentiality and liability issues, the counselors of these agencies are mandated against granting interviews and/or providing any information which in any would compromise a client (i.e. they would-not/could-not participate in the study); and (2) Many "PWA-counselors" are well-intentioned and probably effective, but are not professionally trained. Many are volunteers who serve "support, information and advocacy" functions rather than professional counseling and/or psychotherapy. Given these two issues, a relatively small number of professional counselors were left to choose from. Again, given the time constraints and limited resources of the researcher, the notion of creating a randomized sample was not reasonably possible.

Ultimately, four counselors were located in western Massachusetts: two men and two women, and all met the study's requirements as listed above.

The problems inherent with small, non-randomly sampled groups with no direct comparison or control group will be presented in the "Limitations" section of Chapter 5.

3.2 Instruments.

From the beginning, all group members - directly and indirectly - received the message that they were seen, respected and expected to function as co-researchers in the generation of hypotheses. Rather than "subjects", the group members were referred to as co-researchers; The investigator was researcher-facilitator vs. "experimenter."

In an individual interview, each of the group-members generated a personal theory of survival: important AIDS-survival skills and origins from which those skills developed. In a group setting, they interacted with each other in order to expand their own personal theories. Concluding their group meeting, they attempted to achieve consensus on either individual survival skills and/or origins of those skills.

In this descriptive multiple-case study, the only "formal" instruments were the two processes: individual interviews and group process. There were no objectively standardized instruments. As will be discussed, this

research style can be viewed as appropriate for accomplishing the goals of this study.

3.3 Research Design.

In 1981, Reason & Rowan introduced a "new paradigm research" of "co-operative experiential inquiry: research that was with and for rather than on people" (Reason, 1988). They believe that "roots of the new paradigm" lie within behavioral sciences, and especially within the tradition of humanistic psychology.

Not-withstanding other influences, the foundation of the new paradigm of "human inquiry" was the "grounded theory" of Glaser & Strauss (1967). "Generating grounded theory is a way of arriving at theory suited to its supposed uses ... [vs.] theory generated by logical deduction from a priori assumptions" (p. 3). The "new paradigm of human inquiry" grew from within the tradition of "endogenous research," " cross-subjective comparisons." "theoretical sampling," "resonance-relevance," "comparative analysis," and "generation and verification of theory inductively derived from evolving data" (Reason and Rowan, 1967; Reason, 1988). Crucial to the new paradigm is a "dialectical engagement with the world." Random House (1972) defines dialectic as "the art or practice of logical discussion, as of the truth of a theory or opinion." In a very systematic way, that is what the research design was intended to do. As co-researchers and co-subjects, all

played a role in generating, verifying and modifying developing theory.

Given that this dissertation was a descriptive multiple case study of a topic with no established precedent, this method of human inquiry seemed suitable. This study intended to generate tentative conclusions about exceptional AIDS survival, a topic resonant with the investigator's interests, and expectedly, with those of the participants.

This study was not purely "endogenous" as Maruyama (1974) defines it: Rather than fully open-ended and self-generated, the inquiry process was semi-structured, and included questions specific to categories established by previous survivor research (as reported in Table 2.2, page 33): Communication, Control, Confidence, Challenge, Support and Meaning. The investigator also chose the sequence of events. The tentative conclusions, however, were generated from the data, and the data evolved from the participants' individual theories. In the group meeting, participants were subjected to the opinions and ideas of the other participants. If the information stimulated the need for alteration of their own theories, they were allowed time to make changes. Finally they attempted to achieve consensus about the most important and common themes regarding long-term survival of AIDS. The process was one of working towards an "ever-developing entity, not as a perfected product" (Glaser & Strauss, 1967).

This design stands in distinct contrast to - but does not preclude - future quantitative research. Some would argue against this design on the grounds of issues of reliability and validity. As advised by Reason & Rowan (1988, p. 123), these validity procedures were utilized in this study:

-Research cycling: "the notion of recycling implies that data gathering in one cycle will be used to inform plans for the next cycle..."

-Divergence: utilizing different ways of gathering pertinent information: e.g. individual interview and group process; LTAS and AIDS-counselor groups.

-Authentic collaboration: including the perspectives of all co-researchers in the generation and verification of the theory.

-Countertransference: working at keeping issues and relationships clear in the research process.

-Chaos: especially initially, not letting the generation process be overly structured. Reason (1988) purports that actual chaos can "bring about new levels of order" (p. 125).

Rogers (1961) believes that "scientific methodology needs to be seen for what it truly is, 'a way of preventing me from deceiving myself in regard to my creatively formed subjective hunches which have developed out of the

relationship between me and my material'" (as cited in Reason & Rowan, 1967, p. 240). Especially in generating new theory, the collaborative research paradigm is one way of avoiding researcher bias and self-deception. It is a way of discerning "inter-subjectively valid knowledge" (Reason & Rowan, 1982, p. 242).

The notion of validity is at the foundation of new paradigm research: a dialectic logic. As Reason (1988) quotes the Shorter Oxford English Dictionary, validity is "the quality of being well-founded." "Any notion of validity must concern itself both with the knower and with what is to be known: valid knowledge is a matter of relationship" (Reason & Rowan, 1967, p. 241).

As expressed in Table 3.1 (below), Guba & Lincoln (1981) describe analogous criteria for establishing the "well-foundedness" of the research findings of both quantitative and qualitative inquiry:

Table 3.1 Guba & Lincoln's (1981) Criteria for "Trustworthiness" of Research Findings.

Quantitative Research	vs.	Qualitative Research
Internal Validity		Credibility
External Validity		Transferability
Replicability		Dependability
Objectivity		Confirmability

Guba & Lincoln suggest that "credibility" is a more suitable term than "internal validity." "Credibility" is

an indication of the degree to which "extraneous" variables have been controlled. It is a reflection of:

(1) the degree of accuracy of the research methodology in actually measuring what it was designed to measure.

(2) the accuracy and honesty of information offered by those studied; and

(3) the degree to which experimenter biases - including attitudes, values, expectations and stage of development - have influenced the design and findings of the study.

This study's relatively endogenous and semi-collaborative design suggested that the findings would be credible. The interview process was semi-open-ended, and the actual generation of hypotheses were performed by the co-researchers. They were based on the relative uniformity of their own information as derived from the individual interviews. The investigator's primary function was to serve as record keeper and facilitator.

For qualitative research, Guba & Lincoln suggest the term "transferability," vs. "external validity." "Transferability" is an indication of the degree to which the sample is representative of the targeted population. A study's applicability or generalizability of findings relative to similar settings or samples is - to a large degree - dependent upon the abundance, fullness or wholesomeness of the data generated. Because of the proposed study's multiple cycles and formats of information gathering (interview, re-statement, verification of content

of statements in writing, group process aimed at establishing consensus) and "cross-subjective comparisons," it was expected that the information derived would be rich, and the findings transferable.

The "nature" of the sample is another factor governing transferability. The sample was very small, but similar in ratio with the various subgroups of the target population (e.g. gay men, IV drug abusers, and hemophiliacs). If the information generated in the study paralleled findings of researchers in other "exceptionality" studies, then the transferability of the findings would be enhanced.

In qualitative study, the issues of "replicability" - the consistency of forms and findings of qualitative inquiry - are more appropriately labeled "dependability." The relative stability of a study's findings over time is a reflection of the degree of "confidence" in the information generated. As described in the previous criteria, due to the proposed study's adherence to the earmarks of new paradigm inquiry, the findings are expected to be relatively dependable.

As described in "transferability," the nature of the population is another factor relevant to the issue of dependability, and can be seen as a potential strength or weakness. Given that the character of the sample was small but similar in ratio with the actual subgroups of the total population of LTASs, and that the data was gathered carefully (in cycles, and relatively in accordance with

"human paradigm research"), the information derived was likely to be transferable.

As with the more quantitatively-oriented "objectivity," "confirmability" is also largely dependent upon freedom from bias and/or investigator neutrality. With confirmability, the question is whether or not another independent investigator could either: (1) come to the same conclusions based on the proposed study's findings: or (2) replicate the study and arrive at the same conclusions. Given that, by design, the proposed study findings (tentative conclusions) were semi-collaboratively and relatively endogenously generated by the co-researchers themselves, it is expected that the proposed study will prove to be confirmable.

3.4 Procedures / Timelines.

Within a radius of approximately 150 miles from Amherst, AIDS-resource centers and AIDS-counselors were contacted in early April. The investigator attempted to gather two groups of three-to-six representatives of both LTASs and AIDS-counselors. The availability of able-and-willing LTASs and AIDS-counselors was so limited that the investigator had to resort to using one group of each (with advisor approval). The co-researchers were contacted by phone and/or mail, and were briefly oriented with respect to goals, expectations, research design, rationale, philosophy and hopes. Background information gathering

began then, and continued at the individual interviews. Appointment-times were set for the individual interviews.

In the first week of April, various individual interview formats were pilot-tested with four "survivors" of other life-crises (e.g. cancer, child abuse, etc.), and with one AIDS-counselor (see Appendix C: "Development of the Interview: Piloting Four Styles"). In constructing the interview and group-process guides, the investigator considered and incorporated guidelines and strategies from:

(1). "Qualitative Evaluation Methods" guidelines by Patton (1980);

(2). "High Performance Dynamics" coaching techniques by Fletcher (1989); and

(3). "Cancer as a Turning Point" philosophy and approach by LeShan (1989).

Fletcher (1989) seeks to assist people in identifying their "high performance patterns" from past moments of exceptional efficiency.

LeShan (1989), takes a very similar focus:

> 1. What is right with this person? What are his [or her] special and unique ways of being, relating, creating, that are his own and natural ways to live? What is his special music to beat out in life, his unique song so that when he is singing it he is glad to get up in the morning and glad to go to bed at night? What style of life would give him zest, enthusiasm, involvement? (p. 22).

2. How can we work together to find these ways of being, relating, and creating? What has blocked their perception and/or expression in the past? How can we work together so that the person moves more and more in this direction until he is living such a full and zestful life that he has no more time or energy for psychotherapy? (pp. 22-23.)

For specifics, please see Appendix C; however, the four piloted interview styles were constructed with variations such as:

-"conversational" vs. "interview guide" approach.

-degree of "directness" in accessing information.

-use of metaphor.

-use of visualization.

-use of story-telling.

-specifically focusing on the positive (survival skills).

-variations in interview segment sequencing: (especially as relates to degrees of emotional risk: e.g. speaking about survival/coping skills.

Starting in mid April, the audio-taped-interviews began. In these interviews, information was gathered about origins, thoughts, feelings, influences, skills and functions (see Appendix D: "Interview and Group-Process Guides").

After the individual interviews and before the group process, the interviewer gave each group member an outline of his/her individual before- and after-HIV diagnosis origins, feelings, thoughts, skills that emerged, and functions of the skills.

The second cycle of the research process, the group process, occurred in the last week of April (see Appendix D, "Interview and Group Process Guides"). The goal for the group phase was that each individual be subject to the thoughts of each of the other co-researchers. The group phase was designed to accomplish three things: (1) for each person to be able to more fully develop his or her own individual "survival theories;" (2) to attempt to reach some consensus regarding common origins and conditions for development of special survival skills; and (3) initial or possible team action planning: "how could PWAs be helped to acquire the exceptional survival style?"

3.5 Data Analyses.

The data was analyzed with respect to these three levels:

(1). Content: similarities of:

-special survival skills.

-circumstances of "having AIDS."

-thoughts and feelings about "having AIDS."

-special survival skill influences: people, places, things and/or events that somehow facilitated the development of skills.

-etc.

(2). Process: similarity with respect to the process of developing special survival skills: e.g. as a result of:

-having reached a "critical turning point" where a "quality of desperation" leads to a "moment of surrender" or to a "decision to take charge."

-etc.

(3). Conditions: similarity with respect to certain conditions which were present and influential in the development of special survival skills: e.g.:

-significant support network in place.

-period of physical well-being.

-having the time and space to stop and consider needs and strategies.

-etc.

In considering these data, it must be remembered that the results of analysis were - at best - a relatively accurate picture of a small sample of a large group of people. In spite of this limitation, this multiple-case descriptive study was seen as a starting point for further exploration.

The findings and analyses follow in the next chapter.

C H A P T E R 4

RESULTS: PRESENTATION AND ANALYSIS

This introduction precedes four chapter sections:

Section one will present individual profiles of each of the survivors. For comparison, the individual profiles will be followed by a summary profile drawn from the AIDS-C-group data.

The categorization of skills in past survivor research suggested that exceptionality was determined by a static set of traits or skills. In contrast, however, the skills in this study are organized according to a hypothesized six-step model of a dynamic process of developing exceptionality in long-term survival of AIDS.

Section two is a descriptive presentation of the reported psycho-social skills organized according to the model. A definition of terms will precede a presentation of the most representative and most frequently cited skills. The key conditions that exist and events that occur within the sequence of steps will also be presented.

Section three presents the second major difference between past survivor research and this study. Apparently for the first time, the theme of origins of AIDS-survival skills is developed. Specific before-HIV-diagnosis and after-HIV-diagnosis origins are presented. The skills that emerge from these origins are arranged according to their fit within the six steps of the hypothesized model. The

theme of individual variations and expressions of exceptionality will be presented. And finally, before- vs. after-HIV-diagnosis origins will be discussed relative to developmentally more or less "mature" skills.

Section four will take a broader look at the issue of exceptionality: (1) How the model developed from the data: (2) Statement of Hypotheses; and (3) Underlying themes.

4.1 AIDS Survivor Skill Profiles.

In **Appendix A**, every reported skill of each LTAS-group member and each AIDS-C-group member is listed and described. In most cases, the feeling and functions identified with each skill are included as well. Presented here, is a brief skills-profile for each of the survivors.

4.1.1 Long Term AIDS-Survivor "AV".

LTAS-AV is a black woman and former IV drug abuser who probably contracted AIDS by needle sharing with a person infected with the HIV virus. She is a strong woman who deals with her situation with AIDS in many ways. When her situation with AIDS becomes overwhelming, she does things to try to distract herself from the gravity of her situation: she occasionally uses drugs, and also distracts herself via her sense of humor.

Her use of protective denial, however, doesn't keep LTAS-AV from seeing her disease as a challenge. She has

faced her disease "arrogantly." and "looks AIDS square in the eyes: bigger things have tried and not gotten me, and you won't either."

LTAS-AV confronts herself and others: she is publicly open about having AIDS, and is also forward about identifying and expressing her feelings. She actively works of "taking care of unfinished business" and "dumping anger" in order to "get down to business." Her expression of emotions, includes "love and caring."

LTAS-AV has taken charge of her life and her disease. She describes her long-term style of being a "control queen" as a positive force in not allowing AIDS to control her. Her relationship with her disease is adversarial, and LTAS-AV does "whatever she has to do" to help herself and other PWAs. She has turned her lifestyle around, and is politically active in trying to modify society's perspective on AIDS and PWAs.

LTAS-AV is firm in her belief that "AIDS is just another disease [i.e. "not a death sentence"]." She avoids "becoming too dependent on doctors:" she sees them as "human beings, not deities." Contrary to her "control queen" characteristic, she is also accepting and loving of self and others. Her "purpose and reason for being here" is to help herself and others to survive AIDS." Although she offers help, she does not push her self or her beliefs onto other. She teaches, encourages and supports (and is

supported by) them "the way they are." She moves with a feeling of "confidence and empowerment."

4.1.2 Long Term AIDS Survivor "CM".

LTAS-CM is a white gay man who "fiercely enjoys living." He too teaches and supports others, but is firm about "not making decisions for others." LTAS-CM is very active in confronting AIDS, his "wily adversary:" he is politically active; he is the founder and president of several AIDS-related organization; and he writes and has published hundreds of pages about living with and surviving AIDS. By confronting his AIDS so strongly, he not only retains control and hope, but also give his body a "live" message.

LTAS-CM is "brutally honest" with himself, and maintains a "healthy skepticism" about his own (and others') beliefs. He fervently works to update his knowledge by seeking out and collecting "everything he can about AIDS;" and he doesn't allow himself to become overconfident by believing he has "all the answers."

He describes himself as "frisky and gritty:" he speaks out for himself and others, especially against injustice. His approach is "pragmatic:" he conserves his energy, collaborates with his doctor, and he "routinely cleans house:" he gets rid of the negative (beliefs and relationships) and spends time with people who are supportive. He also expresses his emotions.

LTAS-CM attributes much of his success to the love and support he has received from his parents, his doctor and his lover. His goals are: (1) to help others ("you never know a subject so well as when you teach it"): and (2) to "constantly strive towards the truth" ("my life depends on it.")

4.1.3 Long-Term AIDS Survivor "LB".

LTAS-LB also sees his disease as a challenge. He experiences a strong "want for life" and does not believe he will die from AIDS.

LTAS-LB is a white, male hemophiliac. He has spent his entire life actively and affirmatively dealing with his hemophilia, a disease that can impose a very restrictive lifestyle on the afflicted. He has always been a fighter: he takes a very independent posture in taking responsibility for controlling his diseases. Occasionally his situation feels "a little overwhelming:" at those times, he distracts himself with "hobbies, television and joking around."

Maintaining clear "goals in life," he stubbornly does "whatever he has to do." He has always worked at "being normal," a task that he said required being an "aggressive risk taker." He courageously "lives life to the fullest."

LTAS-LB "focuses on his strengths and abilities." Although he is "stubborn and independent," he willingly accepts outside support and help. He believes that his

faith in his doctor and his medicine have been crucial in his successful survival.

Throughout his life, he has been able to be very "sensitive to and in-touch-with" his body. He is realistic, "knows his limits," and "takes things one day at a time."

LTAS-LB accepts, likes and loves himself and others. He maintains a feeling of purpose, meaning and pride in his life by helping others. He also believes that his "spirituality" and "being in touch with Nature" has given him he confidence to maintain his continuing survival.

4.1.4 Long Term AIDS Survivor "PD".

LTAS-PD is a white, gay man who experiences a "driving force from within," a "will to live" and the "fortitude to survive." Believing that "attitude is more important than even medications," he sees his disease as an opportunity and a challenge. He is quick to seize the "opportunity to become a whole person." By believing in his survival and by maintaining hope, he is "better able to help self and others."

With "determination and perseverance," he fights hard at "maintaining a sense of well-being." By taking responsibility for his situation, he gains a "role to play" in his survival. He feels "compelled and driven to control and be in control of AIDS." By "believing in myself and in what I'm doing," LTAS-PD avoids "looking back." Being in

control, however, he is better able to allow others to help him, but "by my own rules." He keeps a sense of humor, but is assertive about "allowing the positive and getting rid of the negatives" in his life.

One of the ways LTAS-PD actively "chooses to live" is by letting go of his fears: "maintaining calm, and putting fears forward." He tries his best without kidding himself, and he "lives in the now" ("when I look back to the past, I see guilt; when I look to the future, I see fear; I'm going to experience 'the now.'"

LTAS-PD is very active in teaching PWAs and the community-in-general about hope, responsibility, and dignity in living with AIDS. As he reaches out to help others, he receives acceptance, support and the respect of others. His caretaker roles - his "vocation" - give him a sense of purpose and meaning. He feels confident, and believes in his own abilities. Loving himself and others, he is able to maintain a sense of calm and self-healing.

4.1.5 AIDS-Counselors' Perspective.

As a group, the AIDS-counselors confirmed the general survival profile expressed in the previous four descriptions. They describe long-term survivors as people who not only take their disease very seriously, but also see it as a challenge: an opportunity to truly live and experience the joy in life. They actively choose to live, and in fact, reject any message - internal or external -

that they will die from AIDS. They have their moments of feeling overwhelmed, but they all do specific things to cope with those moments: they use humor, drugs, hobbies, and/or focus on their missions or vocations.

Survivors are highly responsible people. Their sense of responsibility extends to respecting, responding to, and expressing needs and feelings, including anger. They "take care of unfinished business" in order to "get it out of the way [of enjoying life, and surviving]." Their goals frequently include re-establishing bonds with family.

The AIDS-C-group also described survivors as people who take control of their situation with AIDS. They work hard, do whatever it takes, and attempt to focus on the positive. They live life to the fullest.

Survivors are fully focused on the fight, but they ultimately reach a point of having to respect the reality of their situations. They still keep their strengths and abilities in the forefront, but also grow to respect their limitations. They learn to accept and appreciate help in maintaining control of AIDS. They also become more selective in choosing settings and people who support them "the way they are."

Finally, the AIDS-C-group described survivors as a group that moves with confidence, purpose and meaning in life. They seek self fulfillment, and they extend their surviving to others by taking active teaching and caretaking roles.

4.2 The Survival Skills.

4.2.1 Presentation of Skills According to Hypothetical Model of Developing Exceptionality.

The data gathered in this study strongly parallels the findings of past research with respect to content. In Table 2.2 of chapter two (page 33), a synopsis of all the reviewed survivor research was presented (predominantly cancer and AIDS). The categories used to organize the psycho-social skills were: Communication; Control; Confidence; Challenge; Support; and Meaning. These categories were adapted from Segal (1986), and Kobasa (1980; Kobasa, Maddi & Courington, 1980; Kobasa, Maddi & Kahn, 1982). As described earlier, the data in this study present survival as a dynamic process. Chart 4.1 (page 64) is a presentation of the model: steps or phases of developing exceptionality in long-term survival of AIDS.

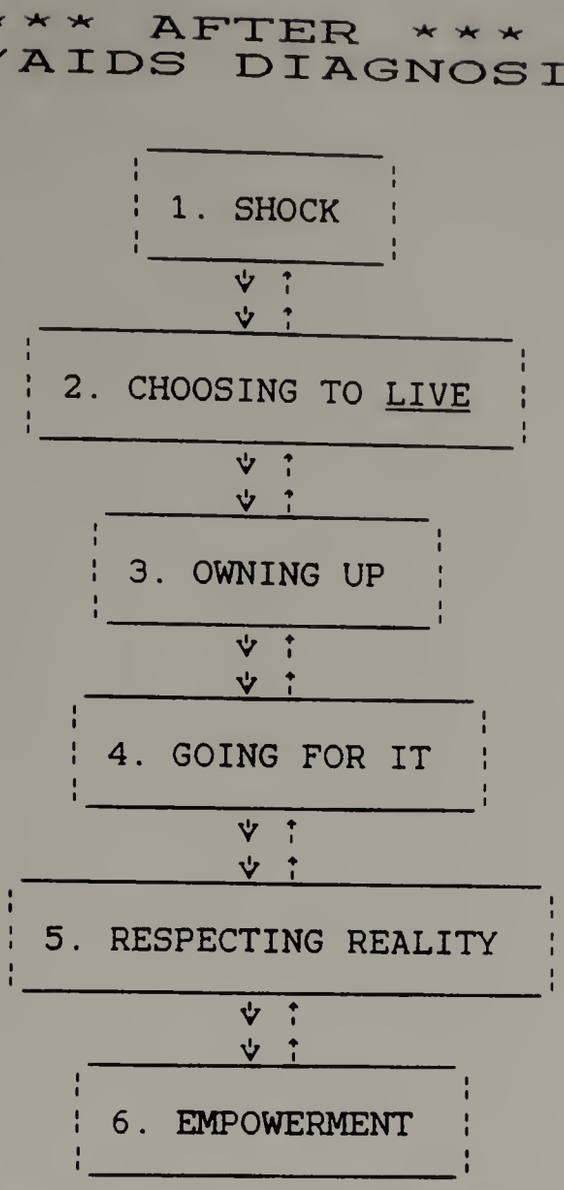

Chart 4.1 Marchetto Model: Hypothesized Process of Developing Exceptionality in Long-Term AIDS Survivors.

In the long-term survivor research that was reviewed (predominantly cancer and AIDS), no other phase models were found. As will be presented, however, the data in this study indicated a progressive and stepwise development of exceptionality. Although the categorization of survival skills according to psycho-social grouping (communication; control, etc.) may be appropriate, that organization gives

no suggestion of the process involved in developing those skills.

The development of a phase-model had its own course of development. The investigator initially attempted to fit the skills described in this study, into the same psycho-social skill-groups. It was possible to do this; however, in many cases, the skills did not seem to clearly or easily fall within one category or another. Some seemed to fit within several categories. After working and reworking the data several times, the feeling for a phase-model emerged, and the skills seemed to fall more naturally and more appropriately within the particular steps. In follow-up telephone conversations with each group-member, the hypothesized model was unanimously acknowledged as fitting and appropriate to their individual situations.

Although not specifically aligned with survivor-research, two phase-theories that address other life traumas were located. Kubler-Ross (1969) presented her "stages of death-and-dying:" (1) Denial and Isolation; (2) Anger; (3) Bargaining; (4) Depression; and (5) Acceptance. Winder & Winder (1985) described a sequence observed in their work with women facing the need for breast reconstruction: (1) Denial; (2) Guilt; (3) Shame; and (4) Decision for Reconstruction (A. Winder, personal communication, June 22, 1989). In these models, the researchers describe what the researcher in this study

considers to be representative of the substeps[1] involved in step two of the Marchetto Model, Choosing to Live. The previous models fail to describe, however, the continuing sequence that occurs after the decision to "accept death" or to "choose breast reconstruction." The Marchetto Model describes the development beyond "choosing to live."

The steps of the hypothesized model will be functionally defined later in this chapter. In order to organize the survival skills of this study, however, this brief explanation of the steps of the model is provided. The sequence of developing exceptionality is hypothesized to include skills development within each of these steps: (1) Shock, the first experience after receiving an HIV or an AIDS diagnosis; (2) Choosing to Live: the decision must be made to actively go on living in contrast with a more limiting decision to merely "survive;" (3) Owning Up, the third phase: identifying, acknowledging and actively dealing with issues; (4) Going For It: survivors - in their own way - fully invest themselves in living; (5) Respecting Reality: survivors identify, acknowledge and actively deal with the realities of their situation; and, (6) Empowerment, a final phase of fully being self, and of supporting others in their own true expression of self. Rather than meaning "politically active," empowerment is presented as a form of "self-actualization."

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[1] See Section 4.3 of this chapter: The Process of Developing Exceptionality in Long Term Survival of AIDS.

Utilizing the Marchetto Model, Table 4.1 (below) lists the survival skills most commonly cited by the two groups:

Table 4.1 AIDS-Survival Skills Most Frequently Cited by Both Experimental Groups, Arranged According to the Steps in the Hypothesized Model of the Process of Developing Exceptionaltiy in Long-Term Survival of AIDS.

SURVIVAL SKILLS PER STEPS IN MODEL

SHOCK	CHOOSING → LIVE	OWNING UP	GOING FOR IT	RESPECT REALITY	EMPOWERMENT
PARTIAL DENIAL	SEEING AIDS AS A CHALLENGE	HIGHLY RESPONSIBLE	TAKE CONTROL	SUPPORT SYSTEMS	HELPING OTHERS
OCCASIONALLY USE DRUGS	WILL TO LIVE	EXPRESSING FEELINGS	FOCUS ON POSITIVE	FOCUS → POSITIVE GET RID OF NEG.	CONFIDENCE
HOBBIES	HOPE	TAKING CARE OF UNFINISHED BUSINESS	DO WHATEVER NEED TO DO	LIVING IN THE NOW	PURPOSE AND MEANING
	NEVER SAY DIE FROM AIDS	CONFRONTATION	HARD WORK	COLLABORATE WITH DOCTORS	SPIRITUALITY
	FIERCE JOY OF LIVING	IDENTIFY/LABEL STRESS	ASSERTIVENESS	ASKING FOR HELP	LOVING SELF
	GIVING MY BODY A LIVE MESSAGE	BRUTALLY HONEST WITH SELF	FIGHTER	AIDS: JUST A DISEASE	DIGNITY AND SELF-WORTH
		IN TOUCH WITH BODY CUES	LIVE LIFE TO THE FULLEST	ACCEPTANCE OF SELF & OTHERS	STRIVING TOWARDS TRUTH
		TELLING PEOPLE I HAVE AIDS	POSITIVE LIFESTYLE CHANGE	KNOWING LIMITS	APPRECIATE LOVE & CARING
		EXPRESS LOVE & CARING	PHYSICAL SELF CARE	REALISTIC	SELF FULFILLMENT

4.2.2 Functional Definitions of the Steps of the Hypothetical Model (Shock; Choosing to Live; Owning Up; Going For It; Respecting Reality; Empowerment).

The steps are organized according to the general function of its aligned skills. The labels indicate the discordance (and transition issue) to be negotiated per step. Movement from step to step may be similar to cognitive stage-shifts: new information can no longer fit well within the existing conceptual scheme (way of making sense of the "world"). As the conceptual scheme ceases to provide the appropriate order, a tension or an anxiety promotes progression to a new perspective/stage/step. The function of the various steps of the proposed model follow:

4.2.2.1 Shock.

In describing the initial period of time following the news of positive HIV-diagnosis, shock is the expression most frequently used by the group members. It is a period of numbness and of denial. The use of denial is the major functional characteristic of the skills that seem to emerge during this period of time (and used as needed at any point in time). The skills that are categorized in the Shock step also function to help the survivors: "deal with the worst times" (LTAS-LB #2)[2]; "distract myself to keep from being overwhelmed" (LTAS-AV #4, AIDS-C-AD2 #21); "get my

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[2] This code attempts to identify the subject and the source of the mentioned skill. e.g. LTAS-LB #2 = Source: LTAS-LB, Skill #2, found in APPENDIX B.

mind off AIDS" (LTAS-AV #1); and "avoid becoming debilitated by terror" (AIDS-C-AD1).

4.2.2.1.1 Specific Examples of Some AIDS-Survival Skills Arranged Within "SHOCK."

4.2.2.1.1.1 Skill AIDS-C-AD1 #2: Functional Denial.

Feeling "terror and doubt," and fearing that "there may be no life after this," survivors may occasionally "get through the difficulties of the day" by partially denying the apparent realities of AIDS. This skill functions primarily in helping survivors to avoid "debilitating terror, anxiety, giving up and suicide."

4.2.2.1.1.2 Skill LTAS-AV #20: Partial State of Denial.

To avoid "being overwhelmed" when the feelings of "fear, anger and isolation" become too intense, LTAS-AV "partially denies." She mostly uses humor, and occasionally uses drugs: "it keeps me from going crazy."

4.2.2.2 Choosing to Live.

The skills in this category function primarily to affirm a "will to live." The group members report that survivors "send my body a live message" (LTAS-CM #14). Although they report that they "accept one's condition" (AIDS-C-AD2 #9b), they also "maintain hope" (LTAS-LB #9) and "decide to go on" (LTAS-AV #21).

4.2.2.2.1 Specific Examples of Some AIDS-Survival Skills Arranged Within "CHOOSING TO LIVE."

4.2.2.2.1.1 Skill AIDS-C-DK #16: Urge to Live: Choosing to Survive.

Experiencing the "desperation, fear and urgency" of the situation brought on by HIV diagnosis, AIDS-C-DK's long term survivors decide, "I want to experience some positive in life." In order to avoid a "continuation of negative past life experiences," they develop an "urge to live ... they choose to survive." As a result, they "take time to smell the flowers," and do experience some of "the positive in life."

4.2.2.2.1.2 Skill LTAS-PD #3b: Opportunity.

By striving to see "opportunity" in his situation with AIDS, LTAS-PD actually seeks the "opportunity to become a whole person." Seizing the opportunity, he is better able to "help self and others," and think that "there is a reason to my surviving: perhaps to help." "When a door closes, a window opens."

4.2.2.2.1.3 Skill AIDS-C-FJ #2: Maintain Hope.

"After the initial shock phase of the AIDS crisis," many PWAs experience feelings of "fear, loneliness and isolation." Coming from difficult family situations, many survivors "maintain hope" by never abandoning the "belief in the possibility of reconciliation of unresolved family

issues." Possibly gained by the use of this skill are "reconciliation of unresolved issues," and, "ability to continue to survive."

4.2.2.2.1.4 Skill LTAS-CM #18: Fierce Joy of Living.

LTAS-CM "loves life:" "However much time I have left, I want to revel in the joy of existence. I want to live, feel, fully. Although it's hard work, you can avoid getting caught up in the momentum, plodding along."

4.2.2.3 Owning Up.

After Shock and Choosing To Live, survivors Own Up: they come to terms with their internal and external environment. Survival skills that fall within the context of Owning Up function to "achieve peace for self and for others" (LTAS-AV #10; AIDS-C-FJ #s 7 & 8). By "becoming honest with myself" (LTAS-CM #17), survivors "take responsibility" for their illness (AIDS-C-DK #12). In so doing, they are able to "get down to business" (LTAS-AV #8) and ultimately feel "more in control" (LTAS-CM #8).

4.2.2.3.1 Specific Examples of Some AIDS-Survival Skills Arranged Within "OWNING UP."

4.2.2.3.1.3 Skill AIDS-C-AD1 #4a: Taking Responsibility.

Feeling "fear, terror and isolation," "taking responsibility" accomplishes overall goals of "health and survival," as well as facilitating "accomplishing

missions." By taking responsibility, "giving up" is avoided.

4.2.2.3.1.2 Skill LTAS-CM #16: Brutally Honest With Myself.

In every way, LTAS-CM believes that he must "give my body a 'live message.'" By "being honest with myself, I stay on track and in control."

4.2.2.3.1.3 Skill LTAS-AV #14a: Express Feelings.

LTAS-AV "expresses feelings" in order to "take care of unfinished business," and to "feel good about self and others." Expressing feelings "gets them out of the way."

4.2.2.3.1.4 Skill AIDS-C-FJ #7: Working Towards Acceptance by Family.

Motivated by a "desire for reconciliation of unresolved family issues," and also by feelings of "fear and loneliness," AIDS-C-FJ's survivors "worked towards acceptance by his family." The major gains achieved by this skill are "forgiveness and peace."

4.2.2.4 Going For It.

After the survivors deal with the SHOCK, actively CHOOSE TO LIVE, and OWNING UP, they are very ready for "surviving:" they are ready for GOING FOR IT. When survivors go for it, they "get on with the business of living" (LTAS-CM #5). By "taking control" (LTAS-AV #13;

LTAS-LB #22; and LTAS-CM #13), they are able to "maintain a vigilant watch over AIDS" (LTAS-AV #5). They feel "better able to help self and others" (LTAS-LB #13), and maintain a sense of "hope and purpose" (LTAS-CM #11).

4.2.2.4.1 Specific Examples of Some AIDS-Survival Skills Arranged Within "GOING FOR IT."

4.2.2.4.1.1 Skill LTAS-AV #3: Fighter Spirit.

Feeling "horrible" about her situation with AIDS, she maintains a fighting spirit in order to "keep on top of AIDS," in order to avoid "letting AIDS take over." Her spirit is exemplified in this statement: "If I fall, I'll fall fighting ... I'm not ready to go yet."

4.2.2.4.1.2 Skill AIDS-C-DK #25: Focus on the Positive.

Feeling "hope," and "wanting some "joy," AIDS-C-DK's survivors "focus on the positive" in order to "keep on track" and maintain their sense of "hope." By maintaining a positive focus, they avoid "being a victim," and "not taking responsibility." A "supportive someone" is frequently involved in their developing and maintaining this skill.

4.2.2.4.1.3 Skill LTAS-PD #1a: Perseverance.

One of the ways LTAS-PD deals with feelings of "anger and helplessness" brought on by his situation with AIDS, is to persevere, to work hard. He believes that "staying well

is a full time job." By persevering, he is better able to "get well, and get on with what's really important [in life]." This skill functions to gain him "praise, support and acceptance" from others, and helps him avoid "letting the virus control my life." His doctor and his respiratory therapist have played key roles in influencing him to continue to persevere.

4.2.2.4.1.4 Skill AIDS-C-AD1 #1: Adaptable: Developing New Skills.

By being "adaptable" survivors may gain "partial crisis resolution" as well as become more able to "accomplish a purpose, a mission in life." This skill may develop in response to feeling "depressed, anxious and terrified," and to having thoughts such as, "I'm not going to die without finishing my missions in life." Significant others can play an important role in supporting the development and utilization of this skill.

4.2.2.5 Respecting Reality.

RESPECTING REALITY is the step in the development of exceptionality when survivors are faced with the reality of human limitations. At this point, survivors become "more willing to accept help" (LTAS-PD #19), and are able to identify, "acknowledge and respect their limits" (LTAS-LB #20). One of the ways they "conserve their energy" (LTAS-CM #25) is by "living in the 'now'" (LTAS-PD #15). Although they become more willing to share the

responsibility for their survival, they ultimately "feel more in control" (LTAS-LB #16), and they "feel better about themselves" (LTAS-PD #17). By taking advantage of the resources of others, they are better able to "keep going" (LTAS-LB #34), "better able to survive" (LTAS-PD #19), and more able to "achieve a feeling of being at peace with self and others" (LTAS-AV #12). By opening to, and working with others, they "gain support and share bonds" (LTAS-AV #22).

4.2.2.5.1 Specific Examples of AIDS-Survival Skills Arranged Within "RESPECTING REALITY."

4.2.2.5.1.1 Skill LTAS-LB #19: Willing to Accept Help.

When LTAS-LB is "willing to accept help," or "allowing dependence," he maintains a strong, "realistic" posture. He is able to achieve a higher degree of "comfort," to continue to "think positively," and to "help himself get better through the help of others."

4.2.2.5.1.2 Skill AIDS-C-FJ #3: Realistic but Hopeful.

Acknowledging and respecting their crisis, survivors "make necessary changes" in order to deal with the reality of the situation; they don't, however, lose hope. They believe "there is still something to live for." By being "realistic but hopeful," survivors are better able to "cope with the situation," and more able to "experience 'more' in life."

4.2.2.5.1.3 Skill AIDS-C-DK #10: Identifying, Acknowledging and Avoiding Negative Influences.

In order to deal with feelings of "desperation" and fearful concern for "getting caught up in another abusive situation," long-term AIDS survivors learn to "identify, consciously acknowledge and avoid negative influences."

4.2.2.5.1.4 Skill AIDS-C-AD2 #14b: Using Healers as Consultant vs. Being a "Patient."

When faced with so many physicians, consultants and health care providers, survivors frequently become "frustrated with this plethora of health care providers." They find either a "vacuum of answers or a plethora of conflicting answers." Thinking, "there are so many people, maybe I had better take the helm." In so doing, they gain "control and competency."

4.2.2.5.1.5 Skill LTAS-PD #10: Support.

Support has been important in helping LTAS-PD cope with feelings of "fear, frustration, isolation and rejection." LTAS-PD participates in formal and informal support groups with other PWAs and friends: by "being willing to give something, I get something back." Sharing "common bonds, we realize that there are others out there with the same fear and frustration." Participating in supportive relationships helps LTAS-PD in other ways: "it keeps me from giving in, and also from having to make it harder on

my family." Within his support structures, LTAS-PD gains "respect, acceptance," and a feeling of "calm."

4.2.2.6 Empowerment.

The final step in the hypothesized model of developing exceptionality is EMPOWERMENT. It is an internal and an external acknowledgement and enactment of self, and serves as a "foundation to support other skills" (LTAS-PD #11). Survivors tend to "rebond with families and others" (AIDS-C-DK #2), and also feel more "calm, confident and capable" (AIDS-C-AD2 #18). In being "loving of self and others" (LTAS-PD #17; LTAS-AV #22; AND LTAS-LB #33), they gain "support" (AIDS-C-AD1 #3) and ultimately become "more prepared for death" (AIDS-C-AD1-3). Their mode may switch somewhat from being mainly concerned for their own survival, to also being "caretakers of others" (AIDS-C-AD2 #1). They develop a sense of self fulfillment and achieve greater "meaning and purpose in their lives" (LTAS-PD #3a; and AIDS-C-DK #27).

4.2.2.6.1 Specific Examples of AIDS-Survival Skills Arranged Within "EMPOWERMENT."

4.2.2.6.1.1 Skill AIDS-C-DK #27: Seeking Self Fulfillment.

Feeling "desperate" that "if I don't do something new, I may die before I reach self-fulfillment," AIDS-C-DK's survivors work hard at "seeking self-fulfillment." Encouraged by formal support, encouragement and coaching,

they maintain this skill in order to achieve "meaning" in their lives.

4.2.2.6.1.2 Skill LTAS-PD #3a: Purpose and Meaning.

LTAS-PD's "purpose and meaning" comes from "helping self and others: really caring and taking time: Life is about family: being a loving, caring person." Believing that "whatever you give out, you get back tenfold," this skill helps LTAS-PD gain "acceptance, care, support and approval" of others.

4.2.2.6.1.3 Skill AIDS-C-AD2 #18: Self Confidence, Empowerment and Healthy Entitlement.

Feeling "competence and self-esteem," survivors tend to "believe in their rootedness and relatedness." Feeling "good about themselves, they avoid any sense of diminishment or foreclosure."

4.2.2.6.1.4 Skill LTAS-CM #12: Helping Others.

LTAS-CM "help others," "supporting them in their decisions, and by providing information:" "You're making life or death decisions ... get all the points of view." This skill is also "self motivated: you never know a subject as well as when you teach it." By helping others, he enhances his own survival.

4.2.3 Analysis of Survival Skills Data.

As previously indicated, Table 4.1 (page 68) lists the skills most commonly cited by both groups. As can be seen in Appendix B, Appendix Tables B.1a-B.8, there were other skills reported by the members of both groups. These "skills cited" tables in Appendix B illustrate a noteworthy point. In each category, there were a few commonly cited skills ("clusters"); beyond those few commonly cited, however, most of the other skills cited within each step-category are singly cited ("variations"). Regardless of the frequency of citations, the investigator believes that all the skills listed (multiply and/or singly-cited) fall reasonably within the functional context of each of the steps of the hypothesized process of developing exceptionality in long-term survival.

This phenomenon of "clusters and variations" of skills within each step-category, can be interpreted in several ways:

(1) The clusters of common skills organized at each of the six steps of the model, lends credence and validity to the accuracy of the model. If the frequency of citation is an accurate indication of the relative importance of the particular skills, then frequently-cited skills could be especially important ones for PWAs to command: they could enhance survival. This opens a cautious option for a literal "prescription" of skills that could be developed if they were not naturally occurring within a PWA's repertoire

of skills. The notion of prescribing is further developed within the next point.

(2) This investigator believes that the high incidence of variations is a critically important finding: In the preceding point, it was indicated that there may be specific skills that could be important to survival for most anyone. The possibility for prescribing was also mentioned. Prescription may be possible, but given the variation within step-categories, the implication is that the prescription should be primarily categorical (vs. overly specific). The possibilities, precautions and possible dangers of a prescriptive approach will be discussed in Chapter 5.

Partially confirming the notion of variation, and simultaneously illustrating the need for a categorical perspective is the long-term AIDS survival research done by LTAS-CM. LTAS-CM has interviewed "twenty" long term survivors who have lived more than three years beyond their diagnosis of AIDS. He wrote his impressions in a book entitled Striving and Thriving with AIDS (Callen, 1988, pp. 137-138). Regarding the issue of "what is most characteristic among the survivors," he reports that "there are patterns, but no one pattern:" many resisted the pressure to use the medication AZT; many had "rekindled religious sentiment;" and virtually all had "grit:" These people were all fighters; they are opinionated, incredibly knowledgeable about AIDS, stubborn, and passionately

committed to living. These men and women work hard to stay alive." In the final analysis, however, LTAS-CM "can't really say ... what's truly different about these long term survivors.... I have known many who had rekindled spirituality yet succumbed to AIDS. Others passionately committed to the political fight against AIDS have fallen in battle. ... In the end, even after meeting more long term survivors than anyone else in the world, I have concluded that there simply isn't an answer. ... The best I can surmise is that hope -- a passionate commitment to fighting for one's life -- is a necessary, but not sufficient ingredient for survival. It won't guarantee that you'll beat AIDS, but you've gotta [sic.] have it to even be in the running."

In a conversation with LTAS-CM after the formal data-gathering process was concluded, he acknowledged the hypothetical model as accurate in his case, but was unable to speculate beyond that. This investigator speculates that LTAS-CM may have been looking too specifically at individual skills. If LTAS-CM looks at individual variation within the functional contexts of the steps of the hypothesized model, he may see more in common among his survivors.

In the final analysis, if the categorical model is accurate, it would be expected that there would be a high incidence of survivors who each report individualized skills for <u>each</u> step/category. In this study, each member

of two groups of four people (survivors and counselors) cited AIDS-survival skills. If each person cited skills for each of the six steps of the model, there would have been 48 possible sets of skills. In reality, there were 44 sets: (LTAS-PD did not mention skills that fell within the context of Shock or Owning Up; LTAS-CM did not identify skills related to Shock; and LTAS-LB did not mention skills from Owning Up). Such a representatively high frequency of skills having been cited - for each category by nearly every subject - supports the accuracy and appropriateness of the hypothesized categorical model.

The data and the way the data emerged also supports the hypothesized categorization of the skills: As presented in the Methods section, data gathering was designed to occur in three stages: (1) individual interviews (interviewer and one subject): discovering and recording "personal survival theories;" (2) after the interviews and before the group meeting, subjects privately review and modify the written information taken from their own interview; and (3) presentation and additional refinement of the individual survival skills (within-group process). In actuality, no one made changes in the written information taken from their original individual interview transcripts. Members expressed that the written materials were accurate. They also said that even though each person used slightly different language, they were all saying essentially "the same things." The investigator interprets this within-

group confirmation as further support for the hypothesized categorical model.

4.3 The Process of Developing Exceptionality in Long-Term Survival of AIDS.

Considering the previously discussed high incidence of skills mentioned by each subject for each possible category, it would seem that exceptionality requires development of skills within each element, Shock through Empowerment. Each of the survivors and the counselors supported the hypothesized steps of exceptionality as regards long-term survival of AIDS. It cannot be determined from the data, however, just how development through the elements of the process actually proceeds. The actual progression may be erratic, or alternately progressive and then regressive. Two or more elements or "steps" of the process could be simultaneously active, or one could be most salient given the uniqueness of a PWAs current experience and/or needs.

4.3.1 Choosing to Live: The Pivotal Step in The Process of Developing Exceptionality.

Although the data does not indicate how the sequence progresses, it does address the question of whether or not the process will begin at all. In both of the group meetings (survivors and counselors), each person reported knowing many former PWAs who did not choose to live. They quickly died. "They just gave up." Choosing to Live is

perhaps the pivotal step that surfaces within each of the steps, a choice that probably needs to be frequently renewed.

4.3.2 Experiencing HIV/AIDS as a "Turning Point."

Each group member vividly described the response to HIV/AIDS - theirs or their clients' - as a "turning point:" "...bottom of life falling out," (LTAS-PD); "...moment of choosing," (LTAS-CM); "...hitting bottom ... the moment of truth, and foreclosed options," (AIDS-C-AD2); "... no place left to run," (AIDS-C-DK). The feelings expressed include fear, anger, time urgency, anxiety, desperation, isolation and insecurity. The thoughts and feelings are crisis-oriented. The situation is a critical choice point. Later in this chapter, Table 4.4 (page 97) lists the most commonly cited feelings experienced "early after news of HIV-diagnosis."

As indicated, all of the group members cited instances of unfortunately rapid declines and deaths of other PWAs. The context of the discussion was the need to actively choose to live. None said that everyone who died quickly had "given up;" they all did say, however, that those who had given up, did die quickly. AIDS is a physiologically compromising disease that affects the body's immune system in a forceful way. As presented in the literature review, attitude, stress and other psycho-social variables affect the immune system and its ability to resist disease.

4.3.3 Strongly Perceived Lack or Need in Life.

The experience of a significant need or perceived lack in their life experience was also frequently mentioned. As she rebelled against oppressive parents and society in the past, LTAS-AV strongly felt the need not to let "AIDS take over." LTAS-PD's past declaration of never being willing to personally experience a situation as his mother did with her husband's death, he vowed "not to let this happen (letting AIDS cause the 'bottom of his life to fall out')." AIDS-C-AD1 described the need to avoid "dying alone" and "dying without finishing life missions." AIDS-C-AD2 described the need to "get right again." AIDS-C-DK cited "something is missing," and the "need to experience something positive in life." And AIDS-C-FJ reported the need to "take care of unfinished business."

Several group members implied or directly identified the experience of "possible lost opportunity." Each AIDS-counselor mentioned the experience of time urgency, or "compressed time" (AIDS-C-AD2). "I've gone as far as I can go [astray] ... I've found the limit," (AIDS-C-AD2). "I'm running out of time," (AIDS-C-DK).

4.3.4 Motivation to Make the Choice to Live.

The survivors and the AIDS-counselors' survivors experience of thoughts and feelings seems to have motivated them strongly enough to compel them to "say NO to the stigma" (the compelling message that "no one lives with

AIDS"). In his research with social stigma, Goffman (1963) reports that people who possess some form of stigma are frequently "reduced in our mind from a whole and usual Operson to a tainted, discounted one .... The term stigma, then ... refer[s] to an attribute that is deeply discrediting" (pp. 2-3). Goffman also reports that stigmatized individuals typically cope with their situations in one of several ways: they (1) attempt to directly eliminate the stigma (e.g. surgery, as in the case of a superficial deformity); (2) devote "much private effort to the mastery of areas of activity ordinarily felt to be closed on incidental and physical grounds to one with his shortcomings; or (3) "He may see the trials he has suffered as a blessing in disguise, especially of what is felt that can teach one about life and people .... Correspondingly, he can come to re-assess the limitations of normals ..." (p. 11).

The survivors of this study clearly reported the need to "sidestep the stigma:" they "manage the tension" (Goffman, 1963, p. 138) by "finding a niche." Rather than trying to directly oppose or change the social stigma, they created an environment of people and places where they were accepted and loved as they are. As Goffman reported, "the relationship of the stigmatized individual to the informal community and formal organizations of his own kind is, then, crucial" (p. 39). To put it in Goffman's words, the

survivor described in this study "shifts through his[3] problem, learns about himself, sorts out his situation and arrives at a new understanding of what is important and worth seeking in life" (p. 40). In this study, the survivors' motivation was strong enough for them to stop and analyze their current situations, and then to make appropriate changes: they give their bodies a "live message" (LTAS-CM, skill #19, Appendix A), they <u>choose to live</u>.

Motivation may not be all that is necessary for survivors to be able to successfully <u>choose to live</u>. According to AIDS-C-FJ, <u>hope</u> is probably the one most common factor among LTASs. As quoted in a previous section in this chapter, LTAS-CM expressed very similar thoughts, and in speaking about stages of death-and-dying, Kubler-Ross (1969) says, "the only things that usually persist through all the stages is hope" (p. 138).

4.3.5 <u>External Support</u>.

Most of the group members cited people who played important roles in influencing the development of AIDS-survival skills. Some were people from the past, some from current times. Some provided direct and positive influences, and some influenced the development of coping skills by providing a negative example. Doctors, parents, lovers, other empowered PWAs, and other long-term survivors

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[3] Please read as his/her.

were cited as having had a profound influence on several of the survivors. The predominant role they played was to provide hope and support. Please see Appendix A of each person's account of origins, descriptions of skills, and of important influences, feelings and functions (of skills).

4.3.6 Willingness and Ability to Progress Through the Steps of the Process of Developing Exceptionality.

As mentioned earlier, it seems that the process of exceptionality in long-term survival of AIDS requires skill development in all of the steps. Developing skills in all of the categories may require the "willingness and ability to progress through the steps of the process." The willingness and ability may partially depend on a constant reaffirmation of choosing to live.

If a survivor's level of cognitive development plays a role in the ability to progress through the steps, the data of this study is insufficient to accurately assess that fact. The essence of the development of exceptionality, however, seems dependent on one's willingness to become honest with self and others, and to fully be oneself in the midst of others. The ability to progress through the entire sequence of exceptionality may be more aligned with the previously mentioned key conditions: experiencing a lack or need in life, and possible lost opportunity, feeling strong motivation to continue to experience life, being influenced by key people, AND persevering in reaffirming the choice to live, and maintaining hope and

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determination through the entire process. Fulfillment of the conditions seems to facilitate development of long-term AIDS-survival skills.

The data of this study does indicate at least one important key condition common among the survivors: past experience with previous personally challenging and/or compromising situations. This will be presented in the next section, "Origins."

4.4 Origins of Skills.

All group members identified critical "before-HIV-diagnosis," and "after-HIV-diagnosis" situations that directly influenced the development of particular coping skills that ultimately became important in successful long-term survival of AIDS.

4.4.1 Before-HIV-Diagnosis Origins.

Table 4.2, (page 90) is a modified histogram indicating the frequency and source of all of the "before-HIV-diagnosis originating situations that led to the development of critical AIDS-survival skills." The boxes in the left-hand column indicate the LTASs who mentioned the "origin" listed within the center column (e.g. "difficult family situation:" "AV-BO1" in the first LTAS-column box references the subject , (LTAS-AV), and the source of the quotation, (BO1 = "Before HIV-Origin #1" [found in Appendix A]. Likewise, the right-hand, or "AIDS-

C" column identifies the individual source and subject reporting the center-column's aligned origin. Relative to frequency of citation, the items are arranged in a descending order.

Table 4.2 Before-Diagnosis Origins as Cited by LTAS-GROUP and AIDS-C-GROUP. (e.g. AV-BO1 = "Before-HIV-Diagnosis Origin #1" Cited by LTAS-AV, Appendix A).

BEFORE-HIV-DIAGNOSIS ORIGINS

LTAS-GROUP FREQUENCY OF RESPONSE			ORIGIN CITED	AIDS-C-GROUP FREQUENCY OF RESPONSE			
PD BO1	AV BO1		DIFFICULT FAMILY SITUATION.	AD1 BO1	AD2 BO2	DK BO1	FJ BO1
	AV BO4		RECOVERY FROM ADDICTION	AD2 BO3	DK BO3		
	AV BO2		CROSS-CULTURAL OPPRESSION				
	AV BO3		WITHIN-CULTURE OPPRESSION				
	CM BO1		HOMOPHOBIC CULTURAL OPPRESSION				
	LB BO1		HEMOPHILIA				
	PD BO2		SUCCESS IN BUSINESS				
			HAVING EXPERIENCE WITH SERIOUS ILLNESS OF OTHERS.	AD2 BO2			
			NORMAL HEALTHY FAMILY / CHILDHOOD	AD2 BO4			

Six of eight members of both groups cited "difficult family situations" as influential in the development of survival skills. LTAS-AV described parents who exerted "very high pressure and expectations," a situation that she thoroughly rejected. LTAS-PD spoke about the death of his

father: when PD was five years old, his father died. His mother experienced severe difficulty in coping with her loss, and turned to PD for support. The parent-child roles were reversed, creating a situation that led LTAS-PD to develop several coping skills.

All of the AIDS-counselors described their survivor-clients as having origins in dysfunctional families. In these situations, various family members were subject to different types of abuse. The situation most frequently described: the "negative effects of addiction," and the resultant "co-dependent" and "adult-child" responses.

Other skill-development-inducing situations included: "recovery from addiction," "cross-cultural oppression," "within-culture oppression," "homophobic cultural oppression," "hemophilia," and "having dealt with serious illness of others."

Two "positive" skill-inducing situations were also described: "a small proportion" of AIDS-C-AD2's survivors experienced "normal, healthy family / childhoods;" and LTAS-PD described the positive effects of his "success in business." [For full descriptions of these "origins" and the skills that developed from them, see Appendix A.]

Table 4.3 Feelings Cited Within Before-Diagnosis AIDS-Survival-Skill Origins in Appendix A. (e.g. AV-B01 - Feeling Cited by AV in "Before-HIV-Origin #1").

BEFORE-DIAGNOSIS CITED FEELINGS

LTAS-GROUP FREQUENCY OF RESPONSE					CITED FEELINGS	AIDS-C-GROUP FREQUENCY OF RESPONSE				
LB B01	CM B01	AV B03	AV B02	AV B01	ISOLATION	AD1 B01	FJ B01			
PD B01	LB B01	CM B01	AV B03	AV B02	ANGER	AD2 B03				
				PD B01	HELPLESSNESS	AD2 B01	AD2 B02			
		CM B01	AV B02	AV B01	REJECTION					
					LONELINESS	AD1 B01	FJ B01			
				AV B03	NEGLECTED	AD1 B01				
					DESPERATION	DK B01	DK B02			
				PD B01	FEAR	AD2 B03				
					TIME URGENCY	DK B02				
					SEPARATED	FJ B01				
					FRUSTRATION	AD2 B02				
					OVERWHELMED	AD2 B01				
					LOVE	AD2 B04				
					POSITIVE SELF-ESTEEM	AD2 B04				
				PD B02	RESPECT					
				PD B02	SUPPORT					
				PD B02	HARMONY					
				PD B02	COOPERATION					
				PD B02	CALM					
					CARE	AD2 B04				
					CONFIDENCE	AD2 B04				

The majority of skill-development-influencing origins seem to have been negative in nature. The feelings reported could suggest situations within which the individuals felt that they were subject to a situation that was beyond their control. The feelings of anger may have been indicative of their rejection of the situation. Those feelings could also have influenced them to develop skills so they could change their response to the situation (accommodate to the situation), vs. continuing to try to change it to meet their needs. It may have been relatively unyielding over a long period of time, or just seemed "too big" to handle.

All of the positive feelings were reported by only one survivor and one counselor. This indicates, however, that although the majority of before-HIV-diagnosis AIDS-survival were developed from negative situations, the possibility for developing effective coping skills may also be possible from more positive skill-influencing situations.

4.4.2 After-HIV-Diagnosis Origins.

All group members described receiving the news about HIV-diagnosis as a very critical incident, a "turning point," a "moment of truth."

LTAS-AV reported a strong reaction: she felt anger, and fear for her life. As she did in her childhood, she strongly rejected and outwardly rebelled against a perceived external threat of unreasonable pressures and

expectations: in childhood, she reacted against oppressive parents and society-in-general; after HIV-diagnosis, she fiercely decided that she was "not going to let AIDS take over."

LTAS-CM described a HIV/AIDS as a "moment of choosing." In Callen (1988, p. 136), he said, "AIDS was kind of a cosmic kick in the ass for me. It made me realize the preciousness of life. It made me ask hard questions and make some difficult choices. I jettisoned a lot of bullshit and got on with the business of living."

LTAS-LB was "touched by the spirit" in a near-death experience. In that situation he realized the degree of choice he had over his health and his survival.

LTAS-PD described thinking that "the bottom of my life was falling out." Back early in his childhood, he experienced his mother's anguish with her loss of her husband, his father. At age five with his mother, and more recently with HIV/AIDS, LTAS-PD's response was: "I'm not going to let this happen to me." LTAS-PD also said that "HIV/AIDS forced me to 'take a strong look' at my life."

AIDS-C-AD1 described "time urgency," and "not wanting to die without finishing life missions," and "not wanting to die alone."

AIDS-C-AD2 reported that his clients "hit bottom" with the news: "a moment of truth." He described their sense of foreclosed options, and the pressure of time urgency: "I've gone as far as I can go [astray] ... it's time to

deal. I've found the limit. I'm going to 'get right' again."

AIDS-C-DK said that her survivor clients felt "desperate," and "motivated by the urgency of the situation: I'm running out of time. There's no place left to run. Something is missing. I need to experience something positive in life ... "

Finally, AIDS-C-FJ indicated that her survivors experienced "anxiety about death," and a "sense of urgency ... to complete unfinished business."

4.4.2.1 Feelings Experienced in After-HIV-Diagnosis Origins.

The impetus to "fight back," and CHOOSE TO LIVE, seems to be fueled by the thoughts described above, but motivated by the strong emotions felt in the experience. Table 4.4, page 97) is another modified histogram. It indicates the frequency and source of the center-column's "feelings cited early after HIV/AIDS diagnosis."

Table 4.4 Feelings Cited Early After HIV/AIDS Diagnosis, as Expressed in "After-Diagnosis AIDS-Survival-Skill Origins" in Appendix A. (e.g. AV-AO1 = Feeling Cited by LTAS-AV in "After-HIV Origin #1").

CITED FEELINGS
EARLY-AFTER-HIV/AIDS-DIAGNOSIS

LTAS-GROUP FREQUENCY OF RESPONSE			CITED FEELINGS	AIDS-C-GROUP FREQUENCY OF RESPONSE				
LB AO1	AV AO1		FEAR	AD1 AO1	AD2 AO1	FJ AO1		
PD AO1	AV AO1		ANGER	AD1 AO1	AD2 AO1			
			TIME URGENCY	AD1 AO1	AD2 AO1	DK AO1	FJ AO1	
	LB AO2		ANXIETY	AD1 AO1	FJ AO1			
	CM AO1		DESPERATION	DK AO1				
PD AO1	CM AO1		ISOLATION					
LB AO1	CM AO1		INSECURITY					
	AV AO1		OVERWHELMED	AD2 AO1				
			TERROR	AD1 AO1				
	LB AO2		DEVASTATED					
			LONELINESS	FJ AO1				
	PD AO1		REJECTION					
	LB AO2		DESERTED					
	PD AO1		HELPLESSNESS					
	PD AO1		DEPENDENCY					
			DEPRESSED	AD1 AO1				

There is a strong resemblance between feelings experienced in the early-diagnosis time-period, and those cited in "before-HIV-diagnosis critical situations" (Table

4.3, page 93). The implication is that AIDS itself, presents to the survivors a crisis situation that is in some way similar to the before-diagnosis origins. Although possibly more life threatening, living with AIDS may leave the person feeling subject to an overwhelmingly negative and hard to control entity. They feel alone, rejected and afraid, but choose to change their response to the situation, rather than attempting what may seem like the impossible, changing AIDS. With HIV/AIDS, the "life threatening" factor seems to significantly add a sense of urgency with respect to time. The urgency could function in one of at least two ways: PWAs may be apt to (1) give up; or, (2) choose to live. As described in a previous section (4.3, The Process of Developing Exceptionality ..., page 83), the survivors make the latter choice, they <u>choose to live</u>.

4.4.3 <u>Categorization of Skills Learned Before HIV-Diagnosis</u>.

On pages 99 and 100, Tables 4.5 and 4.6, respectively, present the number of skills cited by the LTAS-group and the AIDS-C-group. It presents the number cited, per category, per origin cited. Finally, the bottom line indicates the percentage of the grand total of within-group skills that is attributable to the particular categories/steps of the hypothesized process of developing exceptionality in long-term survival of AIDS.

Table 4.5 Number of AIDS-Survival Skills Developed Per Before HIV-Diagnosis Origin, Per Step of the Hypothesized Model. LTAS-Group.

L T A S G R O U P

NUMBER OF SURVIVAL SKILLS PER STEP

BEFORE HIV DIAGNOSIS

ORIGIN:	STEPS OF PROCESS					
	SHOCK	CHOOSING TO LIVE	OWNING UP	GOING FOR IT	RESPECTING REALITY	EMPOWERMENT
DIFFICULT FAMILY SITUATION	(1)	(2)	(1)	(6)	(2)	
RECOVERY FROM ADDICTION			(1)		(1)	
CROSS CULTURAL OPPRESSION				(1)		
WITHIN CULTURE OPPRESSION				(1)		
HOMOPHOBIC SOCIETY				(2)		
HEMOPHILIA	(2)	(1)		(11)	(8)	(5)
SUCCESS IN BUSINESS					(1)	(4)
TOTAL PER STEP	(3)	(3)	(2)	(21)	(12)	(10)
PERCENT OF GRAND TOTAL (51) PER STEP	5.9%	5.9%	3.9%	41.2%	23.5%	19.6%

Table 4.6 Number of AIDS-Survival Skills Developed Per Before HIV-Diagnosis Origin, Per Step of the Hypothesized Model. AIDS-C-GROUP.

A I D S — C — G R O U P

NUMBER OF SURVIVAL SKILLS PER STEP

BEFORE HIV DIAGNOSIS

ORIGIN ↓ / STEPS OF PROCESS →	SHOCK	CHOOSING TO LIVE	OWNING UP	GOING FOR IT	RESPECTING REALITY	EMPOWERMENT
DIFFICULT FAMILY SITUATION	(2)	(1)	(1)	(6)	(1)	(6)
RECOVERY FROM ADDICTION	(1)	(2)	(7)	(8)	(12)	(5)
PREVIOUS EXPERIENCE WITH SERIOUS ILLNESS OF AN OTHER			(1)			
"NORMAL / HEALTHY" FAMILY				(2)	(1)	(1)
TOTAL PER STEP	(3)	(3)	(9)	(16)	(14)	(12)
PERCENT OF GRAND TOTAL (57) PER STEP	5.3%	5.3%	15.8%	28%	24.6%	21.1%

As will be indicated following the presentation of Table 4.9 ("Before vs. After-HIV Diagnosis Skill Development Percentage of All Skills Cited Per Step, and Per Group, page 103), the AIDS-C-group's professional and personal experience was biased towards chemically dependent survivors. This fact can be strongly seen in the across-all-steps (horizontal) representation of "Recovery from

Addiction" on Table 4.6 (35 skills cited) vs. the "Recovery from Addiction" citation on Table 4.5 (LTAS-group: 2 skills across 2 categories out of 6 possible). Relative to the total population of LTASs, it is expected that the importance of "Recovery from Addiction" to survival is more accurately portrayed in the LTAS-group presentation on Table 4.7 (i.e. minimal).

Tables 4.5 and 4.6 do, however, suggest that compromising situations experienced from early childhood and onward may influence skill development in nearly every category of the hypothesized model of developing exceptionality.

4.4.4 Categorization of Skills Learned After-HIV-Diagnosis.

On page 102, Tables 4.7 and 4.8, respectively, present the number of AIDS-survival skills developed after HIV-diagnosis. They presents the number cited per group, and per category-step of the hypothesized model of exceptionality. The bottom line indicates the percentage of the grand total of within-group skills that is attributable to the particular category-step of the model.

Table 4.7 Number of AIDS-Survival Skills Developed After HIV-Diagnosis, Per Step of the Hypothesized Process of Exceptionality. LTAS-GROUP.

L T A S — G R O U P

NUMBER OF SURVIVAL SKILLS PER STEP AFTER HIV DIAGNOSIS

ORIGIN: STEPS OF PROCESS	SHOCK	CHOOSING TO LIVE	OWNING UP	GOING FOR IT	RESPECTING REALITY	EMPOWERMENT
RESPONSE TO HIV / AIDS	(1)	(8)	(9)	(8)	(22)	(11)
PERCENT OF GRAND TOTAL (59) PER STEP	1.7%	13.6%	15.3%	13.6%	37.3%	18.6%

Table 4.8 Number of AIDS-Survival Skills Developed After HIV-Diagnosis, Per Step of the Hypothesized Process of Exceptionality. AIDS-C-GROUP.

A I D S — C — G R O U P

NUMBER OF SURVIVAL SKILLS PER STEP AFTER HIV DIAGNOSIS

ORIGIN: STEPS OF PROCESS	SHOCK	CHOOSING TO LIVE	OWNING UP	GOING FOR IT	RESPECTING REALITY	EMPOWERMENT
RESPONSE TO HIV / AIDS		(2)	(4)	(5)	(5)	(6)
PERCENT OF GRAND TOTAL (22) PER STEP		9.1%	18.2%	22.7%	22.7%	27.3%

Except for Shock in the AIDS-C-group, after-diagnosis skills presented were represented within every step of the hypothesized process. This lends credence to the accuracy of the model.

4.4.5 Before vs. After Origins: Comparisons.

4.4.5.1 General Comparisons.

Table 4.9 (page 103) lists the number and percentage of all skills cited per step and per group, before vs. after HIV diagnosis. The bottom line indicates before-vs.-after percentage of all skills, per group.

Table 4.9 Before vs. After HIV-Diagnosis Skill Development Percentage of All Skills Cited Per Step, and Per Group: LTAS-GROUP vs. AIDS-C-GROUP.

CATEGORY	NUMBER / PERCENT			
	LTAS-GROUP		AIDS-C-GROUP	
	BEFORE	AFTER	BEFORE	AFTER
SHOCK	3 / / 75%	1 / / 25%	3 / /100%	0 / / 0
CHOOSING TO LIVE	3 / /27.3%	8 / / 72.7%	3 / / 60%	2 / / 40%
OWNING UP	2 / /18.2%	9 / / 81.8%	9 / /69.2%	4 / / 30.8%
GOING FOR IT	21 / /72.5%	8 / / 27.6%	16 / /76.2%	5 / / 23.8%
RESPECTING REALITY	12 / /35.3%	22 / / 64.7%	14 / /73.7%	5 / / 26.3%
EMPOWERMENT	10 / /47.6%	11 / / 52.4%	12 / /66.6%	6 / / 33.3%
# BEFORE / AFTER	51	59	57	22
BEFORE VS. AFTER PERCENT OF ALL SKILLS, PER GROUP	46.4%	53.6%	76.2%	27.8%

As can be seen in Table 4.9 the survivors and the counselors disagreed about the total percentage of skills developed before- vs. after-HIV diagnosis. The survivor group indicated that 46.4% of all skills were developed before-HIV diagnosis, as compared with the counselors' indication that 76.2% were developed before. Looking at Tables 4.5 and 4.6, it can be seen that the major discrepancy was due to a different perspective on the role that "recovery from addiction" played in the lives of the survivors. The counselors cited 35 skills across all six categories, and the survivors cited two skills across two of the six categories. This is potentially an indication of AIDS-C-group bias as a result of professional and/or personal experience. Indeed, the bias could be in the direction of accuracy; however, the sample group profile may show reason why the bias potentially presented the data in an inaccurate fashion:

The LTAS-group profile was very representative of the overall total PWA-population: two gay men, one person with hemophilia, and one former IV drug-abuser. "Recovery from Addiction" was included as an "origin" for only one-of-four of the survivors: the former IV drug abuser. Two of four counselors, however, cited "Recovery from Addiction" as an important before-HIV-diagnosis origin: Those two counselors are professionally involved with large chemically-dependent populations. At least one of the two also has personal experience as a former child of one

chemically dependent parent. The long-term AIDS survivors that the two counselors have experienced were predominantly former chemically-dependent people. The same two counselors cited the greatest number of skills (33 and 27) vs. (10 and 8) by the other two counselors. This probably accounts for the discrepancies, and represents a biased before-vs.-after-diagnosis skill-base relative to the total PWA-survivor population.

Given the apparent bias in the AIDS-C-group, the LTAS-group portion (left side) of Table 4.9 will be considered to be more representative of the total population, and will be referenced in these comments:

Regarding the number of skills cited per before- vs. after-HIV-origins, some of the skills seem to be <u>older</u> or more <u>well-established</u>. On the LTAS-group portion of Table 4.9, it can be seen that approximately three-out-of-four <u>Shock</u> and <u>Going For It</u> skills were developed <u>before</u> HIV diagnosis. <u>Choosing to Live</u>, <u>Owning Up</u> and <u>Respecting Reality</u> seem to represent the newest skills: an average of approximately one-out-of-four were developed <u>after</u> HIV diagnosis. <u>Empowerment</u> is nearly even split relative to before- vs. after-HIV-diagnosis-developed skills.

4.4.6 Before vs. After Origins: Analysis.

4.4.6.1 New vs. Old Skills.

The investigator believes that the implications for the older skills (developed long before HIV diagnosis) are at least twofold: (1) The older skills (Going For It and Shock) were the skills most necessary for "survival" of their before-HIV-diagnosis situations; and/or, (2) The older skills may be the more basic or more externally oriented skills.

Within the context of Going For It, skills such as "taking control," "focusing on the positive," "working hard," "fighting spirit," and "physical self-care" seem - relative to level of cognitive development - more basic, and more external-environment-oriented skills.

The existence of newer skills can be interpreted similarly. Unless the before-HIV-diagnosis-origin were life-threatening, it seems that, by definition, Choosing To Live would be a relatively newly developed set of skills.

Owning Up and Respecting Reality, however, seem like skill-sets that require greater maturity and higher cognitive function. They require a higher degree of internal dialogue/thought-processing, greater awareness of subject-object differentiation, and thus, represent more developmentally specialized skills (higher level of cognitive development). Within the context of Owning Up,

survivors "express feelings," "identify and label stress," and act in a fashion that is "highly responsible to self and others." In the Respecting Reality set of skills, survivors "learn and acknowledge their limits," "collaborate with doctors," "live in the 'now'," and are "realistic." These skills seem indicative of higher level cognitive functioning.

The final skill-set, Empowerment, was nearly equally split. The skills themselves also seem to be evenly split relative to their representative level of cognitive functioning. For example, "appreciating love and caring," "helping others," "having confidence," and "loving self" could all be more basic skills; whereas, "striving towards the truth," "self-fulfillment," "dignity and self-worth" and striving toward "purpose and meaning in life" all seem more mature: they seem to indicate higher-level cognitive function.

4.4.6.2 Variation vs. Importance of Skills.

If frequency of citation of skills is an accurate indication of importance, then the skill-sets of Going For It and Respecting Reality are the most important. This investigator does NOT believe, however, that the number of skills per category is an accurate indication of importance. The investigator interprets the phenomenon of "greater vs. lesser numbers" of skills as indicative of variation vs. importance. For example, Choosing To Live is

likely to be as important as Going For It or Respecting Reality, even though there are relatively more skills listed within the latter two skill-set categories.

Although the investigator believes that overall frequency is NOT an accurate indicator of importance, he does believe that the number of people reporting the same skills is a more valid indication of importance. This was discussed in the "Survival Skills" section earlier in this chapter.

4.5 Closing Comments.

4.5.1 How The Model Developed from the Data.

In the LTAS-group meeting, the survivors briefly presented their ideas about the critical skills and issues of their own survival. After that, the interviewer posed this question to the group: Considering you own material, and all of the presentations of the others' information, what do you think is most important in long-term survival of AIDS? It was at that point in their meeting that a broader perspective on the development of exceptionality began to take form: viewing exceptionality as a continuing process. Rather than further refinement of individual survival skill presentations, it was this broader perspective that was the unexpected but "additional" information that the group process phase was designed to facilitate.

The following is a synopsis of the survivors' responses to the first question: "most important and underlying themes in long-term survival of AIDS:"

(1) Survival is a "choice."

(2) It takes "work." (Perseverance).

(3) You have to "deal with the stigma:" actively rejecting society's message that "AIDS is invariably - and rapidly - fatal." Rather than "bucking" it. the message needs to be side stepped:

(4) "Finding a niche where I can be me: accepted, loved and genuine."

(5) "Got to do it." (Read two different ways:

(a) "Got to do it." [i.e. mission in life].

(b) "Got to do it." [i.e. working and fighting for it.)

In the days that followed the final meeting and the conclusion of the originally designed data-gathering process, the interviewer began the task of systematizing and otherwise organizing the data gathered to that point. The "broader perspective that began to take form" in the concluding minutes of the LTAS-group meeting, emerged as a stepwise process of developing exceptionality in long-term survival of AIDS. Each of the members of the two groups (survivors and counselors) was contacted and presented this scheme. All were in full agreement regarding the appropriateness of the developmental sequence as presented in Chart 4.1 (page 64).

4.5.2 Statement of Tentative Conclusions Generated.

Each survivor experienced the following - and seemingly crucial - ingredients to the development of exceptionality. Survivors have characteristically:

(1) experienced past challenging and/or personally compromising situations;

(2) felt a strong need to accommodate and adapt to the critical situations (before and after-HIV diagnosis);

(3) actively adapted to the compromising situation: (i.e. they change their response to the situation, rather than changing the situation: they choose to do something about their experience within what probably is an unyielding situation).

(4) been influenced - positively or negatively - by key people to develop coping/survival skills;

(5) been willing and able to progress through and develop skills within the functional contexts of the six steps of the hypothesized process of developing exceptionality (i.e. Shock, Choosing to Live, Owning Up, Going for It, Respecting Reality, and Empowerment).

(6) developed skills that are uniquely suited to themselves, and functionally representative

of all six steps of the hypothesized model: i.e. they do it their own way, fully.

4.5.3 Underlying Themes.

Each step of the hypothesized process of developing exceptional in long term survival of AIDS, seems to require a choice to live, a choice that seems to require a strong enough caring about self to maintain the process. Caring enough to persevere.

Caring enough and persevering is likely to require self acceptance, and each step of the process can be seen as progressive steps of developing empowerment. In this context, empowerment means accepting, acknowledging and fully presenting/being the person you are. It also implies accepting and supporting the same in others. As LTAS-AV says, you have to "talk the talk, AND walk the walk."

In whatever configuration it actually occurs or evolves, however, it can be safely said that exceptionality is one option in life that may help people to recover from (and avoid) dis-ease. This and other themes will be addressed in chapter five.

CHAPTER 5

DISCUSSION AND IMPLICATIONS

5.1 Summary of Dissertation Study.

Worldwide, people are contracting and dying from AIDS at a devastating rate: in varying degrees, an avalanche of fear and desperation has affected every segment of society. AIDS demands action. Successful AIDS action seems to require the finest physiological, biochemical and psycho-social coordination ever demanded by any human crisis. To date, this finesse has possibly been achieved by only a few individuals: there are some exceptional or long-term AIDS-survivors [LTASs] who survive far beyond the expected life-expectancy with AIDS: By the Federal Center for Disease Control's definition, long-term survivors are those people with AIDS [PWAs] who have lived at least three years beyond diagnosis. Their extended survival is especially notable given that 70% of PWAs die within two years after diagnosis (Douglas & Pinsky, 1987; Frumkin & Leonard, 1987; Runck, 1986).

AIDS and cancer-survivor researchers assert two facts: psycho-social variables play an important role in survival; and (2) there are certain psycho-social variables that seem to be outstanding in terms of fostering survival. The investigator found no research which systematically addressed the issue of how the exceptional survival skills of LTASs develops. The purpose of this study was to

identify possible origins of some of the most common exceptional responses. The goal was to generate tentative conclusions about the common origins and the process of development of effective AIDS-survival skills.

5.1.1 Background Information.

Psychoneuroimmunology [PNI], is a field of study of the links between the central nervous system and the immune system (the body's primary defense system against invading micro-organisms). The seat of the mind is expected to be in the brain. The state of mind, consequently, affects those links. The state of mind, therefore, is believed to have an direct effect of the health and well-being of a person.

PNI survivor research suggests that LTASs' most distinguishing characteristics appear to be the determined, self-realized, abundant psycho-social styles recognized in survivors of other life crises. In the past, these psycho-social factors and styles were organized according to themes such as: COMMUNICATION: identifying, acknowledging and expressing inner beliefs, feelings and needs; CONFIDENCE: positive self-beliefs and expectations in life; CONTROL: accepting responsibility for self, and taking charge of personal life situations with determination, persistence and individual personal style; CHALLENGE: seeing one's crisis as an opportunity to grow and experience life more fully; SUPPORT: accepting,

loving and caring for self and showing acceptance and compassion towards others; and MEANING: internally conferred meaning and a sense of purpose in life.

The question, however, was still unanswered: "how does one develop this style?" Is it a gradual, life-long acquisition of traits, or one which can evolve during or after a major life crisis? ... such as AIDS? What are the influences or conditions which promote development of individual survival skills? The implications for research and education and the potential benefits for society at large could be significant in even partial answers to these questions.

5.1.2 Approach to the Problem.

A qualitative, multiple-case descriptive study was conducted with long-term AIDS survivors and AIDS-counselors. The definition of "long-term AIDS survivor" was modified to 2 1/2 years beyond AIDS diagnosis. (One of the survivors was at 2 1/2 years at the conclusion of this study. The others survivors were 3, 3 1/2 and 7 years beyond diagnosis.) The project proceeded in four phases:

(1) Individual Interview, Part One: "SURVIVAL SKILLS": In part one of an semi-open-ended interview, subjects discussed their personal perspectives on the factors they believe important in their own or in their clients' long-term AIDS survival.

(2) Individual Interview, Part Two: "ORIGINS": In part two of the open-ended interview, subjects discussed the "origins" of their survival skills: past or current situations that influenced development of AIDS-survival skills. They described feelings that were associated with the development of the skills, and also described other influences upon them which led to their developing their own individual survival skills (e.g. influential people and their roles).

(3) Written feedback: the main points of each interview was outlined by the investigator. These data sheets were provided to each subject for verification of accuracy, and for use in the group process.

(4) Group process: in a group meeting lasting approximately three hours, subjects presented and compared their origins, skills, feelings and other factors that influenced development of their unique survival skills. The groups attempted to reach consensus on the most important conditions conducive to the development of skills. This was an attempt to allow the subjects to modify and/or expand their personal theories of survival.

5.1.3 Findings.

The LTAS- and the AIDS-C-groups identified many skills believed important for successfully surviving AIDS. Some of the skills were common among the subjects, but most were varied and frequently cited by one person only. The phenomenon of "clusters and variations" among common themes, was interpreted to suggest that: (1) there may be some skills that are more universally appropriate, but that most skills are unique to the individual survivors; and (2) in spite of individual style and variations, categorically speaking, the skills may have functional ties that create common sets of skills across the population of LTASs.

The skills seemed to fit well within these functional categories: Shock, Choosing to Live, Owning Up, Going For It, Respecting Reality, and Empowerment. The categories are steps of a hypothesized model of the process of developing exceptionality in long-term survival of AIDS.

The clustering of common skills at each of the steps was interpreted as indicative of the relative accuracy of the proposed model. Even the unique and varied skills seemed to align well within the functional contexts of the steps. Representative skills cited by each subject for virtually every step within the hypothesized sequence also suggested that the model may be accurate, representative and appropriate. The possibility of a categorical prescription for individualized but aligned development of

skills within one or more of the steps was presented as an option that could be cautiously exercised.

The descriptive labels for the hypothesized process were described as indicative of a dynamic process of accommodation: these functional process-labels are seen to be more appropriate than the relative stasis-connoting labels used to organize the previous survivor research (i.e. Communication, Control, Confidence, Challenge, Support and Meaning).

The survival skills were further categorized as having been developed before or after-HIV diagnosis. A predominance of before-HIV-developed survival skills within the contexts of Going For It and Shock was interpreted to suggest that these were not only "older" skills, but also more basic and "external" (relative to stage of cognitive development). Skills functionally categorized within Choosing to Live, Owning Up, and Respecting Reality tended to be "newer," more sophisticated, and seemed to be more dependent on more mature and higher level cognitive functioning. Skills categorized with Empowerment were approximately evenly split, before- vs. after-diagnosis: Some of the skills seem more basic (e.g. confidence) and some more sophisticated (e.g. sense of dignity and self-worth).

"Origins," -both before-and after-diagnosis - were presented: they are those situations that influenced the development of coping skills that ultimately became

functional and important in effectively coping with HIV/AIDS. Although the before-diagnosis origins tended to be "negative" in nature, the situations were perceived as personally compromising and/or challenging the survivors. The survivors were seen to choose to accommodate to the situation, vs. giving up, or trying to change the (possibly unchangeable) situation.

The skills developed and the feelings experienced within those origins were associated with the six step-categories of the hypothetical model of developing exceptionality. Critical and long-lasting situations such as "difficult family situations," and/or "hemophilia" typically tended to foster development of skills across five out of six of the step-categories. This was interpreted as verifying the appropriateness of the model, and indicative of the degree of compromise experienced by the survivors within those situations.

The two major themes of the dissertation (the hypothesized process of developing exceptionality and the relationship of the survival skills to origins of development) is represented in these tentative conclusions generated from the data:

Survivors have characteristically:

(1) experienced past challenging and/or personally compromising situations;

(2) felt a strong <u>need</u> to accommodate and adapt to the critical situations (before and after-HIV diagnosis);

(3) actively adapted to the compromising situation.

(4) been influenced - positively or negatively - by key people to develop coping/survival skills;

(5) been willing and able to progress through and develop skills within the functional contexts of the six steps of the hypothesized process of developing exceptionality (i.e. Shock, Choosing to Live, Owning Up, Going for It, Respecting Reality, and Empowerment).

(6) developed skills that are uniquely suited to themselves, and functionally representative of all six steps of the hypothesized model: i.e. they do it their own way, fully.

Progression through the sequence of steps was presented as dependent upon self acceptance. The steps are also suggested to be progressive steps of developing empowerment: identifying, allowing and being consistent - internally and externally.

AIDS is a life-threatening disease. Exceptionality is one way of potentiating living with AIDS vs. dying from it. Exceptionality includes striving for health in every possible way, including rationally choosing and participating in the various other means of regaining / maintaining health.

Each survivor described their process of survival as "hard work." "Sometimes it is easier, but often it's very hard." Often, during the most difficult times, survivors

can become discouraged, confused, frightened, angry, frustrated, etc. Exceptionality does not mean full-time good feelings and success. It means congruence and consistency in experience and expression. These are not super-human, infallible people. Their exceptional style, however, is characterized by self acknowledgement and respect. Their exceptional style probably represents a predominant vs. a permanent style; and their experience of love, health and/or wellness may be the result of having chosen exceptionality "frequently enough" (or soon enough) over the course of their lives.

Maslow (1968, pp. 196-202) lists many "basic propositions of a growth and self-actualized psychology." Several are especially fitting in the context of this study:

> (1) No psychological health is possible unless this essential core of the person is fundamentally accepted, loved and respected by others and by himself ...
>
> (2) Self-actualization is defined in various ways but a solid core of agreement is perceptible. All definitions accept or imply, (a) acceptance and expression of the inner core or self, i.e., actualization of these latent capacities, and potentialities, "full functioning," availability of the human and personal essence.
>
> (3) ...best to bring out and encourage, or at the very least, to recognize this inner nature, rather than to suppress or repress it. Pure spontaneity consists of free, uninhibited, uncontrolled, trusting, unpremeditated expression of the self...

(4) Coordinate with the "acceptance' of the self, of fate, of one's call, is he conclusion that the main path to health and self-fulfillment ... is via basic need gratification rather than via frustration.

(5) ... self actualizing, Being, expressing, rather than coping...

Maslow's fifth point was substantiated by AIDS-C-DK in the final counselor's meeting: "Survivors choose to live, rather than to survive," The LTAS-group members emphatically stated the same, maintaining that one of the best ways of inhibiting potential for survival, is to strive to survive, rather than to live. Focusing on living is expansive and liberating, just focusing on surviving is diminutive and limiting.

5.2 Limitations.

Problem areas of this study fell within these categories:

-Lack of True Control Group.

-Control of variables.

-Measuring past experience or occurrences.

-Intragroup homogeneity.

-Sample Size.

-Lack of Random Sample.

5.2.1 Lack of True Control Group.

The most significant weakness inherent in survivor-vs.-deceased research is that concurrent analysis of both groups is impossible. Relative to tradition research

protocol, this dissertation's research design is weak since no control group is directly available for study and comparison. The issue is the potential problem of false-positive conclusions (i.e. conclusions that also are true for a significant number of short-term AIDS survivors), and false positive conclusions (conclusions that are also true for other PWAs who have different origins from which they developed survival skills). Without a control group to adequately provide the alternative perspective, one simply can't fully rely on the results for the full and accurate picture.

Given three or more years to complete a longitudinal study of PWAs and the pertinent variables of this study, a valid control group could be created; that period of time, however, seems unreasonable for a dissertation study. Although AIDS-counselor opinions must be considered secondary and possibly unreliable data, this indirect strategy can be seen as a best-option starting place. The information derived from this study will hopefully serve as a challenge to generate future hypothesis generating and testing studies.

5.2.2 Control of Variables.

A second major limitation in this dissertation - and in long-term survivor research in general - is related to control of variables. Coates, Temoshok & Mandel (1984) suggest that "an interaction of genetic, environmental, and

psychosocial factors ... may ... influence the course of disease once contracted." A review of PNI literature yields no mention of a relationship between genetic changes and either long-term or short-term survival: "the most important link ... is evidently not a genetically acquired phenomenon" (Gong, 1985, p. 17). Genetic changes aside, LTASs live at least three years from the time of diagnosis (2 1/2 years for one of this study's survivors): environmental and psychosocial factors will probably have varied among LTASs within that period of survival time. Considering "types of therapies pursued," the literature reviewed revealed no difference between LTASs and short term AIDS survivors [STASs]; in fact, the only major distinctions noted between short and long-term survivors in both non-AIDS and AIDS-survivor research, are those regarding coping styles and other psychosocial variables. For this dissertation, therefore, coping styles and other psycho- social factors were the major focus.

5.2.3 Measuring Memories of Past Situations.

Survivor-vs.-deceased research lends itself to a third major limitation related to the validity and reliability of measuring past situations, events, or reactions to events after significant periods of time have elapsed. "Events which occur shortly after diagnosis or other factors which may be important in terms of survival may be difficult to measure several years later" (A.M. Hardy, personal

communication, January 17, 1989). Once again, this study attempted to counterbalance that problem by using past survivor research and AIDS-counselor interviews to provide additional perspective.

5.2.4 Intragroup Homogeneity.

The study's fourth major limitation concerns LTAS intragroup homogeneity. Of the four subjects within this study's LTAS-group, two were gay men, one a hemophiliac man and the last, a former IV drug abusing woman. (Two men and two women comprised the AIDS-C-group). I find nothing in the literature to warrant or advise subgroup differentiation within the targeted population for this study, the LTAS population. The critical survivor-characteristics identified in the literature and within this study, seem to be representative of a homogeneous LTAS population. Furthermore, any attempt to differentiate among four individuals would have been unrealistic. For the purposes of this study, the LTAS-group was considered a homogeneous sample.

5.2.5 Sample Size.

As addressed in the "Samples" section of Chapter 3, this study's fifth limitation was the small sample size. There are very few long-term AIDS survivors. Finding them within reasonable distance of each other, and reasonably close to New England was a major task. Ultimately, the

networking accomplished by the investigator was sufficient to gather the small study sample. Three out of four of the LTAS individual interviews were conducted in-person, but one had to be carried out by telephone; Only two of the four LTAS-group members were able to attend the group meeting, but the other two were engaged in follow-up phone conversations after the formal group meeting.

Finding AIDS-counselors with greater than one year of experience with PWAs and personal experience with long-term survivors was equally difficult. A group of two men and two women were finally composed; after that, the research process went smoothly. All of the AIDS-Counselors were interviewed in person, and all attended the group meeting.

It is believed that the data that was gathered was accurate and appropriate in spite of the use of the telephone. It is further believed that the data was consistent, and sufficient for the creation of tentative conclusions.

5.2.6 Lack of Random Sampling.

This study's lack of random sampling can also be seen as a limitation. All subjects gathered were volunteers: The long-term survivor population pool is so small, that non-random selection was the only way the groups could have been comprised. It is believed that the information gathered from this study's small but well-represented group was sufficient to generate some tentative conclusions.

These may be more quantitatively tested in more empirical and more controlled fashions in future and separate investigations.

5.2.7 Use of "New Paradigm Research Model of Human Inquiry."

Although it may be considered a limitation by some, this study's research process was reasonably closely aligned with the new paradigm model of Reason & Rowan (1981). As a multiple case study from which tentative conclusions were drawn, the study did divert from the suggested "purely endogenous" research style. The study was semi-structured, and the interviews were semi-open-ended. The information fed back to the group members was a synopsis organized by the researcher. These points may be considered as researcher-biasing influences, however, they seemed appropriate and necessary in order to accomplish the desired goals within a reasonable amount of time. The same ends may have been achieved, but according to the researcher, too much would have been left to chance. As a free-flowing, natural and therapeutic process of discovery, the new paradigm research seems powerful. As an action-orientation, it seemed somewhat lacking and was consequently moderately modified as indicated.

5.3 Degree of Confidence in Findings.

Giba & Lincoln (1981) suggest four criteria for establishing the "well-foundedness" of qualitative (vs. quantitative inquiry):

-credibility (vs. internal validity)

-transferability (vs. external validity)

-dependability (vs. replicability)

-objectivity (vs. confirmability)

5.3.1 Credibility.

According to Guba & Lincoln (1981), "credibility" is an indication of the degree to which "extraneous" variables have been controlled. It is an indication of: (1) the degree of accuracy of measurement of what was intended to be measured; and (2) the degree of experimenter bias: the degree to which the investigator's "attitudes, values, expectations and stage of development" influence the design and findings of the study.

The interview process was semi-open-ended. The interviewer attempted to function as a record keeper and moderator until that point in an interview or in the group meeting when no further information was forthcoming. At that point, he probed content areas indicated by pervious survivor-research (e.g. "do you express your feelings, or tend to keep them in? ... is that an important skill for you, one that has been important in your survival of AIDS?).

The data gathered was categorically similar, but individually unique. This probably would not have been true if the investigator was somehow biasing the findings in a particular direction. The cycles of the data-gathering, and the opportunities for the subjects to check and verify their data, avoided misrepresentation and generally set the stage for a credible study. A further indication of the credibility of the findings was that after the individual interviews, not one person changed their own "survival theories" even after hearing the information presented by the other group-members during the group meeting. They were not pushed to conform, nor did they.

5.3.2 Transferability.

Transferability is an indication of the degree to which the sample is representative of the targeted population. The sample size of both groups was small (four each, survivors and counselors). The group of interest, the LTAS-group, as indicated, was two gay men, one hemophiliac male, and one former IV-drug-abusing woman. The proportion was very similar to that found in the general population: the two largest subgroups on the general AIDS population are homosexual men (69%) and IV drug abusers (24%) (Douglas 7 Pinsky, 1987). With such a small group, the approximate proportion couldn't have been closer.

The transferability or generalizability of the findings relative to the actual population, is dependent on the richness and fullness of the data presented. Because of this study's multiple cycles and different formats of information gathering (interview, re-statement, verification of content of statements in writing, group process aimed at establishing consensus), and "cross-subjective comparisons," the investigator believes that the information derived was rich, and the findings transferable. Another indication of the "richness" of the information, was that the interviewees were so eager, willing and generous with heir time and information. Although the interviewer asked for "one to one-and-one-half hours" for the individual interview, the interview times averaged nearly two and one-half hours for the LTAS-group, and two and three-quarters of an hour for the AIDS-counselor group. The subjects were very motivated to share and learn.

Beyond the "richness" of data, the information generated in this study closely parallels findings of researchers in other "exceptionality" studies: It is expected that the findings will prove to be transferable or generalizable. Ultimately, however, it must be understood that the study's data (and the interpretation thereof) suggest at least <u>one</u> process or pattern of exceptionality that seems to prolong life with AIDS. In the final

analysis, however, there are, two questions that remain unanswered:

(1) Are there other patterns, processes or syndromes of exceptionality, distinct from this study's, that also serve to prolong life with AIDS?

(2) What percent of people with this study's exceptionality profile did not survive beyond three years?

Longitudinal and more empirical studies may provide at least partial answers to these questions. The seemingly categorically uniform data of this study suggests that the recognized exceptionality profile seems to have made a difference for this group of people. No one knows, however, how much of a difference. Has it extended their life by 10%, 20%, ...? No one knows, yet. Interestingly, though, exceptionality - whether it prolongs life with AIDS or not - may be one healthy was of resolving or coping with the issues of facing the ultimate reality for all, death.

That these two questions remain unanswered must be considered a major limitation of the study. This is undoubtedly a major limitation, however, of any qualitative multiple-case descriptive process of human inquiry.

5.3.3 Dependability.

Dependability is the relative stability of a study's findings over time: it is a reflection of the degree of "confidence" in the information gathered. Categorically, the data gathered was relatively stable across subjects and

between groups. Additionally, the degree of similarity of findings of this study and past survivor research studies is high. The following are examples of past research that was particularly aligned with this study's data (also presented in the chapter two, the literature review):

UCSF-BAP and Temoshok (1983) are currently conducting a longitudinal psycho-social study of men with AIDS and ARC. Relative to this study, most notable among their initial findings are: (1) The "deceased" [short-term survivors] individuals seem to be "low in control ... with little or no buffering of distresses," with a resultant negative effect on health; (2) The survivors tend to seek problem-solving help, i.e. they are active in addressing their problems, and enlist others for advice, guidance and direct support or service; and (3) The deceased tended to "look to others for validation or worth," whereas the survivors showed more of an independent and "fighter spirit."

Solomon et al. (1988) is also currently conducting a LTAS study. Many of their initial findings are closely aligned with the tentative conclusions of this study: e.g. LTASs tend to (1) collaborate with others for their care; (2) take "personal responsibility" for their health; (3) have a "commitment to life;" (4) "have a sense of meaningfulness and purpose in life;" (5) found "new meaning as a result of the disease itself;" (6) have "prior mastered experience with a life-threatening illness

or very serious life event; and (7) developed a "personalized means of active coping."

It is believed that the data generated in this study are dependable.

5.3.4 Confirmability.

Confirmability is the degree to which independent investigators could either: (1) come to the same conclusions based on this study's findings; or (2) replicate the study and arrive at the same conclusions. The data gathered in this study was strongly generated by the subjects themselves. Within the interview and within the group meetings, the conversation flowed smoothly at most times. It is quite possible that a different logic could be applied to the data, and possibly different information would surface. If, however, independent researchers were to utilize the same organizational scheme, I believe the same or very similar results would result. The investigator believes the results will be confirmable, and will suffice as the starting point for other studies: tentative conclusions have been generated per plan.

5.4 Implications.

5.4.1 Next Research Steps.

Qualitative research has distinct advantages as well as limitations. Qualitative research is not as strictly bound by the rigors of tightly controlled empirical science.

Presence of a control group, limited sample size, lack of random selection, assumptions made about memories of past experiences and events: these liberties were tolerated within the looser boundaries of qualitative research. The limitation mentioned, however, virtually mandated a looser research design, and indeed, it was very well designed for the expressed purposes of this study: drawing tentative conclusions about the origins and development of exceptionality in long-term survival of AIDS.

In this study, the experts were polled: the long-term survivors and their counselors. They were provided a forum where it was possible for them to identify, to express and to further develop their own ideas about survival. The opportunity for expression came predominantly within the initial individual interview; the group meeting, however, allowed each to experience other survivors' points of view, and to brain storm, discuss and develop new ideas, themes and options. In what seemed like a safe, supportive and hopefully empowering environment, limits were limited: reasonably speaking, the data evolved relatively unchecked. The qualitative style of human inquiry was appropriate and conducive to the establishment of this environment, and to the generation of new ideas.

This research has provided future researchers the opportunity to expand the findings. The tentative conclusions generated, as listed above, have laid a

foundation for these possible qualitative and quantitative studies:

5.4.1.1 Verification Studies.

Verification studies: empirically designed, fact-finding and hypothesis-confirming studies that could more validly establish particular origins and development of exceptionality in long-term survival of AIDS. They could more systematically assess:

(a) the notion of many important survival skills having emerged from past personally compromising and/or challenging situations. Which skills? What circumstances? What feelings and/or influences? Age when it occurred? Relationship within the family? Family messages, roles and expectations?

(b) choosing to live: successfully negotiating the "moment of truth." Feelings about self, others and life before the critical incident? Previously semi-fulfilled lifestyle, with knowledge of personal capability to "do/experience/give more?"

(c) the influences and roles that others play, direct of indirect, negative or positive. Having at least once experienced unconditional positive regard, support and/or love? Purely role models? Intimate/close encounters, or anonymous/distant relationships? Role of receiving, giving, or mutually supporting?

(b) willingness to persevere thorough the steps of developing exceptionality. Inner-directed? Externally supported? Inner directed/externally supported?

5.4.1.2 Developmental-Theory-Related Studies.

Theories of Development Studies: Potential roles of cognitive function, moral development, etc., with respect to: (1) "older" vs. "newer" skills (e.g. "Going for It, vs. Respecting Reality); and (2) exceptionality / survival exceptionality cognitive functioning?

These studies could continue in the qualitative mode of human inquiry, or could document and validate the findings with more quantitatively objective and empirical data-gathering studies. Some longer term longitudinal studies are underway at the University of California's Bio-psycho-social AIDS Project. More are needed in order to effectively assess the hypotheses governing, and the realities underlying exceptionality and survival.

5.4.2 Support for PWAs.

In the closing minutes of their group meeting, the investigator asked the survivors this question, "How can you help other PWAs to "choose to live?" There was full consensus in their replies. The message to be heard for counselors, health-care providers, family, friends and passerbys alike, is "GIVE LIVE MESSAGES:"

(1) Be a constant example, constantly talking, sharing.

The clearest communication of health and love is frequently not what is said, but how it is said, and what is done. Show love. Give no messages of personally rejecting life, PWAs, or yourself.

(2) Approach PWAs in an empowering way: "If you choose to die, I'll be supportive ... if you choose to live, I'll be supportive."

Without side-stepping the reality of human limitations, the choice for experiencing life fully is ultimately our own. If we are pushed to make a choice, we'll frequently rebel against, or conform to the message. Both are reactions to external pressure. If PWAs are accepted - not judged - for who they are, the way they are, their choices may be more fully their own, and hopefully more fully supportive of their own health and well-being.

(3) Confront only when it can be done in a "loving and an empowering way."

By being there, supporting and accepting others, helpers can't give up who they are in the process. There may be times when the best support is to outwardly reject a behavior, thought or attitude, without rejecting the person. By being honest, genuine and supportive, we can confront choices, attitudes and behaviors without deserting the person. Approach from an empowered perspective, and facilitate an empowered response.

(4) You have to give them reason to believe that you really want them to survive, and that you'll help them: be there to give them support, love and understanding.

Literally being there, mind, body and spirit, to give support, love and understanding, gives powerful "live" messages.

(5) Provide information. People need to have "purpose, support and hope.'"

Provide information: understanding he disease and some of the options available in responding to the disease hopefully helps people deal with the fear of the unknown. There can be strength when an issue is approached from an informed position.

(6) Help them avoid the "stigma."

AIDS can impose devastating and ferociously negative physical consequences upon the body. Many thousands have died from AIDS. Facilitating the choice to live with AIDS may involve "avoiding judgmental attitudes and negative expectations." The survivors suggest creating a "niche" for yourself: sidestepping the negative "die" messages, by finding or creating a place where "you can be you, supported and loved by others the way you are."

5.4.3 Generalizing the Message.

PWAs are, first of all, people. They are forced to abruptly and fully face the question and the challenge that death-and-dying can put forth: "Have you lived?" The data

indicates an overall angst experienced by PWAs in their situation. It also suggests that their way of responding is by actively choosing to live fully, NOW. This research, however, can be seen as a case study of a larger problem: developing exceptionality in life (vs. only in long-term survival of AIDS). As such, implications exist for exceptional response to any life trauma, and to the quest for health and wellness. The survivors of this study actively and assertively meet and inter-relate with problematic issues and obstacles in life, while relatively concurrently embracing the fullness and abundance also available to us in our life-situations.

It seems that the previously presented advise by this study's survivors for those who support PWAs could be generalizable to anyone helping others face any critical moments or choices in life. The information, in fact, seems appropriate for anyone in a leadership role, including health-care providers, teachers, parents, supervisors in business, etc. All the suggestions seem to apply: support, love, allow and accept self and others; lovingly confront; enable by providing rather than making choices for others; guide without leading; empower others in an empowering way. If the generalization is appropriate, implications exist for helping and empowering people with cancer, asthma, Alzheimer's disease, multiple sclerosis, etc., etc. To this end, related survivor-research could be completed within those critical life-

issue areas in order to directly assess the generalizability of exceptionality as defined in this study.

Couched within this message of hope, love, and affirmation, is the precaution against a prescriptive and symptomatic approach to health care, to caring for others, and indeed, to self care. The "clusters and variations" of the survival skills cited in this study can be interpreted in this way: there may be some things that are commonly good for all, but usually, the way to truly achieve the common good, is our own way. Being overly prescriptive by suggesting a particular look of exceptionality, is perhaps doing major disservice to those we may truly wish to help. Health care by empowerment is an interactive process of discovery, affirmation, and being. A symptomatic approach falls far short.

The tentative conclusions drawn from the data of this descriptive multiple-cases study could serve as the foundation for the development of training programs for PWAs and for their professional and non-professional support personnel. Some of the training activities could include:

(1) Education:

- HIV/AIDS facts, figures, prevention, risk behavior, etc. (continued, next page).

- MARCHETTO MODEL: the process of developing exceptionality in long-term survival of AIDS.
- Issues of oppression in society.

(2) Assertiveness Training

- including "sidestepping the stigma" and creating a "niche."

(3) Role Models

-direct interaction with and witnessing by other empowered PWAs.

(4) Psychological Education / Cognitive Therapy

-discovery of behavioral patterns, thoughts and beliefs, their origins and their effects on life, health and wellness.

(5) Support

-individual, professional, non-professional.

-group process

(6) Personal Power Training

Identifying problems and origins, learning how to "stop" unwanted behaviors, brainstorming options, choosing, leaping/trying it out, assessing the effects, etc.

(7) Centering

-intunement with God, self and with others.

5.5 Effect on the Researcher.

In her book, AIDS: The Ultimate Challenge, Elizabeth Kubler-Ross wrote:

> Since we can no longer deny that AIDS is a life-threatening illness that will eventually involve millions of people and decimate large portions of our human population, it is our choice to grow and learn from it, to either help the people with this dread disease or abandon them. It is our choice to live up to this ultimate challenge or to perish (Kubler-Ross, 1987, p. 13).

The researcher's program of study, and in fact, this dissertation, was undertaken with the hopes of gaining insight about "how to help people choose health/life/love." Participating in a process of discovery within the context of this research, the researcher took the perspective of learner: "teach me about the good in you." I saw people willingly and fully respond. Feeling "accepted, acknowledged and affirmed," the survivors and counselors alike, seemed fully committed to the project, and showed nearly boundless energy in their participation. Thankfully, they supported me, the researcher, seemingly as fully as the research itself. They saw me as a caring person who could have the power and the choice to share their knowledge and love with others.

I accept their perception as a personal challenge. More than ever, I know just how much choice is mine.

Closing

This research has provided me an opening in life. A glimpse at the effect of choosing love and life. A chance to formally and informally go on being myself, choosing love and life for myself ... so that I can offer the same to others.

Purpose, hope, support, love and choice. The option for living life is ours.

people care
love is real
life is a choice
now is for living

I put myself
in the stream of life,
on purpose.

APPENDICES

APPENDIX A

Origins and Survivor Skills: Survivors & Counselors.

A.1 BEFORE Initial HIV-Diagnosis Origins.

This section presents the variously cited AIDS-survival skill origins and the specific skills derived from each of those origins. Separated by group and by individual, profiles of each of the "currently useful and critical AIDS-survival skills" that developed from situations that occurred before AIDS diagnosis are also presented. For the LTAS-group members, the origins are specific situations (experiences, conditions and/or individuals) that somehow influenced active, current and person-specific AIDS-survival skills. For the AIDS-C-group, the origins and skills are representative of the long-term survivors whom they have personally encountered. The descriptions are those provided the group members during the course of their individual interviews and/or during the group meeting following the interviews.

A.1.1 Past Survived Crises: LTAS-Group.

All four LTASs cited "past survived crises" as common origins for the development of many critical skills currently utilized in their long-term survival of AIDS:

A.1.1.1 LTAS-AV: Before-Diagnosis Cited Origin #1 (of 4): High Parental Pressure and Expectations.

LTAS-AV reported that she was a member of a black family with a long history of "firsts:" first black family living on Long Island; first black nobel laureates; etc. She described her parents' posture and expectations for her to become a "first whatever" as "high pressure." She felt "rejected and isolated," and remembers rebelling against their pressures: "I'll do anything just to get my mother to gag," or, "I'll be very 'street' just to be obnoxious." As a way to "get at my mother," LTAS-AV would "go to the City, and bring home street people to Sunday dinner: pimps, prostitutes, junkies ...!" LTAS-AV also would "bring home 'strays:' animals when I was a kid, and men when I was a teenager!" She did have some young friends and one particular aunt, however, who helped her through her difficult childhood situation. They "dumped on each other" as a way of "unstressing." From this situation, LTAS-AV believes that she developed several coping skills which have become important survival skills in her long-term survival of AIDS:

A.1.1.1.1 Current AIDS-Survival Skills Developed From "High Parental Pressure and Expectations" - LTAS-AV.

A.1.1.1.1.1 Skill LTAS-AV #1: Arrogance.

By taking an "arrogant" posture in life, she "looks AIDS in the eyes," avoiding "letting AIDS make me fall."

She confronts AIDS by saying, "Things bigger than you have tried and not succeeded [at making her fall] ... so why should you?"

A.1.1.1.1.2 Skill LTAS-AV #2: Dumping Anger.

LTAS-AV helps maintain control of her situation with AIDS by "dumping anger." "If I don't let it go, I won't be coping and maybe start drugs again: don't want that." A current positive influence in her using this as a coping mechanism is a particular man she met while in a drug-rehabilitation program.

A.1.1.1.1.3 Skill LTAS-AV #3: Fighter Spirit.

Feeling "horrible" about her situation with AIDS, she maintains a fighting spirit in order to "keep on top of AIDS," in order to avoid "letting AIDS take over." Her spirit is exemplified in this statement: "If I fall, I'll fall fighting ... I'm not ready to go yet."

A.1.1.1.1.4 Skill LTAS-AV #4: Occasional Use of Drugs to Deny.

In order to avoid "fear" and "being overwhelmed by AIDS," she "occasionally uses drugs to deny." She describes this as a "coping mechanism" used throughout her life that now functions to "get my mind off AIDS when it becomes too oppressive."

A.1.1.2 LTAS-AV: Before-Diagnosis Cited Origin #2 (of 4): Cross Cultural Oppression: Racism.

LTAS-AV described the "racism" she experienced as a black girl in the "Jewish, white, male-oriented," Long Island culture as "oppressive." She felt "horrible, rejected, isolated and angry." She believed that she had to be "better at everything just to assimilate." Her young friends and one particular aunt also served in this situation as a vehicle for unstressing: "we dumped on each other."

LTAS-AV reports that LTAS-AV Skill #s 1-4 (above, in "High Parental Pressure and Expectations" section), were further influenced by her experiences with racism on Long Island. From this situation, however, she did develop two additional skills that she believes have been important in her long-term survival of AIDS:

A.1.1.2.1 Current AIDS-Survival Skills Developed from "Cross Cultural Oppression: Racism on Long Island" - LTAS-AV.

A.1.1.2.1.1 Skill LTAS-AV #5: Control Queen.

Feeling "angry" about AIDS, LTAS-AV works to "control it instead of it controlling you ... and then it will pass." She describes maintaining a vigilant watch over AIDS.

A.1.1.2.1.2 Skill LTAS-AV #6: Helping Others: Nurturing.

LTAS-AV "feels good when I can help others. I feel useful." Believing that she has "stuff to offer and help others with," she currently avoids feeling useless by helping others.

A.1.1.3 LTAS-AV: Before-Diagnosis Cited Origin #3 (of 4): College Experience: Intra-Racism Oppression.

LTAS-AV attributes other current survival skills to her college experience in Boston. This was her first move from Long Island. In Boston, she "again had to assimilate," but this time the pressure was from her black peers. In the group session phase of this study, she described the problems she experienced because of her former "Lon-GI-Land" accent. She believed that she "had to prove I was black in spite of where I grew up." She felt rejected, isolated and angry: "Why are you ostracizing me? Where I grew up isn't my fault. I'll fight!" Her college years in the 1960's were also times of political unrest.

A.1.1.3.1 Current AIDS-Survival Skills Developed from "College Experience: Intra-Racial Oppression" - LTAS-AV.

In dealing with her college experience, LTAS-AV utilized all her childhood coping skills. During that time, however, LTAS-AV developed and describes another coping skill currently useful to her successful encounter with AIDS:

A.1.1.3.1.1 Skill LTAS-AV #7: Politically Active: (Currently AIDS-Related).

Believing that she "just couldn't not be active," she chooses to "talk the talk, and walk the walk." LTAS-AV recalls participating in past civil rights and anti-Vietnam War political action. By being "politically active in AIDS," LTAS-AV "feels useful: have a purpose."

A.1.1.4 LTAS-AV: Before-Diagnosis Cited Origin #4 (of 4): Life "On the Street"and Drug Rehabilitation.

Another way LTAS-AV coped with the pressures of college life was to escalate an old coping mechanism: "doing drugs." In the group session, she described "starting right off on heroin when I was a kid." This led to an extended period of time (years) "on the street," and resulted in experience in drug rehabilitation programs to which she attributes "positive skill development." Her experiences in the rehabilitation programs included, "encounter groups, unstressing ... and everything was 'confrontation.'"

A.1.1.4.1 Current AIDS-Survival Skills Developed from "Life on the Street and Drug Rehabilitation" - LTAS-AV.

LTAS-AV developed two more coping strategies that she believes have helped her successfully deal with AIDS:

A.1.1.4.1.1 Skill LTAS-AV #8: Confrontation.

Explaining that she doesn't "have time," confronting others with problems or issues "helps get the hog-wash out of the way ... can get down to business."

A.1.1.4.1.2 Skill LTAS-AV #9: Support Systems.

Feeling "fear, anger, isolation and lonliness," in her situation with AIDS, LTAS-AV participates in formal AIDS-related support groups, and maintains informal supportive contacts as well. It helps her "deal with fear, isolation, lonliness, anger and the unknown."

A..1.1.5 LTAS-CM: Before-Diagnosis Cited Origin #1 (of 1): Homophobic Cultural Oppression.

LTAS-CM described growing up in a midwestern town: "the people there viewed homosexuality in the darkest of terms, [viewing homosexuals as] child molesters, vagrant criminals ... who hang out in public restrooms and write notes to each other on toilet paper." He recalled feeling "rejection, isolation and anger" in that situation.

LTAS-CM described his parents as positive influences during that time: "they were liberal. Father is cynical, bright and intellectualized, and motheris optimistic, simple, loving, religious without being judgemental. She has compassionate ideas of right and wrong." During that period of time, LTAS-CM decided, "I know it's not going to

be a good life, but it'll be better than living the life I was living."

After high school, LTAS-CM attended college in Boston and became politically active in "gay rights." Even in leadership roles of the gay rights ogranizations, LTAS-CM felt "incapacitated, with classic low self esteem and uncertainty." He explained that "gay people get the shit kicked out of you in life." He eventually rebelled against his situation, asserting, "I don't have an illness, I'm gay."

A.1.1.5.1 Current AIDS-Survival Skills Developed from "Homophobic Cultural Oppression" - LTAS-CM.

As a result of these experiences, LTAS-CM developed skills that still function today. He sees them as instrumental in his extended survival of AIDS.

A.1.1.5.1.1 Skill LTAS-CM #1: Speak Out Against Injustice.

LTAS-CM is very active in his own and others' survival of AIDS. In this mission, he faces federal government programs and policies which he describes - at best - as "slow moving." By speaking out against injustice, he stays active in his "fight against AIDS," never turning his back on his "wiley adversary."

A.1.1.5.1.2 Skill LTAS-CM #2: Speak Out For Myself.

As a way of ensuring his survival, LTAS-CM speaks out for himself. Angry about difficulties confronting all PWAs, he speaks out for others, and also for himself. By actively speaking out for himself, he won't allow himself to be oppressed as a PWA as he was in the past as a gay person.

A.1.1.6 LTAS-LB: Before-Diagnosis Cited Origin #1 (of 1): Hemophilia: Restricted Lifestyle.

From birth, LTAS-LB was severely limited by hemophilia. Minimal activity resulted in tissue trauma ("bleeds"), and at age five, mandated his using crutches to protect his joints from internal bleeds. Feeling "anger, isolated," LTAS-LB felt "like an outcast. Missing out on life." He recalled thinking, "I'm not a bleeder ... I'm not different. I want to do things others can do."

At age fourteen, LTAS-LB went to an Easter Seals Camp. Seeing children his own age "living with handicaps worse than mine," he "stopped feeling sorry for myself." Having struck a common bond with his peers, he "felt better."

At age seventeen LTAS-LB developed a limb-threatening bloodclot. In Boston, he met a surgeon who not only saved his arm, but also introduced him to a new medication: "factor nine." With this new medication, LTAS-LB was able to walk with assistive devices for the first time since age five. He saw "possibility, a brighter future." He was

inspired by this surgeon: "he gave me hope and confidence that I could be more independent." By teaching him new skills (self-infusing medications), his nurse-neighbor was also instrumental in LTAS-LB seeing a brighter future.

With factor nine, and without crutches, LTAS-LB went to college and "lived successfully away from home for the first time." He was fully responsible for coordinating his own personal and medical care. This was a true "liberation" for LTAS-LB: "I can do it ... I'm free!" Still inspired by a supportive doctor, LTAS-LB was also strongly influenced by being "accepted and affirmed" by his college peers.

A.1.1.6.1 Current AIDS-Survival Skills Developed from "Hemophilia: Restricted Lifestyle" - LTAS-LB.

A.1.1.6.1.1 Skill LTAS-LB #1: Courage.

LTAS-LB's "courage" gives him "hope: the ability to face the challenge of AIDS." By being courageous, he avoids the "worse possible condition" [death by AIDS].

A.1.1.6.1.2 Skill LTAS-LB #2: Denial.

In order to deal with the "worst times," LTAS-LB selectively denies the seriousness of his situation with AIDS. He accomplishes this by distracting himself with television, joking and hobbies.

A.1.1.6.1.3 Skill LTAS-LB #3: Discipline: Stubbornness.

Developed as a child to get through the rigours of hemophilia, LTAS-LB disciplines himself to "keep fighting" in order to "have the strength to endure this terrible hardship." His stepmother has played and continues to play a strong role in influencing LTAS-LB to continue to develope a sense of discipline. Feeling disciplined, LTAS-LB retains the "ability to take it, day by day." "I can do it."

A.1.1.6.1.4Skill LTAS-LB #4: In Touch With Body.

Aware of a "body-mind communication" in anticipating a "bleed," LTAS-LB developed a keen awareness of his body. LTAS-LB describes "being out of control with AIDS as 'very demanding.'" By being in touch, he can "control and know better what's happening."

A.1.1.6.1.5 Skill LTAS-LB #5: Control Over My Body.

By being in tune with his body, he keenly senses physical difficulties, and avoids "becoming sick." "Exerting a sense of control over my body - via. mind - I feel better about myself."

A.1.1.6.1.6 Skill LTAS-LB #6a: Confidence.

With confidence, LTAS-LB "keeps in touch with my body and with reality." Having experienced difficult health

problems all his life, LTAS-LB feels capable of "getting through the bad times."

A.1.1.6.1.7 Skill LTAS-LB #6b: Relying on Self to Control.

Influenced by effective past and current doctors and medications, and his previous successes in managing his own medical situation, LTAS-LB generates a sense of confidence. By "getting through the bad times, I should be able to get through it [AIDS] all."

A.1.1.6.1.8 Skill LTAS-LB #7: Faith in Doctors and Medication.

By maintaining a strong faith in his doctors and his medication, LTAS-LB fosters a feeling of "security, calmness, " and a belief in his ability to "get well."

A.1.1.6.1.9 Skill LTAS-LB #8: Aggressive Risk Taker.

For LTAS-LB, physical activity has always been a risk that he was willing to take in order to be "just like the others." LTAS-LB sees being an "aggressive risk taker" as a challenge and as a way of "exercising my natural powers of healing."

A.1.1.6.1.10 Skill LTAS-LB #9: Disease as a Challenge.

Instead of seeing AIDS as a death sentence, for LTAS-LB, maintaining a sense of challenge is a way to "get well,

hope and love." Seeings AIDS as a challenge "stimulates me to go on."

A.1.1.6.1.11 Skill LTAS-LB #10: Pride in Myself.

Thinking of how successful he has been in dealing with hemophilia and now AIDS, LTAS-LB musters the "confidence to go on."

A.1.1.6.1.12 Skill LTAS-LB #11: Develop Creative Skills.

In order to avoid "getting stagnant," LTAS-LB develops creative skills such as gardening, ham radio operation, etc. Seeing his work gives him a "sense of accomplishment, and a better, wholesome feeling. It also keeps me in touch with people."

A.1.1.6.1.13 Skill LTAS-LB #12: In Touch with Nature.

By maintaining a feeling for Nature, especially through his work with plants, LTAS-LB develops a "wholesome feeling." He also reports the feeling of "watching things grow," and "having a chance to nuture" has a positive role in his survival of AIDS.

A.1.1.6.1.14 Skill LTAS-LB #13: Having Goals in Life.

Having goals keeps LTAS-LB "more aggressive: keeps me going forward." His stepmother continues to influence LTAS-LB to maintain and to strive towards fulfillment of goals.

A.1.1.6.1.15 Skill LTAS-LB #14: Helping Others.

Developed in his adolescence at Easter Seal Camp, LTAS-LB helps his wife to cope with their situation with AIDS. He is also active in helping other PWAs to successfully survive AIDS as well as he has. LTAS-LB gains a "feel for the quality in people," and "bonds with people."

A.1.1.6.1.16 Skill LTAS-LB #15: Accepting Self.

Considering his past and current successes, LTAS-LB continues to accept himself as a healthy person and can "endure hardships more easily." By accepting self, he can continue to "push forward, no matter how hard it becomes."

A.1.1.6.1.17 Skill LTAS-LB #16: Focusing on Strengths and Abilities vs. weaknesses of limitations.

By keeping his mind on "what I'm capable of, I feel more in control." I definitely want to avoid feeling "out-of-control."

A.1.1.6.1.18 Skill LTAS-LB #17: Collaborate with Doctors in Own Care.

In maintaining an active role in understanding and deciding on "what's going on," LTAS-LB maintains a "sense of control and confidence." "I don't want to be left in the dark."

A.1.1.6.1.19 Skill LTAS-LB #18: Independence.

Maintaining an independent posture with AIDS and with his life and medical care, LTAS-LB maintains a sense of "control." He better maintains "the fight" in order to avoid "giving up."

A.1.1.6.1.20 Skill LTAS-LB #19: Willing to Accept Help.

When LTAS-LB is "willing to accept help," or "allowing dependence," he maintains a strong, "realistic" posture. He is able to achieve a higher degree of "comfort," to continue to "think positively," and to "help himself get better through the help of others."

A.1.1.6.1.21 Skill LTAS-LB #20: Realistic.

By "knowing the facts," LTAS-LB "can analyze things ... and know my limitations."

A.1.1.6.1.22 Skill LTAS-LB #21: Fighter.

As a hemophiliac, LTAS-LB believes he had to be aggressive to survive. "AIDS imposes a challenge on me ... I'm not going to let go of my fighting nature ... and give up."

A.1.1.6.1.23 Skill LTAS-LB #22: Doing Whatever Have to Do.

As in Skill #21, LTAS-LB "fights," and is willing to do "whatever it takes." This attitude helps him maintain control, and keep from "giving up."

A.1.1.6.1.24 Skill LTAS-LB #23: Living Life to the Fullest.

"Even in a wheelchair, it's important for me to live life to the fullest." It helps me to "focus on the good," and to keep a "sense of control." I avoid "falling victim" by living fully.

A.1.6.1.25 Skill LTAS-LB #24: Sense of Accomplishment: Pride.

LTAS-LB's sense of past and current accomplishments - especially with respect to having maintained his health - help him to "feel like I can go on. It sustains me, makes me energetic, ambitious. Helps me to put up the fight."

A.1.1.6.1.26 Skill LTAS-LB #25: Knowing Limits: When to Stop.

By "knowing my limits, I can control myself in an out-of-control environment. I can do what's best for my survival."

A.1.1.7 LTAS-PD: Before-Diagnosis Cited Origin #1 (of 2): Death of Father During LTAS-PD's Early Childhood.

When LTAS-PD was five years old, his father died, leaving him feeling "helpless, fearful and angry." Most notable about the situation, however, was his mother's response to her husband's death: "her whole world ended when father died, and she needed me." From that time forward, LTAS-PD has provided comfort and support to his mother and to his brothers and sisters as well: he became a caregiver, a role he willingly accepted. In this role he felt a "warmth in helping," but also developed a "fear about ever having to go through the painful feelings of losing another [as his mother had done]."

A.1.1.7.1 Current AIDS-Survival Skills Developed from "Death of Father During LTAS-PD's Early Childhood" - LTAS-PD.

A.1.1.7.1.1 Skill LTAS-PD #1a: Perseverance.

One of the ways LTAS-PD deals with feelings of "anger and helplessness" brought on by his situation with AIDS, is to persevere, to work hard. He believes that "staying well is a full time job." By persevering, he is better able to "get well, and get on with what's really important [in life]." This skill functions to gain him "praise, support and acceptance" from others, and helps him avoid "letting the virus control my life." His doctor and his respiratory

therapist have played key roles in influencing him to continue to persevere.

A.1.1.7.1.2 Skill LTAS-PD 1b: Maintaining Own Sense of Well-being.

In order to "maintain control of my life and my well-being," LTAS-PD works hard at this skill. Feelings of "helplessness, anger, dependency, rejection and isolation" have influenced the use of this skill, and have led to him saying, "I'm not going to let this happen to me ... letting the bottom of my life fall out." By maintaining his own sense of well-being, and thus controlling his life, he avoids "letting the virus control my life."

A.1.1.7.1.3 Skill LTAS-PD #2: Allowing Positive, Getting Rid of Negative.

By "turning negatives into positives," LTAS-PD is "able to sort through." In any situation, LTAS-PD asks himself, "what can I get from this? What can I do to perhaps help others?" Believing that "nothing can be accomplished in negatives," LTAS-PD works to allow the positive in order to avoid "having 'it' eat away at you: HIV 'Pac Man.'"

A.1.1.7.1.4 Skill LTAS-PD #3a: Purpose and Meaning.

LTAS-PD's "purpose and meaning" comes from "helping self and others: really caring and taking time: Life is about family: being a loving, caring person." Believing that "whatever you give out, you get back tenfold," this

skill helps LTAS-PD gain "acceptance, care, support and approval" of others.

A.1.1.7.1.5 Skill LTAS-PD #3b: Opportunity.

By striving to see "opportunity" in his situation with AIDS, LTAS-PD actually seeks the "opportunity to become a whole person." Seizing the opportunity, he is better able to "help self and others," and think that "there is a reason to my surviving: perhaps to help." "When a door closes, a window opens."

A.1.1.7.1.6 Skill LTAS-PD #4: Believing in Survival: Maintaining Hope.

By truly believing in his survival, LTAS-PD "maintains hope," and is better able to "sort through" the obstacles confronting him because of AIDS. "By thinking well, I am well. Attitude is more important than even medications."

A.1.1.7.1.7 Skill LTAS-PD #5: Sense of Humor.

"If I can't laugh, forget it. I'm going to be pissed when they find a cure and I have to go back to work!" A sense of humor as he remembers in his father, will help him to retain control and composure.

A.1.1.7.1.8 Skill LTAS-PD #6: Caregiving: Helping Others to Stay Well.

AIDS gives LTAS-PD a feeling of "isolation." By caregiving, LTAS-PD gains the "support, acceptance and

approval of others. It breaks down barriers." Currently, a particular nurse, doctor and his landlady have all encouraged him to continue his "mission of caregiving."

A.1.1.7.1.9 Skill LTAS-PD #7: Focusing on Vocation.

By "focusing" on his vocation of "staying well and helping others to stay well," LTAS-PD is able "maintain a sense of well-being," as well as "acceptance, love and support by others." His landlady told him that "God will give you the strength you need to finish your work," a line which has inspired LTAS-PD to continue his work, and "avoid feeling that there is 'no purpose in life' because of AIDS."

A.1.1.7.1.10 Skill LTAS-PD #8: Taking Control. Taking Responsibility.

When LTAS-PD "takes responsibility for my situation, I gain a role to play in my own survival." LTAS-PD feels "compelled and driven ... to take control to be in control." By "believing in myself and in what I'm doing," LTAS-PD is better able to allow others to "help me, but play by my rules." By taking control, LTAS-PD avoids "looking back and allowing 'whatever' to occur."

A.1.1.7.1.11 Skill LTAS-PD #9: Confidence: Belief in My Own Abilities.

Previous successes in helping his mother through the loss of his father, and later-life successes in business

have helped LTAS-PD gain "confidence." Because of his confidence, he is more "secure and better able to be in control," and able to "keep 'whatever' from happening."

A.1.2 Past Survived Crises: AIDS-C-Group.

Speaking about their long-term survivors and those PWAs who are surviving the longest, all four AIDS-Counselors cited "past survived crises" as common origins for many critical survival skills which their clients utilize in successfully coping with AIDS.

A.1.2.1 AIDS-C-AD1: Before-Diagnosis Cited Origin #1 (of 1) Dysfunctional Family History.

AIDS-C-AD1 cites origins of many current survival skills to "dysfunctional family histories: situations of 'reverse hierarchy' or 'parentified children.'" Feeling "neglected, lonely and isolated," and "desperately wanting a family," those who developed these particular skills tended to do better in coping with their situation with AIDS:

A.1.2.1.1 Current AIDS-Survival Skills Developed from "Dysfunctional Family History" - AIDS-C-AD1.

A.1.2.1.1.1 Skill AIDS-C-AD1 #1: Adaptable: Developing New Skills.

By being "adaptable" survivors may gain "partial crisis resolution" as well as become more able to "accomplish a purpose, a mission in life." This skill may develop in

response to feeling "depressed, anxious and terrified," and to having thoughts such as, "I'm not going to die without finishing my missions in life." Significant others can play an important role in supporting the development and utilization of this skill.

A.1.2.1.1.2 Skill AIDS-C-AD1 #2: Functional Denial.

Feeling "terror and doubt," and fearing that "there may be no life after this," survivors may occasionally "get through the difficulties of the day" by partially denying the apparent realities of AIDS. This skill functions primarily in helping survivors to avoid "debilitating terror, anxiety, giving up and suicide."

A.1.2.1.1.3 Skill AIDS-C-AD1 #3: Caretaker.

Dealing with feelings of "anger, fear" and a "concern for others," "caretaking" functions in at least two ways: "(1) gaining support; and (2) being more prepared for death by helping others prepare/die."

A.1.2.1.1.4 Skill AIDS-C-AD1 #4a: Taking Responsibility.

Feeling "fear, terror and isolation," "taking responsiblity" accomplishes overall goals of "health and survival," as well as facilitating "accomplishing missions." By taking responsiblity, "giving up" is avoided.

A.1.2.1.1.5 Skill AIDS-C-AD1 #4b: Making Lifestyle Changes.

By actively "making lifestyle changes," a sense of control over "health and survival" can be attained. Feelings of "fear, terror and isolation" motivate these changes, which in turn serve to assist in avoiding "giving up."

A.1.2.2 AIDS-C-AD2: Before-Diagnosis Cited Origin #1 (of 4): Dysfunctional Family Systems.

AIDS-counselor AIDS-C-AD2's experience in working with PWAs reveals that many of the most successful AIDS survivors' past histories include childhood "dysfunctional family systems." He also believes that many of the critical AIDS-survival skills may originate within these experiences. Occurring within a "vacuum of responsibility in the parental generation," AIDS-C-AD2 describes "parent-child role reversals, physical, sexual and/or emotional abuse, and at least one parent using drugs as a way of 'false coping.'" Feelings of "helplessness" and of "being overwhelmed" lead the children to wonder, "am I good enough? Will anyone like me? Is there any order or sense to all of this?" Although there are many possible childhood reactions to the described situation, those who develop the following skills tend to be the long-term survivors of AIDS:

A.1.2.2.1 Current AIDS-Survival Skills Developed from "Dysfunctional Family Systems" - AIDS-C-AD2.

A.1.2.2.1.1 Skill AIDS-C-AD2 #1: Caretaker of Others.

Feeling "overwhelmed, fearful and helpless," within their situation with AIDS, many survivors assume caretaker roles, especially for other PWAs. In this context, they feel "useful," in that their life gains renewed "meaning and purpose: that of helping others," a skill they developed in the past.

A.1.2.2.1.2 Skill AIDS-C-AD2 #2: Adaptive: Doing What Needs to be Done.

Frequently "inspired by the achievements of other 'empowered' PWAs," survivors tend to become "adaptive," in their response to AIDS. They figure out ways of "doing what needs to be done." Being adaptive can lead to a sense of personal "empowerment," and can avoid "sitting back and taking it."

A.1.2.2.1.3 Skill AIDS-C-AD2 #3: Reading People at a Glance: Knowing How to React.

Developed from a perspective of "fear and insecurity," "being able to read people at a glance" is a skill that can lead to "effective interpersonal interaction" and avoided "unnecessary stress and strain."

A.1.2.2.1.4 Skill AID-C-AD2 #4: Transcending Negative Influences.

By "getting by negative influences," survivors "maintain hope" and "avoid becoming overwhelmed."

A.1.2.3 AIDS-C-AD2: Before-Diagnosis Cited Origin #2 (of 4): Experience in Having Dealt With Serious Illness of Others.

AIDS-C-AD2 describes another situation that frequently occurs within the dysfunctional-family-context: "having to deal with serious illness of others." Feelings of "frustration, helplessness and 'responsibility'" often lead the children in the situation to think, "this will never happen to me ... I'll see to it." AIDS-C-AD2 believes that the AIDS-C-AD2 Skills 1-4 (above-cited in "Dysfunctional Family Systems"), are further enhanced by this situation. Two additional important AIDS-survival skills arise from survivors' "experience in having dealt with serious illness of others:"

A.1.2.3.1 Current AIDS-Survival Skills Developed from "Experience in Having Dealt with Serious Illness of Others." AIDS-C-AD2

A.1.2.3.1.1 Skill AIDS-C-AD2 #5: Knowing What Good Care Really is.

Having assumed caretaker roles as children (and frequently throughout their lives) survivors truly know what good care really is by the time they contract AIDS. AIDS-C-AD2 describes this knowledge as useful in personal

care and in care of others. As good caretakers, bonds are formed and mutual support realized.

A.1.2.3.1.2 Skill AIDS-C-AD2 #6: Highly Responsible.

Having assumed and maintained highly responsible roles as children, these survivors maintain their responsible posture "even in the face of frustration of their efforts by others." By being highly responsible, they maintain "control."

A.1.2.4 AIDS-C-AD2: Before-Diangosis Cited Origin #3 (of 3): Recovery from Addiction.

Especially in the IV-drug-abuser AIDS population, many survivors who recover from addiction develop specific survival skills currently useful in dealing with their situation with AIDS. They come to terms with addiction in a "systematic way: 'twelve-step' programs" [e.g. Alcoholics Anonymous]. They "work on a set of attitudes and skills, formally and informally, with a set of people who are similarly invested [to achieve 'recovery']." As addicts, the options they faced were: "steal, deal, hook or heal." In the rehabilitation programs they were choosing to "heal." Feeling experienced in that situation included "anger, fear and an upwelling of emotion in general."

A.1.2.4.1 Current AIDS-Survival Skills Developed from "Recovery from Addictions" - AIDS-C-AD2.

A.1.2.4.1.1 Skill AIDS-C-AD2 #9b: Living with AIDS vs. Dying from it.

Believing they "always have a chance," survivors maintain a feeling of "hope" by believing that they can "live with AIDS vs. die from it." By maintaining this constant attitude, they possibly gain "self-acceptance, acceptance of one's condition, and resistance to nay-sayers and 'judgemental types.'" "Does AIDS make me a pariah? I think not." Survivors help maintain this attitude by "connecting with other empowered PWAs and with other supports."

A.1.2.4.1.2 Skill AIDS-C-AD2 #10b: Living in the Moment.

Rather than "projecting," survivors tend to "live in the moment." Understanding that "now is really the only time I ever have," they respond emotionally to situations in ways "appropriate to the situation, vs. projecting." They gain "spontaneity and a sense of freedom and of infinite possibilities: a chance to take a divergent path."

A.1.2.4.1.3 Skill AIDS-C-AD2 #11: Acceptance without Rumination.

"By accepting, as it were, survivors are able to get off the treadmill and deal with issues as they occur." Rather than excessively "ruminating" over problems and avoiding dealing with the problem, "accepting" - even in terms of identifying and acknowledging - the problem, begins a potential problem resolution.

A.1.2.4.1.4 Skill AIDS-C-AD2 #12: Taking Action After Due Consideration.

Rather than "obsessing and ruminating," "taking action after due consideration" gets one "out of the rut." The choice is "action rather than obsession."

A.1.2.4.1.5 Skill AIDS-C-AD2 #13: Physical Self Care.

Having felt "anger and fear," the survivor actively decides "I value myself. I'm worth my own best care."

A.1.2.4.1.6 Skill AIDS-C-AD2 #14a: Taking Charge of Treatment of all Types.

Feeling "frustrated and 'at the whim' of the 'establishment,'" survivors usually decide, "I'll direct rather than be directed."

A.1.2.4.1.7 Skill AIDS-C-AD2 #14b: Using Healers as Consultant vs. Being a "Patient."

When faced with so many physicians, consultants and health care providers, survivors frequently become "frustrated with this plethora of health care providers." They find either a "vacuum of answers or a plethora of conflicting answers." Thinking, "there are so many people, maybe I had better take the helm." In so doing, they gain "control and competency."

A.1.2.4.1.8 Skill AIDS-C-AD2 #15: Staying Connected: Maintaining / Forming Interpersonal Relationships.

By "remaining connected," survivors "maintain their dignity." Within interpersonal relationships, they "value and be valued as an other." Staying connected avoids feelings of "detachment and isolation."

A.1.2.4.1.9 Skill AIDS-C-AD2 #16: Centering.

By "centering," survivors maintain their composure and control by gaining an "internal connection." This skill functions to "quiet the chaos" felt in their situation with AIDS.

A.1.2.4.1.10 Skill AIDS-C-AD2 #17: Congruence.

Feeling that "time is limited," survivors usually begin to function in an integrated and mature fashion. Both "emotionally and intellectually, they begin moving in

coordinated ways, bringing things into line, and achieving peace of mind."

A.1.2.4.1.11 Skill AIDS-C-AD2 #18: Self Confidence, Empowerment and Healthy Entitlement.

Feeling "competence and self-esteem," survivors tend to "believe in their rootedness and relatedness." Feeling "good about themselves, they avoid any sense of diminishment or foreclosure."

A.1.2.4.1.12 Skill AIDS-C-AD2 #19: "Screw Guilt."

Directly or indirectly experiencing an abusive situation, leaves some feeling "paralyzed or immobilized by feelings of guilt." Some survivors, however, realize "I did not like what happened to me and/or to someone else, but I have the option to change it: the option not to stay stuck, but to change the situation and move on: 'screw guilt.'"

A.1.2.4.1.13 Skill AIDS-C-AD2 #20: Taking Care of Business (including Unfinished Business).

Sensing that "only I can make the final decisions," survivors may decide to avoid the feelings of "helplessness and defeat and 'just waiting for the coup de grâce,'" and decide to "take charge, to get things in order." They move to "take care of business" and decide to take over "one's own case management."

A.1.2.4.1.14 Skill AIDS-C-AD2 #21: Functional Denial.

In order to avoid "getting 'hung up' or overwhelmed by the 'AIDS-in-my-face Syndrome,'" some survivors may choose to - occasionally but temporarily - deny the reality of their situation with AIDS.

A.1.2.4.1.15 Skill AIDS-C-AD2 #22: Purpose and Meaning.

"Feeling somewhat overwhelmed by the disease and a static situation with it," some survivors choose to find "purpose and meaning" in their lives. They become "centered, and gain strong identity, rootedness, relatedness and connectedness within oneself and within one's community."

A.1.2.4.1.16 Skill AIDS-C-AD2 #23: AIDS as a Challenge or an Opportunity.

Deciding "I'm going to use whatever I have going for me," some survivors choose to discover possible opportunity available within their situation with AIDS: "I can't change the cards I've been dealt, but I can decide how to play them." Avoiding "vegetating," some survivors may choose to "become active" in some way which improves their feelings of "self-worth."

A.1.2.4.1.16 Skill AIDS-C-AD2 #24: Skill at Grieving Losses.

Feeling appropriate "separation anxiety," survivors may utilize previously acquired "skill and facility at grieving

losses." "By having learned how to 'let go,' they are better able to embrace new people and new ways," and thus avoid "getting stuck" in a situation where they face potential loss.

A.1.2.4.1.17 Skill AIDS-C-AD2 #25: Commanding Dignity and Respect vs. Allowing Pity.

Rather than "getting hooked into the secondary gain [of being pitied]," survivors frequently choose to "command dignity and respect." Feeling "anger at being seen as 'pathetic,' being 'reduced' as an object of pity and censure," survivors assert, "I know what I'm doing: I'm not going to base my response on what someone else thinks."

A.1.2.4.1.18 Skill AIDS-C-AD2 #26: Assertiveness.

Subject to a "vacuum of, or too much extenal leadership," PWAs frequently feel "angry, helpless, confused and despondent." By being "assertive especially of their own needs," survivors avoid "getting what people want to heap on them, vs. what they really want or need."

A.1.2.4.1.19 Skill AIDS-C-AD2 #27: Expressing Thoughts, Feelings and Emotions.

By actively "expressing thoughts, feelings and emotions," survivors "make the best use of their time, and gain a feeling of mastery, control and competence."

A.1.2.4.1.20 Skill AIDS-C-AD2 #28: Caretaking Within One's Limits: Generativity.

"Having been given-to and helped" by others, survivors can reciprocate, form bonds with others and feel better about themselves: "not only am I managing myself, but I am now capable of giving to someone else. I'm in this with everyone else."

A.1.2.1.21 Skill AIDS-C-AD2 #29: Control.

Frequently feeling "angry and isolated," survivors "take control of their situations: they become active in the process of managing whatever confronts them." As a result, they gain a vision of themselves "as not being alone," and feel "empowered."

A.1.2.4.1.22 Skill AIDS-C-AD2 #30: Politically Active.

Feeling "anger, indignation and fear," survivors choose to become "part of something greater than their own lifes and times:" they become "politically active" especially in the politics of AIDS. Frequently "experienced in politics of more or less traditional domains," survivors become politically active in order to gain "adaptation, self-assurance, empowerment, support, attention and affirmation."

A.1.2.4.1.23 Skill AIDS-C-AD2 #31: Giving it Up/Over: Surrendering.

Realizing that "the more I insist on the selfish options, the more unmanageable my life becomes." Feeling that they've "run amuck," survivors "give it over or surrender, usually to the care of a 'higher power.'" "Knowing they need an influence from outside of self, they surrender 'obsession:' one's 'personal demons.'"

A.1.2.5 AIDS-C-DK: Before-Diagnosis Cited Origin #1 (of 2): Abusive , Neglectful, Chaotic Childhood Family Situation.

AIDS-counselor AIDS-C-DK's PWA experience is largely with women who are former IV drug-abusers. Most of the survivors she has worked with come from childhood family situations where "the child's characteristic response was to assume an 'adult-child' role: high responsiblity, adaptable, caretakers, holding the family together (vs. giving to the 'addictive draw.'" Feelings of "desperation" are common in this situation.

A.1.2.5.1 Current AIDS-Survival Skills Developed from "Abusive, Neglectful, Chaotic Childhood Family Situations" - AIDS-C-DK.

A.1.2.5.1.1 Skill AIDS-C-DK #1: Focusing on Strengths.

Thinking "if I could survive this, I can survive anything," survivors "focus on strengths" in order to "maintain control." AIDS-C-DK cites support for this skill

by a "someone" who has cared enough to "reach out in support."

A.1.2.5.1.2 Skill AIDS-C-DK #2: Caretakers.

Feeling "fear, lonliness and isolation," survivors frequently assume caretaker roles in order to "gain purpose" in their lives. Many assume caretaking roles with other PWAs, but frequently, re-bonding with families occur as caretaking responsiblities are resumed with their children. "Having helped someone else survive past 'grisley' experiences," many survivors are especially adept at this skill.

A.1.2.5.1.3 Skill AIDS-C-DK #3: Knowing I Have Something to Give.

By maintaining this attitude, survivors who feel they "still have something to give" gain a sense of "meaning" in their lives.

A.1.2.6 AIDS-C-DK: Before-Diagnosis Cited Origin #2 (of 2): Successfully Completing a 6-Month Drug Rehabilitation Program.

AIDS-C-DK's AIDS-survivor clients who had become addicts in the past, explain feeling that they were "floundering with desperation and a sense of urgency:" "My body is getting older, and I don't want to lose my childrens' childhood." Having their children grow up with a "positive image of mom" was a frequent motivation for completing a six month program. In the program, "someone

gives the opportunity, and provides structure: timing, schedules, etc." That "someone" who "reaches out in caring," plays an important role in the survivors' recovery from addiction and survival of AIDS. For AIDS-C-DK's AIDS-survivors, "successfully completing a six-month drug rehabilitation program" frequently occurs before HIV diagnosis, but occasionally occurs after diagnosis as well.

A.1.2.6.1 Current AIDS-Survival Skills Developed from "Successfully Completing Drug Rehabilitiation" - AIDS-C-DK.

A.1.2.6.1.1 Skill AIDS-C-DK #4: Identifying and Labeling Stress.

Frequently "feeling overwhelmed [by AIDS] and by the 'force of addiction,'" survivors utilize this skill in order to maintain "control" over their impulses and their situation with AIDS.

A.1.2.6.1.2 Skill AIDS-C-DK #5: Sense of Dignity and Self-Worth.

By maintaining a "sense of dignity and self-worth," survivors gain "positive self esteem" and a "reason to act out in their own behalf."

A.1.2.6.1.3 Skill AIDS-C-DK #6: Viewing Self as Separate, Autonomous and Basically Positive.

Many of AIDS-C-DK's survivors came from situations where their sense of self was enmeshed in "abusive relationships with others." Coming to "view self as

separate, autonmous and basically positive" is a more indepent posture more representative of long-term survivors. Possible gains achieved through this skill include "seeing self as existing separately from another person," and a "sense of self-dignity from within."

A.1.2.6.1.4 Skill AIDS-C-DK #7: In Touch with Body Cues.

AIDS-C-DK's survivors have often reached a point of thinking, "my body is getting too run down," or, "I feel old. I don't have the stamina [to continue an abusive lifestyle]." By developing the skill of staying "in touch with body cues," survivors "actively counteract learned denial," and can act more appropriately on their own behalf.

A.1.2.6.1.5 Skill AIDS-C-DK #8: Consciously Communicating.

Driven by feelings of "fear, desperation and urgency," survivors develop the skill of "consciously communicating." With this skill, survivors avoid a "build-up of fear ... and being overwhelmed by fear of their situation with AIDS and its "potential draw towards renewed addictive behavior." They also gain "trust, new friends," and "actively counteract 'learned denial.'"

A.1.2.6.1.6 Skill AIDS-C-DK #9: Asking for Help.

Feeling "old, run-down, vulnerable and desperate" in their situation with AIDS, survivors learn to "ask for

help" in order to "avoid becoming overwhelmed by fear of the situation."

A.1.2.6.1.7 Skill AIDS-C-DK #10: Identifying, Acknowledging and Avoiding Negative Influences.

In order to deal with feelings of "desperation" and fearful concern for "getting caught up in another abusive situation," long-term AIDS survivors learn to "identify, consciously acknowledge and avoid negative influences."

A.1.2.6.1.8 Skill AIDS-C-DK #11: Physical Self Care.

Consciously realizing that "time is running out," and "I don't have the stamina [to continue the abusive style]," AIDS-C-DK's survivors address their own "physical self care needs" in order to maintain "control" of their situation.

A.1.2.6.1.9 Skill AIDS-C-DK #12: Responsibility: Understanding and Taking.

Frequently with the realization that "my children are getting older," and, "I'm missing their childhood," AIDS-C-DK's AIDS survivors learn to "understand and take responsibility." Often coming from "years of abuse and several incarcerations," the survivors utilize this skill in order to avoid "drugs, prostitution and exploitative relationships."

A.1.2.6.1.10 Skill AIDS-C-DK #13: Re-bonding with Children.

Regretfully "fearing missing out on all of their childrens' childhoods," AIDS-C-DK's survivors also feel "desperation, fear of dying and guilt:" "My life is almost over. My children are getting older. I've missed time. I've hurt myself and my kids." By "re-bonding with children," they are actively choosing to "leave it all behind (years of abuse and denial)," and to regain the "joy of parenting." Also serving to motivate this skill is their need to "have their children develop a positive sense of 'mother.'"

A.1.2.6.1.11 Skill AIDS-C-DK #14: Support by Another.

During their drug rehabiliation experience and training, AIDS-C-DK's survivors experience - sometimes for the "first time" - "someone reaching out with love and laughter." Feeling of "comfort, acceptance, approval and of being nurtured," as well as "self acceptance" develop from having received "support by another."

A.1.2.6.1.12 Skill AIDS-C-DK #15: Sense of Humor.

Often feeling "desperation and urgency" about "time running out," AIDS-C-DK's survivors realize that they "don't have time not to laugh!" Having "someone reach out and show them that they can laugh [usually during their drug rehabilitation experience]," they learn to

"experience some joy" and to "improve relationships with others."

A.1.2.7 AIDS-C-FJ: Before-Diagnosis Origin Cited #1 (of 1): Dysfunctional Family Situations.

AIDS-C-FJ recalls that "most if not all" of the LTASs that she has encountered in the past, have come from "dysfunctional family situations." Most have been "children of chemically dependent parents/adults," and as such, were subject to feeling "separated, lonely and isolated." These survivors, in fact, experienced a "general lack of caring in their lives." Specifically from their dysfunctional family histories, they developed several skills which are instrumental in their long-term survival of AIDS:

A.1.2.7.1 Current AIDS-Survival Skills Developed from "Dysfunctional Family Situations" - AIDS-C-FJ.

A.1.2.7.1.1 Skill AIDS-C-FJ #1: Caretakers.

In order to avoid "being alone" in their situation with AIDS, survivors rekindle an old skill: "caretaking." By caring for others, particularly other PWAs, survivors form bonds, and achieve their goal of "not being alone." Motivating this skill is the thought, "If I can do good for someone else ... maybe I'll be told 'I'm OK' [and won't be left alone]."

A.1.2.7.1.2 Skill AIDS-C-FJ #2: Maintain Hope.

"After the initial shock phase of the AIDS crisis," many PWAs experience feelings of "fear, lonliness and isolation." Coming from difficult family situations, many survivors "maintain hope" by never abandoning the "belief in the possibilty of reconciliation of unresolved family issues." Possibly gained by the use of this skill are "reconciliation of unresolved issues," and, "ability to continue to survive."

A.1.2.7.1.3 Skill AIDS-C-FJ #3: Realistic but Hopeful.

Acknowledging and respecting their crisis, survivors "make necessary changes" in order to deal with the reality of the situation; they don't, however, lose hope. They believe "there is still something to live for." By being "realistic but hopeful," survivors are better able to "cope with the situation," and more able to "experience 'more' in life."

A.1.2.7.1.4 Skill AIDS-C-FJ #4: Healthy Denial.

In order to "retain their sanity" and to at least occasionally avoid feeling "anxious about possible future loss," survivors frequently choose "not to think about death."

A.1.2.7.1.5 Skill AIDS-C-FJ #5: Adaptive: Make Necessary Changes.

The "AIDS-crisis" serves as "the boot" [motivator] for survivors to become "adaptive: to make necessary changes in order to improve the quality of their life, as well a to improve the quality of their relationships with others." This skill at least indirectly functions to avoid the feelings of "lonliness and isolation."

A.1.2.7.1.6 Skill AIDS-C-FJ #6: Appreciative of Love and Caring.

"Fearing lonliness and isolation," survivors are especially "appreciative of love and caring: I want someone to go through this with me."

A.1.3 Past Positive Influences on Skill Development: LTAS-Group.

A.1.3.1 LTAS-PD: Before-Diagnosis Origin Cited #2 (of 2): Success in Business.

LTAS-PD experienced was "very successful" in the workplace. He maintained a managerial position in "personnel." In that situation, the work load could become heavy and the stresses significant. LTAS-PD was a manager who was "available:" people could come to him, ask him for help, and share their difficulties. In this environment, LTAS-PD's interpersonal skills left him very successful, and feeling "success, calm, support, harmony, cooperation and respect." LTAS-PD developed the following skill which

was important to him then, and to him now in his long-term survival of AIDS.

A.1.3.1.1 Current AIDS-Survival Skills Devloped from "Success in Business." LTAS-PD.

A.1.3.1.1.1 Skill LTAS-PD #10: Support.

Support has been important in helping LTAS-PD cope with feelings of "fear, frustration, isolation and rejection." LTAS-PD participates in formal and informal support groups with other PWAs and friends: by "being willing to give something, I get something back." Sharing "common bonds, we realize that there are others out there with the same fear and frustration." Participating in supportive relationships helps LTAS-PD in other ways: "it keeps me from giving in, and also from having to make it harder on my family." Within his support structures, LTAS-PD gains "respect, acceptance," and a feeling of "calm."

A.1.4 Past Positive Influences on Skill Development: AIDS-C-Group.

A.1.4.1 AIDS-C-AD2: Before-Diagnosis Origin Cited # 4 (of 4): "Normal Family Situations."

In AIDS-C-AD2's experience, he has known a "small percentage" of long-term survivors who came from "normal family situations." In their family situation, they felt "love, care, confidence, security and self-esteem," and were raised with "some notion of faith and religious affiliation. There was a consensual set of values was

adhered to and they performed well in school. They were loved and felt 'confidence bestowed' by positive parental models who provided a firm foundation in esteem." From their situation, several positive coping skills developed and are important AIDS-survival skills in the survivors' current situation:

A.1.4.1.1 Current AIDS-Survival Skills Developed from "Normal Family Situations" - AIDS-C-AD2.

A.1.4.1.1.1 Skill AIDS-C-AD2 #7: Spiritual Connectedness.

Having been "accorded esteem by others," and having a foundation in a stable family life of "love and positive influence," this small percentage of survivors maintain an sense of "spiritual connectedness." This was developed within their childhood situation, and functions to help them maintain a feeling of "trust, security and confidence."

A.1.4.1.1.2 Skill AIDS-C-AD2 #8: Attending to Whatever Needs to be Done.

By "attending to whatever needs to be attended to." survivors "stay active and in control of their situation with AIDS." By using this skill, they avoid "inactivity" and feelings of "fear, isolation and lonliness."

A.1.4.1.1.3 Skill AIDS-C-AD2 #9a: Active in Treatment Process.

Similar to AIDS-C-AD2 Skill #8, being "active in their treatment process" helps survivors to "stay active and in control of their situation with AIDS." By using this skill, they avoid "passivity," feelings of "fear, isolation and loneliness," and "giving up."

A.1.4.1.1.4 Skill AIDS-C-AD2 #10a: Gracefully Dealing with the Disease.

By "gracefully dealing with the disease," survivors deal with their feelings of "anger and resentment" by encountering the disease with a "sense of congruence and empowerment and control: they make the best of their situation."

A.2 Origins of Current Survival Skills Developed AFTER Initial HIV-Diagnosis.

Several members from each group described their first knowledge of their HIV-diagnosis, as "the boot." After the initial shock phase, they saw AIDS and life "looking me right in the eye." As previously described in "choosing to live with AIDS," they faced a moment of truth. For the survivors, "the boot" was enough motivation for them to actively choose to "get on with life," to "live," to pursue "the joy." All members of each group described their HIV diagnosis as a very critical time that strongly influenced positive and adaptive action.

A.2.1 Response to HIV/AIDS Crisis: LTAS-Group.

A.2.1.1 LTAS-AV: Response to HIV/AIDS Diagnosis. #1 (of 1).

For LTAS-AV, news of her "status" was "overwhelming." "After the shock wore off," however, she felt "fear" for her life and "anger" at herself and whomever had infected her. She soon realized, however, that she was "not going to let AIDS take over." Mustering a "survival spirit from past difficult situations," she "arrogantly looked AIDS right in the eyes" and decided that it wasn't going to "get me down." She took charge of her situation, and is "still here kicking" with her humor and many other important survival skills:

A.2.1.1.1 Current AIDS-Survival Skills Developed from "Response to HIV Diagnosis and AIDS" - LTAS-AV.

A.2.1.1.1.1 Skill LTAS-AV #10: Homework with Unfinished Business.

By "taking care of unfinished business," LTAS-AV works on unresolved issues. As a result, she achieves "peace for myself and for others," and is "working out negative and positive family issues: Mother actually was OK!" LTAS-AV is also "coming to grips with unfinished goals."

A.2.1.1.1.2 Skill LTAS-AV #11: Seeing AIDS as Just Another Disease.

In order to avoid feeling "fearful and overwhelmed," LTAS-AV "sees AIDS as just another disease [i.e. not a "death sentence"]. Summoning her "survival spirit from past difficult situations," she maintains control: "You won't take me."

A.2.1.1.1.3 Skill LTAS-AV #12: Acceptance of Self and Others.

Feeling "urgency," with respect to time, LTAS-AV doesn't "have time to be judgmental." By being "accepting of self and others," she achieves "peace with myself and with others."

A.2.1.1.4 Skill LTAS-AV #13: Positive Life-Style Changes.

LTAS-AV has made "positive life-style changes" in order to gain "control over AIDS." Feeling "anger and fear," she asserts that "AIDS is not going to get me."

A.2.1.1.5 Skill LTAS-AV #14a: Express Feelings.

LTAS-AV "expresses feelings" in order to "take care of unfinished business," and to "feel good about self and others." Expressing feelings "gets them out of the way."

A.2.1.1.6 Skill LTAS-AV #14b: Express Love and Caring.

Avoiding "taking the easy way: saying 'I hate you.'" LTAS-AV "feels good" using a new skill for her: "expressing love and caring." In so doing, she receives "support, acceptance, validation, 'reparenting,' and a good feeling." She has realized that "I'm not the only one who cares about me."

A.2.1.1.7 Skill LTAS-AV #15: Confidence.

"Bigger and better things have tried to get me down, and didn't. You [AIDS] won't." LTAS-AV's "confidence" "keeps me going," "deals with her anger," and keeps from "letting AIDS take over."

A.2.1.1.8 Skill LTAS-AV #16: Dialogue with God.

Avoiding "despair" and "feelings of anger," LTAS-AV has an active "dialogue with God." Although her dialogue is sometimes not prayer-like or friendly, she gains "hope and meaning." "Why did you let me do this?" She "concludes that there must be a reason I'm 'still here and kicking.'"

A.2.1.1.9 Skill LTAS-AV #17: Purpose and Reason for Being Here.

Believing "there is a reason I'm still here and kicking," LTAS-AV avoids "despair" and "keeps straight" by focusing on her purpose and reason for being alive.

A.2.1.1.10 Skill LTAS-AV #18: Telling People I Have AIDS.

By "telling people I have AIDS," LTAS-AV "takes responsibility for having (not getting) AIDS." She expresses "anger with others who disregard their responsibility with AIDS."

A.2.1.1.11 Skill LTAS-AV #19: Humor.

In order to avoid "being overwhelmed [by AIDS]," LTAS-AV partially "denies" the gravity of her situation with AIDS by using "humor:" "I have just a 'touch' of AIDS!" "Another one 'bit the dust.'"

A.2.1.1.12 Skill LTAS-AV #20: Partial State of Denial.

To avoid "being overwhelmed" when the feelings of "fear, anger and isolation" become too intense, LTAS-AV "partially denies." She mostly uses humor, and occasionally uses drugs: "it keeps me from going crazy."

A.2.1.1.13 Skill LTAS-AV #21: Challenge.

Seeing her situation with AIDS as a "challenge," LTAS-AV will have "control over how it gets me." Feeling "fear and anger," she avoids "giving up:" "I'll control it."

A.2.1.1.14 Skill LTAS-AV #22: Accepting and Loving Self and Others.

LTAS-AV gains "support" and "shares bonds" by "accepting and loving myself and others." This skill is

effective in dealing with feelings of "fear and isolation." and generates feelings of "caring." By believing "it's OK to be an 'asshole,' as long as you own up to it!," she avoids "isolation."

A.2.1.1.15 Skill LTAS-AV #23: Willing to do Whatever to Help Self and Others.

LTAS-AV is willing to do "whatever it takes" to avoid "giving up and being alone." She "enhances her survival," as well as gaining "control and support," shares "common bonds, and feels helpful." She uses this skill to deal with her feelings of "fear and anger," and to avoid "giving up or being alone."

A.2.1.1.16 Skill LTAS-AV #24: Empowerment.

Feeling "angry and fearful," LTAS-AV is "determined to keep choosing life: to be 'empowered.'" "I always have a choice: live vs. die; good vs. bad. I CHOOSE LIFE."

A.2.1.1.17 Skill LTAS-AV #25: Seeing Doctors as Human Beings, not deities.

"They're just people." LTAS-AV cites "previous experience in health care," as a help in avoiding becoming too "dependent" on doctors. By seeing them as "humans," she achieves a "better relationship," and maintains "control in the therapeutic relationship."

A.2.1.2 LTAS-CM: Response to HIV / AIDS Diagnosis. #1 (of 1).

For LTAS-CM, HIV diagnosis was a "moment of choosing." Taken from some of his writing about "long-term AIDS survival" in Callen (1988, p. 136), "AIDS was kind of a cosmic kick in the ass for me. It made me realize the preciousness of life. It made me ask hard questions and make some difficult choices. I jettisoned a lot of bullshit and got on with the business of living." Initially feeling "isolated, insecure, desperate" and like "factory seconds ... damaged merchandise. I felt like I was on the dung heap of life."

In Callen (1988, p. xix), LTAS-CM writes about the personality of AIDS: "AIDS is a wily adversary. One cannot turn one's back for an instant. The moment you feel you've wrestled it to the ground, it slithers out from under you, to return in another form at another time in whatever way you'd least expect."

LTAS-CM cites the importance of his parents in having provided him some foundation for his later development of skills critical in his survival of AIDS: he recalls his "cynical, witty and intelligent father," and his "non judgmental, optimistic, simple and loving" mother "who had compassionate ideas of right and wrong." The most important people in his survival, however, are his doctor and his lover. "My doctor is the smartest and kindest person I know: he refuses to allow me to just do what he

tells me. He makes me make my own decisions, and has helped me to save my life. He convinced me regarding certain responsibilities to having the disease, including responsibility to others. He encouraged me to get active [LTAS-CM is president and co-founder of several AIDS-related organizations], and to write [he is currently finishing a book on "long term survival"]." Regarding the role his lover played in his survival: "when I felt like factory seconds, he picked me up off the dung-heap of life. He showed me love was still possible. He got me to do more music, to produce my first album ... I'm a very much different person because of him."

Another positive influence on his survival was "having been lucky enough to have met the person referred to in Dr. R's study as the 'longest survivor of AIDS.' He was an inspiration to me." LTAS-CM is very active in dealing with his situation with AIDS, and cites the following skills as important skills which developed after his diagnosis:

A.2.1.2.1 Current AIDS-Survival Skills Developed from "Response to HIV Diagnosis and AIDS" - LTAS-CM.

A.2.1.2.1.1 Skill LTAS-CM #3: Pragmatism.

LTAS-CM is very "pragmatic" in his approach to life with AIDS. In order to "maintain control and health," he carefully scrutinizes all options, and then does "whatever is necessary."

A.2.1.2.1.2 Skill LTAS-CM #4: Impatient with Sideline Critics.

In his relationships with others, especially other PWAs, LTAS-CM expects people to "talk the talk, and walk the walk." He takes "the responsibility of having AIDS" very seriously, and expects others to do the same. His "impatience" is a form of continually keeping himself going forward, and "not giving up."

A.2.1.2.1.3 Skill LTAS-CM #5: Work: Do Something About It.

LTAS-CM actively models "working and doing something about it." He "jettisoned a lot of bullshit and got on with the business of living" (Callen, 1988, p. 136).

A.2.1.2.1.4 Skill LTAS-CM #6: Accepting and Supporting Other Points of View.

LTAS-CM is "very against censorship." He uses the expression "supporting and accepting other points of view in two ways:" one is supporting others and their view as a way of empowering them, of helping them to make their own choices; the other perspective is similar to that expressed in LTAS-CM #3 ("Pragmatism"): he is fastidious about gathering "all available information on the topic" so that he can make "rational and informed decisions" that his "life depends on."

A.2.1.2.1.5 Skill LTAS-CM #7: Refusing to Make Decisions for Others.

LTAS-CM explains that he has become a "celebrity survivor of sorts." He is frequently asked to make decisions for others. He doesn't want that responsibility. He indirectly empowers others by "refusing to make decisions" for them, and he maintains "control" of his own situation as well.

A.2.1.2.1.6 Skill LTAS-CM #8: Healthy Skepticism.

LTAS-CM maintains a "healthy skepticism of what I believe and of what others tell me to believe." He continually "strives towards the truth," but is cautious about "making any claim on having the final truth." In this posture, he is open to and receives new information, creates options for himself, and is "more in control."

A.2.1.2.1.7 Skill LTAS-CM #9: Active Dialogue Regarding Diverse Opinions.

As in the previous skills, LTAS-CM stays informed and makes the best choices when he is able to "gather as much information as possible." He stays more "active" in his survival, maintains "control" and doesn't "make assumptions."

A.2.1.2.1.8 Skill LTAS-CM #10: Striving Towards the Truth.

LTAS-CM believes that his "life depends on ... striving towards the truth." Constantly seeking new information, he maintains a forward movement in his own care by continually striving.

A.2.1.2.1.9 Skill LTAS-CM #11: Not Giving Up On Love.

LTAS-CM believes that having "found the love of a good man" is one of the most crucial elements in his survival. In love with another, he maintains "hope and purpose." From Callen (1988, p. 12): "Love is worth fighting for, but one must constantly nurture the love which makes life worth living."

A.2.1.2.1.10 Skill LTAS-CM #12: Helping Others.

LTAS-CM "help others," "supporting them in their decisions, and by providing information:" "You're making life or death decisions ... get all the points of view." This skill is also "self motivated: you never know a subject as well as when you teach it." By helping others, he enhances his own survival.

A.2.1.2.1.11 Skill LTAS-CM #13: Frisky, Gritty.

By being "frisky and gritty," LTAS-CM "keeps himself from plodding along," and he "stays in control."

A.2.1.2.1.12 Skill LTAS-CM #14: Cleaning Up House: Getting Rid of the Negative.

LTAS-CM "got rid of relationships that were not supportive. He found that these relationships were "draining," and "would get you off the track."

A.2.1.2.1.13 Skill LTAS-CM #15: Spend Time With People Who Are Supportive.

LTAS-CM not only "cleans up house," he also "spends more time with people who are supportive." In so doing, he better "experiences the joy," and "maintains his energy."

A.2.1.2.1.14 Skill LTAS-CM #16: Brutally Honest With Myself.

In every way, LTAS-CM believes that he must "give my body a 'live message.'" By "being honest with myself, I stay on track and in control."

A.2.1.2.1.15 Skill LTAS-CM #17: Having and Expressing Feelings.

Although he said that "it can be really 'hard to feel,'" one of the ways LTAS-CM remains honest with himself ("inwardly and outwardly") is to "have (i.e. not deny) and express feelings."

A.2.1.2.1.16 Skill LTAS-CM #18: Fierce Joy of Living.

LTAS-CM "loves life:" "However much time I have left, I want to revel in the joy of existence. I want to live,

feel, fully. Although it's hard work, you can avoid getting caught up in the momentum, plodding along."

A.2.1.2.1.17 Skill LTAS-CM #19: Giving My Body a Live Message.

"Being brutally honest with myself," "taking responsibility," "cleaning up house," "loving life," etc., "gives my body a live message: my life depends on it."

A.2.1.2.1.18 Skill LTAS-CM #20: Responsibility: Making My Own Choices.

LTAS-CM's doctor has been instrumental in his "making my own choices." "He won't let me tell him to 'just tell me what to do.'" "By taking responsibility, I maintain control of my situation."

A.2.1.2.1.19 Skill LTAS-CM #21: Great Faith in Doctor.

With "faith in my doctor," I can have "confidence" and feel "more in control."

A.2.1.2.1.20 Skill LTAS-CM #22: Support and Love.

LTAS-CM believes that having "found the love of a good man" is one of the most crucial elements in his survival. In love with another, he maintains "hope and purpose."

A.2.1.2.1.21 Skill LTAS-CM #23: Collaborate With My Doctor in My Own Care.

By collaborating with his doctor, LTAS-CM stays "active in his care," avoids "plodding along," and "stays more in

control." "When you have worked to come to the knowledge and belief that this person [doctor] is worthy of your faith and trust, then you can invest in him/her the power to heal.

A.2.1.2.1.22 Skill LTAS-CM #24: Hope.

"I think you have to have 'hope,' ... can't make it without it." From Callen (1988, p. 1380: The best I can surmise is that hope - a passionate commitment to fighting for one's life - is a necessary, but not sufficient ingredient for survival. It won't guarantee that you'll beat AIDS, but you've gotta [sic] have it to even be in the running" (p. 138).

A.2.1.2.1.23 Skill LTAS-CM #25: Conserving Energy.

"I can't afford to waste my time, my life or my energy." From Callen (1988, p. 12): "...my limited time is best spent (a) staying alive, and (b) working ..."

A.2.1.3 LTAS-LB: Response to HIV/AIDS Diagnosis. #1 (of 2).

After he learned of his HIV diagnosis, LB felt "fear and insecurity." He felt similarly after his AIDS diagnosis, especially when he was "hospitalized by a severe illness." Several people played roles in his recovery from that illness: his doctor gave him "hope," and helped him to set a goal (going home);" his stepmother "created

suggestions, gave me support and strengthened me." An esteemed co-worker and fellow PWA "inspired me too."

His response to AIDS was heightened by a "near death experience." He was "fearful of dying," but resisted the thought. Through his experience, he felt "touched by the spirit," and continues to feel "special in the eyes of God."

A.2.1.3.1 Current AIDS-Survival Skills Developed from "Response to HIV Diagnosis and AIDS" - LTAS-LB.

A.2.1.3.1.1 Skill LB #26: Purpose and Meaning in Living.

"Some people suffer for the benefit of others. It's just not my time to 'hang it up.' God gives me a purpose and a meaning in living." "Purpose and meaning" gives LTAS-LB "confidence to 'keep going' and to help others through it." Using the "wisdom I have acquired," he teaches and counsels other PWAs.

A.2.1.3.1.2 Skill LTAS-LB #27: Spirituality.

"God has a special place for me. I'm more special in the eyes of God. I'm a martyr for God, one of God's chosen people." LTAS-LB's "spirituality" "keeps me going and gives me confidence."

A.2.1.3.1.3 Skill LTAS-LB #28: Support: Giving and Taking.

Formal and informal "support" is a relatively new skill for LTAS-LB and his wife. Through their mutual

difficulties encountered in dealing with his AIDS, they have both routinely need and receive "the help of others [LTAS-LB Skill #33]."

A.2.1.3.1.4 Skill LTAS-LB #29: Taking Things One Day at a Time.

To avoid "letting the fear get too much," "taking things one day at a time" helps LTAS-LB to "do the best I can" and to "get through the day."

A.2.1.3.1.5 Skill LTAS-LB #30: Focus on Getting Through It.

Feeling "insecure" especially in the most difficult time with his AIDS, LTAS-LB uses his strong will to "focus on getting through." Thinking "enough is enough," he developed this skill most fully during his experience with one particularly bad bout with pneumocystis pneumonia.

A.2.1.3.1.6 Skill LTAS-LB #31: The Want for Life.

Feeling "touched by the Spirit" during a "near-death experience," LTAS-LB experiences a "want for life" that gave him "the desire to get better." His want for life "keeps me positive even through the pain and suffering."

A.2.1.3.1.7 Skill LTAS-LB #32: Never Believing I'm Going to Die From AIDS.

LTAS-LB's "near death experience" expanded his "spirituality" and his "want for life." The cumulative

experience has diminished his "fear of dying," and left him believing "I'm not going to die from AIDS."

A.2.1.4 LTAS-PD: Response to HIV/AIDS Diagnosis. #1 (of 1).

When LTAS-PD first learned of his HIV diagnosis, "it felt like the bottom of my life was falling out." "After the shock wore off, I decided, 'I'm not going to let this happen.'" Feeling "helplessness, anger, isolation, rejection and dependency," LTAS-PD says that, "HIV and AIDS forced me to 'take a strong look at my life.'" He called upon all the skills he developed in the past, including his "previous role in helping Mom survive, and his prior successes in business and management." He also developed other skills that he believes have been important in his survival of AIDS:

A.2.1.4.1 Current AIDS-Survival Skills Developed from "Response to HIV Diagnosis and AIDS" - LTAS-PD.

A.2.1.4.1.1 Skill LTAS-PD #11: Sense of Self Healing.

LTAS-PD's "sense of self-healing" is a responsibility. In his firm posture to "not let this happen," he looks inward. This is his foundation that supports many of the following skills.

A.2.1.4.1.2 Skill LTAS-PD #12: Driving Force From Within.

Influenced by his landlady and one of his nurses, LTAS-PD believes that, "God will give me whatever I need (time,

resources) to finish my work." This "force" gives me "hope," and "makes me go on."

A.2.1.4.1.3 Skill LTAS-PD #13: Will to Live: Fortitude.

LTAS-PD believes, "it's already within. Everyone has the fortitude [to survive], you just have to find it and bring it out." A "will to live" helps him "survive" and "keep from giving in."

A.2.1.4.1.4 Skill LTAS-PD #14: Fighting Spirit.

Feeling "fear and anger," LTAS-PD frequently senses "the time bomb ticking: time running out." Feeling that "there is no one here to give me the answers," he has developed a "fighting spirit." Influenced by health professionals and others, he works for the "gift within: it's there, but I have to bring it out." By fighting, he "gets rid of fears and frustration," and achieves a "sense of well-being."

A.2.1.4.1.5 Skill LTAS-PD #15: Living in the Now.

"When I look into the past, I feel guilt. Look to the future and I see fear. So I stay here and experience 'the now.'" By "living in the now," LTAS-PD believes that "the external environment will not dictate my experience."

A.2.1.4.1.6 Skill LTAS-PD #16: Maintaining Calm. Putting Fears Forward.

"Attitude is more important than even medications [for survival]." Occasionally LTAS-PD fearfully thinks, "Oh God, the virus is taking over ... what's going to happen next?" He relaxes, and does a "sort of meditation: maintaining calm, putting fears forward: I choose to live." This technique helps him "let go" of the fears: "it's a way of getting past it, and of maintaining my health."

A.2.1.4.1.7 Skill LTAS-PD #17: Accepting, Liking and Loving Self.

"For the first time," says LTAS-PD, "I like what I see when I look in the mirror." "Whatever energies I put in are worth the efforts." He attributes the development of this skill to himself, "I've been trying and working at it [for a long time]." By "accepting, liking and loving himself," "things fall into place, I get through the 'dark moments,' and I feel better about myself:" he gains "well-being."

A.2.1.4.1.8 Skill LTAS-PD #18: Trying my Best Without Kidding Myself.

LTAS-PD is "honest with myself" about "trying my best without kidding myself." The more honest he can be with himself, "the better I'll be."

A.2.1.4.1.9 Skill LTAS-PD #19: Reaching a Point Where I Want To Be Helped.

Acknowledging that "I can't do it all myself," he believes it was important for him to "reach a point where I was willing to be helped." When he and others work together, he is "better able to survive."

A.2.2 Response to HIV/AIDS Crisis: AIDS-C-Group.

A.2.2.1 AIDS-C-AD1: After-Diagnosis Origin Cited #1 (of 1): AIDS-Crisis.

AIDS-C-AD1 describes typical feelings of "depression, anxiety, terror, anger, fear and 'a sense of urgency.'" Within this crisis, several significant needs develop: "having a trusted loved one to die with - i.e. not wanting to 'die alone' - and realizing life goals." The "sense of urgency" motivates "working on finishing missions," and influences the development of many coping or survival skills. Gaining approval of support people and/or therapists, as well as new approval from family, especially father, are cited as positive influences.

A.2.2.1.1 Current AIDS-Survival Skills Developed from "AIDS-Crisis" AFTER HIV Diagnosis - AIDS-C-AD1.

A.2.2.1.1.1 Skill AIDS-C-AD1 #5: Actively Pursuing a Mission in Life :Fulfilling a Purpose.

Feeling "terror, fear and a sense of urgency," and thinking, "I don't want to die without finishing my missions," may influence the development of this skill.

Possible gains include effectively "shifting focus from the terror," as well as "feeling fulfilled as a person in spite of the diagnosis." Use of this skill may assist in avoiding "despair and suicide."

A.2.2.1.1.2 Skill AIDS-C-AD1 #6: Actively Reorganizing the Family Unit.

Feeling "depressed, anxious and terrified," this skill may largely develop out of concern for the well-being of family members... including having "mom better cared for in the future."

A.2.2.1.1.3 Skill AIDS-C-AD1 #7: Expressing Anger.

Underling the use of this skill may be "taking care of unfinished business." Feeling "anger, fear and isolation," possible gains include "reorganization of the family and gaining approval" of support people. Potentially avoided by the effective use of this skill is "dying alone."

A.2.2.1.1.4 Skill AIDS-C-AD1 #8: Active in the Politics of AIDS.

Frequently influenced by other PWAs to become "politically active," use of this skill may help achieve "support, esteem, and fulfillment of missions." It may also serve to redirect "focus on work" rather than on "anger." The business of political activity may also be a way to achieve contact with people, without having to deal with "intimacy issues with potential partners."

A.2.2.1.1.5 Skill AIDS-C-AD1 #9: Spirituality.

"Becoming spiritual" may "help in 'crossing over' to the next life," and may be a response to not wanting to "die alone." It may develop of the need to deal with feelings of "fear, terror and isolation."

A.2.2.1.1.6 Skill AIDS-C-AD1 #10: Support from Family.

"Support from family" may help meet the need to "be held by someone I love and trust when I die." Feeling "neglected, lonely and isolated ... and impending death," support and family cohesion may be a valuable asset.

A.2.2.2 AIDS-C-AD2: After-Diagnosis Origin Cited #1 (of 1): "Hitting Bottom."

PWAs often encounter a "tidal wave of emotions, including anger and fear," and feel a distinct "pressure: a condensed time-sense." "I have 'IT.'" At the point of "hitting bottom," they "reach a moment of truth, of forclosed options: 'I've gone as far as I can go [astray]; it's time to deal: I've found the limit. I'm going to 'get right' again.'" Twelve-step programs frequently play a positive role during this time: it provides a "place to 'lay your hat,' a structure." Many AIDS-survival skills develop from the situation after that "moment of truth:"

A.2.2.2.1 Current AIDS-Survival Skills Developed from "HIV Diagnosis: 'Hitting Bottom'" - AIDS-C-AD2.

A.2.2.2.1.1 Skill AIDS-C-AD2 #32: Fear, Respect, Awe of Death.

Initially fearing "being blown away" by the thoughts of death, survivors frequently reach a point where they are able to "face death," and thereby "remain calm, determined and capable."

A.2.2.2.1.2 Skill AIDS-C-AD2 #33: Seeing AIDS as a Piece of the General Human Condition.

Driven by "fear," and "inspired by seeing the achievements of empowered PWAs," survivors "avoid giving-in to that fear." By "seeing AIDS as just a piece of the general human condition," survivors can "transcend the oppressiveness, and get on with life."

A.2.2.3 AIDS-C-DK After-Diagnosis Origin Cited #1 (of 1): Desperation and Urgency.

AIDS-C-DK describes the experience of learning about HIV-diagnosis as a severe "crisis and confrontation that follows [a series of] life dissappointments." The diagnosis and "years of a relative lack of the 'positive,' and abusive life experiences," usually influences AIDS-C-DK's survivors to realize that "I'm running out of time," or, "There's no place left to run. Something is missing." They decide that they "need to experience something positive in life," and they strongly experience a need for

some "joy with my kids." Feeling "desperate," and motivated by the "urgency" of the situation, the survivors develop new skills, or, following successful completion of a six-month drug rehabilitation program, foster some newly emerging ones. An "important someone who reaches out" to them plays an important role in suporting their survival.

A.2.2.3.1 Current AIDS-Survival Skills Developed from "Desperation and Urgency" AFTER HIV Diagnosis - AIDS-C-DK.

A.2.2.3.1.1 Skill AIDS-C-DK #16: Urge to Live: Choosing to Survive.

Experiencing the "desperation, fear and urgency" of the situation brought on by HIV diagnosis, AIDS-C-DK's long term survivors decide, "I want to experience some positive in life." In order to avoid a "continuation of negative past life experiences," they develop an "urge to live ... they choose to survive." As a result, they "take time to smell the flowers," and do experience some of "the positive in life."

A.2.2.3.1.2 Skill AIDS-C-DK #17: Challenge.

Feeling "urgency" and even some "excitement" at the thought of "experiencing some positive in life," AIDS-C-DK's survivors see their situation with AIDS as "challenge." They see it as an "opportunity." The challenge helps them to avoid "continuing to miss out on the joy."

A.2.2.3.1.3 Skill AIDS-C-DK #18: Perseverance.

Feeling "desperate" for "some of the joy in life," AIDS-C-DK'S survivors "persevere" in striving for some of that joy.

A.2.2.3.1.4 Skill AIDS-C-DK #19: Problem Solving.

In order to avoid "becoming overwhelmed," AIDS-C-DK's survivors learn "problem solving skills: stopping, breaking the problem down to solvable parts, choosing what to act on, and doing it." Realizing that "I have a choice: I don't have to act on everything," they attain "resolution of some issues."

A.2.2.3.1.5 Skill AIDS-C-DK #20: Support Network.

Feeling "desperate," the survivors seek comfort and support from "a few intimate friendships."

A.2.2.3.1.6 Skill AIDS-C-DK #21: Taking Time to Smell the Flowers.

From a "sense of previous lack," AIDS-C-DK's survivors "desperately want some joy." Influenced by positive experiences in drug rehabilitation programs, they "take time to smell the flowers:" throughout the day, they take "rests" in order to "experience the joy."

A.2.2.3.1.7 Skill AIDS-C-DK #22: Seeker Mentality.

Feeling "hope," in the possibility of "experiencing some joy," AIDS-DK's survivors seek "everything you can give me." They are "open to exploring" and are "motivated by joy."

A.2.2.3.1.8 Skill AIDS-C-DK #23: Confidence.

Experiencing some positive results in their quest for "joy," AIDS-C-DK's survivors develop "confidence and a belief in their abilities:" "I can do it." With confidence and action, they also achieve "self acceptance."

A.2.2.3.1.9 Skill AIDS-C-DK #24: Sense of Wanting to Contribute Something.

Developing an improved and "recovered" sense of self, and drawing on their "caretaker roles in their past histories," AIDS-C-DK's survivors generate a "sense of wanting to contribute something." Frequently they are "motivated by their own children's needs:" in so doing, however, they do "feel better about themselves," and secondarily attain "support" in return for their contribution to others.

A.2.2.3.1.10 Skill AIDS-C-DK #25: Focus on the Positive.

Feeling "hope," and "wanting some "joy," AIDS-C-DK's survivors "focus on the positive" in order to "keep on track" and maintain their sense of "hope." By maintaining

a positive focus, they avoid "being a victim," and "not taking responsibility." A "supportive someone" is frequently involved in their developing and maintaining this skill.

A.2.2.3.1.11 Skill AIDS-C-DK #26: Positive but Realistic.

AIDS-C-DK's survivors maintain a sense of reality in order to "maintain control." A formal program and formal support is usually a key factor in helping them develop and use this skill.

A.2.2.3.1.12 Skill AIDS-C-DK #27: Seeking Self Fulfillment.

Feeling "desperate" that "if I don't do something new, I may die before I reach self-fulfillment," AIDS-C-DK's survivors work hard at "seeking self-fulfillment." Encouraged by formal support, encouragement and coaching, they maintain this skill in order to achieve "meaning" in their lives.

A.2.2.4 AIDS-C-FJ: After-Diagnosis Origin Cited #1 (of 1): Crisis of the Disease.

AIDS-C-FJ describes a typical AIDS crisis situation as replete with feelings of "fear, lonliness, anxiety and a 'sense of urgency'." The overall "crisis of the disease," and especially "anxiety about death," surfaces one very significant need for most of the survivors with whom she worked: "taking care of all unfinished business" ... and

especially that leading to a major goal of "reconciliation within and acceptance by one's family." The "sense of urgency" motivates the development of many coping or survival skills:

A.2.2.4.1 Current AIDS-Survival Skills Developed from "Crisis of the Disease:" AFTER HIV Diagnosis - AIDS-C-FJ.

A.2.2.4.1.1 Skill AIDS-C-FJ #7: Working Towards Acceptance by Family.

Motivated by a "desire for reconciliation of unresolved family issues," and also by feelings of "fear and lonliness," AIDS-C-FJ's survivors "worked towards acceptance by family." The major gains achieved by this skill are "forgiveness and peace."

A.2.2.4.1.2 Skill AIDS-C-FJ #8: Taking Care of Unfinished Business.

The "crisis of the disease" and the sense of "not much time left," creates significant feelings of "anxiety about death." Achieving relative degrees of success with "taking care of unfinished business," survivors potentially "resolve past issues," and achieve "forgiveness and peace."

A.2.3 Skill Development in Response to Other Crises AFTER HIV/AIDS Diagnosis. LTAS-Group.

A.2.3.1 LTAS-LB: After-Diagnosis Cited Origin #2 (of 2): Marital Discord.

The fear and uncertainty with their situation with AIDS led to "marital discord" between LTAS-LB and his wife. His wife wondered, "Why do I have to go through this?" LTAS-LB felt "deserted, devastated, nervous, paranoid and 'anxiety prone.'" His health rapidly and drastically "took a turn for the worse," a situation he firmly attributes to his emotional response to the discord. At that point, his doctor and his stepmother both "reached out ... gave me hope, coaching, and 'just talking' and encouragement." LTAS-LB realized that, "there's more to life." He attributes his rapid recovery of his health to that "feeling of support" he received. Feeling his heath positively respond, he began to help his wife through her difficulties with their situation: "I knew I could help my wife from my new inner wisdom."

A.2.3.1.1 Current AIDS-Survival Skills Developed from "Marital Discord" - LTAS-LB.

A.2.3.1.1.1 Skill LTAS-LB #33: Accept, Like and Love Self.

Through his experiences with marital discord and its negative effect on his health, LTAS-LB realized his "inner wisdom." Coming more from a perspective of health and strength, he was able to recover his health, and help his

wife. The experience left him more fully "accepting, liking and loving" himself. LTAS-LB believes that "one of the most important things is to love yourself. If you don't, you can't keep up the fight."

A.2.3.1.1.2 Skill LTAS-LB #34: Outside help.

LTAS-LB's doctor and stepmother played important roles in his recovery of heath following his bout of marital difficulty. Through this experience, he realized the importance of "outside help: it can keep me going."

A.3 Summary.

This is an assemblage of unique and diversified skills. As seen in the charts and tables of this chapter, however, there are themes that seem to unify them into a more tangible context. The analysis and discussion of this presentation of skills is the topic of Chapter 5.

APPENDIX B

B. AIDS Survival Skills Arranged Per Step.

B.1 Shock.

Regarding the SHOCK step of the hypothesized model of developing exceptionality, TABLE B.1 (page 219) presents the only survival skill cited by members of both groups: two survivors and three counselors cited partial denial - or "partial distraction" in AIDS-C-DK's words - as an important skill useful in coping with AIDS.

The following is an explanation of the format and the subject/source codes used in these B.1-type tables that appear in this appendix:

> TABLES B.1, B.3, B.5, B.8, B.11 and B.14 are modified histograms: they present the skills - per category - that were mentioned by at least one member of BOTH EXPERIMENTAL GROUPS.
>
> The particular (SKILL CITED) by one or more of the group members is listed in the middle column.
>
> The LTAS-GROUP data falls to the left of the center column.
>
> The AIDS-C-GROUP data falls to the right of the center column.
>
> The (FREQUENCY OF RESPONSE) columns are the second and the fourth major columns. The citations reference the subject and the source: e.g. in the first block to the left of center-column-citation "Partial Denial" is "LB 2" (arranged vertically on the chart). Read as follows: Subject = LTAS-LB. Source = Skill LB #2 (found in APPENDIX A).
>
> The (# DEVEL BEF/AFT DIAGNO:) columns are the first and fifth major columns. They reference the "number of skills that were described - respectively - as having been developed BEFORE or AFTER HIV-DIAGNOSIS.

The SECOND LINE UP FROM THE BOTTOM presents the BEFORE/AFTER-DIAGNOSIS TOTALS.

The BOTTOM LINE indicates - per group - the PERCENTAGE OF "BEFORE VS. AFTER" SKILL CITATIONS.

Table B.1 Cited Skills that Both LTAS-GROUP and AIDS-C-GROUP Agree On. Category: SHOCK (e.g. AV-1 = AIDS Survival Skill #1 Cited by LTAS-AV, and Found in Appendix A).

S H O C K										
LTAS-GROUP							AIDS-C-GROUP			
# DEVEL BEF/AFT DIAGNO:		FREQUENCY OF RESPONSE			SKILL CITED		FREQUENCY OF RESPONSE			# DEVEL BEF/AFT DIAGNO:	
			AV	LB			AD2	AD1	FJ		
1B	1A		20	2	PARTIAL DENIAL		21	2	4	3B	
1B	1A	TOTAL BEFORE / AFTER			****	TOTAL BEFORE / AFTER				3B	0A
50%	50%	PERCENT BEFORE / AFTER			****	PERCENT BEFORE / AFTER				100%	0%

Also relating to the category SHOCK, TABLE B.2 (page 220) cites two other survival skills that fit within the context of the SHOCK category: one survivor reported "occasional use of drugs to deny," and another survivor cited the use of "hobbies."

The following is an explanation of the format and the subject/source codes used in these B.2-type TABLEs that appear in this appendix:

TABLES B.2, B.4, B.6, B.9, B.12 and B.15 are modified histograms. They present the skills - per category - that were mentioned ONLY BY MEMBERS OF THE LTAS GROUP.

The particular (SKILL CITED) by one or more of the group members is listed in the first, or left column.

The LTAS-GROUP data falls to the right of the Skills-Cited column.

The (FREQUENCY OF RESPONSE) column is the second major column. As in TABLE B.1, the citations reference the subject and the source.

The (# DEVEL BEF/AFT DIAGNO:) column is the third major column. It indicates the "number of skills that were described - respectively - as having been developed BEFORE or AFTER HIV-DIAGNOSIS.

The SECOND LINE UP FROM THE BOTTOM presents the BEFORE/AFTER-DIAGNOSIS TOTALS.

The BOTTOM LINE indicates - per group - the PERCENTAGE OF "BEFORE VS. AFTER" SKILL CITATIONS.

Table B.2 Skills Cited Only by LTAS-GROUP Members: Category: SHOCK (e.g. AV-1 = AIDS Survival skill #1 Cited by LTAS-AV, and Found in Appendix A).

S H O C K

SKILL CITED	LTAS-GROUP FREQUENCY OF RESPONSE	# DEVEL BEF/AFT DIAGNO:
	AV	
OCCASIONAL USE OF DRUGS TO DENY	4	1B
	LB	
HOBBIES	11	1B
TOTAL BEFORE / AFTER		2B 0A
PERCENT BEFORE / AFTER		100%

B.2 Choosing to Live.

TABLE B.3 (page 221) presents the survival skills that fall within the CHOOSE TO LIVE category, and that are mentioned by both groups. Three survivors and two counselors cited "seeing the disease as a challenge," as an important survival skill. Two survivors and one counselor cited "will to live" and "hope;" and one survivor and one

counselor cited "never believing I'm going to die from AIDS" as another important survival skill.

Table B.3 Cited Skills that Both LTAS-GROUP and AIDS-C-Group Agree On. Category: CHOOSING TO LIVE (e.g. AV-1=AIDS Survival Skill #1 Cited by LTAS-AV, and Found in Appendix A).

CHOOSING TO LIVE

LTAS—GROUP						AIDS—C—GROUP			
# DEVEL BEF/AFT DIAGNO:		FREQUENCY OF RESPONSE			SKILL CITED	FREQUENCY OF RESPONSE		# DEVEL BEF/AFT DIAGNO:	
		AV	LB	PD		DK	AD2		
2B	1A	21	9	3b	SEE THE DISEASE AS A CHALLENGE	17	23	1B	1A
		PD12	LB			DK			
	3A	13	31		WILL TO LIVE	16			1A
		PD	CM			FJ			
1B	1A	4	24		HOPE	2		1B	
			LB			AD2			
	1A		32		NEVER BELIEVE GOING TO DIE FROM AIDS	9b		1B	
3B	6A	TOTAL BEFORE / AFTER			****	TOTAL BEFORE / AFTER		3B	2A
33.3%	66.6%	PERCENT BEFORE / AFTER			****	PERCENT BEFORE / AFTER		60%	40%

Also regarding the category CHOOSING TO LIVE, TABLE B.4 (page 222) lists the survival skills cited only by LTAS-group members. "Fierce joy of living," and "giving my body a 'live' message" are both single citations.

Table B.4 Skills Cited Only by LTAS-GROUP Members:
Category: CHOOSING TO LIVE (e.g. AV-1-AIDS Survival Skill #1 Cited by LTAS-AV, Found in Appendix A).

CHOOSING TO LIVE

SKILL CITED	LTAS-GROUP FREQUENCY OF RESPONSE	# DEVEL BEF/AFT DIAGNO:
	CM	
FIERCE JOY OF LIVING	18	1A
	CM	
GIVING MY BODY A "LIVE" MESSAGE	19	1A
TOTAL BEFORE / AFTER		2A
PERCENT BEFORE / AFTER		100%

B.3 Owning Up:

TABLE B.5 (page 223) lists "cited skills that both LTAS-group and AIDS-C-group agree on." These skills were cited as "important survival skills" and fall within the context of OWNING UP (the number citing - per group - is parenthetically expressed following the citations): "highly responsible" (one survivor and three counselors); "expressing feelings" (two survivors and two counselors); "taking care of unfinished business" (one survivor and two counselors); and "expressing anger" (one survivor and one counselor).

Table B.5 Cited Skills that Both LTAS-GROUP and AIDS-C-GROUP Agree On. Category: OWNING UP (e.g. AV-1=AIDS Survival Skill #1 Cited by LTAS-AV, Found in Appendix A).

OWNING UP

LTAS—GROUP						SKILL CITED	AIDS—C—GROUP				
# DEVEL BEF/AFT DIAGNO:		FREQUENCY OF RESPONSE					FREQUENCY OF RESPONSE			# DEVEL BEF/AFT DIAGNO:	
					CM		AD2	AD1	DK		
	1A				20	HIGHLY RESPONSIBLE	6	4a	12	3B	
				AV	CM		AD2	DK			
	2A			14a	17	EXPRESSING FEELINGS	27	8		2B	
					AV		FJ	AD2			
	1A				10	TAKING CARE OF UNFINISHED BUSINESS	8	20		1B	1A
					AV		AD1				
1B					2	EXPRESSING ANGER	7				1A
1B	4A	TOTAL BEFORE / AFTER				####	TOTAL BEFORE / AFTER			6B	2A
20%	80%	PERCENT BEFORE / AFTER				####	PERCENT BEFORE / AFTER			75%	25%

Also relating to the category OWNING UP TABLE B.6 (page 224) lists "skills that were cited only by certain members of the LTAS-group. These skills were each identified by one LTAS-group member as an "important survival skill: "healthy skepticism;" "brutally honest with myself;" "confrontation;" "telling people I have AIDS;" "dialogue with God;" "Express love and caring."

Table B.6 Skills Cited Only by LTAS-GROUP Members: Category: OWNING UP (e.g. AV-1 = AIDS Survival Skill #1 Cited by LTAS-AV, and Found in Appendix A).

OWNING UP	LTAS-GROUP					
SKILL CITED	FREQUENCY OF RESPONSE				# DEVEL. BEF/AFT DIAGNO:	
HEALTHY SKEPTICISM	CM 8					1A
BRUTALLY HONEST WITH MYSELF	CM 16					1A
CONFRONTATION	AV 8				1B	
TELLING PEOPLE I HAVE AIDS	AV 18					1A
DIALOGUE WITH GOD	AV 16					1A
EXPRESS LOVE AND CARING	AV 14b					1A
TOTAL BEFORE / AFTER					18	5A
PERCENT BEFORE / AFTER					16.7%	83.3%

TABLE B.7 (page 225) lists important survival skills that were cited only by certain members of the AIDS-C-group and fall within the context of OWNING UP (the number citing the particular skill is parenthetically expressed following the citations): "rebonding with family" (three counselors); "in touch with body cues" (one counselor); and "identifying and labeling stress" (one counselor).

The following is an explanation of the format and the subject/source codes used in the indicated tables:

TABLES B.7, B.10, B.13, and B.16 are modified histograms. They present the skills - per category - that were mentioned ONLY BY MEMBERS OF THE AIDS-C- GROUP.

The particular (SKILL CITED) by one or more of the group members is listed in the first (left) column.

The LTAS-GROUP data falls to the right of the Skills-Cited column.

The (FREQUENCY OF RESPONSE) column is the second major column. As in TABLE B.1, the citations reference the subject and the source.

The (# DEVEL BEF/AFT DIAGNO:) column is the third major column. It indicates the "number of skills that were described - respectively - as having been developed BEFORE or AFTER HIV-DIAGNOSIS.

The SECOND LINE UP FROM THE BOTTOM presents the BEFORE/AFTER-DIAGNOSIS TOTALS.

The BOTTOM LINE indicates - per group - the PERCENTAGE OF "BEFORE VS. AFTER" SKILL CITATIONS.

Table B.7 Skills Cited Only by AIDS-C-GROUP Members: Category: OWNING UP (e.g. FJ-1 = AIDS- Survival Skill #1 Cited by AIDS-C-FJ, and Found in Appendix A).

OWNING UP

AIDS-C-GROUP

SKILL CITED	FREQUENCY OF RESPONSE			# DEVEL BEF/AFT DIAGNO:	
	DK	FJ	AD1		
	13	7	6	1B	2A
REBONDING WITH FAMILY	DK				
	7			1B	
IN TOUCH WITH BODY CUES	DK				
	4			1B	
IDENTIFYING AND LABELING STRESS					
TOTAL BEFORE / AFTER				3B	2A
PERCENT BEFORE / AFTER				60%	440%

B.4 Going For It.

TABLE B.8 (page 227) lists "cited skills that both LTAS-group and AIDS-C-group agree on." These skills were identified as "important survival skills" and fall within the context of GOING FOR IT (the number citing - per group - is parenthetically expressed following the citations): "focus on positive" (three survivors and three counselors); "take control" (three survivors and two counselors); "do whatever need to do" (two survivors and three counselors); "hard work" (three survivors and one counselor); "assertiveness" (three survivors and one counselor); "politically active" (one survivor and two counselors); "positive lifestyle changes" (one survivor and one counselor).

Table B.8 Cited Skills that Both LTAS-GROUP and AIDS-C-GROUP Agree On. Category GOING FOR IT (e.g. AV-1 - AIDS Survival Skills#1 Cited by LTAS-AV, and Found in Appendix A).

GOING FOR IT

LTAS-GROUP # DEVEL BEF/AFT DIAGNO:		LTAS-GROUP FREQUENCY OF RESPONSE			SKILL CITED	AIDS-C-GROUP FREQUENCY OF RESPONSE			AIDS-C-GROUP # DEVEL BEF/AFT DIAGNO:	
		LB	PD	CM		DK	DK	AD2		
2B	1A	16	2	14	FOCUS ON POSITIVE	1	25	4	2B	1A
		AV	PD	LB		AD2	AD2			
4B		5	8	5,6b	TAKE CONTROL	29,9a,14a			3B	
			AV	LB		AD1	AD2	FJ		
1B	1A		23	22	DO WHATEVER NEED TO DO	1	2, 8	5	4B	
		PD	LB	CM		DK				
2B	1A	1a	3	5	HARD WORK	18				1A
		LB	AV	CM		AD2				
2B	1A	14	3	21	ASSERTIVENESS	26			1B	
				AV		AD1	AD2			
1B				7	POLITICALLY ACTIVE	8	30		1B	1A
				AV		AD1				
	1A			13	POSITIVE LIFESTYLE CHANGES	4b			1B	
12B	5A	TOTAL BEFORE / AFTER			****	TOTAL BEFORE / AFTER			12B	3A
70.6%	29.4%	PERCENT BEFORE / AFTER			****	PERCENT BEFORE / AFTER			80%	20%

Also relating to the category GOING FOR IT TABLE B.9 (page 228) lists skills that were cited only by certain members of the LTAS-group. "Fighter" is a skill that was mentioned by three of the survivors. These skills listed were each identified by one of the survivors as an "important survival skill:" "living life to the fullest;" "not giving up on love;" "courage;" "focus: getting through;" "having goals in life;" "aggressive risk taker;" "speak out for myself;" "speak out against injustice;" "maintaining own sense of well-being."

Table B.9 Skills Cited Only by LTAS-GROUP Members: Category: GOING FOR IT (e.g. AV-1 = AIDS Survival Skill #1 Cited by LTAS-AV, and Found in Appendix A).

GOING FOR IT

SKILL CITED	LTAS-GROUP FREQUENCY OF RESPONSE			# DEVEL BEF/AFT DIAGNO:	
	PD	AV	LB		
FIGHTER	1a	3	5	2B	1A
LIVING LIFE TO THE FULLEST	LB 23			1B	
NOT GIVING UP ON LOVE	CM 11				1A
COURAGE	LB 1			1B	
FOCUS: GETTING THROUGH	LB 30				1A
HAVING GOALS IN LIFE	LB 13			1B	
AGGRESSIVE RISK TAKER	LB 8			1B	
SPEAK OUT FOR MYSELF	CM .2			1B	
SPEAK OUT AGAINST INJUSTICE	CM 1			1B	
MAINTAINING OWN SENSE OF WELL-BEING	PD 1b			1B	
TOTAL BEFORE / AFTER				9B	3A
PERCENT BEFORE / AFTER				75%	25%

TABLE B.10 (page 229) lists important survival skills that were cited only by certain members of the AIDS-C-group and fall within the context of GOING FOR IT (the number citing the particular skill is parenthetically expressed following the citations): "physical self care" (two counselors). The following were singly cited:

"seeker mentality;" "problem solving skills;" "viewing self as separate, autonomous and basically positive;" "screw guilt."

Table B.10 Skills Cited Only by AIDS-C-GROUP Members: Category: GOING FOR IT (e.g. FJ-1 = AIDS-Survival Skill Cited by AIDS-C-FJ, and Found in Appendix A).

GOING FOR IT
AIDS-C-GROUP

SKILL CITED	FREQUENCY OF RESPONSE			# DEVEL BEF/AFT DIAGNO:	
PHYSICAL SELF CARE	AD2 13	DK 11		2B	
SEEKER MENTALITY	DK 22				1A
PROBLEM SOLVING SKILLS	DK 19				1A
VIEWING SELF AS SEPARATE, AUTONOMOUS AND BASICALLY POSITIVE	DK 6			1B	
"SCREW GUILT"	AD2 19			1B	
TOTAL BEFORE / AFTER				4B	2A
PERCENT BEFORE / AFTER				66.6%	33.3%

B.5 Respecting Reality.

Regarding the category RESPECTING REALITY TABLE B.11 (page 230) lists "cited skills that both LTAS-group and AIDS-C-group agree on." These skills were cited as "important survival skills" (the number citing - per group - is parenthetically expressed following the citations): "support systems" (four survivors and two counselors); "living in the now" (two survivors and three counselors); "focus on positive, get rid of negative" (three survivors and one counselor); "collaborate with doctors" (two

survivors and one counselor); "sense of humor" (two survivors and one counselor); and "see AIDS as 'just another disease'" (one survivor and one counselor).

Table B.11 Cited Skills that Both LTAS-GROUP and AIDS-C-GROUP Agree On. Category: Respecting Reality (e.g. AV-1 = AIDS Survival Skill #1 Cited by LTAS-AV, and Found in Appendix A).

RESPECTING REALITY

LTAS—GROUP # DEVEL BEF/AFT DIAGNO:		LTAS—GROUP FREQUENCY OF RESPONSE				SKILL CITED	AIDS—C—GROUP FREQUENCY OF RESPONSE				AIDS—C—GROUP # DEVEL BEF/AFT DIAGNO:	
		PD	LB	CM	AV		DK	AD1				
2B	2A	10	28	22	9	SUPPORT SYSTEMS	20,14	10			1B	2A
				LB	PD		FJ	DK	AD2			
	2A			29	15	LIVING IN THE NOW	3	26	10b		2B	1A
			LB	PD	CM		DK					
2B	1A		16	2	14	FOCUS ON POSITIVE, GET RID OF NEGATIVE	10				1B	
				CM	LB		AD2					
1B	1A			23	17	COLLABORATE WITH DOCTORS	14b				1B	
				AV	PD		DK					
1B	1A			19	5	SENSE OF HUMOR	15				1B	
					AV		AD2					
	1A				11	SEE AIDS AS "JUST ANOTHER DISEASE."	33					1A
6B	8A	TOTAL BEFORE / AFTER				####	TOTAL BEFORE / AFTER				6B	4A
42.9%	57.1%	PERCENT BEFORE / AFTER				####	PERCENT BEFORE / AFTER				60%	40%

Also relating to the category, RESPECTING REALITY, TABLE B.12 (page 231) lists skills that were identified by more than one LTAS-group member as an "important survival skill" (number of survivors citing particular skill follows in parentheses after the skill citation): "acceptance of self and others" (three survivors); "accepting/supporting other points of view" (three survivors); "faith in doctor" (two survivors); and "realistic" (two survivors). These skills were identified as important survival skills by one

survivor only: "pragmatism;" "knowing limits: when to stop;" "in touch with body;" "conserving energy;" "active dialogue: soliciting diverse opinions;" "refusing to make decisions for others;" "maintaining calm: putting fears forward;" "seeing doctors as humans, not deities;" and "spend time with people who are supportive."

Table B.12 Skills Cited Only by LTAS-GROUP MEMBERS: Category RESPECTING REALITY (e.g. AV-1-AIDS Survival Skill #1 Cited by LTAS-AV, and Found in Appendix A).

RESPECTING REALITY	LTAS-GROUP				
SKILL CITED	FREQUENCY OF RESPONSE			# DEVEL BEF/AFT DIAGNO:	
	PD	LB	AV		
ACCEPTANCE OF SELF AND OTHERS	17	15	12	1B	2A
	LB	PD	CM		
ACCEPTING / SUPPORTING OTHER POINTS OF VIEW.	34,19	19	6	1B	3A
	LB	CM			
FAITH IN DOCTOR	7	21		1B	1A
	PD	LB			
REALISTIC	18	20		1B	1A
	CM				
PRAGMATISM	3				1A
	LB				
KNOWING LIMITS: WHEN TO STOP	25			1B	
	LB				
IN TOUCH WITH BODY	4			1B	
	CM				
CONSERVING ENERGY	25				1A
	CM				
ACTIVE DIALOGUE: SOLICITING DIVERSE OPINIONS	9				1A
	CM				
REFUSING TO MAKE DECISIONS FOR OTHERS	7				1A
	PD				
MAINTAINING CALM; PUTTING FEARS FORWARD	16				1A
	AV				
SEEING DOCTORS AS HUMANS, NOT DEITIES	25				1A
	CM				
SPEND TIME WITH PEOPLE WHO ARE SUPPORTIVE	15				1A
TOTAL BEFORE / AFTER				6B	14A
PERCENT BEFORE / AFTER				30%	70%

TABLE B.13 (page 232) lists important survival skills that were cited only by certain members of the AIDS-C-group and fall within the context of RESPECTING REALITY (the number citing the particular skill is parenthetically expressed following the citations): "gracefully dealing with the disease" (two counselors). The following were singly cited: "acceptance without rumination;" "centering;" "giving it up/over: surrendering;" "asking for help;" "caretaking within one's limits;" "taking action after due consideration;" and "congruence."

Table B.13 Skills Cited Only by AIDS-C-GROUP Members: Category: RESPECTING REALITY (e.g. FJ-1 = AIDS-Survival Skill #1 Cited by AIDS-C-FJ, and Found in Appendix A).

RESPECTING REALITY
AIDS-C-GROUP

SKILL CITED	FREQUENCY OF RESPONSE			# DEVEL BEF/AFT DIAGNO:	
GRACEFULLY DEALING WITH THE DISEASE	AD2 10a	DK 21		1B	1A
ACCEPTANCE WITHOUT RUMINATION	AD2 11			1B	
CENTERING	AD2 16			1B	
GIVING IT UP/OVER: SURRENDERING	AD2 31			1B	
ASKING FOR HELP	DK 9			1B	
CARETAKING WITHIN ONE'S LIMITS	AD2 28			1B	
TAKING ACTION AFTER DUE CONSIDERATION	AD2 12			1B	
CONGRUENCE	AD2 17			1B	
	TOTAL BEFORE / AFTER			8B	
	PERCENT BEFORE / AFTER			100%	

B.6 Empowerment.

TABLE B.14 (page 233) lists "cited skills that both LTAS-group and AIDS-C-group agree on." These skills were cited as "important survival skills" and fall within the context of EMPOWERMENT: "helping others" (four survivors and four counselors); "confidence" (three survivors and two counselors); "purpose and meaning" (three survivors and one counselor); and "spirituality" (one survivor and two counselors).

Table B.14 Cited Skills that Both LTAS-GROUP and AIDS-C-GROUP Agree ON. Category: EMPOWERMENT (e.g. AV-1 = AIDS Survival Skill #1 Cited by LTAS-AV, and Found in Appendix A).

EMPOWERMENT

LTAS—GROUP						AIDS—C—GROUP					
# DEVEL BEF/AFT DIAGNO:		FREQUENCY OF RESPONSE				SKILL CITED	FREQUENCY OF RESPONSE				# DEVEL BEF/AFT DIAGNO:	
		LB	AV	PD	CM		AD1	AD2	DK	FJ		
3B	1A	14	6	6	12	HELPING OTHERS	3	1	2	1	4B	
		LB		PD	AV		AD2	DK				
4B	1A	24,10,6a		9	15	CONFIDENCE	23	18			1B	1A
		PD		LB	AV		AD2					
1B	2A	3a		26	17	PURPOSE AND MEANING	22				1B	
					LB		AD1	AD2				
	1A				27	SPIRITUALITY	9	7			1B	1A
8B	5A	TOTAL BEFORE / AFTER				####	TOTAL BEFORE / AFTER				7B	2A
61.5%	38.5%	PERCENT BEFORE / AFTER				####	PERCENT BEFORE / AFTER				77.7%	22.2%

Also relating to the category, EMPOWERMENT, TABLE B.15 (page 234) lists "skills that were cited only by

certain members of the LTAS-group. This skill was identified by more than one LTAS-group member as an "important survival skill" (number of survivors citing particular skill follows in parentheses after the skill citation): "loving self" (three survivors). These skills were identified as important survival skills by one survivor only: "empowerment;" "focus on vocation;" "sense of self-healing;" "in touch with nature;" and "striving towards truth."

Table B.15 Skills Cited Only by LTAS-GROUP Members: Category: EMPOWERMENT
(e.g. AV-1 = AIDS Survival Skill #1 Cited by LTAS-AV. and found in Appendix A).

EMPOWERMENT

SKILL CITED	LTAS-GROUP FREQUENCY OF RESPONSE			# DEVEL BEF/AFT DIAGNO:	
	LB	AV	PD		
LOVING SELF	33	22	17		3A
	AV				
EMPOWERMENT	24				1A
	PD				
FOCUS ON VOCATION	7			1B	
	PD				
SENSE OF SELF HEALING	11				1A
	LB				
IN TOUCH WITH NATURE	12			1B	
	CM				
STRIVING TOWARDS TRUTH	10				1A
TOTAL BEFORE / AFTER				2B	6B
PERCENT BEFORE / AFTER				25%	75%

TABLE B.16 (page 235) lists important survival skills that were cited only by certain members of the AIDS-C-group and fall within the context of EMPOWERMENT . The following were singly cited important survival skills: "pursuing mission;" "seeking self fulfillment;" "commanding dignity and respect vs. allowing pity;" "fear, respect, awe of death;" "sense of dignity and self worth;" "appreciative of love and caring;" "forming interpersonal relationships;" "sense of wanting to contribute something;" and "knowing I have something to give."

Table B.16 Skills Cited Only by AIDS-C-GROUP Members: Category: EMPOWERMENT (e.g. FJ-1 = AIDS-Survival Skill #1 Cited by AIDS-C-FJ, and Found in Appendix A).

EMPOWERMENT
AIDS-C-GROUP

SKILL CITED	FREQUENCY OF RESPONSE	# DEVEL BEF/AFT DIAGNO:	
PURSUING MISSION	AD1 5		1A
SEEKING SELF FULFILLMENT	DK 27		1A
COMMANDING DIGNITY AND RESPECT VS. ALLOWING PITY	AD2 25	1B	
FEAR, RESPECT, AWE OF DEATH	AD2 32		1A
SENSE OF DIGNITY AND SELF-WORTH	DK 5	1B	
APPRECIATIVE OF LOVE AND CARING	FJ 6	1B	
FORMING INTERPERSONAL RELATIONSHIPS	AD2 15	1B	
SENSE OF WANTING TO CONTRIBUTE SOMETHING	DK 24		1A
KNOWING I HAVE SOMETHING TO GIVE	DK 3	1B	
TOTAL BEFORE / AFTER		5B	4B
PERCENT BEFORE / AFTER		55.5%	44.4%

B.7 Other.

In the investigator's opinion, a few skills cited by the two groups would not comfortably fit within the contexts of the hypothesized model of developing exceptionality in long-term survival of AIDS. TABLE B.17 (page 236) identifies those "other" skills cited by the LTAS-group. TABLE B.18 (page 237) identifies the "other" skills cited by the AIDS-C-group.

Table B.17 Skills Cited Only by LTAS-GROUP Members: Category: "OTHER" (e.g. AV-1 = AIDS Survival Skill #1 Cited by LTAS-AV, and found in Appendix A).

OTHER

LTAS-GROUP

SKILL CITED	FREQUENCY OF RESPONSE	# DEVEL BEF/AFT DIAGNO:
	CM	
IMPATIENT WITH SIDELINE CRITICS	4	1A
TOTAL BEFORE / AFTER		1A
PERCENT BEFORE / AFTER		100%

Table B.18 Skills Cited Only by AIDS-C-GROUP Members:
Category: "OTHER" (e.g. FJ-1 = AIDS-Survival Skill #1
Cited by AIDS-C-FJ, and Found in Appendix A).

OTHER

AIDS-C-GROUP

SKILL CITED	FREQUENCY OF RESPONSE	# DEVEL BEF/AFT DIAGNO:
	AD2	
SKILL AT GRIEVING LOSSES	24	18
	AD2	
READING PEOPLE AT A GLANCE	3	18
	AD2	
KNOWING WHAT GOOD CARE REALLY IS	5	18
TOTAL BEFORE / AFTER		38
PERCENT BEFORE / AFTER		100%

APPENDIX C

Development of the Interview: Piloting 4 Styles: Presentation, Interview Guide, Analysis: each style:

C.1 Pilot Interview #1: Conversational, "BF".

The interview with BF was informally conversational in style. A fair amount of information was generated by this style. As the title suggests, this interview was informal, conversational, and replete with the inherent limitations of such a style: It takes more time and it depends on the conversational skill of the interviewer (Eve, 1987). Without an interview guide, obvious crucial segments were omitted, such as my directing the interviewee towards describing the origins of his skills. Contributing to difficulties with this style was the following: this was the first real conversation I had had with an AIDS survivor and it was early in the proposal process. It did function, however, to help me grow more comfortable with the project. It also served to illustrate my need for the structure contained in the following three pilot interview styles.

C.2 Pilot Interview #2: "BM": Metaphor, Story-telling.

Pilot interview #2 utilized a few steps from Fletcher's (1989) "High Performance Coaching" process guide. Patton's (1980) ideas regarding content and

sequencing were also employed. This interview form was different from interview #1 in these ways: (1) description of the survived situation (trigger) follows listing of the coping skills; and (2) use of story-telling and metaphor.

C.2.1 The Interview Sequence.

C.2.1.1 Step 1. Introduction and orientation: purposes, goals, expectations.

C.2.1.2 Step 2. Isolate what worked in the past: Generate a list of individual's survival skills. Check out "fit" of categories of characteristic skills cited in the long-term survivor literature: communication, control, confidence, challenge, support, meaning.

C.2.1.3 Step 3. Determine a metaphor for the feelings when survival skills are functioning at their best.

C.2.1.4 Step 4. General description of the survived situation: "triggering factor."

C.2.1.5 Step 5. Determine a metaphor for the (worst) feelings experienced in that situation.

C.2.1.6 Step 6. Describe skill-development influences: positive or negative role models, conditions, etc.

C.2.1.7 Step 7. Tell a story: "imagine 'reincarnation' is real; however, you must design your next life now" (LeShan, 1989). Consider what you know about your survival strengths and the conditions that helped them develop in you.

C.2.1.8 Step 8. Establish the "first step" of a plan of action which could lead to that "ideal" life situation of Step 7.

C.2.2 Feedback and Impressions: Interview #2.

In this interview, the interviewee spent a fair amount of time on her weaknesses vs. her strengths: directly establishing "focusing on survival strengths as assets" as a goal early in the interview should help. LeShan (1989) focuses on "what is right about a person" in his work with cancer survivors.

A general exploration of the survived situation (triggering situation) early in the interview is expected to provide clearer interviewer orientation. This is expected to help the interviewer maintain a more natural flow within the interview.

The near-final section ("imagine 'reincarnation' is real ...") may have been too far out of context. Coupled with the final question ("first step..."), it was intended to suggest and encourage continued survival for the individual; it was also, however, intended to stimulate suggestions for survival conditions and styles which could

be helpful to other PWAs. A more direct approach may work better: "Knowing what you know about your skills and the conditions which helped you to develope them, are there things that you could be doing now to further improve your well-being and survival? What advice would you give others?"

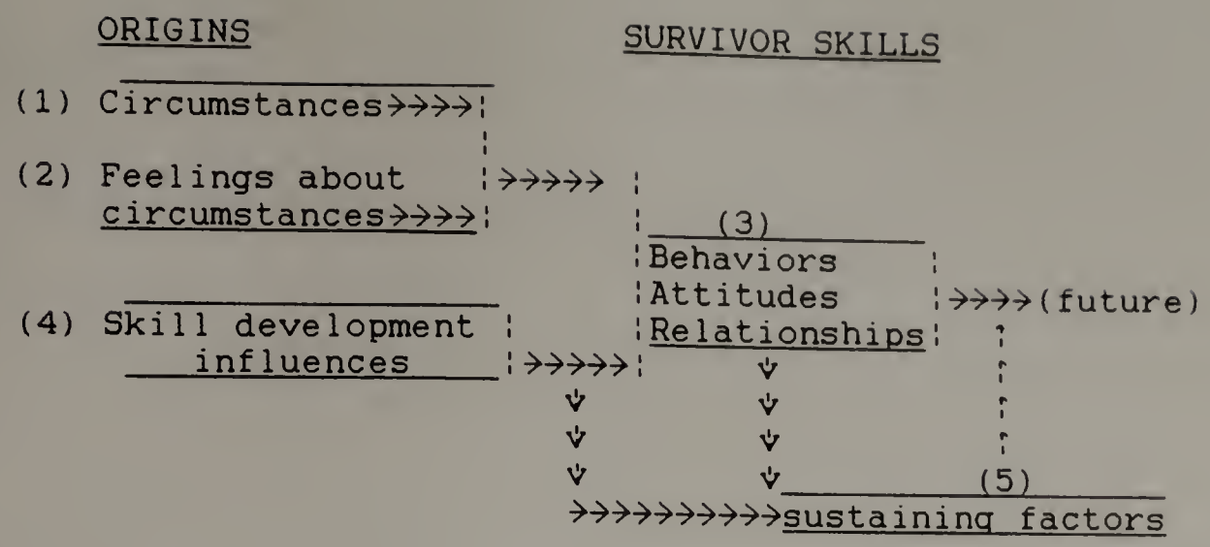
C.3 Pilot Interview #3: Direct Approach.

Pilot interview #3 was different from both #1 (conversational) and #2 (metaphor and story telling). Maintaining the use of metaphor, but eliminating the use of story-telling, the interview was designed to go more directly to the information. Interviewee participation started off with a description of the survived situation, rather than being deferred until after the survival skill listing as in interview #2. With only moderate introduction and minimal mood-setting by the interviewer, pilot interview #3 followed these steps:

C.3.1 Steps of Interview #3.

C.3.1.1 Step 1. Introduction and orientation: purposes, goals, expectations of research project and of this interview.

C.3.1.2 Step 2. The design of the interview was outlined with a flow diagram similar to this (page 242):



C.3.1.3 Step 3. General description of the survived situation: "triggering factor."

C.3.1.4 Step 4. Determine a metaphor for the feelings in that situation.

C.3.1.5 Step 5. Generate a list of the individual's survival skills. Check out "fit" of categories of characteristic skills cited in the long-term survivor literature: communication, control,confidence, challenge, support, meaning.

C.3.1.6 Step 6. Determine a metaphor for the feelings experienced when the psycho-social survival skills are most effective.

C.3.1.7 Step 7. Describe skill-development influences: positive or negative role models, conditions, etc.

C.3.1.8 Step 8. Future planning and advice: "Knowing what you know about your skills and the conditions that helped you to develope them, are there things that you

could be doing now to further improve your well-being and survival? What advice would you give others?

C.3.2 Feedback and Impressions, Pilot Interview #3.

Interview-style #3 was a direct and economical approach. It outlined the interview strategy most clearly, asked the questions most directly, and culled out the information most rapidly. At the end of the interview, both interviewer and interviewee expressed feeling energized by the experience, and both felt as though the information had been accurately presented and received. The interviewee did offer one specific bit of advice: refrain from use of the expression, "interview." She suggested that "interview" has a negative connotation, or one that suggests that a person is being evaluated, rather than being talked with. She suggested that "conversation" or some similar expression would be more appropriate.

C.4 Pilot Interview #4: "VP": Visualization, Metaphor, Story-telling, Individual Strengths.

Pilot interview #4 was adapted from Fletcher's (1989) "High Performance Coaching" process guide, and LeShan's (1989) Cancer as a Turning Point. Fletcher's design is oriented toward an "average, healthy" population, designed to facilitate problem-solving and ultimately "high performance," and frequently applied to professional situation. According to LeShan, his perspective is a result of thirty-five years of research and psychotherapy

designed to foster survival of cancer. Both emphasized a positive orientation on individual strengths ("what's 'right' with the person"), and on creating an action plan designed to enable a more self-supporting and self-actualized life situation. LeShan encourages the use of visualization and story-telling, and both advocate the use of metaphors to enhance the power of recall and action-planning. The steps of the interview were:

C.4.1 Sequence of Steps of Interview #4.

C.4.1.1 Step 1. Introduction and orientation: purposes, goals, expectations.

C.4.1.2 Step 2. Visualize most powerful survival style and skills. Set stage for positive focus on skills and strengths for the interview.

C.4.1.3 Step 3. Determine a metaphor for the feelings.

C.4.1.4 Step 4. Isolate what worked in the past: Generate a list of individual's survival skills. Check out "fit" of categories of characteristic skills cited in the long-term survivor literature: communication, control, confidence, challenge, support, and meaning.

C.4.1.5 Step 5. General description of the survived situation: "triggering factor."

C.4.1.6 Step 6. Determine a metaphor for the feelings in that situation.

C.4.1.7 Step 7. Describe skill-development influences: positive or negative role models, conditions, etc.

C.4.1.8 Step 8. Tell a story: "fairy godmother:" design a life of full and uninhibited use of personal survival skills, strengths, and positive conditions that encouraged skill development.

C.4.1.9 Step 9. Establish "first step" of a plan of action to implement "ideal" life situation of Step 8.

C.4.2 Feedback, Interview #4.

Good discussion and feedback were the result of pilot interview #4. The interviewee was an experienced interviewer with a Master's degree in Education (Counseling), and was able to be clear in her feedback, and offered specific suggestions:

1. "Stay objective as a recorder of information: don't try to get people to hone in on your categories or wording (when checking out research-derived categories)."

2. Regarding the use of visualization: "have people visualize the difficult situation as it is/was ... then bring in the positive: the survival skills or coping styles. This brings things to the present moment, so they can be talked about."

3. Sequence of interview steps: "Have person describe the skill-development-triggering situation first ... then to visualization, then to metaphorizing feeling and then to describing skills and origins."

C.5 Overall Assessment of the Four Pilot Interviews.

Interview #3's direct approach was the most economical, but not necessarily the most productive. All styles produced seemingly significant data; there were, however, portions of each of the interviews that seemed important to include in the final interview guide. Although the story-telling technique seemed the weakest, it may be useful as an option if the data is not forthcoming. Seemingly, one of the most important pieces of feedback was to remain "objective" in data-gathering.

The final interview-flaw affected the most crucial area of the interview: discerning the influencing factors involved in the development of the individual skills. The influential "what" or "who" involved in skill development was well established; however, the role played or function served by the "what/who" (i.e.the "how"), and the "when" were not fully addressed in any of the pilot interviews.

APPENDIX D

D. Interview and Group Process Guides: LTAS and AIDS-C-Groups.

D.1 Interview Guide, Long-Term AIDS-Survivors and AIDS-Counselors.

Because the interviewer used an interview guide, the interviews were considered "semi-structured." With marginal wording changes, the survivor and the AIDS-C- interviews proceeded similarly in flow and in content.

D.1.1 Introduction and Orientation.

(a) Establishing tone of interview. Focus on skills and strengths as assets. Establish their role as "teacher" or "expert:" they are describing their own situations: there are no wrong answers.

(b) Visual orientation. Interview proceeded according to the numbering sequence in Chart D.1 (below):

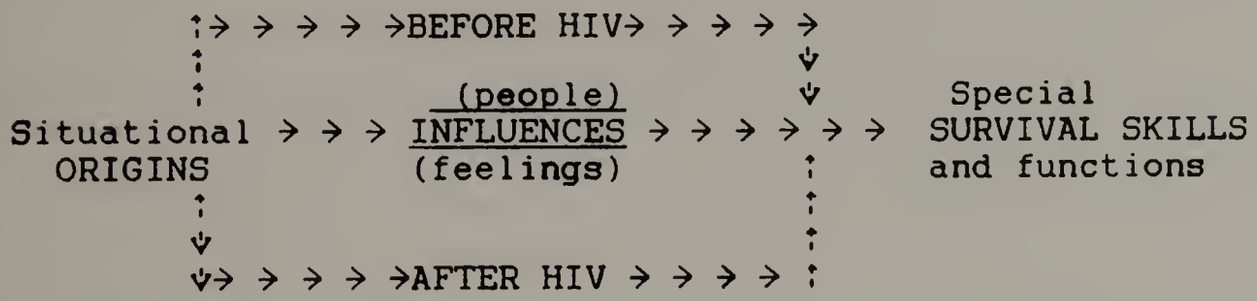


Chart D.1: Visual Orientation to the Interview Sequence

Surviving AIDS, usually requires developing special coping skills that were learned somewhere, sometime. The learning may be directly related to specific Before and/or

After HIV-diagnosis situations/origins (influences, feelings, people, etc.).

D.1.2 Origins and Skills: Typical Script and Probes.

Think of all the things that you do that have helped you survive AIDS as well as you have ... some of the things you may have learned long ago, and some recently. Think back to the farthest past time when you learned some skills that were important to you then, and have been important in your continuing survival of AIDS.

-Explain the situation, and how you feel about it.

-Did other people influence you? How?

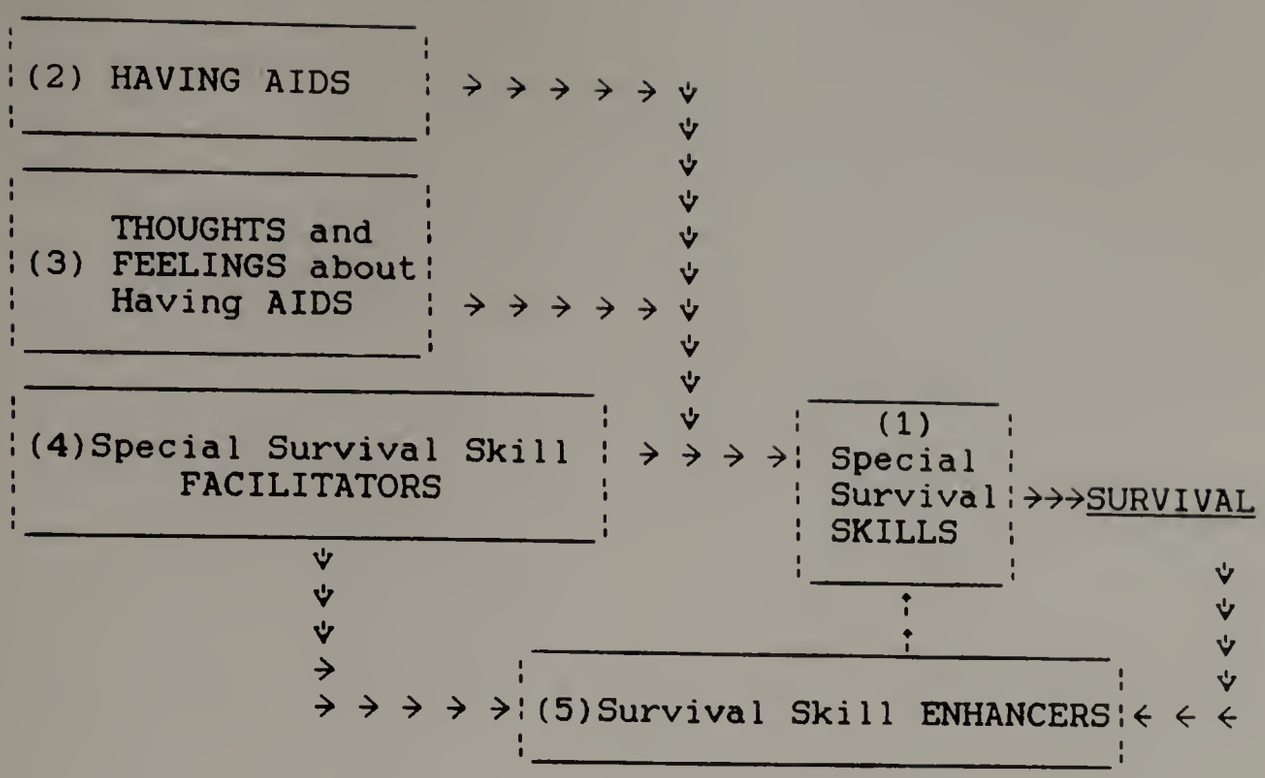
-What thoughts did you have? What did you learn?

-How do those skills function for you today?

The investigator recorded each of their points (in writing and with audio tape). He asked questions for clarification, and progressed with the subjects from the farthest past origins, to the current origin of skills, "dealing with HIV/AIDS."

Figure 1 (page 249) is designed to facilitate the flow of information, and is correlated with the final sections of this appendix:

Figure 1.



D.1.2.1 (1) Special Survival Skills.

(a). Self generated: To have gotten through especially the hardest of times, you coped, somehow. And you seem to have done better than most.

What do you consider your special survival skills ...

the things that have made a difference for you?

Have those special skills changed as you progressed?

Developed new ones?

(b) Response to Survivor Literature. Probe for personal relevance of factors characterized and identified in the literature review of long-term survivor research:

////////// COMMUNICATION //////////

Do you express your thoughts, feelings and emotions ... including anger?

Do you characteristically acknowledge or deny your own needs?

////////// CONFIDENCE //////////

Are you confident?

Do you believe in your own abilities to "make a difference" in your situation?

Do you see yourself as capable and competent?

////////// CONTROL //////////

Do you take charge of situations in order to make things right?

Are you assertive? ... speak up for your rights/needs?

Are you in charge of your survival? Is the doctor?

How do you see your doctor? The role he or she plays?

Do you consider yourself "realistic" about your situation with AIDS, but not being willing to see it just as a death sentence?

Do you make life-style changes to help your survival?

Do you seek out help when you have hard problem to solve ... Or try to solve them on your own?

////////// CHALLENGE //////////

Do you see yourself as a fighter? Spunky?

Do you take personal responsibility for your survival?

Do you do everything possible to improve your chances?

////////// SUPPORT //////////

Do you have a lot of support from others?

Do you seek it out?

How about giving support: do you help others?

Do you allow others to help you?

////////// MEANING //////////

Do you see a greater purpose or meaning in life?

Do you see misfortunes as part of life's challenges:

as opportunities for growth?

//

(c). Feelings about skills. Determine a metaphor for the feelings experienced when the survival skills are most effective:

When your survival skills are at their best, what is it like? How does it feel?

D.1.2.2 (2) HAVING AIDS

(a) Brief, indirect, eyes-open visualization of: the circumstances-of and feelings-about "having AIDS."

(b). Describe personal situation with AIDS:

How has being a PWA changed your life?things?

Has it changed the things you do? The people you see?

Family? Finances? Recreation? Hobbies?

How was it when first diagnosed? Different now?

D.1.2.3 (3). THOUGHTS and FEELINGS about HAVING AIDS.

(a). Describe feelings about "having AIDS."

In your situation with AIDS, especially in the most difficult times, how do you feel? [looking for a metaphor: "It feels like ..."]

What has it been like being a person with AIDS?

How was it in the beginning? How about now?

Do your feelings continue to change as your survival progresses?

(b). Describe thoughts about having AIDS.

When first diagnosed, what thoughts did you have?

Did you find yourself telling yourself things?

Messages? What were they? Whose voice?

Have the thoughts or messages changed as you progress with your survival?

D.1.2.4. (4) SPECIAL SURVIVAL SKILL FACILITATORS.

Identification of origins (influences and circumstances) of the factors identified as important for their own long-term survival: who, what, where and when.

Introduction: When we think about what "having AIDS" was/is like for you, and about some of the feelings and thoughts you had/have, its easy to see that you had to develop ways to cope, special ways to survive your situation. But when you look at each of the unique and special skills, it's likely that someone or something who especially influenced that particular skill or style would come to mind. Sometimes we learn a particular approach to the world from a specific person, like the way I learned "look for the best in people" from my "never say anything bad about anybody" dad, or "being industrious: making things from things," from the boy next door to my grandmothers who was always fixing and selling something, to buy something better. It might not be a person, but rather an event (e.g. having experienced the depression of

1929, my parents learned many things about being frugal... and indirectly I learned much of the same from them).

So lets talk about where each of your skills came from: what or who influenced you, or in a way "facilitated" your learning or developing each of your survival skills. The answer may be the same for several, but I would still like to get an understanding - if I could - of each one. OK?

This is an important step, because if we can understand how you perceived your situation with AIDS, and then some of the influences which helped you to develop your unique and special survival skills, you might be able to use that information to come up with ways of even further enhancing your skills and your survival. OK?

For example, think back to the feelings and thoughts you had and have about "having AIDS."

Did they play a role in your survival? ... or in developing some of your survival skills?

Or did they trigger something which you learned in the past, from someone or something?

Who or what influenced you in developing your special survival skills? How? When?

What role did then/he/she/it play?

Was if trial and error? Your own ingenuity?

If so, did someone in your past role model that same use of ingenuity and problem solving style?

Did some event occur that influenced you similarly?

Was it something you learned from someone, either by direct example, or even in spite of them?

Did it come about by your reaching a certain point of desperation, or some other kind of turning point, when you knew what you had to do, and did it?

Was it a response to something which happened: an event, surviving a previous crisis, learning about HIV-status/ARC/AIDS?

Did experiences you have had with others contribute? Losing a loved one? Helping others?

D.1.2.5 (5) SURVIVAL SKILL ENHANCERS.

(a). FOR YOURSELF: Describe possible strategies for furthering personal well-being and survival:

Knowing what you know about some of the influences for some of the skills which especially help you in your survival, are there any of your skills which you could be emphasizing, or further developing?

Any additional skills which you think might help?

What would be the first step you would make if you were going to further your well- being as you just described to me?

[IF UNABLE TO DO THE GROUP FOLLOW-UP DUE TO GEOGRAPHICAL CONSTRAINTS, ADD THIS SECTION:]

(b) SURVIVAL SKILL ENHANCERS: SUGGESTIONS FOR OTHERS:

Describe possible strategies for furthering the well-being and survival for other PWAs:

Knowing what you know about your own survival, and especially about the conditions and influences which helped you to develop you own brand of survival skills, what could you suggest other PWAs do to enhance their own survival?

//////////////////////////////////////

THANKS and CLOSE. PLANS FOR UPCOMING GROUP MEETING.

D.2 Group Process Guide: all Groups.

Although both group meetings were only semi-structured in nature, the facilitator used a group-process guide to direct the AIDS-counselors in the following activities:

1. INTRODUCTION.

(a). Welcome.

(b). Re-introduce self and project. Goals. Hopes.

(c). Introductions.

(d). Check for problems and/or concerns (now and throughout process). Ask for people to raise concerns - as possible - in the group when they arise, or privately after the meeting.

(e). Ground rules and guidelines:

-confidentiality.

-no outside gossip: may discuss personal reactions and feelings, group process and content, but may not

discuss other people's statements and/or feelings expressed unless they have somehow given you permission.

-feedback: non-judgemental.

-questions: for clarification.

(f). A moment to center: moment of quiet, bringing to mind PWAs who might benefit in some way by our project.

(g). Agenda: visual orientation to group process plan:

Group:	Introduction
Individual:	Review personal theory.
	STAS comments.
Individual:	Personal theory modifications.
Group:	Present groupings and implications of groupings to practice, education.
Group:	Discussion.
Group:	Thanks and close.

(a). Make any necessary changes/additions/deletions to personal theory after each presentation of an "other's" personal theory of survival.

(6) WHOLE GROUP:

Diad/triads present their hypotheses groupings and rationale.

(7) WHOLE GROUP:

Discussion per group interest.

(9). THANKS. CLOSE.

E. Individual Interviews (Two Samples).

E.1 Interview: LTAS-DL.

LTAS-DL I am going to be doing dishes in the background but if that causes a problem for the purpose of this recording, just tell me and I will go somewhere else.

INT. I just finished the breakfast dishes myself. Let me tell you a quick thought, about my hopes here. I looking mostly at conditions, kinds of thing that help people develop their own personal survival skills, possibly more than what survival skills are. And if people developed survival skills, then they developed them in reaction or response to a particular situation. When you think about your, and I know many of them from reading your publication, but when you think about the skills that you have developed, that you feel that are most important for your survival. Some of them you probably learned long ago, some of them you probably learned not that long ago and some of them you probably learned or acquired since your diagnosis. What I'd like you to do is to tell me about the most past situation when you developed some of the skills that you currently use and are important for your survival. Am I clear about that?

LTAS-DL Well, you are clear about what you want but I guess I am not clear in my own mind about .. I don't know...I think of myself as a person who is only more now who he has always been. There was a major sea change in my life when I was diagnosed, but it had to do sort of more with the diagnosis made me who I actually was, and I had been trying to be someone else. Not the other way around.

INT. Allright, then some of the skills that you recognized in your book, like politically active, maintaining hope. That's have been characteristic

LTAS-DL As a gay person you get the shit kicked out of you in life. And you can react to that in any of a variety of ways, you can internalize it and decide all these horrible things they say about you are true. And I tried that, and that is what I mean by saying that I was a very different person. I come from the mid-west and you know,

INT. = INTERVIEWER
LTAS = LONG TERM AIDS SURVIVOR

the word homosexual was, much less gay, was never spoken. And when one would alluded to it would be in the darkest of terms. There was not any type of person or crime worse than that. And I came across everything I always wanted to know about sex but were afraid to ask. At a formative age it had a chapter on homosexuality and I read it like it was the Bible, and it said that people who were gay, you know, were child molesters, and they were criminal and hung out in public restrooms, and wrote notes to each other on toilet paper, so that is what I did. I went to public restrooms to find other queers like me. I knew it was not going to be a good life, but I knew it was better than the life I was leading. I'll give you the short version. I came out in public restrooms and sort of formed my gay identity there. But then after about two years in public bathrooms somebody wrote me a note that said "Didn't I see you at the bath" and I wrote back "Where are they" and I met him outside and he told me that there were these places, so then I started to go out to the baths in addition to the restrooms and then two years after going to the baths someone finally said "Didn't I see you in the bar?" and I said "What are you talking about", and he said "Well, the gay bar, the disco", and see where I come from bars are rednecks, alcoholics go, no one would ever go to a bar. I don't drink and I don't dance and it never occurred to me that there was all this activity.

INT. Was this after you moved from the mid-west to..

LTAS-DL Went to College in Boston. My senior year in college I discovered that my own college had a lesbian and gay rights organization. And I went there, and after about four meetings I ran for president and became president. So, it was like this was a place to let me be who I really was. Who I was raised to be. But then I got kind of beaten and battered. We had the lesbian separatist contingent who walked out and you know, it was sort of political. And so I quickly got burned out on politics. And then, other than reading avidly about gay culture, my political involvement consisted in marching in the parade once a year. And in the decades between when I left college and got AIDS, it was not a decade I guess, six years, seven years, I became a sort of pathetic version of the clone. I looked ridiculous in a mustache, but even towards the end of my brilliant sexual career grew a mustache. I had a tremendous amount of sex, a tremendous amount of venereal disease. I had no friends, no social life, I would go to work and then I would have sex. I did not talk to anybody. I was not politically involved. And then when I got diagnosed I sort of realized that it was "now or never" and I decided "I'm going to be who I was always meant to be".

TAPE INTERRUPTION : The following block is from my notes. Transcript of actual recording begins after these indented notations:

- became more fully who I always was
- developed a pragmatism: would rather get a room full of people who disagree.. and then hash it out. Truth, then, somewhat like shit, will somehow surface, float to the top!
- Very impatient with people who are "side-line critics"; they aren't willing to roll up their sleeves and do something about it.
- Healthy skeptic of what I believe.
- Collect a diversity of opinions. Very much against censorship. Have to keep the dialogue going. My life depends on the truth.

LTAS-DL The improvement in the survival of AIDS are attributable to pneumocystic prophylaxis and not AZT and that in fact they are pretty much in spite of AZT. So, I am pretty passionately convinced, I am not on AZT myself. But I don't like my friend Don to believe that because I have come to the conclusion that I have an obligation to break into my friends' houses to flush the AZT down the toilet. I have many friends who are on AZT, they know how I feel about AZT, that I am not on AZT, but I would not say that I am supportive of their taking AZT but I don't harass them, I urge them to be regularly monitored for signs of muscle disintegration or toxicity. And to stay up on the literature and I send them reprints of articles that kind of argue against it, and I am always willing to talk and stuff. I mean I feel that one has the right to take stands, to say I flipped through all the evidence and this is what I decided and this is why and sort of put it out there. I used to not be willing, because I was not sure that I was right to speak up. Now, I speak up and don't claim to have unique access to the truth. The main principle that I willing to fight passionately for is against censorship, for diversity of opinion. It is to keep the dialogue going.

INT. So you're willing to put out the information but your are not going to take responsibility for other people.

LTAS-DL I have to fight that battle all the time, it is really weird. My AIDS celebrity-hood, sometimes people want someone, anyone to tell them what they should do. And because I am a long term survivor, or because I am infamous for having AIDS, I get people who call me and want me to tell them what they should do and I really, really fight ... I won't take responsibility for what other people do. I tell them what I am doing, why I am doing it, I give them the names of my critics, I give them the names of

people who hold completely opposite views and say this is a life and death decision you are making, please be sure that you get all the viewpoints. Then whatever they do they do. I am able to let go at that point.

INT. I am reading in what you are saying and also in what you wrote that you believe that an act of choice is really important.

LTAS-DL You know, something interesting has occurred. I am in the middle of my own long term survivor book. You can gather from my writing that I do believe that being sort of frisky I think is the word I use, or having grits. But there is a whole other approach to it, which I call sort of a medicine man phenomenon, investing some authority figure with the powers to heal you and than doing what they say without questioning it. That can work too, provided that one has spent some effort determining whether the person in whom you are going to invest this power is deserving of that power. You know, for some people reading about treatment options and reading about side effects, is disempowering and so I don't feel anymore that I should sort of insist that only those people who are really educated and really involved are going to be long term survivors. There were a couple of long term survivors that I encountered who were pretty passive about it.

INT. Did they in fact have as you said the medicine man phenomena, did they have faith in a particular ...

LTAS-DL Yes, they did.

INT. Is that true in your case. I know you are also active but I hear you and read you mentioning your doctor.

LTAS-DL Ya, I have great, great faith in him but he, like me, refuses to allow me to just do what he tells me. He makes me read the literature, he does not make me, but, you know sometimes I get very tired and I say "Oh, I don't want to know", and he says "No, it is your body and you have to know, you have to take responsibility for this choice if that is what you want.

INT. So he has played a role.

AIDS-C-DL Oh, profoundly. I would say that the three people that most affected who I am, well I should not count my parents as one, so that would be four people, my parents and my upbringing, I am very much in my private moments I am very much a mid-western boy from a small town. And then my doctor, Joe S. who has not only, I think, helped me save my life by being an incredible doctor but has...I don't know...convinced me that there is a certain responsibility

that goes with having this disease, responsibility to others and has encouraged me to get political and write and keep the dialogue open, start CRI (?), start up the PWA Coalition, import drugs from other countries. He is the smartest and kindest person I know, a strange combination.

INT. That is a wonderful combination. And the fourth one is your lover?

LTAS-DL He picked me up at the lowest moment of my life and when I was sure that I was factory second as I say, damaged merchandise, he told me that love was still possible. He has got me to do more music and produce my first album, I am just a very different person because of him.

INT. Is that important in other survivors you meet?

LTAS-DL Well, many of them don't have lovers but they are certainly looking. I think not giving up on love is a trait that I came across.

INT. How about in terms of support?

LTAS-DL Well, what I found with other long term survivors is that they basically clean house and got rid of relationships that were not supportive and start spending more time with those people who are supportive.

INT. Including yourself?

LTAS-DL Yes, but I did not have much house to clean.

INT. You were relatively anonymous especially since College.

LTAS-DL Pretty much alone.

INT. You must have a lot of dishes.

LTAS-DL First goes the housekeeping, then goes personal hygiene, and then the only thing I have left to bargain away is sleep.

INT. Of course you will never bargain away your Coke, right?

LTAS-DL That is right.

INT. Coke as in "Coca-Cola". Let's see. Maybe I will get a few of your skills here. Well, you said really clearly that you never allowed yourself to do anything but believe in the possibility of living with AIDS.

LTAS-DL That gets sorely tested all the time.

INT. Is that kind of hopeful I don't know if you call it optimism. Is that new stuff for you?

LTAS-DL Well, when I get together with gay friends we all admit that as we grow older we are becoming our mothers. I sort of started out being this hybrid between the best and worst of my father and the best and worst of my mother and they could not be more dissimilar. He is very cynical, very bright. She is kind of simple, optimistic, very loving. And so, you know, I would say the first part of my live I spent honing my rapier wit and my intellect and really trying to over-intellectualize everything, rationalize everything, and figuring everything out and as I am growing older I have realized life is a lot more messier than that and feelings are very important and having them and expressing them and all that. Now I am trying to integrate both aspects of my personality.

INT. So you are bringing your mother to the fore in your recent history. And that helps you to be calmer and quieter and easier?

LTAS-DL Easier I would not say. Feelings can be painful.

INT. So, you are more honest with yourself.

LTAS-DL Yes.

INT. Is that part of it new?

LTAS-DL Oh, well, I would say, certainly the degree. It is an order of magnitude. I like to think that I was always honest with myself, I don't know.

INT. You were always honest with yourself but now you are more open about it? Are you also more willing to be outwardly honest about yourself.

LTAS-DL Ya, OK, I buy that.

INT. Some of the survivors that I have spoken with ...by the way, X says Hi.

LTAS-DL Say hello to X.

INT. I am interviewing counselors as well as survivors and I have three of you who are beyond three years and two more people who are two and a half or so, and I think they have a valid point of view, but many of the counselors experiences and of the survivors experiences is that they have survived previous crises. And that their

skills are already practiced by the time they get to AIDS. How does that feel for you? Not necessarily the crises, but how about your skills...as you said you have always been that person, they were in place, you are just more of what you are? Does that somehow ring true for you, that you were already prepared to ..?

LTAS-DL Well, I don't want to exaggerate and get too political. But I really think that gay people live in a culture that wishes them dead. And I think if I had been born five years earlier I'd be dead, I would have committed suicide. I was lucky enough to have been born on the cusp of the birth of the .....(?) that gay people had a right to exist and, you know, I had a very hard time of it, coming to term with my gayness and I got no support from the culture around me and as you know, the choice of who to love, whether to love is probably the most intimate choice one is gonna make in terms of defining who you are and your own happiness. And to have I cultural situation where you are expected to internalize that what you naturally want to do is somehow despicable is a pretty insidious form of colonization. Somehow I did not kill myself.

INT. Why not.

LTAS-DL I tried once or twice sort of halfheartedly when I was young. I don't know, I think that the fierce joy of living is what was sort of down on the bottom of all of it. And that is what has really come out with AIDS. However much time I have left I want to revel in the exhilaration of existence.

INT. Yes, and it is too bad more of us don't choose that till a crisis.

LTAS-DL It is true.

INT. It is incredible. What is in our way? Fear? Self-doubt, what?

LTAS-DL It is hard work. It is hard work to live. There is a certain momentum we set up, sort of dulls the senses, plodding along.

INT. You know, as you describe that situation you came from, an oppressive society, and not just mid-western society. I see you as having survived that as a crisis. You are continuing to survive it much more successfully. So I do see you as somewhat practiced by the time you got to AIDS. Would you say that probably the major underlying condition for skill development is that you have survived and that you actually choose to survive?

LTAS-DL Well, I go around and around about the concept of luck. We don't really understand why people survive. I know that is part of what you are trying to do. I knew people who had he right attitude who really wanted to survive, who had good doctors and died anyway. And I know long term survivors who did not set out to be long term survivors who were not particularly assertive people who are still here. I know there is a pattern, there is no question that there are trends, but in terms of actually saying why I think I am still here, I just don't know.

INT. Well, one thing is for sure. You look like long term survivors of cancer of AIDS and all, you do look that way. And I am glad you do. The big question that I have and I am sure that you have dealt with many many times is for people and especially PWAs who don't come from that situation where I guess they are gay and they have had to almost come from that crisis situation ... what if it was not so bad for them, and you are saying it was he ...

LTAS-DL No I was saying we are discussing the negative impact of liberation. That is actually something that I have wondered about. Is there anything special about being gay as some of us would like to believe or are we special because we successfully overcome some test. And if our ultimate goal, which is that gay people will be integrated into society is ever achieved, will it be at the price of specialness?

INT. I wondered about that. I mean that has all sorts of implications even in terms of parenting skills. I mean if you want children to grow up to be a true survivor-of-life-type, do you have to oppress them!? And that is a pretty ridiculous question. But how do you interact. I mean, granted, you are not going to make anybody's choice for them, but is there a way to help a PWA make their own choice to survive? If they are not in that mode of long-term surviving, is it confrontation, is it loving confrontation? You certainly cannot do it for them. Do you agree with that?

LTAS-DL Right, you cannot do it for them. I don't know. You have to give them reason to believe that you really want them to survive and you will help them.

INT. So you are giving them support and love?

LTAS-DL Or, as I put it in my article, I suspect that people need a reason to live. I really think that ultimately there is going to prove to be some sort of wiring in the body interconnected with the immune system, that we need joyjoice to live, you know, the body has to receive a "live" message. And I suppose different people will engage that system in response to different stimuli.

INT. Yes. So they need to have some purpose. they need to feel some support, they need to have a little hope and are you hoping to give people hope in writing your book?

LTAS-DL Yaw, I give the "bus and truck tour" of hope! That is what I call it. And, you know, I am not unaware that part of it is convincing myself. You never know a subject as well as when you teach it. Because you encounter every objection that there can possibly be and you are forced to think of it in a three dimensional way, instead of a linear way.

INT. Well, I admire what you are doing.

LTAS-DL Well, thank you.

INT. And what ever way I can provide it for you, you have my support, love and hope.

LTAS-DL Well, thank you.

INT. If you ever get in the neighborhood, stop by. I'd appreciate that. We are going to have our survivor group meeting on Sunday.

LTAS-DL The event that was supposed to take me to Western Mass. completely fell through.

INT. Oh, did it?

LTAS-DL Someone apparently absconded with funds for the agency or something. I don't quite understand, but it is not happening.

INT. Well, maybe another time.

LTAS-DL Will you send me a copy of whatever ...

INT. I will. It is a mass of information and data at this point. I think I have to develop a skill of keeping it simple in order to make whatever sense I can make out of it. The goal is, though, for you to make sense of it, which you have done, rather than for me. My role is to record it. You guys are the experts. Thanks M..., I'll be in touch.

LTAS-DL OK.

E.2 Interview: AIDS-C-BC2

INT. Just giving you a brief overview of what we want and ask you to speak generally about your clients who are people with AIDS, who have done best in surviving and ask you to speak about them as a general group of people and I'd ask you to think of any representative kind of common experience that they might have had, that could have contributed to their development of currently used survival skills. I am asking you to go back as far into the past and work forward about the situations that could have influenced the development.

AIDS-C-BC2 OK. It is hard to think in aggregate. I would rather go with saying what I see some of the skills are and try to work backwards to specific examples, is that possible?

INT. Then I go to a scratch pad here and so would rather go from the skills and then try to speculate on what...

AIDS-C-BC2 What I prepared was some things, some skills and abilities that I believe are effective, they may be redundant. I feel I need to discharge that in order to free up to say what else I understand about reflecting back.

INT. As you are doing this is it possible for you to say these are new skills versus old skills. Or do you want to save that.

AIDS-C-BC2 I can try. Keep asking me.

INT. OK

AIDS-C-BC2 One, I think, is the PWA Coalition pushing the attitude of living with AIDS versus dying from it. I think people cope well if they don't presume that they are goners and just marking time, regardless of how much or how little. I think, one attitude I find in a lot of people who do fairly well is that one never does know. There is always a chance. And a corollary of that is sort of acceptance with the emphasis on the quality of life, living in the here and now versus projecting or catastrophising or setting up scenarios that could happen, may eventuate, but kind of thinking of them and not allowing themselves to ruminate.

INT. = INTERVIEWER
AIDS-C= AIDS COUNSELOR

INT. So, acceptance as a second skill and you let me know if it is true. By the way, don't let me write down anything that is not you. You said living with AIDS versus dying with AIDS. And then you said something about living in the moment. You see that as a separate and important skill?

AIDS-C-BC2 Sure. Versus projecting, and by projecting I don't mean in a psychological sense that a paranoid person does it. I mean in the sense of a twelve step program, which means creating present anxiety and present sort of functional paralysis by trying to predict the future. I see it sort of as an attempt to control that goes out of control, if you will. So, if they think of themselves briefly what could be and prepare for it and then let it go and go on with living versus living their projected death every moment of every day. I am saying that they need to deal with those issues of death and all, acceptance without rumination. So projection in the sense that I described it.

INT. Acceptance without rumination.

AIDS-C-BC2 And preparation as opposed to rumination, taking action, whatever form that is, as opposed to making it a obsession and a compulsion in terms that ruminations act.

INT. So, say that again. It sounds like another separate skill. You are saying acting on...it almost sounded as if you are talking about problem solving versus ....

AIDS-C-BC2 Yes, but taking action after due consideration instead of continuing to obsess.

INT. Versus obsessing. This is a characteristic of those who do best. I think I am going to ditch the new or old.

AIDS-C-BC2 Maybe too basic, but basic physical self-care as a means of action. Talking diet, talking hygiene, talking grooming, doing whatever they can that is caring for one-self and hopefully trying do it in a loving way.

INT. I am here in a bunch of skills, let me ask here. You are talking about physical self-care and then about whatever they can now.

AIDS-C-BC2 Self-care, but at a level of improving their diet, paying good attention to hygiene, which needs particular care in dealing with the skin. Most people have some kind of skin disorder, ranging from KS down to like creepy crawlies and dry skin. OK, and grooming. Very important to self-image.

INT. Ya, OK. So that is one of the functions, that it has to do with self image.

AIDS-C-BC2 Yes, and acceptance of a rapidly changing self-image in many ways. Kind of like aging gracefully on an accelerated scale. I think a biggie for me, as separate skill.Are you with me Don? You are still scribbling.

INT. Yes,I did want to know, you also mentioned, whatever they need to do and I wanted to go a little further on that. Do you just... and I don't think you probably mean just in terms of physical... whatever they need to do.

AIDS-C-BC2 Physical self-care. Allright, let me connect that with something that I have farther down the page. That does not necessarily connect. Let me break it down. I will check these off as I get them out and then I will go on to others. Allright. I have this listed as care in choosing their healers and supervising their healers.

INT. Care in choosing and supervising.

AIDS-C-BC2 In other words, taking charge of their treatment, of all types, physical, counseling, whatever it is and the idea as using these healers as consultants versus being a passive patient. And ultimately trusting their own judgment about what is truly best.

INT. So you want them to be a consultant versus being a patient?

AIDS-C-BC2 No, I want them to use their healers as consultants versus being "doc what do you think, I'll do anything you say".

INT. Use healers as consultants.

AIDS-C-BC2 Let's see, allright let us back up to the order I had. How are we doing there.

INT. Great, I am with you.

AIDS-C-BC2 A biggie for me is staying connected to other people as opposed to detaching or isolating. Maintaining relationships or forming new ones if they need to.

INT. Maintaining or forming relationships. And one of the functions there is to remain connected.

AIDS-C-BC2 Versus detachment and isolation.

INT. Versus detachment and isolation.

AIDS-C-BC2 And a lot of people kick back and accept the attitude that is pinned on them of being sort of the modern day lepers. People who are very resistant resilient to that who have their own dignity, respect and integrity do better.

INT. So in a way it is way of also maintaining their dignity. Are you saying that?

AIDS-C-BC2 I think so, because valuing others and being valued in return and allowing oneself to be valued as opposed to being devalued is sustaining. We can go to John Dunn here, I mean.

INT. So they resist the modern day leper kind of notion.

AIDS-C-BC2 Sort of a separate skill but along the same lines is what I would call centering. Doing something meaningful in which they can become absorbed and feel meaning and purpose.

INT. So one of the functions of becoming absorbed and feeling meaning and purpose.

AIDS-C-BC2 But also centering in a sense now, this could be meditation, this could be keeping a journal, this could be political activism. Empowerment for PWAs, becoming part of the movement, learning all they can.

INT. Is empowerment part of this or is there a separate connection.

AIDS-C-BC2 I think this is one important aspect of empowerment and thereare many things that feed into it. Exercise, arts, crafts, music, in a way whatever turns them on that they find absorbing and creative in some way. Because even within a discipline you are always doing something new. And that's as opposed to like cutting oneself off from new experiences and just marking time.

INT. Great.

AIDS-C-BC2 I'd like to reintroduce the Rogerian concept of congruence. And to do that and in teaching that I use a method of the ABC triangle and the FAT triangle for affect behavior and cognition or feeling, action and thought. This is what I mean by integrity in the form of integration. Meaning that if they are affectively attuned but behaviorally they have been doing something that runs against that, trying to bring those things into line. Or if they need a better cognitive connection. So the Rogerian concept of congruence.

INT. So, it functions to keep bringing things into line. Say just a touch more about that. I'm less well trained.

AIDS-C-BC2 OK, well let's just say that if a person, any person I mean, this is for anybody, but it is certainly helpful for PWAs. That is, if their thoughts and their actions and their feelings are continent and known to each other, then they move in a coordinated and in an integrated way as opposed to if there are splits, and a particular problem for many people is, you know, they can be doing the doing and they can be thinking the thinking, but they are not letting their feelings come through, I mean, I am a social worker, so just the feelings. A little Jack Webb. And bringing all of these into line and finding out in which area or areas there may be deficits in promoting expression or action as necessary. This is very global, but sort of the idea of self confidence, empowerment and a healthy entitlement, as opposed to primary narcissism.

INT. Self-confidence, empowerment and healthy entitlement. You have to tell me a little bit more about that.

AIDS-C-BC2 That goes back to the idea of using healers as consultants in terms of entitlement. They are consumers of services of the AIDS industry. They are also people of the world, they have all the rights and privileges of anyone and to feel...resisting the sense of diminishment by virtue of the disease.

INT. Virtue, a funny word. Just in a sense of diminishment.

AIDS-C-BC2 Yes, and foreclosed options. Except for the central problem, of course, of time. And I would say more about the here and now, part of that is in the article that I furnished. One thing that I find is really helpful is an attitude of screw guilt.

INT. Screw guilt.

AIDS-C-BC2 Screw guilt. If there is anything that they need to have remorse about, then there is the aspect of not repeating it. I am speaking generally to PWAs but often guilt is felt when there is a physical result to activities in the past. If that's culturally dissident, we are condemned, as in addiction. We live in a homophobic society with all the injustices that that creates, and if they can resist a societal guilt trip and if there is anything that they are remorseful about, get that down to what went down between them and whoever else and deal with it and form conclusions in order go on versus endlessly flagellating.

INT. So I hear another skill there. It almost sounds like taking care of business.

AIDS-C-BC2 TCOB and UFB.

INT. UFB, what is that.

AIDS-C-BC2 Unfinished business.

INT. OK. You can keep going on screw guilt.

AIDS-C-BC2 I think encouraging an attitude of remorse versus guilt. And remorse has the component of not endlessly feeling guilty but forming a personal protocol to rectify and avoid future commission of anything. And I also think that there need to be healthy, healthy doses of destigmatization for both addicts and homosexuals. There is a lot of cultural disapproval. Homosexuality is not a disease but it is socially disapproved. Addiction is a disease in its own right and there are a lot of things that can be put on having been a sick person if one is willing to accept that.

INT. You said, working on an attitude of remorse versus guilt and it sounds like you are saying by doing that one of the outcomes can be that they can do almost some problem solving or action planning, or something. Is that right?

AIDS-C-BC2 Ya, there could be the program idea of making amends. If that is necessary, if that would not be hurtful, but I think the main thing for me about that is not getting stuck in the past. Not getting hung up, and that leads into another skill, which is the skill of grieving losses.

INT. OK. Are we going back to TCOB and UFB.

AIDS-C-BC2 I don't see any real need to elaborate on that.

INT. OK. But do you see that as an important skill though. An important skill in terms of long term survival.

AIDS-C-BC2 Yes.

INT. I am just going to leave it on the list then. I missed what you just said about...

AIDS-C-BC2 Skill at grieving losses. The most important skill I ever learned in Social Work School is loss is boss. Meaning that separation anxiety, loss which is the shadow of death, if you will..

INT. Especially in this situation.

AIDS-C-BC2 Yes. Is the consumate human concern and thing to deal with. And if you want to you can get into the whole existential thing of life asan attempt to triumph over death and transcend the shadow of mortality. OK. But I think that philosophizing on this level and bringing people into that gives a greater perspective and tends to normalize and make the condensation and the value of human life to be important to anyone at any stage excepting any reality. Either we strive or we quit.

INT. I need you to ...you said by doing this you increase your perspective ...

AIDS-C-BC2 And scope. We are talking big picture and what I think is ..

INT. You said something about normalizing?

AIDS-C-BC2 Well, when you get down to fundamental and classic, if you will, understanding of the human condition, then having AIDS is a particular piece of the general existential problem. And so that destigmatizes.

INT. AIDS as a piece of the general human condition.

AIDS-C-BC2 The central problem of existence is death and its transcendence.
I mean Rollo May, however you like on this one, Becker..

INT. So the function of that is that you're able to soften your focus a little bit instead of ...

AIDS-C-BC2 You are able to feel like Yes, you have a special condition which is atypical in the long term human experience, except for other fatal, supposedly fatal or probably fatal illnesses. But within that there is ...it is sort of eternal that the pressure to live and to function and to work and do...you know work and love, opportunity to live a normal live as much as possible in the present time is always the obligation, no matter what situation the great wheel of fortune deals you.

INT. So if they can see it in this way they will be better able to do what?

AIDS-C-BC2 Transcend.

INT. And deal with life?

AIDS-C-BC2 And get on with it. Yes, and realize that, OK, there is a natural condensation to the quality of life. It is fragile and fleeting, sic transitory, whatever you want to call it. But that also...this just ups the ante a little bit but the essential condition and the essential obligation to live is the same.
And I have just a couple more quick things. Commanding dignity and respect by presence versus..

INT. Dignity and respect by presence versus..

AIDS-C-BC2 versus allowing pity or getting hooked into secondary gain. So, in a way what we are talking is supported autonomy as opposed to getting hooked into secondary gain and pitty pot.

INT. Supported autonomy versus petty pot.

AIDS-C-BC2 That sounds like a harsh term, I really wish you would not quote me on that, but essentially we are getting there. Let me try and put that another way. Secondary gain or feeling sorry for oneself excessively. You can grieve your losses, you can do anticipatory grieving, but not getting caught up in oneself as an overwhelmingly tragic figure.

INT. OK, there is a word I am looking for.

AIDS-C-BC2 How many syllables?

INT. Three. Supportive autonomy, well I just write this down versus getting secondary gain.

AIDS-C-BC2 And you know what I mean by secondary gain?

INT. Yes. And what is the function of this skill.

AIDS-C-BC2 The function of this skill is functioning itself as opposed to letting other people take over. It's autonomy. As much as possible. And supported autonomy where necessary. Yes, you let other people help as much as is needed, but you don't get hooked into, you know, would you please do this for me, when you can do it yourself. And knowing when your can, and not when you can't. When to ask for help and doing it in a way that invites pity along with it. Just frankly this is what I need. An expression of need. If someone is assertive, I guess I am working around to that. Assertiveness is an important skill. You've got to say what you need loud and clear.

INT. How about expression in general? Feelings, thoughts and emotions.

AIDS-C-BC2 Right. And that gets back to my idea of congruence. Not my idea. Roger's idea. But that gets back to connectiveness, overall wellness, holistic idea of mental health. "Mens", Which means healthy mind and healthy body, as much as is possible. Thinking of oneself as being healthy despite overwhelming physical evidence that one is not. Sort of, who is the man who was told he was dying of cancer and laughed his way healthy. Ed Asner did a movie.

INT. Cousins.

AIDS-C-BC2 Cousins, ya. That kind of thing.

INT. Is that a little bit of healthy denial or something.

AIDS-C-BC2 Functional denial. Of course denial also is not a river in Egypt. I hoped you would like that. And euthanasia is not backpacking in the Himalayas. And I don't know, I mean let's go off the record for a second. Can we do that?

OK, Functional denial, we really did not work that very much. You want to stay with it?

INT. If you want to say a little bit.

AIDS-C-BC2 In the sense that a combat soldier, in the sense that a surgeon needs it, in the sense that many people need it, and that is continuing to function in the face of the situation. You can also call it courage in the sense that courage is not the denial of jeopardy for danger, for risk, but the will to continue in the face of it. And doing what needs to be done in spite of massive intrusion. That is not to say that people should closet their emotions and clam up, it is just that there need to be periods of functioning with relatively less self consciousness than more. Absorption and distraction, I be lieve, are valid.

INT. So the way it functions is the continuance...

AIDS-C-BC2 One thing that people in the group that I have done with PWAs talk about is the syndrome of AIDS is my face. And being a PWA 247 to the exclusion of just being a human being at large. And obsessing on that is sometimes detrimental.

INT. So by maintaining a bit of functional denial they are able to continue to function and they avoid getting overwhelmed.

AIDS-C-BC2 Hung up. Overwhelmed is a good word too. And I know I am not a Californian neither.

INT. OK, you can't prove that by me, but..

AIDS-C-BC2 Are you a Californian?

INT. No, Western Mass all the way. I heard you say and I heard you say before "doing what needs to be done". And that is a skill that others in other situations have referred to. I want to know if you feel that is important, doing whatever needs to be done, going for it, you know, is that in there?

AIDS-C-BC2 Yes, I would say that is empowerment. It touches on a lot of other core concepts, but ya, whatever needs to be done. Not sitting back and taking it.

INT. OK. A sense of purpose and meaning in life. How do you want to say that? Purpose and meaning? What is the function of that?

AIDS-C-BC2 To have a being an existence, an identity, and as strong a one as possible. You get to, if you want to, you can get to Eichenvelt and Midvelt and all that good stuff, but a sense of connectedness within oneself and within a community of one's own choosing. Be that a literal community, a grouping of people or a loose affiliation of connections that people have, that rootedness, relatedness and also being centered. I am finding all this stuff in behavioral terms is difficult and is really what you are trying to do.

INT. And obviously being centered and maintaining relatedness and rootedness, they are avoiding...what? What would be the result of not having this skill.

AIDS-C-BC2 Well, I suppose we can begin with the ..... concept of enemy or being really overwhelmed by the disease and the ramifications of the disease and kind of like powerstall. A crisis of identity leads to paralysis, paralysis leads to rumination, rumination leads to vegetation, vegetation leads to decay. Or atrophy if you will.

INT. Good stuff.

AIDS-C-BC2 So, stasis versus ...you want to avoid a static situation. And what it avoids really is a kind of stuck reafication, you know, I am just this, I am not continuing to evolve, I am stuck in time and basically waiting in the sense of a play like endgame with no exit.

INT. How about people's ability to more or less see this as a challenge or an opportunity.

AIDS-C-BC2 Yes, absolutely. And I don't know what they are but there are two Chinese characters in their language which stand for crisis, one means just crisis, an overwhelming situation, normal all fouled up and the other one also means opportunity on the flip side. So, ya, definitely a critical skill is an opportunity to snatch victory from the jaws of defeat. Or transcendence, that is what I get back to when I start talking about this.

INT. So you are transcending what..?

AIDS-C-BC2 The shadow of death, loss and continued loss and hopefully by being in a genuine way you are being generative, you are seeking to feed yourself, also to feed others, so you get into twelve step program skills of sharing one's hope, experience, fate, whatever it is. If you are transmitting you have to be thinking for yourselves.

INT. Now you mentioned "don't hang up", being generative and you mentioned possibly about helping others and all, and is that a skill that you see common among your survivors.

AIDS-C-BC2 It can be, but I think that gets tricky. It is a question of limits and especially a lot of people who have come into it with dependency disorders, which would mean your addicts, could have grown up in a codependent situation and they may be what I call terminal caretakers. And I use that outside of the context of...so it is the rap-about therapist, really if you get down to it, why do we all go into it while we want to work through our own issues, but not with our own stuff. And so, what does that lead to, in anticipating your next question. That gets one out of absorption in the other and a healthy balance of self-knowledge and the generativity needs to be limited to the extent that someone is not caretaking as a dodge.

INT. So can we call this one caretaking?

AIDS-C-BC2 We can call caretaking within one's limits and knowing where they are. Taking care of oneself is number one. You only give back and give to others in the capacity that is also helpful to you to do so and without compromising whatever routine and structure you need. So, I guess if you want to pick an example of someone who has worked extensively in AIDS who is a legendary workaholic, you look at Erica Kubler-Ross and you wonder. Does she feed herself by doing this or does she get absorbed? And this is for the helper as well as for the help.

INT. I just had a thought a minute ago and I lost it. I won't worry about it. Let's see.

AIDS-C-BC2 Are we about to roll around the specificity.

INT. Well, you have been pretty specific. Now I do want to get more specific. How about ...now, I have heard you say this but I don't know if we wrote it down, and that is just kind of taking control. Although you did say "doing everything possible", and I guess that is taking control.

AIDS-C-BC2 Right, I personally put a lot of stock in control theory. Howard Glasser. OK. ..... those kinds of people. I believe that control can be seen as a central human motivation and you gain a sense of control by being active in the process of management of whatever confronts you. If it is the disease, that gets back to the idea of healers as consultants and not, you know, gurus or ....

INT. You gain empowerment as well?

AIDS-C-BC2 Yes, and also, with connectedness, seeing yourself as part of a larger picture, a larger scope, a larger phenomenon. Not being alone in this. And many of the most empowered PWAs that I have met have not only been politically active in the PWA movement, but they have also had a sense ....I lost my thought... feed me back.

INT. You are talking about gains. About seeing self as a larger phenomenon, not being alone, and you talked about politically ..

AIDS-C-BC2 Ya, they are connected, they have a really connected sense of this and you spoke with Larry Kessler, right?

INT. No.

AIDS-C-BC2 Who was it?

INT. Michael Callen.

AIDS-C-BC2 OK. The idea that even though I may go down in the next couple of years the torch will be passed and I am not alone in this, this is a thing that confronts all of us. And this is also resistance to victimization.

INT. I am going off tape for a second.

AIDS-C-BC2 For this part I am trying to specify when and where, how people got these skills. I'd like to first talk about a special population within the population, if I can do that. Is it OK to be a little bit divisive? About addicts in recovery. I want to talk about what recovery offers them.

INT. Sure, go ahead.

AIDS-C-BC2 I would refer you to use and incorporate as part of this interview the essay that I have given you on the diagnosis of addition and AIDS. To give a kind of brief extract of how that works, I would like to just read a paragraph about recovery skills and the PWA who is an addict in recovery. OK?

INT. Go for it.

AIDS-C-BC2 However recovery begins, maintaining is critical and relapse is never out of the question, except in denial. Detoxification, inpatient treatment, supportive aftercare and participation in Narcotics Anonymous or Alcoholics Anonymus are all recommended. The twelve step programs offer many resources and teach many skills and attitudes also useful in living with AIDS. Self-care, compassionate understanding, companionship and support, structure and routine, identification with the strength, hope and experience of others, courage to change and serenity to accept, spirituality, thinking things through versus impulsive reactivity, sponsor as mentor or confessor and spiritual guide, and a method of coming to terms with one's life, even coffee.

INT. How about the...

AIDS-C-BC2 Now, as to when this population comes to this, there is the old concept of bottoming out. A lot of people that's precipitated to, when they come into the system, through legal route or medical route, something has gone really, really wrong and they are feeling in their bodies as well as this nagging sort of conscience they have had of what they have done to themselves and other people. When this comes in, having somehow learned that they have "IT", and they think of it as "IT" at first, capital I, capital T, it can precipitate an enormous reawakening and with the realization of the pressure, the dynamic tension generated by the awareness of death has been more rather than less imminent and the tendency is to try and work feverishly to get right again and do the opposite of many things that they were doing, which includes the skills just outlined. So there is sort of a precipitating moment, with learning that, yes, not only have I been screwing around with needles and maybe with people, but now I have got this thing, and this is serious enough for me to say that I have hit bottom. I don't believe in the concept of hitting bottom in the way you will hear it in many programs, because you can always raise the bottom, you can always figure things have gotten bad enough and not figure, well, I have got another round before it gets bad enough to do something.

INT. So they reach a point where they...

AIDS-C-BC2 It is a moment of truth if you will. They sort of stare death and its possibility as being more imminent than less in the eye and decide they are going to fight , rather than the short of the serenity prayer, which is, forgive my vulgarity "fuck it".

INT. Tell me about some of the feelings that are coincident with that moment or before or after that moment.

AIDS-C-BC2 Let me read you a couple of more paragraphs of this essay if you don't mind.

INT. Go ahead. As long as we can condense it.

AIDS-C-BC2 Talking about what happens in the process of addiction, leading to recovery. The mind is continually blurred and numb. Interests, skills and beliefs that don't produce white powder and green bills fade away in atrophy. The body is exhausted, malnourished and neglected. Damage can be seen at the cellular level and major organs and systems are particular vulnerable to malfunction, damage and infection. For some unknown reason addicts are heavy smokers but there is no known documented reason for this baffling phenomenon. A joke. This is the paragraph I wanted to get in. In abstinence with recovery an addict gains some clarity after withdrawal. Yet for a while denies, blames and manipulates out of force of habit. Often the addict sobers up to a ruined life, angry or pitying families, severed relationships, deaths, pending charges, wired minds, and hurting bodies that crave, haunting memories and little trust to invest or offered. Denial melts down a bit causing seepage to a torrent of suppressed toxic experiences and emotions which wash over them. Often the impulse is to seek oblivion by relapsing. In recovering the addict must mature and overhaul behavior perception. Relationships and values demand physically, mentally and spiritually.
And there may be another piece in here that tells more about their feelings. Let me look.

OK. For all PWAs there is a condensed time sense, a pressure generated by the realities of losses and probabilities of the disease. For the PWA in recovery from addition this condensation or pressure from foreclosed options and an indefinite future can be intensified still more as denial and flight have usually amassed a huge pile of frozen emotional baggage, that held back social development. This baggage must be brought out, untangled and sorted with care, inventoried and the new item's present value cleaned up, pressed and repacked in a new grip for a shorter trip. To be specific, it could be said, the recovering PWA is compelled to face the past, gain from that pain, finally grow up quickly, learn to live with AIDS, and prepare for a transcendent death all at the same

time, when the amount of quality time is unknown but surely limited and compressed.

INT. Just give me some basic feelings.

AIDS-C-BC2 A really non-specific upwelling of very strong feelings, including foremost anger and fear. Fear often can be projected at retaliation, knowing what one has done to support one's habits. And the anger is what has been stuffed by the drug use over time and accumulated. I use as an analogy, if this is not the stuff you can whip out of their freezer and thaw in the microwave, it will explode unless it is paced. With the time pressure that is there it is very hard to pace trotting these things out of the closet and processing them and it tends to happen in a big global rush, so have people who are used to numbing their feelings routinely, chemically and extremely efficiently, who just get hit with a tidal wave of their own emotion, and they don't know where it is coming from. Often it feels like it comes from outside. And the tendency to project and blame and resist can cut them off from others by their own behavior. You know, it is never the consequence, or it is hard to get used to the idea that this is a natural consequence of having a disease as opposed to this or that, incompetent, stupid, whatever SOB did this to me.

INT. Now, those are what I call some internal influences on developing these skills. Those are internal processes that happen. How about in this population, especially those who do well, are other people important? What we are talking about now is the situation and development of skills after diagnosis. That's is what we have been talking about.

AIDS-C-BC2 Diagnosis and the beginning of recovery. The connection to a program of really spiritual guidance when one has suppressed their spiritual aspect almost totally and that has been sacrificed to drug use. It is a spiritual reawakening. Now, let me do also one quick piece of a paragraph here, allright.

It is talking about relapse , about how people stop. OK. I'll read the whole paragraph. - Many reflexively " pick up" again and again, but if they don't OD enough to be declared DOA, the health care and/or the legal systems will see them repeatedly, sicker and more compromised each time usually. Intervention will attempt to encourage, even enforce recovery. Some surrender from exhaustion. Some want to go out with dignity. I hear that a lot. Some want in from the street and the cold. Some hit bottom. Some

find God, and some had to take to the outer limits and stop at the brink, knowing that they have gone about as far as they can go.

INT. There is a thought right there, "I have gone as far as I can go."

AIDS-C-BC2 Yes, like, you know, here it is, I have been playing a game of chicken with death and now I have got it. Now I have got it and it is time to deal because I found the limit. It is not here yet but I know it is coming. And so then the quality of life with whatever time one has that remains... and I also think there comes after that a realization that I can increase the amount and definitely the quality of the time that remains if I am active in this. And it gets back to living in the here and now, versus let's do the time warp again.

INT. So, you said "you found the limit, it is not here yet but it is coming".

AIDS-C-BC2 Yes, and I can have more control by being active rather than snuffing.

INT. So, do these people typically need help or this is something they can do on their own.

AIDS-C-BC2 They need a lot of help and if you want to get into control theory and there are a lot of aspects that pertain on this, but one of the essential features of the program is surrendering, in that the individual has run amuck trying to control their lives and they need to turn it over. They need to find some form of spirituality and connectedness which they can experience as supportive and not intrusive.

INT. Sounds like another important skill.

AIDS-C-BC2 Maybe, surrendering. Yes, well giving it over means acknowledging...Gee, the more I try to control the worse things got and so maybe I let someone else steer the boat and be guided in that. Maybe I will take some cues from someone else instead of seeing everybody else as a potential sucker or what they can be useful for. What are they offering me that I can use. And the program stresses placing principles before personalities. But there always has to be the interpersonal aspect, there has to be some "who" involved somewhere. But I think, there is a difference between secondary gain as help and accepting help in terms of taking what is useful to you, that has worked for someone else, that is offered in a free way. I mean, NIMH has spent millions of dollars over the years trying to figure out how twelve step programs work. They still have not exactly figured it out. But if you would

like I could lend you a really interesting article that has to do with control and surrender and that whole nexus of things by Bateson.

INT. Sure. So, you are talking about programs here. Are programs important.

AIDS-C-BC2 Specifically to addicts, they are. Nothing has worked as well for as many for as long. I am talking about twelve step programs of recovery and I could fill up a couple of tapes for you on that. But I'll leave it there.

INT. In your experience, that when a common characteristic of the people has done well.

AIDS-C-BC2 The addicts in recovery take their recovery seriously. And they do participate in programs and they do try to absorb the principles with the steps and become absorbed, and in another way you can look at it as a substitute addiction. Turning on to people and people power as supposed to drugs. So Nancy Reagan might not have been that wrong.

INT. OK, and you said that most if not all of these skills can come out of this situation with AIDS, and recovery.

AIDS-C-BC2 The principles embodied in the twelve step program. Now, there is in Northampton itself and spreading around Positive Anonymous meetings, which are often run and facilitated by addicts in recovery who use the twelve step model but address it to the disease. And so I guess the trade-off there that really applies again, and a lot of things come down to the serenity prayer, which is "God, grant me the serenity to accept the things I cannot change, the courage to change the things I can and the wisdom to know the difference". If you can do all of that you don't tend to get hung up or stuck. You roll them into one category or the other and you strive in giving your damnest if it is something you can change, if not acceptance is preferable to rumination, stasis and defeat. Am I logical?

INT. In my mind, I don't know if that's consensual validation.

AIDS-C-BC2 I'm an affiliate, you know.

INT. Now, you mentioned in your speaking about addictions, family problems, relationship problems, haunting memories, that is some of the stuff I want to know

about. And if having survived or coped with some of these situations, fosters some of these skills before this twelve step program.

AIDS-C-BC2 It fostered the antithesis to these skills, so they know what the wrong road is. Because they went down it and the more they went down it the more screwed up their lives got. They can see, even if they are in enormous pain in early recovery, that stuffing is not the way, running away from their feelings as opposed to dealing avoidance is not the way and you can see addiction very clearly as avoidance and they know how much they have had to stuff when it all comes out in this wave. Say again what you really want.

INT. You're addressing it clearly. I want to know about situations, conditions, events, that happened before the diagnosis which led down to develop these skills. Now, I am writing down here a general situation which happened before addiction.

AIDS-C-BC2 I have here in a couple of paragraphs, if you would like them on tape, you also have them in print, what I believe is a brief etiology of the disease of addiction.

INT. I wouldn't at this point. I want you to get real specific. You know what I'd like you to do? I would like those paragraphs, but I would like them to come at the end of this interview as an appendix almost. OK. Because I really like your stuff and I would like them to be a part of this. If it helps you to now formulate those things. I'd rather have it now then.

AIDS-C-BC2 Let me read a couple of paragraphs.

Denial is not a river in Egypt; it is the prime defense, operating principle and driving force of the addict. He or she injects ultimately as a matter of efficient administration of an expensive commodity for maximum high and instant effect. This act alone is desperate but denied easily and soon. Dynamically the addict thus commands the power to change their mood, their mode, and block out toxic experiences and emotions with liquid denial. They can move from depression to ecstasy, from inhibition to boldness, from anger to peace, from neediness to contentment, from inadequacy to superman, superwomen and so on. By the time ever larger doses have ever less desired effect addiction is an obsession and a grim compulsion with a life of its own, seemingly only hosted by the addict much like a virus. It is said that an addict is only as sick as his or her secrets. With denial at the helm and a driven lifestyle the addict starts with some core secrets and racks up many more. Unless one is very well off materially, feeding a growing habit forces one to the standard street option.

Steal, deal, hook or heal, heal meaning withdrawal. Deceit and manipulation become ingrained survival skills. The addict often becomes predatory and hardened as a matter of course. Projective blame and anger at authority, their victims, their families, lovers, anyone and anything. Deflects, insulates and rationalizes guilt for misdeeds. Family and friends tire of lies, threats, abuse, missing items and unpaid loans. They either cut off, detach, or enable and sicken as codependent caretakers themselves.

INT. That is great. Let me tell you what I got from that. Addiction, I am talking about the situation now of addiction, denial, changing mood, mode and toxic influences. Obsession and a grim compulsion. Steal, deal, hook or heal?

AIDS-C-BC2 Heal meaning going through withdrawal. Which is not considered a fun thing to do.

INT. So, you are saying that is an important thing which has happened in the lives of the long term survivors that you experienced.

AIDS-C-BC2 Of addicts. That is a course of events which happens to all but the most wealthy addicts. Sooner or later they have to resort to this to feed the monkey. And I bounced this article off a lot of PWAs who are recovering addicts and universally I have gotten the feedback that it is all true. Nobody has contested me on a word of it.

INT. It is powerful. I am glad you read it now. I also wrote that a thought was "avoidance is not the way", a realization they may get to when they decided to heal. Some of the feelings generated, I heard you say clearly "anger".

AIDS-C-BC2 Anger and fear. And a lot of that fear is stemmed by having an upwelling of emotion, and not being experienced for a long long time at dealing or holding an emotion. They are at a total loss to deal with that, I mean, whenever there was a strong upwelling of emotion before, he, just a prick in the arm and twenty seconds later you feel great.

INT. Incredible, what an out.

AIDS-C-BC2 Until the drugs don't do it anymore. The Chinese have a saying about alcohol, they say "A man takes a drink and the drink takes a drink, then the drink takes the man." It is a disease.

INT. So it does not do it anymore and so they try more.

AIDS-C-BC2 Yes, and sooner or later it is just as I said, an obsession and a grim compulsion, without the previously desired effect. But, random reinforcement is the most effective schedule. And so, part of other things, just in the aspect of use that stem into that is to get a more or less potent drug, sometimes it does it, sometimes it doesn't, sometimes they are too exhausted to feel the effect, you know, and there is nothing like..for the addict there is nothing like getting high after doing a short prison bit or being in the hospital. They have had two weeks to lower their resistance and they get out there and it feels great again.

INT. Incredible.

AIDS-C-BC2 For about a day, maybe. I seem to be specializing in working with addicts, that is what I have done most of in PWA work. I have also worked with some gay man, and even one or two people who could be said to be "victims". Although PWA is a shoe-in term. But that was a codependency situation. That was being a caretaker too, being in love with someone who was, well, in one particular case I am thinking of, both an IV drug abuser and bisexual on the sly. And the anger at waking up to that, thinking "Gee, this guy probably knew and he infected me", you know, and he did not think boo about it. I buried him with flowers and look what he did to me. I found out reading the autopsy.

INT. My God. What a sad story.

AIDS-C-BC2 I was speaking in a client voice.

INT. Yes, I hear you. So, some of your addicts who are doing well with their AIDS as an assumption have been at least successful at times in dealing with their addictions in the past.

AIDS-C-BC2 If they are in recovery and if they are a working program, as it is said, or if they are remaining abstinent..there is a difference between dry and being in recovery. When you are dry the spiritual and mental attitude persists without essential change and is just a miserable suffering bastard, if you will. But recovery implies working on a whole set of attitudes and skills, which are designed in a way towards congruence. If you really want the background to how Bill W. and company came up with the principles for it, you can look at the Oxford Societies, and their by-laws and principles by which they function. And it is really not a bad system to promote overall mental health for anybody.

INT. So a positive influence on development of some of these skills, if not all of them, is a ....question. Is

being in recovery working on a set of attitudes and skills in a formal way? In a twelve step program?

AIDS-C-BC2 They are not just with their program of recovery when they are in meetings, it is in conversations with people, they hang out with a whole set of people who are similarly interested, who are provided by the program, a consensual nomenclature, a set of concepts, a set of notions and even a set of sort of semi-mandatory prerogatives. See, the program not only offers one thing, but a lot of what to do and you get into the idea of a fourth step inventory, which is making a fearless and searching moral inventory. And in fact, examining the who, what, when and where of their lives, making amends where possible, which is a couple of steps down the line in the progression but it is coming to terms in a systematic way.

INT. OK, coming to terms.

AIDS-C-BC2 In a systematic way and really writing a new script and making new decisions of how they wish to be.

INT. So this formal program, and an informal, assembled people who are similarly invested...

AIDS-C-BC2 Invested is a good word.

INT. And would you also call that somehow a support.

AIDS-C-BC2 Absolutely. You see, if you can't get support in a program, you can't get it.

INT. So from this, can they also develop that whole set.

AIDS-C-BC2 Yes, that is my intention.

INT. Here is a big question. Of the people who are doing well in surviving their AIDS, you are almost purely speaking of addicts, so let's just..are the people who are doing well people who have previously done well with their addiction. Let me ask it in more of a negative way. If somebody has never come to terms with their addiction.....

AIDS-C-BC2 Can they deal effectively with AIDS?

INT. Yes, are they?

AIDS-C-BC2 No, they can't.

INT. So one very important...

AIDS-C-BC2 One quick sentence. In the beginning of the essay is, that it is widely held that the treatment of the addiction is primary because an addict is very unlikely to face, let alone fight AIDS if not abstinent and active in the recovery process.

INT. So, now at the bottom of this page I have coping skills developed from these origins. It is all those skills that you referred to.

AIDS-C-BC2 In the paragraph that I wrote later on about what recovery offers an addict.

INT. It is all those skills we have got listed on those pages.

AIDS-C-BC2 It is many of them. There are a few more that are listed on those pages that are not specific in that way and I am deriving the terms from what I know about programs, so it is sort of a cultured interpretation.

INT. Let me ask you something now. We talked about twelve step programs and all for successful PWAs after diagnosis. Those who were successful are going to those twelve step programs, and I believe you said the coping skills are all listed.

AIDS-C-BC2 Many of them are.

INT. Give me a sense of which ones ...this might be tough...which ones come after diagnosis, which ones came before.

AIDS-C-BC2 For the addict most came after diagnosis and would have to. Having been down the wrong road and having the pain from having been down the road finally catches up with them. And weathering it.

INT. Wait a minute, you just told me that if they have not come to term with it by the time of diagnosis, they are not going to. So they have developed some of these skills before diagnosis.

AIDS-C-BC2 NO, no, no. Diagnosis can be the precipitant to coming to terms and the degree of denial, as I said, the prime defense, operating principle, driving force of the addict, by definition that precludes development of the skills to fight AIDS prior to diagnosis.

INT. Hearing that is real good news. You are telling me that there are some of your population of those who do best who haven't previously developed these skills, they have developed these skills after diagnosis and after coming to terms with addiction.

AIDS-C-BC2 That's diagnosis not only as PWA, in whatever stage, but that is especially accepting that their addiction is a disease.

INT. Great, OK.

AIDS-C-BC2 As opposed to a moral weakness or whatever. Just a brief phrase, hold the tape a second. Addiction is a true disease beyond moral weakness or even lack of will. With continued abuse the mind, body and spirit progressively deteriorate.

INT. The point that I was at in this was hearing you say that ..now, let me clarify this..that it is possible and you have experienced in your people who do best not to have come to terms with their addiction, even before diagnosis.

AIDS-C-BC2 No, by definition they are in denial, because that is the functional principle of addiction.

INT. So these skills that you listed are post diagnosis. Post dual diagnosis. Major. OK. Let's see if you can talk about ....wait a minute let me go back to addiction. You talked about a situation and ..allright now, is there a portion of your people who do well, who were addicts, who have been in recovering before AIDS diagnosis and did they develop this set of skills beforehand. In other words, were they practiced in these skills that are using and did that help.

AIDS-C-BC2 Ya, there are some. Yes, and there is also the case of people being fledgling at it but when the second diagnosis of HIV positivity, ARC or AIDS comes down the pike they get real serious real fast. This is the time condensation, there is no more time left to fart around. I can't still test the waters and see if I can get high one more time.

INT. How about, do you see any of these skills having been developed in previous situations, like surviving dysfunctional families or..

AIDS-C-BC2 Sure, because addicts are likely to come from dysfunctional family systems. Either the actual situation of codependency or some other condition, say abuse, physical, sexual or emotional, where they have needed to be secretive as a matter defense rather than open and drugs have just come into play as the most efficient way of doing that. We live in a society that prescribes instant cures for complex problems.

INT. Now, some of these dysfunctional family systems, now what do you mean by codependency by the way. I want to make sure I understand.

AIDS-C-BC2 By codependency I mean a situation where there is at least one person who is chemically dependent in the family, often many, where the others fill in the slack and by enabling the addict they lose a lot of themselves and become tied up into this, and one of the most common manifestations is parentified children. The true meaning of the term adult children of alcoholics or of addicts of any kind is not that they are now adults that where once children of addicts, although that is true, it is that they were adults as children of addicts. They were more functional in order to enable the chemically dependent person to continue doing what they are doing. They filled the vacuums of responsibility. So you get daughters who were mothers to either their fathers and their mothers and sons who were fathers or older brothers or Dutch uncles to their parents and/or their siblings and down the line.

INT. So you said, children as adults of addicts, and they developed ...

AIDS-C-BC2 No, they are children who functioned as adults.

INT. And so they had to do some role reversal there.

AIDS-C-BC2 Lots.

INT. And what kinds of skills did they learn from that situation?

AIDS-C-BC2 Very often how to care take for others, but the conspicuous lack is caretaking for oneself or applying what one knows about how to take care of someone and take care of situations to themselves.

INT. So.....(?)

AIDS-C-BC2 Ya, exactly.

INT. Any others?

AIDS-C-BC2 Skills, we are focussing on skills that were learned earlier. Right.

INT. Skills that may have been useful now in dealing with their diagnosis.

AIDS-C-BC2 I think I would like, I know this may not be helpful, but I would like to emphasize that you can really

know the wisdom or the utility of a positive concept if you have experienced the flip side to the max. And so a lot of it is coming off the end result of what the negativity can do. If you choked on that, if you chewed on that, if you have tasted the bitter, you develop a thirst for the sweet and necessity is the mother of invention.

INT. So I just wrote that down as a kind of a negative influence. That is not really the right expression. What is the opposite of a positive influence. It does not sound like a negative influence.

AIDS-C-BC2 A negative experience can lead to positive coping strategies in that you have eliminated a lot of what you know does not work.

INT. So that is not just a negative influence.

AIDS-C-BC2 It is back to the crisis opportunity duality that you talked about.

INT. I see that, can you ..what is the expression that signifies.. that you learned something positive from something rather negative. Is there an expression.

AIDS-C-BC2 Transcendence. Or as the African Queen, Kate Hepburn, "nature Mr. Alnut, is what we are in this world to overcome."

INT. Good stuff. OK, so in having experienced the bitter you develop a thirst for the sweet. That's good. Too lyrical.

AIDS-C-BC2 No, no, I love this. Do you imply too lyrical for me, or too lyrical for a dissertation.

INT. It will fit right in, I don't know about my style. So the skills they developed were caretaker brothers, does that stimulate any others ....

AIDS-C-BC2 They learned how to do adaptive things for other people and enabled essentially sick people and do for them. The trick of it is self-abdication. Now, but they have the skills in an other directed way. If they can apply them to themselves.

INT. But the skill about it was being adaptive.

AIDS-C-BC2 And they are consummately sensitive caretakers and another skill is really being able to read people at a glance in a situation that is inherently out of control, vis love requisite variability in systems theory. The addict is the one with the most variable behavior and therefore the controlling member of the system. You got to

be able to read that person and know how to react and that's in the scope of 5 minutes, let alone daily. I mean picture the working alcoholic who comes home a little late after work and they got to instantly get a read pm.. How much did he have to drink, what kind of a mood is he in, is this a good time to ask for anything and you get into all the stuff, and there is volumes of stuff about adult children and what that is about. I would just refer you to that body of literature. I can give you some condensed abstracts, if you would give me another day at the office to put it in an envelope and shoot it to you.

INT. Great. Any other skills.

AIDS-C-BC2 I focus a lot on the dysfunctional aspects, but I am getting stuck on skills.

INT. Tell me about some of the feelings and thoughts they would have had within that situation that led to the development of these skills you just said. What does it feel like in that situation.

AIDS-C-BC2 The feeling of helplessness in the face overwhelming disorder is not unfamiliar in the adult child. Therefore, they have had to cope in a disordered or overwhelming situation many many times before and you can see that this is some practice for the new situation of having a disease within their bodies. Does that make sense.

INT. Yes, really.

AIDS-C-BC2 So there is some functional adaptation to another situation which has transferred effect.

INT. Absolutely, that is what we are dealing with here. Functional adaptation. What are some of the thoughts they are having in mind.

AIDS-C-BC2 A lot of it is "am I good enough, will they like me, is there any sense, is there any order, is there any consistency" The reason that ACOAs are often seen as people who act out a lot and thrash around is because in a situation that has no consistency or limits, they have to constantly test to try and find the baseline. That's another part where recovery comes in, not only for the addict but for the ACOA, is it offers a theoretical spiritual and structural framework, a place to hang your head. Adult children's major characteristic is, they wonder what normal is, because they know one thing for sure, normal was a set of assumptions about chaos when they grew up. The flip side of this, of course is dysfunctional denial. An ostrich always gets shot in the ass.

INT. Now I believe I heard you say, "Am I good enough, will they like me?" What kind of skills come out of that?

AIDS-C-BC2 I would say an ability to please and read what pleases others.

INT. Do you consider that an important survival skill?

AIDS-C-BC2 If it is realized that this availed, not accept continued use or abuse by other people. If that realization is met, then it makes the converse decision to be self-empowering, to go for the gusto and to be independent and to treat ... what is it that Kipling said of those twin impostors: "fame and fortune is the same."

INT. So that feeds into some of the skills you have over here about taking care of self. You said, you just can't please everybody.

AIDS-C-BC2 Reprioritizing so that personhood, selfhood, knowing what they know, functioning for their own best interest is previously an alien skill, but one that is easily derived from the net result of not having done so. In fact, having done the converse.

INT. So, this is a new skill.

AIDS-C-BC2 And often the addiction has stemmed from having tried without getting any traction and damn little thanks. And so, in frustration with a whole lot of stuffed stuff, and a whole lot of abusive memories and everything. they shoot up to get away. Dysfunctional ....

INT. Any other experiences that you can think of that may have led to development of any of these skills? ... or situations, deaths in families? Are you talking about the addict population?

AIDS-C-BC2 Chances are, they have seen a serious illness before or dealt with a lot more loss than the average respectable environment would afford. But that all depends on how you assess the average respectable environment. I believe that the reason America needs the Brady Bunch and ..... and anybody else is because that is a fiction and sort of a familial ideal which needs to be upheld in the chronic absence of same. These are the opinions of myself, they in no way reflect the beliefs of ..... or anyone else that I work for.

INT. I want to correctly quote you here. You said ... maybe I should not try .. "they got experience in serious illnesses before"... Is that what you said? Their own or others'?

AIDS-C-BC2 Others. Because usually when someone is addicted to a substance there is a physical outcome from that, so you are talking about cirrhosis, heart attack, lung disease, all of that, and usually in someone that they are a caretaker of, and so they have experience in dealing with that for someone else's sake and once again, the trick is to bring it home.

INT. What do they learn in that experience, dealing with the serious illness of others.

AIDS-C-BC2 Perhaps they have realized what good care is. how it can get frustrated, and maybe where some of the limits are when caretaking becomes borderline abusive because they have gotten to that stage themselves. They give so much with so little thanks that they get frustrated and act out and if they can realize that this was going on, they then know where to draw the line a little better.

INT. Did I hear you say that out of that experience they really do know what good care is?

AIDS-C-BC2 In trying, in striving to give it to somebody else, yes. Even in the lack of recognition they learn elements of it. I would also say they unfortunately learn what over care and enabling and secondary gain are all about. Lot of two-edged swords in here.

INT. Do they become caretakers out of this situation too? When they had to be caretakers because of ...

AIDS-C-BC2 Many do, many do, and particularly its oldest children or oldest children within a sibling grouping and particularly oldest daughters. And cultural roles, stuff that all feeds into stuff that is pretty obvious.

INT. What are some of the feelings they have experienced in that situation of dealing with somebody else's serious illness or dying, I suppose?

AIDS-C-BC2 Frustration, helplessness and also a lot of responsibilities as both a burden and an obligation.

INT. Is that a skill?

AIDS-C-BC2 Following through with those things and the realization of that as a skill.

INT. Following through with what?

AIDS-C-BC2 With providing care, even though it is frustrating and an uphill battle. Dealing with someone else's denial and very often it is good for people to realize that there are patterns that they could not stand in others, particularly in the ones that they cared for, which lo and behold repeat themselves, and the big ACOA thing is "this will never happen to me." The more they say it, the more it seems to be a script, in the converse.

INT. So that is one of the things that they thought: "This will never happen to me."

AIDS-C-BC2 Yes. I'll see to it. And it does, with alarming frequency.

INT. The children of addicted people?

AIDS-C-BC2 Certainly it is said about alcoholics, but I extend it to addicted people. They are more than twice as likely to become addicts than the general population.

INT. We were just talking about experience in having dealt with serious illness of others and the feelings of frustration, helplessness and responsibility. And with responsibility, skill that developed that was being responsible even in the face of being frustrated in their efforts, being frustrated by the others. an "This will never happen to me. I'll see to it." These skills that were developed, knowing what good care really is, being caretakers, being highly responsible ... Is that what you're calling it?

AIDS-C-BC2 More responsible than a kid has any business being. But assuming that it is their lot in life.

INT. Are there people, or events or things that influence them in taking those roles?

AIDS-C-BC2 Sure. Vacuum of responsibility in the parental generation while they are busy attending to their addiction. Everything else that they would do in a "normal" family context. I am back to the "lack of responsibility in the parental generation," or even in the siblings ... and the more irresponsible they are as a function of their addiction, the more responsible the pull to fulfill the obligation for the adult children.

INT. You want to say more about that? In the other situation before diagnosis that you can think of that may have ...

AIDS-C-BC2 Before diagnosis with AIDS?

INT. Yes.

AIDS-C-BC2 Well, I won't be redundant. I am sure a lot of people have talked about growing up in strong family systems, or having a spiritual foundation with which to approach life, so I would say, I am thinking of a couple of clients that I have had, PWAs, not necessarily addicts, who seem to have grown up in very normal family situations where there were good enough limits with responsibility, where there was some notion of faith, some consentual set of values to adhere to, and that you would call a fairly normally well adjusted person, will tend to continue their adjustment. Maybe they would be set back quite a bit not having developed coping skills in crisis as much as people that grow up in a dysfunctional environment. But still, I would say that they have an enormous well of what you would call normalcy, wellness to draw on. They have that basic trust, that basic security. It is not as hard for them to reach out for help or to know where to get it. Because they have been accorded esteem by others they have their own self esteem and they feel empowered by essentially sound, healthy attitudes, having been valued one values oneself and tends to take care of oneself as a matter of routine, rather than discovery. I would not know, I am an adult child. They are hurt people.

INT. ??. Are you speaking about...you are not speaking of your population of addicts now.

AIDS-C-BC2 No, I am not.

INT. Are you speaking about other long term survivors of AIDS?

AIDS-C-BC2 I am talking about PWAs I have known who seem to be doing better than many in terms of seeming to be not bowled over. Seem to be coping well, seem to be attending to what needs to be attended to, be it their physical condition, their spiritual connectedness, making executive decisions, appointing executors. Being active in their treatment process, all these things kind of tend to stem from a reasonably healthy, wholesome upbringing, where the world was reasonably predictable because the family situation was stable. Community, some connectedness with some kind of religious affiliation, having done well in school, having a value on competence, and some confidence because they have competence.

INT. So of course for these people it is a major blow to lose work or to lose love from quarters where they did not expect it as they come up with "The Plague".

AIDS-C-BC2 I see people who are doing well partially because they have done well and their esteem has a firm foundation.I mean, it is very trendy and popular in the Rod McKuen kind of way to say "You can't love anybody else until you love yourself." I would submit that you can't be loved until you have been loved and the pump needs to be primed. People who have gotten their basic goodies and gone through their Eriksonian stages with basic trust and basic autonomy and industry and all of that good stuff, their development tends to lead to graceful dealing with the disease.

INT. So some of the feelings you described within this situation were feeling of trust and security. Confidence.

AIDS-C-BC2 Confidence. And confidence that has been bestowed and therefore can carry forward.

INT. Were there role models in this situation, is that ..

AIDS-C-BC2 Often parents, often people that they have admired or relationships that they have cultivated because they have enjoyed what other people stand for. It is very common to draw on the ego strength of others, it is not just counselors who learn these things.

INT. So in the other situations of the, certainly the addiction, there is that issue of negative role models.

AIDS-C-BC2 Yes.

INT. And, as we said, they transcend, the people who are doing well transcended that, that negative influence.

AIDS-C-BC2 Or are working on transcending it. But it is kind of like, if you have to come a greater distance to get something you appreciate it more because it is harder won. Even if it seems less tenuous and less congruent with previous experiences.

INT. It sounds like a skill of transcending negative influences.

AIDS-C-BC2 Absolutely.

INT. It is a skill that came out of dysfunctional families.

AIDS-C-BC2 One thing that I'd say generally about counseling to people is "Show me someone who can't learn from their problems and their trials, and I show you someone who cannot learn."

INT. Can we look to some of the skills now over there and see if you can generate some ....just fill it out a little bit more....I want to go off tape for a second.

INT. Allright the first skill that I have is living with AIDS versus dying with AIDS and how does it come about. And the thought was "One never knows, there is always a chance", emphasizing on the quality of life.

AIDS-C-BC2 I think that this is something that comes about largely by education and connection with other empowered PWAs and supporters, along with a basic notion of personal dignity and worth. So I have the disease, does that make me an invalid? Does is make me a pariah. I think not.

INT. You know, I am not going to try to write these down. I'll just let you fly, because I can go back and listen to this section of the tape.

AIDS-C-BC2 Hit me.
INT. OK. Now you can use this cue off this. So you said "connection with other PWAs". that talks about current positive influences and the development of this skill. Functions of having this skill?

AIDS-C-BC2 Self-acceptance, acceptance of one's condition and resistance to the nay-sayers and judgmental types that are out there.

INT. Living in the moment versus projecting.

AIDS-C-BC2 Promotes spontaneity. How is it developed, gee, I don't know, I can send you the to Fritz Pearls on this one, but I think it has to do with burning out the habit of projection and realizing that it get you nowhere. When is it learned? Probably at about the point that you get fed up with trying to live in the past or the future and figuring out "Gee, if I just relax and do what I can right now, this is really the only time I have, the only time any of us have. That is not to say don't make plans, that is not to say don't look towards the future, but don't get lost in it.

INT. What are the feelings in that moment.

AIDS-C-BC2 Whatever they are in the situation as the situation is, as opposed to whatever they were or might

become as projected or transported. Does that make any sense.

INT. Sure. Now you mentioned in the last one that ...

AIDS-C-BC2 What is gained by this, I would like to say, I think is a sense of freedom and of infinite possibilities, rather than being condemned to repeat the lessons of history. The chance to take a divergent path.

INT. Do people and connectedness with other PWAs and that kind of thing help in here or is it important?

AIDS-C-BC2 Yes.

INT. Role models again and support?

AIDS-C-BC2 Role models, or what I would say is being a part of a positive culture, a positive consentual value system rather than a condemning one.

INT. Acceptance without rumination.

AIDS-C-BC2 OK. How is it developed. Either it is something that someone has done habitually. How it is developed, I am not sure in that case but the other one is being where rumination gets you, which is generally stuck, a feeling of running on ice, spinning one's wheels and being woefully unhappy and so "Don't worry, be happy" is not a bad idea.

INT. Is that an old skill or a new skill?

AIDS-C-BC2 It is very often either a new skill or revisited old skill, that one comes to at the point at which they realize that "gee, all I am doing is getting unhappy and putting myself on an endless treadmill. This sucks, I want to get off."

INT. How does that feel?

AIDS-C-BC2 Probably like a tremendous release and relief. Sort of a freeing in space and time. Not to the degree of an out of body experience, although there are some PWAs who have died technical deaths with overdose and when they come back, I hear many PWAs say, a statement I have heard over and over "I do not fear death one bit. Getting sick, facing decrepitude scares me silly."

INT. Is that a skill, not fearing death?

AIDS-C-BC2 It is to be worked towards, I think, fear of death as in awe of it and respect for it and also fear in

the sense of something that makes one clutch one's chest and breath shallowly. It is definitely a skill to learn to face that and to remain calm and remain determined and capable, rather than being blown away. And that gets back to fundamental existential belief that, you know, we gain and we are who we are in dynamic tension to death in the shadow of loss.

INT. This respect and fear of death, especially for your addict population sounds like a very good skill.

AIDS-C-BC2 Yes. And a valuing of life. For other, particularly non addicts, it is nothing that is new, but something that needs reinforcement and reminder. Because, I think, there is almost always some ego and actual regression at the point of information, sort of "Oh, I have got it huh".

INT. OK. Physical self-care.

AIDS-C-BC2 When developed? Often developed in antithesis to poor self-care, sometimes developed from way back when. Many people will have been organic earthy-crunchy, attuned to these things, into an idea of wellness. Not necessarily your addict population, but other populations, and continuation of that gives a sense of continuity, a sense of business as usual, but different. It helps a lot. When is it developed? I guess it is developed as someone values themselves inside, that they are worth their own care.

INT. Is that typically after diagnosis or is that ...

AIDS-C-BC2 For many it is a pre-existing thing. Can be after diagnosis. If there is exposure to this kind of thing, it can be drawn on. The exposure to it can often happen before diagnosis. You know, you can look at someone and say "Gee, they don't seem to live a tortuous life, how do they do it", and the same thing you are wondering in your study, if probed by the person who is now dealing with AIDS, leads to results. They can figure it out.

INT. Right. OK. Caring choosing and supervising the healing. Taking charge of their treatments of all types.

AIDS-C-BC2 When developed? In dealing with consultants or healers who they have used either historically or certainly in the present moment, it sure picks up a bit as most people find the need to be followed by a ..... physician, an infectious disease specialist and then whoever they call in around that. And that is just the medical side. With social services often there is a need not only for case management but for counseling, and than

there is all the support people depending on what degree of physical capacity they are experiencing and it goes right down the line and unless someone is active in that, you have too many cooks spoiling your personal broth very quickly. So, rather than being directed, you direct.

INT. So, what are some feelings that one might experience before assuming this skill, subject to all this input.

AIDS-C-BC2 Before kind of being at the whim of the establishment, wondering where to turn, what advice is sound, what is bullshit. And when I am hearing five different things about the same question from five different people, maybe I better take the helm here.

INT. So there is a particular point of frustration, and they decide to take charge?

AIDS-C-BC2 Yes, frustration and often a vacuum of answers or a plethora of answers and therefore, you know, to thine own self be true, it is not that I disrespect or necessarily distrust all of these people, but they can't all be saying different things and still be wise, I need to adapt my own course as I see some wisdom in it. The feeling that comes from that is competency, which is control and competency, what do they have to do with each other. They are virtually synonymous when you come down to competency theory. And I think competency control means a lot more than the subtleties of psychodynamics. Excuse me for sounding plebeian.

INT. Staying connected to others. I got here that the function of being connected is to maintain dignity versus detachment and isolation. You resist the modern day leper notion. Valuing and being valued as another.

AIDS-C-BC2 What can I say, it is developed at whatever point in time ,it is developed if you have it to draw on before your diagnosis, so much the better. If you develop it afterwards, it is still a good thing.

INT. Is it typically developed before or after?

AIDS-C-BC2 I can't say.

INT. Good, that is a good answer. Centering.

AIDS-C-BC2 When is it developed? I would say either in the past or in the present situation where one has felt a certain amount of chaos and needs an internal connection. Obviously there is greater integrity in people who have had better psychosocial development and a better environment to foster that kind of growth. We are talking in general

terms about all that is known about human development and the more you have been given the more you have to build on.

INT. Right. Congruence.

AIDS-C-BC2 What can I say. In terms of it being a skill and when it is learned I guess it comes around beginning with a period of abstract reasoning and identification with other people as having nerve endings and what have you goes way back in development and then developing a habit of introspection, not just in the intellectual sense but also in the emotional sense and also examining its behavior. These are all aspects that chase one another around.

INT. Its function is that it brings things into line.

AIDS-C-BC2 It brings things into line and really the individual attains integrity in the sense that they are integrated in that functioning. Basically what you see is ...if you want to go into tripartheid theory... the superego lagunae begin to evaporate when people begin to get their act really together. They examine things they did not look at before, they look at the incongruities and inconsistencies and try and bring it all together.

INT. What are some of the feelings that led up to that development skill or to take that action.

AIDS-C-BC2 I would imagine that the adversive converse if you will and the discomfort from that would tend to lead one to want to get their act together for peace of mind and serenity, as opposed to chaos.

INT. Yes, is acting to accomplish one's own congruence a new skill among your survivors?

AIDS-C-BC2 Well, I would say, along with Rogers, that it is a life-long project. But let's say this. It can get accelerated with diagnosis in that people realize there is quite possibly a very limited time to come to maturity, and so I best get on with it, or the other option "screw it."

INT. Self-confidence, empowerment and healthy entitlement. These folks are consumers in the AIDS industry and people of the world. It is a way of resisting any sense of diminishment and foreclosed options. Speaks to the functions pretty clearly. Is this a new skill and what are the thoughts and feelings?

AIDS-C-BC2 As it pertains to empowerment as a PWA it is a new skill because it pretty much comes with diagnosis, unless one is a member of a population and has had some realization in advance of their being diagnosed. This is

happening to others who are like me, and then it can be very much predeveloped and just brought home. And you said thoughts and feelings? That stem from empowerment?

INT. No that lead to development of this skill.

AIDS-C-BC2 The thoughts and feelings that help the empowerment. " Hell it feels good" and that is reinforcing. So the feelings would be competence, self esteem, belief, rootedness and relatedness.

INT. Here is a good word. Screw guilt. Often the result of physical activity in the past.

AIDS-C-BC2 Yes, physical, sexual, or emotional abuse in the past, either committed or done to or done to someone else reflexively as a result of having been done unto, sort of a chain of action as an inherited thing and guilt tends to be paralyzing and immobilizing. You are just stuck with it. There is nothing else and so the recommendation is for remorse, which means "I did not like what happened to someone else or to myself as a result of this situation. I did not like the way I felt about it and therefore I have the option to change it. Not to remain stuck in guilt but to do something different."

INT. Taking care of business.

AIDS-C-BC2 TCOB.

INT. Or unfinished business, those are two different skills.

AIDS-C-BC2 I think the second one is ordinate to the first and regards business that could have been taken care of in the past and was not, usually with adversive results.

INT. Taking care of especially unfinished business.

AIDS-C-BC2 And business in the present in terms of ..there are ...aspects of one's own case management if you will, one can only make the final decisions, about, even if other people could execute that. It's back to consulting with physicians and attorneys and friends and deciding whether or not to make a living will. Taking charge.

INT. The goals, the function is to take things in order?

AIDS-C-BC2 To get things in order and feel as though one has ordered one's own life in as much as that is possible.

INT. What leads up to this. Fear?

AIDS-C-BC2 Back to competency and control as basic human motivations. What is avoided by using that skill is feelings of helplessness, what is avoided is an attitude of having been defeated and just waiting for the coup de grace. And yes, that covers it.

INT. Skill at grieving losses. Loss is boss. Separation anxiety, loss as the shadow of death, seeing AIDS as a ...

AIDS-C-BC2 Grieving is a skill which to man is a high degree of integration and I would refer you to everything that Kubler-Ross has written about this and the stages of grieving and overcoming denial and getting all... it's like playing pinball. You are scoring the most points when you have the most bonus lights lit up. You can get them all lit at the same time, you win the game.

INT. The function of this is, as you say, it increases perspective and scope. It normalizes..

AIDS-C-BC2 And congruence and realizing that yes, to live and to be alive with aspects of yourself, the lives of other human beings, to be alive in time and a limited sense of time, really requires learning to say hello, and goodbye, learning how to feel what you feel, process what you feel and ultimately to let go in order to embrace new things. New people, new ways.

INT. Wonderful. Commanding dignity and respect by presence versus allowing pity. Or getting hooked into secondary gain.

AIDS-C-BC2 When is this skill developed? Probably about the time that someone ... post diagnosis.. it could be developed at any time of course and the earlier the better for anybody.

INT. What is it usually?

AIDS-C-BC2 For the PWAs I can't generalize on this, but what I would say is very often PWAs learn very carefully to gauge their disclosure with anybody.

INT. Don't forget we are asking about PWAs who are doing best.

AIDS-C-BC2 The PWAs that are doing best have learned that it is probably not such a great idea for them to wait and be dependent in their response on what someone else things but to really be forward. Not necessarily in an obnoxious way or an aggressive way, but to be assertive and to appear

that, you know, no matter what other appearances may be that I know who I am, I know what I am doing, I know what I want, and for God sake do not treat me as some kind of cripple, I kick you in the balls.

INT. What is the feeling of being treated as some kind of cripple?

AIDS-C-BC2 It is being reduced, it is being the object of pity or censure. It is being seen as pathetic and really I suppose it is anger at being seen that way.

INT. I understand. Assertiveness, especially about needs.

AIDS-C-BC2 When is it developed. It could be developed at any time, like everything else. The earlier the better, like everythingelse. Post diagnosis. Those people who do best kind of have learned after there have been negative consequences to being railroaded, particularly managed in a medical sense, but also by counselors who have had their own notions or trying to impose them too aggressively or listening to the advice of too many friends that is too divergent in having to find their own course. Therefore they can identify what they need and if they can assert that they tend to get more regularity in their lives, and more of what they want, more of what they truly need as opposed to what people want to heap on them.

AIDS-C-BC2 Is that a traditional stance, to make that stance, or that is something that is developed out of this need to order.

AIDS-C-BC2 I would hope that it is a traditional stance, but like many other things I have said, it is probably accelerated by the process of being bounced around in the service provision network and learning that you need to take control because there is a real vacuum of leadership. Or there is too much leadership in that your doctor might say "I tell you what I want you to do here, items 1 through 45. Follow this rigidly or you are going to die tomorrow."

INT. What does it feel like to be bounced around?

AIDS-C-BC2 Angering, helpless, a little bit confusing, a lot confusing and sort of despondent.

INT. The next one has to do with expressing thoughts, feelings and emotions...being open.

AIDS-C-BC2 All of the above, except that I would say post-diagnosis with the expectation being learned that time is on a reduced scale, most probably. Even though I would

say it is a separate skill to say "Whatever time I have, I have and I will use it to the best". This gets back to congruence. That's what the benefit is, but I think the concision of time forces one to get that together if they are to feel mastery or to feel swept away. If they are given that choice, most people will try and go for mastery. Control and competence. I feel like I am just babbling and repeating myself and Henny is liable to shoot me. Except she does not know who I am.

INT. Doing a great job Henny.
Because a lot of these skills are coming from the same situation, granted and understandable, we are going to be redundant and that is some of the essence of doctoral work.

AIDS-C-BC2 Lucky you.

INT. I am hoping to condense this stuff to real precise things.

AIDS-C-BC2 That is what I feel I am not giving you, this precision.

INT. No, you are, because what you just told me is there is a lot of communality in here. That is the precision I am looking for.

AIDS-C-BC2 OK, consistency.

INT. Yes, that's how precise I want to be. What is consistent among all these things and what you are doing is you are telling me this is consistent, this is consistent, this all came from this. No, that is what I mean by precision. Complexity at this point is diversity and you can't make any profound statements about something that is too complex. So, you are doing good.

Functional denial, it helps them to continue to function and with relatively less self-consciousness, avoid getting hung up and overwhelmed, avoid the syndrome of AIDS in my face.

AIDS-C-BC2 So when is functional denial learned? Usually when someone faces a crisis, and the demand is that they need to continue to function. That can happen at any time but it certainly happens when they learn they have "IT". The feelings are "Get with it, or get lost" in its wake. External influences, people and experience, I imagine role models, being with other empowered PWAs, seeing what works for other people, comparing notes, working towards an identification, figuring out who is sympathetic to one and who has written one off, and to be able to write them off in counterpoint. You don't like mine, I don't like yours.

INT. Doing what needs to be done. An empowering skill versus sitting back and taking it.

AIDS-C-BC2 Learned at any time I guess. We have stated the feelings in the converse so the feelings in what one gains from doing that?

INT. What led to this. What are the feelings that led them to develop that skill. Feelings of helplessness, or

AIDS-C-BC2 They are either experiencing the results of inactivity or lack of initiative, once again learning through adversive conditioning. Or by seeing what someone else has achieved by being an empowered person and taking things on. Inspiration if you will.

INT. Functions of purpose and meaning. You said they gain identity as strong as possible. Connectedness within oneself and within a community. Rootedness, relatedness, being centering, avoid static situations, avoiding being overwhelmed by disease.

AIDS-C-BC2 Stability without stasis. All of the above?

INT. Yes. The function is really clear. As clear as we need to make it. Seeing the situation as a challenge or opportunity.

AIDS-C-BC2 As opposed to seeing it as a death sentence or. This, I think gets back to the essential existential question. You cannot change the cards you have been dealt, but you've got to know how to play it. And that will cost you more money than bad cards. If one is challenged one is responding to a challenge, one needs to become active as opposed to vegetation. An opportunity is an essentially positive thing and a calamity is essentially the opposite. I mean, half full, half empty, that's what we get to. In extremely reductionistic terms.

INT. So these people decide "I am going for it".

AIDS-C-BC2 And they also say "I am going to use what I have going for me to continue to get more going for me as opposed to just cashing in."

INT. Caretaking within one's limits.

AIDS-C-BC2 Also you can label that generativity. If one feels one is given to oneself or has been given to, altruism or other qualities which are admirable, one can feel good about giving it back what one has been given. There is a lot to be said for saying "Gee, not only am I managing about as well as can be expected, maybe even better than

can be expected, but I am now capable of giving to someone else and helping them along the road and I can feel good about my role in this."

INT. Beautiful. And if I don't be generative...

AIDS-C-BC2 OK, am I a citizen of the world or am I an island apart unto the main or am I in this with everybody else. When I hear the bell ring is that just Joe Blow?

INT. Control. I think you really spoke clearly of control in some of the others. And politically active.

AIDS-C-BC2 When does this skill develop? I was referring specifically to being politically active about PWA issues. That means with the FDA, that means with the doctors, that means with the CDC, that means with State Government, with funding, that means a lot of different things right down to street theater.

INT. Is that a new skill for most of these people?

AIDS-C-BC2 Can be but does not have to be. There have been a lot of people who have been politically active before, around either conventional or radical politics or the politics of gay empowerment. And so for many it is not a new skill. For many it is. If you want to do a simple division of major populations, for addicts it is a brand new skill, for many gays it is not a new skill, it is a new application of an existing set of skills. Because to live in a homophobic society and defend one's very essence against constant attack requires a great degree of adaptation, self assurance and the ability to thumb one's nose at people who are just ruckus rednecks if you will.

INT. So they gain self assurance, in being politically active they also gain a support group?

AIDS-C-BC2 And empowerment and they also attract the attention of many non-supportive groups, even aversive groups, but to take that on and to state from the core and from the heart, often at a high volume, often in a pitched arena, who they are and what they believe in is affirming. And it gets around to identity.

INT. Yes. Great. You said "Even when I might go down the next couple of years the torch will be passed on.

AIDS-C-BC2 Yes, a believe that people die but relationships go on. AIDS is here, it is not going away, that they are part of a movement, they are part of a thing greater than just their own lives and times. Transcend-ence.

INT. What leads them to become politically active, what are some of the feelings.

AIDS-C-BC2 I would imagine a lot of anger, indignation, fear and anything else that would be part of being part of the population that has a general perception that some people are trying to do something for us, but a lot are not. And all the bigoted attitudes would tend to promote that, and I have examples of those in the essay I have provided you with.

INT. Now, I wrote a couple over here and just want to make sure that you are considering them skills. And one you said was "giving it over, surrendering". "I have run amuck" is one of the thoughts.

AIDS-C-BC2 Now, when I say "giving it up" it is similar to..

INT. "Giving it up" or Giving it over"?

AIDS-C-BC2 Giving it over to the care of a Higher Power. This is in particular reference to the skills of recovery for an addict. First step in AA is "Admit it to God that we are powerless over alcohol, that our lives have become unmanageable". OK. And if you can admit that and if you can let someone or something else in for guidance and realize the error of your over controlling in a maladapted way, then you can figure out that you need to have another influence from outside of yourself because of what you have doing doesn't work.

INT. And you see this as an essential skill for folks that are doing best.

AIDS-C-BC2 Particularly in my recovering PWAs, yes. Surrendering of control,surrender of obsession, surrender of one's personal demons.

INT. You said "recovering PWAs", did you mean recovering addicts?

AIDS-C-BC2 Yes.

INT. What leads up to them finally giving it over, feelings of what?

AIDS-C-BC2 Well, when the feelings finally come over and when they come face to face with their vapor trail, when they have to fly back through it and realize that it is hot and toxic, that kind of coming to terms generates wanting to have another way. What are we responding to again?

INT. Giving it over, surrendering. Allowing oneself to ...

AIDS-C-BC2 So what leads to it is a realization and that realization is that the more I tried to control, the more I tried to do it my it my way, the more I insisted on the selfish options, the more fucked up my life became, the more unmanageable. Excuse my French.

INT. That is a good way to end.

AIDS-C-BC2 Are we done?

INT. I think we did it. For you and for the record I very much thank you.

AIDS-C-BC2 My pleasure. Hopefully this contributes. I would like to get whatever results you have. I don't need a copy of the dissertation, but.

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