

QUALITY OF LIFE AMONG PERSONS WITH AIDS IN A
HOSPICE SETTING: A QUALITATIVE STUDY

A DISSERTATION
SUBMITTED IN PARTIAL FULFILLMENT OF THE REQUIREMENTS
FOR THE DEGREE OF DOCTORATE OF PHILOSOPHY
IN THE GRADUATE SCHOOL OF THE
TEXAS WOMAN'S UNIVERSITY
COLLEGE OF NURSING

BY
ELIZABETH AMOS, B.A., B.S.N., M.S.

DENTON, TEXAS

MAY 1997

TEXAS WOMAN'S UNIVERSITY


DENTON, TEXAS

December 10, 1996



To the Associate Vice President for Research
and Dean of the Graduate School:

I am submitting herewith a dissertation written by Elizabeth A. Amos entitled
"Quality of Life Among Persons with Aids in a Hospice Setting. A Qualitative
Study".


I have examined the final copy of this dissertation for form and content and
recommend that it be accepted in partial fulfillment of the requirements for the
degree Doctor of Philosophy with a major in nursing.


Diane Ragsdale, Ed.D., Major Professor

We have read this dissertation
and recommend its acceptance:

Accepted


Associate Vice President for Research
and Dean of the Graduate School

Copyright © Elizabeth Amos, 1997

All rights reserved.

ACKNOWLEDGEMENTS

The completion of this educational project was facilitated in many ways by many people. I could not have achieved this goal without the help and support of mentors, family and friends.

I would like to express sincere thanks to my dissertation chairperson, Dr. Diane Ragsdale, and committee member, Dr. Joseph Kotarba. Under their expert wings, I discovered the joys of qualitative research and completed my first flight. And to my other committee member, Dr. Lynn Wieck, I extend my thanks for her encouragement and expertise from this project's inception to completion. I am grateful for the collective efforts of these individuals, as well as many other faculty from Texas Woman's University and The University of Texas-Houston Health Science Center School of Nursing, who contributed to my doctoral education.

I recognize further the support of my friends and colleagues at The University of Texas-Houston Health Science Center School of Nursing, who were there for me and

patiently encourage me, especially Drs. Barbara Shelden Czerwinski, Jim Turley, Ginger Kee, and Mary Joe White.

Haven Hospice (a pseudonym) has provided the first opportunity for nurses to perform research with this project. I am deeply grateful to this wonderful organization and its founder, for supporting this first of hopefully many research opportunities.

Special acknowledgement goes to the persons with AIDS who shared their thoughts, hopes, fears and tears with me. I thank them all for the privilege of allowing me to share in their lives and for being in my memories.

Most importantly, my family has been a source of support and deserves great thanks. Devon and Jenny made many sacrifices in order for me to pursue doctoral studies. My husband, Doug, continued to love and encourage me during this process, and my appreciation is beyond words. This degree is as much theirs as it is mine.

QUALITY OF LIFE AMONG PERSONS WITH AIDS IN A
HOSPICE SETTING: A QUALITATIVE STUDY

ABSTRACT

Elizabeth Amos

TEXAS WOMAN'S UNIVERSITY
COLLEGE OF NURSING
MAY, 1997

Persons with AIDS (PWAs) approaching death face a number of problems that must be effectively managed in order to minimize suffering and to increase the quality of their remaining lives. In order to implement holistic care for PWAs approaching death, nurses and other health care providers need to gain insight into the dying experience of PWAs. This study used a qualitative approach based on grounded theory methodology to explore and to describe the perceptions of PWAs who resided in an AIDS-dedicated hospice. Participants were engaged in semi-structured interviews. Theoretical sampling resulted in a sample size of 10 residents. Interview transcripts were reduced, coded, and categorized in order to uncover emerging themes.

Application of grounded theory techniques to the data identified a process model called *Living while Dying of AIDS* which described the work performed to improve the quality of their remaining lives. The process began with *entering the hospice* followed by *adapting to the hospice*. Quality of life concerns were related to physical functioning ability, relationships with family and significant others, and social and environment satisfaction. Successful outcomes strengthened their capability to work on emotional and spiritual well-being concerns during the final process stage called *managing dying*. Findings and interpretations were validated with caregivers and other members of the research team.

AIDS hospices can provide the support needed to promote quality of life among residents. Quality of life is enhanced when nurses and other care givers support PWAs' work-related activities as they are dying.

TABLE

I.	Table 1.	Participant Characteristics	49
----	----------	---------------------------------------	----

LIST OF FIGURES

I.	Figure 1. Working on Living While Dying of AIDS .	117
II.	Figure 2. Working on Living While Dying of AIDS And PWA's Quality of Life Concerns . . .	118
III.	Figure 3. Process Model of Living While Dying of AIDS	119
IV.	Figure 4. Entering the Hospice	120
V.	Figure 5. Adapting to the Hospice	121
VI.	Figure 6. Managing Dying	122
VII.	Figure 7. Quality of Life Concerns	123

TABLE OF CONTENTS

ACKNOWLEDGEMENTS	iii
ABSTRACT	v
TABLE	vii
LIST OF FIGURES	viii
Chapter	
I. INTRODUCTION	1
Research Questions	9
Summary	9
II. REVIEW OF LITERATURE	11
AIDS	12
Nursing Research	14
Caring for the AIDS Patient	17
Quality of Life	19
Quality of Life and HIV Disease	22
Summary	24
III. METHODOLOGY	26
Sample	29
Setting	31
Study Design	31
Protection of Human Rights	32
Data Collection	34
The Process of Data Analysis	37
Criteria for Rigor in Ethnography	39
Summary	43

IV.	ANALYSIS OF DATA	45
	Respondents	46
	Hospice Setting	47
	Findings	48
	Entering the Hospice	52
	Adapting to the Hospice	59
	Managing Dying	65
	Summary of Quality-of-Life Concerns . . .	73
	Summary of Findings	76
V.	SUMMARY OF THE STUDY	81
	Discussions of Findings	83
	Stage One: Entering the Hospice	86
	Stage Two: Adapting to the Hospice	90
	Stage Three: Managing Dying	91
	Conclusions and Implications	93
	Recommendations for Further Study	94
VI.	References	97
VII.	Appendices	107
	Appendix A. Consents and Approvals . .	108-110
	Appendix B. Demographic Data Sheet . .	111-112
	Appendix C. Semi-Structured Interview Guide	113-115
	Appendix D. Figures	116-123
	Figure 1: Working on Living While Dying of Aids	117
	Figure 2: Working on Living While Dying Of AIDS and PWA's Quality of Life Concerns	118
	Figure 3: Process Model of Living While	

Dying of AIDS	119
Figure 4: Entering the Hospice	120
Figure 5: Adapting to the Hospice	121
Figure 6: Managing Dying	122
Figure 7: Quality of Life Concerns	123

CHAPTER 1

Acquired Immunodeficiency Syndrome (AIDS) is a highly lethal and transmittable disease that emerged during the 1980's as a major global public health problem (Solomon & Temoshok, 1987; Wolcott, Fawzy, & Pasnau, 1985). A person with AIDS (PWA) faces health management problems associated with an illness that is both chronic and terminal (Durham & Cohen, 1991). AIDS is terminal because there are no procedures or vaccines to ultimately arrest the damage to the body's immune system caused by the Human Immunodeficiency Virus (HIV). Persons with HIV are diagnosed to have AIDS when the immune system has weakened to the point that they experience syndromes or opportunistic infections that place them within the United States Center for Disease Control's (CDC) Diagnostic Category of AIDS (Durham & Cohen, 1991). At this point, the PWA can expect to experience chronic health problems due to complications associated with a variety of infections that ultimately will be fatal. The survival time or chronicity of a PWA's

illness varies and may be prolonged through the use of drugs such as zidovudine (AZT). Moore, Hidalgo, Sugland, and Chaisson (1991) reported, for example, that between 1987 and 1989, the PWAs who were given AZT experienced median survival times of 700 days whereas PWAs who did not receive AZT had a median survival time of 190 days. In 1996, Moore Keruly & Chaisson, reported a survival advantage lasting between 1 and 2 years. Protease Inhibitors, the newest approved drug for 1996, has yet to have long term evaluation with a large population. Based on outcomes from research trials prior to the release of this drug, researchers place great hope in reduction of mortality and thus the extension of chronicity of the disease (Mocroft, Johnson, & Phillips, 1996).

The type of care received by PWAs may vary with individual states of illness (acute or chronic) and personal circumstances. PWAs may adopt a home-care strategy and accept hospitalization as health problems become acute. The cost of hospitalization and special drug therapies in the

treatment of PWAs is a major concern as their financial resources diminish. As AIDS complications develop to a point where death is perceived as imminent, PWAs may choose to receive a palliative or hospice style of care. As with many other terminal diseases, both the home and hospice are cost-effective settings to provide the required care for the dying patient (Durham & Cohen, 1991). Scitovsky (1989) suggested that "there is an urgent need to develop methods of long-term care that are especially suited to PWAs" (p. 32). This need is underlined by ongoing statistics reported by the CDC. Since 1981, 338,831 persons in the United States have died of AIDS (CDC, 1996). There were 250,000 new cumulative AIDS cases reported in 1992 in the United States, which reflected an increase of 20% at a current annual rate (CDC, 1996). As of 1996, there continues to be a 20% increase in newly diagnosed cases and cumulative new AIDS cases now total 548,102 (CDC, 1993). As a result, both prevention of HIV infection and care for persons with HIV/AIDS have been defined as high priorities

for nursing research (Larson & Ropka, 1990; Ragsdale, 1993).

Current nursing literature contains useful information on medical regimens and interventions to alleviate physical complications experienced by PWAs. There is, however, only limited literature related to perceptions by PWAs of their situations as they attempt to deal with their problems. This understanding is necessary to conceptualize holistic nursing care for PWAs. Ragsdale, Kotarba, & Morrow (1992a) stated that an understanding of quality of life, as perceived by PWAs, is particularly relevant. Quality of life has been a useful concept in the past to devise strategies for helping clients with the dying process when the notion of a cure is not relevant (e.g., cancer).

Predictions of a continued increase in the spread of HIV/AIDS demonstrates a need for a two-fold approach in nursing care and the entire health care community: (a) to focus on the care and treatment of PWAs, and (b) to determine what PWAs perceive as factors affecting their quality of life (Newman, 1991). Health care professionals

generally refer to quality of life as the impact of sickness and health care on an ill person's daily activities and sense of well-being (Berg, Hallauer, & Berk, 1976; Guidotti, 1976; Moinpour, Hayden, Thompson, Feigl, & Metch, 1990; Sadler & Grausz, 1976; Shaw, 1977). The Agency for Health Care Policy and Research defined quality of life as "an expression used in speaking of issues relating to normalizing the life of a chronically ill individual" (US Dept. Of Health and Human Services, 1994, p. 150). While researchers in the field have yet to develop agreement on how to define and uniformly measure the quality of life (Ragsdale & Morrow, 1990), there is general agreement that chronically ill patients are concerned with maintaining quality of life at the highest practical level, despite the nature of their illness (Katz, 1987; Newman, 1991; Strauss, 1975).

Prior research on quality of life has been concerned with application of instruments which attempt to quantify quality of life as a multidimensional variable (Ragsdale &

Morrow, 1990) that may or may not be positively impacted by successful interventions. The initial study on quality of life of HIV-positive (HIV+) persons used quantitative instruments; it found that quality of life varied according to HIV classification and was most impacted in the AIDS-related complex (ARC) category (Ragsdale & Morrow, 1990). Ragsdale et al. (1992), in a study of quality of life of PWAs in a hospital setting, expressed concern, however, that the traditional quantitative approach of evaluating quality of life research does not fit with the holistic approach in nursing care. As a result, these researchers employed a qualitative approach in order to gather data and describe the PWA's "perceptions of the relative effectiveness of a chosen or ascribed management style in solving practical problems associated with being seriously ill" (p. 259).

There is no nursing literature looking at quality-of-life issues of AIDS persons while in a hospice setting. The hospice setting is increasing as a choice option for the dying PWAs. As AIDS comes to be viewed as a chronic rather

than terminal illness, long term nonhospital based care strategies will become more important. As a result, there is a general need to explore care strategies and patient satisfaction with all out of hospital settings. This quality-of-life study explains and describes PWAs' perceptions as a basis for developing patient-centered holistic care strategies, in which the patient assumes ultimate responsibility for, and control over, health.

The present study is concerned with quality of life perceptions of PWAs who are in the terminal stages of their disease and who have chosen to die in a hospice setting. A hospice setting provides a philosophy of care that includes palliative treatment (symptom, pain, and comfort management) and not curative treatment (Koff, 1980; Kohut & Kohut, 1984). The hospice provides a type of care that is reserved for only those patients with terminal illness (Hurt, 1992; Kohut & Kohut, 1984). Hospice care has a holistic focus and is concerned with "maximizing the quality of life when the quantity of that life cannot be increased" (Magno, 1990, p.

1090). The environment of the hospice is very much like home; the setting contributes to its noninstitutional concept of care (Ley, 1988).

Dying PWAs' perceptions of quality-of-life are important to understand in order to assist them in attaining the highest possible quality of life in dealing with their impending death from AIDS. The hospice setting is an area of nursing care for PWAs that has not been fully investigated; this setting is particularly relevant when trying to understand quality of life perceptions of dying PWAs who have much to share. Research in the field of hospice care issues for PWAs was additionally relevant, since it addressed alternatives to hospital care. These issues must be understood as part of the overall nursing research efforts in order to develop long-term, holistically focused health care strategies for PWAs.

Quality of life issues among terminally ill PWAs are lacking in the literature. Words, thoughts and experiences of PWAs dying of AIDS in a hospice setting are needed to

help describe quality-of-life as experienced within the hospice culture. Therefore, the following research question was proposed. What is quality of life among PWAs residing in a hospice setting?

Research Questions

This study was qualitative and exploratory in nature. The problem that this study investigated was quality of life among residents in a dedicated AIDS hospice. Therefore, the following question was proposed, What is quality of life as perceived by PWAs residing in a dedicated-AIDS hospice setting?

Summary

AIDS is a serious public health problem forging into the 21st century. As increasing numbers of PWAs turn towards to alternate health care delivery settings, use of the once-underutilized hospice has occurred. The increase of PWAs in the hospice setting has also lead to care givers' awareness of a literature deficit. This literature deficit is in the patient perspective area of their disease.

Qualitative methodology is the appropriate way to explore the PWA experience, and grounded theory were selected to guide the study. Knowledge gained from participants in their naturalistic setting can serve as the basis for nurses and other health care providers to generate protocols of care for the hospice AIDS clients.

CHAPTER 2

REVIEW OF THE LITERATURE

Quality of life and HIV disease are controversial issues that have become concerns for all health care workers. There have been many debates in the health care field over the last several decades about how quality of life should be defined and measured and what influence quality of life should play in dealing with patients. Likewise, there has been much controversy about HIV disease in the health care community since acquired immunodeficiency syndrome (AIDS) was identified. The effect on the lives of people diagnosed as having been exposed to the virus has been profound. As persons with AIDS (PWAs) are living longer, it is the nurses who provide the bulk of care to this population. Nurses have long been concerned with all aspects of the patient. In order to facilitate care for the individual, nurses are increasingly turning their attention toward aspects of care which patients identify as affecting their quality of life. Therefore, this chapter presents a

view of the literature relevant to the variables of this study. The morbidity and mortality of AIDS in the United States, the direction of the literature concerning AIDS and hospice as well as discussion of quality of life will be reviewed.

AIDS

The disease, AIDS, was first reported in 1981. According to CDC, there were 500 cases that year and 200 deaths due to AIDS. By December of 1986, there were 30,000 cases with 20,000 deaths (CDC, 1991). In 1989, there were 35,233 reported AIDS cases. This was a 9% increase over 1988 cases and included 2,000 HIV infected neonates (CDC, 1991). In the first six months of 1990, there were more than 20,000 reported AIDS cases (CDC, 1991). The continued increase in AIDS is evident in the 1996 CDC statistics in which the cumulative total of cases reported has reached 548, 102 cases with 338,831 deaths documented. The case numbers are expected to increase progressively, as are the fatalities. Most of the AIDS cases have occurred in the cities of New York, San Francisco, Los Angeles, Houston,

Chicago, and Miami; however, the epidemic is increasing in the smaller communities and represents a major public health crisis (CDC, 1991).

The infectious nature, intractability and terminal nature of AIDS were major sources of fear. That these mostly young people would die soon was a major source of stress not only to the patient, family, and health care workers, but also to the community.

Although there is extensive literature on HIV/AIDS in the health care community and the lay press, very little of the research dealing with HIV disease has been directed from the patient's perspective. Most research on HIV disease has involved the etiology, diagnosis, medical therapy, descriptive epidemiology, prevention, pathology, and complications of the disease, itself (Larson, 1988). As the epidemic of HIV infection continues to grow, identification of individuals with HIV disease is critical, but this identification must not result in denial of needed care or in the provision of suboptimal care within the health care community (Health and Public Policy Committee of American

College of Physicians and the Infectious Diseases Society of American, 1988). Therefore, the next logical step in research is the examination of the effect that HIV infection has on a patient's physical and psychological condition and social position.

Nursing Research

The nursing profession has recognized the need for quality research concerning HIV infection to enhance the basic information already in place on the disease and on how to care for people with HIV infection. Larson (1988) reviewed extensively the nursing literature and found no articles suggesting inquiry into research on the patient's perspective. Larson (1988) also looked at issues of Index Medicus and found that 25% of the entries on HIV infection were related to nursing care "how to" articles and 47.2% of the HIV-related entries were opinions and discussions. Some nursing studies are found in the nursing literature, but most are focused on nurses' attitudes and concerns about HIV disease. Ragsdale (1993) built upon Larson's (1988) and Larson and Ropka's (1991) review of the HIV nursing

literature and found a slight increase in nursing research since the first HIV case was reported. This is disappointing, as the HIV incidence has continued to increase, and nursing has not been instrumental in guiding the research (Ragsdale, 1993). Other findings of this study include the discovery that no articles were found on physiological aspects of care while psychological aspects of care were published discussing quality of life issues, coping, grief of survivors and self-care. Health care delivery, prevention of transmission, knowledge, behavior, and attitudes, research concerns and ethics. The newly founded Journal of AIDS Care, (JANAC), has since been supportive of nursing research and in the last 4 years, has assisted HIV-dedicated nurses in publishing their findings. Also, nurses have now established and are recognized with a new certification at the national level for AIDS specialization. Physiologic studies constitute the majority of topics published and the knowledge-practice gap identified by Ragsdale (1993) is slowly narrowing. However, the patient perspective is still not included in the study

design or research, and controversy at the curricula and funding criteria level need to be better facilitated in order to see an increase in this work. Qualitative work exploded in the late 1980's and early 1990's in nursing research, but lack of funding and lack of support outside of nursing has brought this effort to a halt. The direction recognized by the major funding arenas is patient outcomes, and evaluation mechanisms are being explored in order to best achieve this research design. Outcomes research is underway currently and should become visible in the literature going into the 21st century.

Vachon, Lyall, and Freeman (1977) measured the emotional stress of caring for the dying and found the stress measured the same as that for newly widowed women. This finding might be a variable that PWAs and their significant others experience in their decision to enter the hospice. Lamerton, Bisby, and Sanders (1973, cited by Vachon, 1987) explored the nurse's role of caring for the dying patient. It became obvious that terminal care brought new priorities to the dying patients. Comfort was the goal over cure.

Caring for the AIDS Patient

Nursing care of the AIDS patient is complicated and demanding. The AIDS patient may exhibit: (a) central nervous system alterations that include seizures, ataxia, and inappropriate behavior; (b) tachycardia, mottled and cyanotic skin, purplish Kaposi sarcoma tumors, skin sloughing from allergic reactions; (c) labored and rapid respiratory rate; (d) candidiasis of the mouth, bowel adhesions and perforations, viral bowel disorders and diarrhea; (e) experimental drug side effects that include kidney failure and hair loss; and (f) fever and night sweats. Most early AIDS cases came from marginal social groups such as homosexuals, bisexuals, and intravenous drugs abusers, constitute the early AIDS population (Durham & Cohen, 1991).

The literature is lacking in information on what the perceived the patient needs are. Castles and Murray (1979) assessed nurses' attitudes toward care of the dying. Another study that illustrates how nursing research expands our understanding of people's health-related experience

addresses the problem of personal control among persons with cancer. Concerned about the quality of life of late-stage cancer patients, Lewis (1982) assessed whether perceptions of personal control by these patients resulted in greater self esteem, less anxiety and a greater sense of purpose of life. As one means of supporting patients, nurses commonly have offered them greater control over treatment. Despite the intuitive appeal, of belief that more treatment control produced greater self esteem, this relationship had never been tested. Lewis found that personal control over life in general was associated with greater self esteem, less anxiety and a greater sense of purpose of life. In contrast, perceived control over one's health was not related to anxiety or self esteem and was only weakly related to sense of purpose of life. These results suggested that well being for late stage cancer patients is not a function of the perceived control they maintain over health but a more generalized sense of control over their lives. Lewis (1986a) suggested that late stage cancer patients lose their concern about maintaining a sense of

control over their health as their personal realities are resolved. This change may be a positive sign that the patients are dealing with the realities of their situation. Such studies do not exist with AIDS patients, at this time.

Quality of Life

Quality of life became a priority in Western society following World War II. During the 1960's and 1970's in the United States, surveys to describe quality of life were conducted (Andrews & Whithey, 1976; Campbell, Converse, & Rodgers, 1976; Cantril, 1966; Lui, 1975). Mukherjee (1989) has examined what he calls the two perspectives of quality-of-life research. The first is a social indicators research that considers what people need to attain a better quality of life and the second is a conventional quality-of-life research that ascertains the wants of people to improve the quality of life. He further suggested that the needs-based perspective on quality of life assumes a uniform valuation of social reality, while the people's valuation of want-based quality of life research is considered to be subsidiary. Oleson (1990) suggests that subjectively

perceived quality of life is a crucial factor in health care policy and treatment decision-making. Additional research is needed to further the concept of subjectively perceived quality of life as it is experienced by various populations. As the concept is further clarified and operationalized, nursing interventions may be devised, implemented, and tested for their effectiveness in enhancing subjectively perceived quality of life, thus helping individuals to achieve their desired level of self-fulfillment.

The expression, quality-of-life, refers both to experiences that make life meaningful and conditions that allow people to have such experiences. Multiple interventions of curative medicine and hospice care center on the quality-of-life in the second sense: they deal with conditions enabling people to have experiences that make life endurable and worthwhile (Ferris, Flannery, McNeal, Morissette, Cameron & Bally, 1995).

Survival is obviously one of these conditions, the reason for all of this experience. It explains past and current efforts to develop and expand technology of

medication and surgical advances for the purpose of saving lives. Individuals and their families have learned all too painfully that being biologically alive is necessary, but not sufficient for meaningful, worthwhile living.

Emancipating sick people from pain and unendurable symptoms is one of the conditions that sick, dying people most need in order to live their remaining time as fully as possible, true to themselves and family.

The first meaning of quality-of-life refers both to experiences that make life meaningful and conditions that allow people to have such experiences. But this is only part of the quality-of-life story. One tragedy of the human condition is that people can live and die without ever experiencing even a short moment "where there is no death" (p 13) and where time holds together with transcendent peace. Experiencing or rediscovering such experiences depends primarily on freedom from misery of body and mind (Ferris, Flannery, McNeal, Morissette, Cameron & Bally, 1995).

Quality-of-life in a second sense consists of such

freedom (Ferris, Flannery, McNeal, Morissette, Cameron & Bally, 1995). Multiple interventions of health care professionals have much to do with provision of that freedom. My meaning of quality-of-life differs from other persons' meaning, and we cannot determine the quality-of-life for those who are chronically ill (Fairbain, 1991). One can only imagine what it would be like for one to undergo such an experience (Elliot & Elliot, 1991). Therefore, health care providers are relying on their imagination to understand the PWA's experience. More studies designed to capture the perspective of the PWA with the experience of AIDS in a hospice are needed to base our practice on real experiences versus imagination.

Quality of Life and HIV Disease

A review of the literature revealed few studies published in health care literature concerning the quality of life of persons with HIV or AIDS. Two non-research articles in the nursing literature and one research study by an occupational therapist were found. Lasher & Ragsdale (1989) discussed the role of "significant other" in

improving quality of life for a person with AIDS dementia complex.

Ragsdale & Morrow (1990) conducted a study with 95 HIV-infected people to examine the variables associated with the disease and to determine if classifications differ from the disease status. The Sickness Impact Profile (SIP) and the Symptom Distress Scale (SDS) were used to measure quality of life. The results of the study indicate that, because of a variety of problems that impact the patients' quality of life, there is a need for individualized care with reassessment through the disease process. The emphasis should be placed on psychosocial support.

Research on an AIDS dedicated unit by Ragsdale et al. (1992a), looked at how patients manage everyday life in the hospital and found that patients' quality of life is enhanced to the degree that these styles (management) are supported by the nurse on the unit.

The scientific literature as previously noted does not address quality of life issues to any depth. However, discussions on the fictional list for lay persons found

under the category of spiritual realm contain a body of work weaving faith, myth, medicine, psychology together. Bolen (1996), a psychiatrist, has written and published three such books with the latest, Close to the Bone: Life Threatening Illness and the Search for Meaning. In this work, she describes that a life threatening illness results in a growth in creativity or service as an expression of shared humanity. The patient who has explored the inner impact of catastrophic illness also approaches living life's end with a different outlook. This holistic approach is healing and assists all persons involved to view living with a purpose. There is a need for authors such as Bolen (1996) to share this body of work and explore it in future with scientific rigor to benefit medicine and in turn, clients.

Summary

Health care literature is replete with information on both the concepts of quality of life and HIV disease, even though the subjects are relatively new. Quality of life has been considered a viable outcome variable for two decades. Both nurses and physicians have examined quality of life

most often in patients with cardiovascular disease and cancer. Quality of life, sometimes referred to as the quality of dying, has also been studied in hospice patients with cancer.

Since health care researchers have produced a growing index of research concerning HIV disease, most of this literature has addressed either the epidemiology of AIDS or the disease itself. Nurses, however, have studied how other nurses and health care workers feel about AIDS. Little nursing research has been reported that has examined how HIV disease affects patients.

In 1990, Ragsdale & Morrow studied quality of life as a function of HIV classification. They used a quantitative approach in which quality of life was defined statistically and surveyed by using established instruments. The study indicated that quality of life varied with the subjects' proximity to death; a finding which was consistent with quality-of-life studies for other diseases.

CHAPTER 3

METHODOLOGY

The purpose of this study was to identify what PWAs perceive as quality of life within the culture of a hospice. A qualitative approach to the research was utilized in order to explore this phenomenon. Following a brief overview of qualitative research, this chapter describes the study, including instrumentation and data collection procedures.

Qualitative approaches to nursing research focus on the discovery, meaning and understanding of phenomena in naturalistic settings (Benoliel, 1984; Field & Morse, 1985; Woods & Catanzaro, 1988). The characteristics of qualitative methods oriented to the inductive process provide descriptions of the emic perspective of phenomena significant to nursing (Field & Morse, 1985; Woods & Catanzaro, 1988).

The growing disillusionment of nurses who have used only quantitative methods to study nursing phenomena is giving way to more emphasis on the qualitative methods of study (Leininger, 1985). Qualitative methods also lend

themselves to address the kinds of questions nurses are interested in. In order to examine quality of life from the patient's perspective, the qualitative method was used.

The purpose of this study is to add to the overall literature on quality of life issues as well as the nursing literature. Sandelowski (1986), a nurse researcher, points out that the use of narrative allows researchers to gain invaluable insight into how human beings understand and reconstruct their lives through storytelling.

The choice of qualitative approach fits a trend cited by several nurse researchers: Aamodt (1982, 1983, 1991), Frake (1983), Germain (1982), Leininger (1985), and Watson (1985). Many other qualitative nursing studies have been conducted, and the qualitative method has been established as important for some nursing research questions (Boyd, 1990).

Qualitative research methods attempt to describe experience as it is lived to arrive at the meaning of the experience for the person (Oiler, 1982). Analysis of the patients' views of their lives will help to identify and

describe the elements of meaning in the quality of life.

The study used a qualitative approach, with data analysis driven by the logic of grounded theory as described by Glaser and Strauss (1967). Grounded theory as a research paradigm provides methodological guidelines for conducting research that are consistent with the humanistic, non-received view in nursing (Patton, 1990). The research findings constitute a theoretical framework of the reality under study rather than a group of numbers or a set of loosely related themes. Since its introduction 25 years ago, a number of guidelines and procedures have evolved through the research experience to enhance the effectiveness of this methodology. A central feature of this analytic approach is the constant comparative analysis.

Application of qualitative methods requires that the researcher approach the research questions holistically by going to people in their circumstances, where they are involved in the world. Data collection procedures must preserve the spontaneity of the subjects (Bogdan & Bikten, 1982; Oiler, 1982). Phenomena to be studied must be

experienced in the everyday, real world, and not created through experimental situations (Brink & Wood, 1988).

Sample

The target population for the research consisted of persons with AIDS residing in a hospice. The sample for the study consisted of persons within this hospice who volunteered as participants. The respondents were recruited for the study after being given the information about the research project. A purposive or theoretical sample enabled the researchers to select participants based upon the informational needs of the study (Morse, 1991). The participants selected were willing to reflect and share their perceptions regarding the questions asked with the interviewer.

The sample size was determined through the process of saturation as data were being collected. "Saturation occurs when the information being shared with the researcher becomes repetitive" (Liehr & Marcus, 1994, p. 264); therefore, the determination of sample size coincided with the analysis of the data. Residents were interviewed and as

the study progressed, the sample was assessed for its appropriateness and adequacy. Appropriateness refers to the ability of the researchers to select a sample that provided a broad knowledge base reflecting the perceptions of the study participants. Every potential candidate approached to be included in the study replied immediately. For example, Allan (pseudonym), took the pen out of my hand stating, "use my real name, I want to help others (with AIDS) any way I can. Can we start now?" According to Morse (1991), the test for appropriateness answers the question, "Do the methods used to select a sample facilitate understanding?" (p. 135). Adequacy refers to the quality of the rich descriptions elicited by the interviewer. Adequacy was assessed by the completeness of the information obtained. Adequacy is also referred to as saturation (Morse, 1991). In this study, adequacy was evident as each transcript was shared with team members and caregivers. The caregivers responded with "that is Don" or "sounds like Evelyn." In reviewing the transcripts, team members were correct 100% of the time in identifying narrator even if he or she expired

several weeks previous. The sample size was then based on appropriateness and adequacy.

Setting

All participants were residents of one hospice dedicated to the care of PWAs. This urban hospice, Haven Hospice (a pseudonym), was founded in 1986 by two prominent citizens. During its first 8 years of operation, it has cared for over 175 residents during the terminal stages of their AIDS disease. In 1993, Haven Hospice expanded from 3 to 8 beds to accommodate the increased demands. Haven Hospice is unique in that it is a freestanding, independently managed home, with care being provided mostly by trained volunteer personnel. The volunteers' priority is to provide quality care while supporting residents throughout the dying process. The qualitative method is most appropriate to address the research question of this study: "What is the quality of life as perceived by PWAs residing in a hospice setting"?

Study Design

A qualitative approach based on grounded theory methods

was used in this research. "Grounded theory is a research method used to search out facts or to relate factors that pertain to the research problem at hand" (Stern, 1985, p. 150). The aim of grounded theory is to accurately perceive and present the world of others (Hutchison, 1986). Simultaneous data collection and analysis aided the researcher in linking factors or patterns that helped explain the phenomenon under study. Hutchison (1986) noted that the grounded method is particularly useful if little is known about the topic. The emic perspective of the PWAs is not prevalent in the literature. Grounded theory is appropriate for this study, as exploration of the culture of PWAs will provide an emic description within the culture of a hospice.

Protection of Human Rights

In order to protect the participants in this study, the research protocol was submitted for review both to the Texas Woman's University Human Subjects Review committee and to the Haven Hospice (see Appendix A). During all contacts with the participants, the researcher identified herself as a

doctoral student at Texas Woman's University and as a registered nurse studying hospice residents' perspectives on quality-of-life issues.

Potential participants who expressed willingness to participate received an explanation of the study and were asked to sign the informed consent form. The telephone numbers of the researcher were listed in the informed consent form so that the participants could call if they had questions or concerns. Participants were informed that they could refuse to answer any questions, withdraw at any time, or request to stop the interview and continue at another time. Interviews were conducted in the privacy of participants' choice of settings within the hospice. All interviews were audiotaped. Code numbers were used to identify the participants on the audiotapes, verbatim transcriptions, and all forms of field notes during both data collection and analysis. All written information and audio recordings obtained during the interviews were destroyed upon completion of the data analysis. The master list of participants' names and assigned code numbers was

kept in a separate file under lock and key and was destroyed at the completion of the study. The audiotapes were used for research purposes only. Participants were identified by coded numbers to provide confidentiality. All interviews were held in private settings. Thoughts or feelings that could seriously affect patient safety which were expressed by the participant during the interview were reported to the care givers with the permission of the study participant. The results of this study were disseminated without revealing the identify of the participants.

Data Collection

This qualitative study is driven by the logic of grounded theory. In qualitative studies, the researcher is considered an instrument for data collection. The researcher problem and questions determine the focus of the study and also set the boundaries for data collection.

The data for this study were generated through semi-structured interviewing, audiotapes, sociodemographic data sheets and field notes. Verbatim transcripts of the audiotapes provided a permanent record of the interview

data. Field notes recorded descriptions of the informants, settings, and interview situations, as well as the researcher's impressions, reactions, and ideas experienced during the interview process and analysis. Each of the methods will be described in the following sections:

1. Sociodemographic Data. In order to describe the population of the study, sociodemographic information (see Appendix B) was collected from the informants. This information included age, gender, educational background, occupation, ethnicity, marital status, religiosity, belief system, residence, leisure and primary relationships.

2. The Interview Process. The purpose of the researcher's initial contact with the informant was to set up a mutually convenient date and time for the interview. All of the interviews took place at Haven Hospice for approximately 1 hour. Each interview began with greetings, social conversation, and comfort assessment. This strategy allowed the researcher and informant to become acquainted and to establish a rapport (Spradley, 1979). An explanation of the study was given, followed by the reading, explaining,

and signing of the consent forms. Obtaining the sociodemographic data allowed the researcher to ease into the interview questions.

3. Semi-structured Interviewing. Semi-structured interviewing (Leininger, 1985) is a method of data collection in which the interview is a combination of both the open and closed types of interview. It is designed to elicit both definitive and unexpected kinds of information from the person being interviewed. Semi-structured interview questions can be found in Appendix C. An example of a semi-structured interview item is, "Do you feel you are in charge of your life right now?" Use of this interviewing technique is congruent with the descriptive design of this study, based on the lack of knowledge about the resident's perspective of quality of life.

4. Field Notes. Field notes are the written, objective accounts of the researcher's observations and experiences while collecting data (Field & Morse, 1985). In qualitative studies, field notes are an essential part of data collection, because "even tape recorders and cameras

cannot capture all the relevant aspects of social processess" (Babbie, 1979, p. 216). In this study, field notes were recorded as soon as possible after collection in order to ensure an accurate recall of the interview sessions and observations (Woods & Catanzaro, 1988).

The Process of Data Analysis

Preparing the Data

Semi-structured interviews with the informants were tape-recorded. The tape interviews were transcribed verbatim, using a transcription machine and a word processor, from which the transcribed interviews were entered into the computer program, The Ethnograph (Seidel, Kjolseth, & Seymour, 1988). The Ethnograph provides printed copies of the transcripts that includes line numbers and wide margins on the left and right for use in coding the data reduction. The tapes were played while reading the printed transcripts in order to verify the accuracy of the transcription and to become thoroughly familiar with the data.

Data Reduction and Coding

The process of data reduction and coding began with the use of pre-specified codes (Miles & Huberman, 1993), that were developed from the research question. The preliminary data reduction and sorting provided an organizational structure for further systematic coding and refinement of the emerging categories. Using the latent content analysis, the dimensions and characteristics of these broad categories were examined for similarities. According to Lincoln and Guba (1985), the discovery and identification of meaning is subprocess in coding known as "unitizing" (p. 203). Unitized data described the dimensions, conditions, and relationships within the respective categories (Woods & Catanzaro, 1988).

Categorizing data is the second subprocess of coding by Lincoln and Guba (1985). This process builds on the unitized data and uses the constant comparative method (Glaser & Strauss, 1967) to examine similarities and differences across categories. In inductive analysis, the coding, unitizing, and categorizing of raw data enhances the

uncovering of themes. The identified themes generated theory.

Criteria for Rigor in Ethnography

Trustworthiness

Qualitative and quantitative researchers strive to achieve methodological rigor in their pursuit of scientific inquiry. Evaluative criteria developed in one paradigm do not transfer adequately for use in another paradigm (Lincoln & Guba, 1985); Sandelowski, 1986). Moreover, the conventional trustworthiness criteria of internal validity, external validity, reliability, and objectivity do not "fit" the epistemology of ethnography. Lincoln and Guba (1985) have proposed terms for the criteria that are used to evaluate the rigor of studies based in the ethnographic paradigm. The four criteria for trustworthiness in ethnographic studies can be operationalized as credibility, transferability, dependability, and confirmability; the criteria ensure rigor in this study. A discussion follows of how each criterion was achieved, and therefore, established the trustworthiness of this study.

Credibility

In qualitative studies, truth value resides in the discovery of human experiences and subjects' perceptions of their experiences (Sandelowski, 1986). Credibility is the criterion used to determine the truth value of ethnographic studies (Lincoln & Guba, 1985). Credible studies enable other people to recognize their own experiences in the written descriptions and interpretations of the study (Sandelowski, 1986). The credibility of this study was achieved through several strategies outlined by Lincoln and Guba. Credibility was achieved through triangulation of the methods of data collection, e.g., semi-structured interviewing and use of field notes. Member checks were done to establish credibility. These checks consisted of validating data, findings, and interpretations with some of the participants in the study (Lincoln & Guba, 1985).

Transferability

Qualitative and quantitative research differ in their meaning of representativeness or generalizability. The criteria of transferability refers to the applicability of

the findings to other populations in different contexts (Lincoln & Guba, 1985). That is, the findings have meaning and "fit" into the reader's experience outside of the context of the study (Sandelowski, 1986). In this study, full or "thick" descriptions of the sample, setting, and data will enable readers to determine the "fit" or transferability of the study's findings.

Dependability

In qualitative inquiry, consistency--not replicability -- is a critical issue. The criterion of auditability is used to judge the rigor or consistency of qualitative findings (Sandelowski, 1986). If other researchers can follow the investigator's decisions throughout the study and then come to similar conclusions, the study is auditable (Lincoln & Guba, 1981). Therefore, the decision trail used in the data generation and analysis of study was described explicitly.

Confirmability

All researchers strive to control bias both in the research process and in the product (Sandelowski, 1986).

This freedom from bias is called neutrality. Lincoln and Guba (1985) describe confirmability as the criterion of neutrality in qualitative studies. Although the researcher is subjectively involved with the informants during the research process, confirmability refers to the findings as determined by the informants and to the context of the inquiry but not to the biases or perspectives of the researcher (Lincoln & Guba, 1985; Sandelowski, 1986). In this study, the biases, assumptions and perspectives of the researchers were clearly identified. The researcher's decision trail was explicitly described throughout the research process. Member-checking was conducted with caregivers at the hospice for identification and agreement or disagreement with the interview content. Some PWAs were approached after their initial interview to confirm findings (Kirk & Miller, 1986). Sandelowski (1986, p. 33) states that "confirmability is achieved when auditability, truth value, and applicability are established." The above criteria was used throughout the study in order to maintain rigor and to demonstrate the reliability and validity of

this study.

Summary

A qualitative research approach that uses the semi-structured interview was employed in this study to describe quality of life from the AIDS hospice patient's perspective. Theoretical sampling techniques were used to select the informants for this study.

Informants were interviewed in the naturalistic setting of the hospice. Data were generated through audiotaped, semi-structured interviews, sociodemographic data sheets and the researcher's field notes and observations. An interview guide was used to elicit informants' description of their quality of life.

As part of the emergent design, data collection, coding, reduction, and analysis occurred concurrently. The data were inductively analyzed, using content analysis and the constant comparative method. During content analysis, a codebook was developed and used during the constant comparative process. Data analysis continued until saturation and redundancy occurred in the data, i.e., the

identified categories were mutually exclusive, and no new categories emerged.

Methodological rigor was achieved through the establishment of the study's trustworthiness. Credibility, transferability, dependability, and confirmability, the four criteria of trustworthiness were met through the use of the following strategies: triangulation of data collection methods of semi-structured interviews and field notes; use of thick description of the sample, setting and data; explicit descriptions of the decision trail; and member checks of the data, findings, and interpretations.

CHAPTER IV

ANALYSIS OF DATA

In this study, an ethnographic approach and grounded theory methodology were used to gain an understanding of the perceptions among PWA's in a hospice setting. Through a semi-structured interview process, the hospice residents provided the researcher with rich descriptions of their perceptions of life and death. Since the responses were not standardized, the qualitative analysis techniques of grounded theory and constant comparative analysis were used to develop a model, from their own words, of the respondent's perceptions. According to grounded theory, the conceptual orientation of this study, i.e., the application of a systematic set of procedures to qualitative data, may be used to develop an inductively derived model. This model then leads to a theoretical formulation of the reality under study. The resulting qualitative findings are longer, more detailed and more varied in content than are quantitative measures. A description of the findings are presented in this chapter.

Respondents

The population under study was composed of residents at an AIDS Hospice who volunteered to participate in the study. The respondents participated in a semi-structured interview process which included questions from which demographic data was compiled. This interview questionnaire can be found in Appendix C Semi-Structured Interview Guide. The participants were 7 males and 3 females, with 8 Caucasian and two African-Americans. Their ages ranged from 28 to 55 years. Areas of employment varied; three were laborers (odd jobs) and six were professionals (artist, businessman, manager), and one was a homemaker. Respondents identified the following religions: Catholic (6), Methodist (1), Jewish (1), Muslim (1), Baptist (1). Belief systems reported were religion (3), nature (1), none (3) and individual self (3). The respondents were generally well educated, 1 respondent completed a baccalaureate program, 1 attended college, 4 had completed high school. Only 4 of the respondents did not complete high school. All participants resided in the hospice when they were interviewed. Their stays varied from

one day to two weeks. All respondents of this study died within three months of inclusion in the study. Through the interview process, 10 residents shared descriptions of their perceptions of living and dying in the hospice.

Hospice Setting

Haven Hospice is a residential hospice for terminal-phase AIDS patients. It is licensed as a special care facility and to date has provided residency to over 200 persons without regard for their ability to pay. The hospice's physical appearance is that of a comfortable home. Care is taken by the nurses to preserve an appearance of a home-like atmosphere. Even the nursing station has a writing desk with a telephone. The kitchen hums 24 hours a day as does the laundry room. Home cooked meals can be prepared on-site by the residents or staff whenever needed. The bedrooms are private or semiprivate with volunteer staff always on hand to assist with any needs or requests. The outside gardens resemble a neighborhood backyard where residents and their care givers have access to the outdoors. Outsiders are viewed with suspicion and must gain the trust

of residents and staff (Gaskin, Sowell, & Gueldner, 1991). I had to be invited but my entrance was facilitated due to my supervising baccalaureate students for 3 years in the Hospice.

Findings

From the participants' descriptive expressions obtained during the interviews, emerging themes were identified and categorized. A common emergent theme consisted of working on living while dying of AIDS. A model of *Living while Dying of AIDS* was developed to represent this process schematically (see Appendix D, Figure 1). The processes experienced by the PWAs in responding to approaching death included:

- struggling with daily living and trying to decide what to do and resolving the problem by committing themselves to *entering the hospice*.

Table 1

Participant Characteristics

#	Pseudoname	Gender/Age	Race	Residence	Religion	Occupation	Visitors	Education
1	Allan	Male/31	Caucasian	Illinois	Catholic	Artist	mother, siblings	High school dropout
2	Bob	Male/39	Caucasian	Florida	Methodist	Pizza Manager	lover	HSLC
3	Carl	Male/52	African- American	Pennsyl- vania	Catholic	Odd job laborer	none	High school dropout
4	Dan	Male/55	Caucasian	Maryland	Catholic	laborer	none	HSLC
5	Evelyn	Female/32	African- American	Houston	Baptist	Executive Secretary	mother	4 years college
6	Fiona	Female/28	Caucasian	Florida	Jewish	odd jobs/ waitressing prostitute	friends	1 year college
7	Greg	Male/42	Caucasian	California	Muslim	importer	mother	HSLC
8	Hal	Male/37	Caucasian	California	Catholic	odd jobs	none	high school dropout
9	Ingrid	Female/47	Caucasian	New York	Catholic	homemaker	family	HSLC
10	John	Male/36	Caucasian	New York	Catholic	cook	friends	high school dropout

- feeling sick and trying to get comfortable and opening themselves to building a daily life during a continuing process of *adapting to the hospice*.

- choosing to try to understand and work on *managing dying* in order to summon the emotional and spiritual strength to establish a sense of purpose and control over remaining life.

Through entering and adapting to the hospice, the PWAs attempted to address concerns such as restrictions in functioning ability, satisfaction with social and care environment, and establishment of an environment where relationships with family would focus on emotional and spiritual well-being. For most residents, these efforts provided comfort and strength that enabled them to work more effectively on emotional and spiritual aspects of the difficult task of trying to manage and make sense of dying (see Appendix D, Figure 2).

Through the application of grounded theory to uncover further the social practices and perceived experiences of the PWAs, a process model emerged that described the

conceptual stages of living while dying of AIDS.

A process model involves time and depicts stages of the process with a beginning, an interim period and an end. The stages are conceptual categories and generally represent shifts in perspective or complexity involved with the process. Each stage may proceed at a different pace and involves a series of indicators that summarize how a particular stage in the process evolves. The process model is grounded in the empirical data and provides a framework both for describing how the phenomenon occurs and for understanding its meaning.

The process model of *living while dying of AIDS* was grounded in empirical data based on interviews of PWAs in a hospice setting (see Appendix D, Figure 3). The data indicated that PWAs experience of the process consisted of three conceptual stages:

1. Entering the hospice
2. Adapting to the hospice
3. Managing dying

Further discussion of findings follows the detailed

schematic of the process model of *living while dying of AIDS* and concludes with a discussion of how the process is driven by a consistent set of quality-of-life concerns shared by the PWAs. The model serves as an organizing framework to clarify the discussion of the described perceptions, but the model is not meant to imply a static perception of the experience. The unfolding of the process as humanly experienced by the participants is presented by using the rich, related descriptions that weave their personal stories.

Entering The Hospice

The first conceptual stage, entering the hospice (see Appendix D, Figure 4), was characterized by the process element of "having to do something." The PWAs spoke of a period prior to entering the hospice as one of "knowing things weren't right" and "trying to find the right thing to do." This period was seen as a key link between their prior lives and the process of *living while dying of AIDS* in the hospice. Three conceptual indicators were identified that categorized how the PWAs saw themselves as they became

actively engaged in the experience of entering the hospice. These elements consisted of *struggling*, *deciding*, and *committing*.

Struggling. All of the PWAs spoke of a period of anxiety and stress that varied in duration and depth for each resident prior to making the decision to enter the hospice. Major concerns were:

- issues involved with family and/or significant other regarding the decisions to go to hospice
- losing functional ability
- getting too sick to stay at home
- worrying about strain on family members or significant others providing care
- worrying about the financial impact and care regimens associated with staying in a hospital
- having unpleasant experiences with others who did not understand or disliked dealing with PWAs.

For example, Allan related an experience with his brother as follows:

My family told me something was wrong and that I

needed to go to the hospital. I knew something was wrong, too, but I didn't want to go. They didn't want to take me, but they had to. I was going to put my foot down, but had I done that, I would have fallen down.

Allan now recognizes that his brother had his best interests at heart. But, at the time, he was confused. While in the hospice, the family members were daily visitors.

Another resident, Bob shared his unpleasant experiences about his reasons for entering hospice.

Life was turning gray and I had lost a lot of weight. I didn't want to go back to the hospital. They have people who look down on AIDS, and it's hard to ignore. One nurse found out I had AIDS and left. I didn't feel I got good care.

Greg, an independent laborer had great difficulty in relying on others when physically unwell. His decision to enter the hospice was a result of:

...my roommate couldn't take care of me any more. He was working long hours and my body couldn't keep on his

schedule. He was up all night taking care of me. How can we be close if he has to take care of me that way?

Deciding. The manner in which PWAs decided to enter the hospice was closely linked to the struggling process. Several residents had not seriously considered entering a hospice prior to starting a period of struggling with their deteriorating condition that included admittance to a hospital. These PWAs "discovered" the hospice option through counseling efforts by others as their struggling reached crisis proportions. Several were counseled by professional care givers (physicians and social workers) who showed interest and were ready to guide and support the PWAs in evaluating whether or not to enter the hospice. For these PWAs, the scope of struggling expanded to include developing the emotional or spiritual outlook to consider hospice, and seeking the support of relatives in making a choice. Frequently, this activity took place in a hospital care environment and included evaluating hospice care as a means to resolve the stress of adapting to a hospital environment.

One resident, Bob, was very proud of his career and the fact that he was promoted to manager prior to becoming ill.

I learned about Happy Haven from my doctor at the hospital. He talked to me about my situation. It was a good suggestion. I spent a week worrying and trying to figure it out, but, as usual, I didn't have to worry about a thing.

Allan's decision to enter hospice was particularly stressful. His spiritual strength intensified with his diagnosis.

I was at the hospital, and the social worker told me about the hospice. I talked to my family about it, and God cleared the way for me. I don't know what would have happened to me if I hadn't found out about Happy Haven. When I first got sick, I had to put up with a lot of bureaucracy, and people were rude. At one hospital, they wanted thousands of money in cash, more money than anybody I know has ever had.

In some cases, a decision to enter a hospice "when the time was right" was made far in advance of any period of

struggling and represented a commitment that PWAs had made to themselves and shared with significant others. For these PWAs, the process of struggling was linked to evaluating if this was now the right time to enter the hospice. Typically, these individuals were at home and were being cared for by a significant other or relative. They were concerned about the strain of their deteriorating condition on their home care provider(s). Evelyn described her experiences as follows:

I was at home before coming here. I chose it because I had been a volunteer (here) a few years ago, and I liked it. I volunteered when I found out I had AIDS, and it made me want to discover and share a little bit. It's nice now for my mother. She can visit every day while I do what I have to do here.

Committing. The outcome of the decision process for the patients in this study was a commitment to enter the hospice as a final place to live while dying of AIDS. The commitment was flavored with several characteristic attitudes that influenced the subsequent progress made by the individual in

adapting to the hospice and managing dying. A limited number of individuals experienced significant "regret" for having left the previous care environment. Most PWAs, however, accepted that entering the hospice was necessary to resolve difficulties related to reduced physical functioning, treatment satisfaction and stress on relatives or personal relationships. A few of the residents spoke of choosing the hospice as a place to die. These PWAs "anticipated" the hospice would assist them in addressing important quality-of-life concerns associated with dying of AIDS.

Allan was an outgoing and well spoken. He described himself as a prophet and a teacher.

I knew about Happy Haven from a friend who was caring for me at his home. We had decided to come to this place, but the waiting list is very long. When we got the call that I could come here, he was sad, but I was happy. I was at a point where I couldn't stay alone and kept falling down, and I knew I didn't want to go to the hospital.

Ingrid, a grandmother, describes herself as having

lived it all, shared: "I need to be with others who won't judge me. We didn't know about this [disease] years ago, and no one deserves to be punished. I wanted peace."

Adapting to the Hospice

The next conceptual stage within the process involved adapting to the hospice environment and was characterized by the process element of *spending my time here* (see Appendix D Figure 5). The PWAs were in varying degrees of wellness when they entered the hospice, and they faced the task of adapting to a new environment where they would spend the remaining days of their lives. Three conceptual indicators emerged and could be categorized to describe the experiences of the PWAs as they integrated into hospice environment. The categories were *feeling sick*, *getting comfortable* and *making a life*.

Feeling sick. All of the residents spoke of feeling unwell due to weakness, physical pain or being overwhelmed by amorphous emotional concerns associated with dying of AIDS. For some residents, the experience of feeling sick was only interrupted by sleep. Most residents, however,

tried to manage incidents of feeling sick through relating to others, drawing on their emotional resources to avoid continual struggling and preoccupation with feeling sick and, if needed, taking pain medication. Allan tells of:

Being sick means not feeling well, not feeling up to something... and that is not feeling well. I feel like I've got AIDS, being tired, being restless and I have pain. The pain is more emotional than anything else, and I can't take much for that. I just stay quiet, and it goes away on its own. Sometimes I want to be with others for help, sometimes alone, or sometimes pray.

Bob said, "Feeling sick means having the virus, that's all I know right now." It was interesting that when the respondents talked about feeling sick, no one mentioned specific symptomatology.

Some of the PWAs felt disconnected, Dan, a veteran soldier stated, "I don't know why I am here. The hospital just didn't want to take care of me anymore."

Getting comfortable in the Hospice. Most of the PWAs spoke of a process of "getting used to" the hospice. Volunteers were available to assist residents in coping with physical limitations and accessing facilities to assist in relaxing. The residents could set their own schedules and even prepare their own food or go out for excursions if they wished. Everybody at the hospice was "nice," they were "accepted" and there were no "hassles." Relatives and significant others had flexibility in establishing visiting hours and routines. As the PWAs came to understand the hospice environment, they began to feel "at home" and work at getting more "comfortable." This was the beginning of a continuing process of adapting to the circumstances as a resident of the hospice. Allan stated:

The emotional pain is getting better, and I think I know that has to do with being comfortable here. It's like another home where you can feel in charge, and things can go the way you want them to. I like the idealism, activeness and limitlessness of the place

It makes me very comfortable.

After the interview, Allan continued this conversation with his new roommate and both were still talking together 30 minutes later. The support given to each other in the bedroom was a clear example of getting comfortable in the hospice. Bob feels, "It's nice, the people and all. When you have to do or have something, they are right there, they understand. Happy Haven is home; I have been totally accepted. I feel welcome here and I will be here until I die, and that's all right with me."

Making a Daily Life. The experience of the PWAs adaptation to daily living in the hospice varied. The outcomes of the process of adapting to daily living in the hospice environment may be categorized as:

Having a hard time - preoccupation with feeling sick, with little adaptation or experience of feeling better.

Liking it here - succeeding in getting used to the hospice and deriving treatment satisfaction and emotional benefit from being in hospice.

Some of the residents were too sick or weak to focus

on developing a daily hospice life other than feeling sick and sleeping. Still, these PWAs felt better knowing they were residents of a home-like environment where care and support were available to assist them in coping with dying of AIDS. They shared a sense of satisfaction with all of the residents. The sense of satisfaction was associated with not having to deal with hospital care or strain family resources with significant care requirements.

Most of the residents who adapted to the hospice liked the hospice-provided freedom to establish their own routines and live their own lives within the limitations of their capabilities. These PWAs were able to make additional progress in feeling better through relating to hospice care givers, receiving anticipated visits from relatives, and engaging in routine activities that served as sources of relaxation. Communing over past pleasant experiences, watching television, and preparing for visits were examples of activities used to reduce stress and relax. "Feeling OK" was a frequently used term to describe the experience of deriving benefits from adapting to the hospice environment

due to feeling at home, being accepted, released from financial concerns, being able to relinquish preoccupation with being sick, and having the opportunity to spend time with family while being cared for by others.

Bob, a resident of Haven House for the last two weeks, stated:

A typical day is watching TV, sleeping and smoking. I especially like it if someone comes to visit. I feel pretty good except for missing my old job and going fishing. I sleep in my leisure time. I have always liked to sleep. In the morning when I wake up, they [the volunteer care givers] look after me, since I can't get up. It bothers me, but I live with it. During the afternoon, I watch movies, and I eat when I feel hungry. At night, it is quiet.

Evelyn, a former volunteer care giver at Haven House 5 years ago, stated:

My mother comes to visit once a day. Before she comes, I do my hair. She likes it when I'm ready. The care givers at Happy Haven are very sweet, but

sometimes I need to do things for myself. I have my own room, I dress myself, and I do my own dishes. I can go out for walks if I want.

Carrying on with everyday activities was very important as long as they were able to do so.

Managing Dying

The third and final conceptual stage, managing dying, was characterized by the process element of "trying to make sense of it" (see Appendix D, Figure 6). The PWAs in the hospice knew that death was approaching through sensing their own deteriorating condition and knowing of the deaths of other residents. The PWAs spoke of dealing with this situation as an emotional or spiritual activity that was different from what they had expected. The process of trying to make sense of dying was seen as a separate activity from feeling sick and an alternative to activities associated with trying to feel better by relaxing or visiting. The process stage of managing dying was seen as hard work. The residents engaged in this stage by drawing on their own initiative and strength. Three conceptual

categories were identified that characterized how the PWAs experienced trying to make sense of dying. These categories were *trying to understand*, *living with a purpose*, and *getting it together*.

Trying to understand. All of the PWAs spoke of trying to deal with the emotional and spiritual aspects of dying with AIDS. Some elected to spend considerable time in dealing with this "grey" area while others retreated, since this area required hard work and distracted from efforts to "feel better" through relaxing or sleeping. Indicators of trying to understand involved setting aside time to pray or commune, opening oneself to thinking about difficulties and trying to make sense of their experience of dying of AIDS.

The residents were motivated to try to understand their situation due to a variety of factors. A strong element of "feeling sick" was associated with the emotional pain of suffering from a disease for which no cure could be expected. Many of the residents were religious and felt motivated to develop spiritual rationales as a source of strength and comfort in their lives. Others saw themselves

as members of a culture struggling with a new social experience; it was important to understand what others could learn from the PWAs' experiences in the hospice.

Said Allan, the artist and spiritual thinker, "I think people should really get into trying to understand more about AIDS. Every day longer I live, I try to understand more myself, and I hope I can help."

The PWAs who actively engaged in the process of trying to understand death experienced different outcomes. Some found the work too difficult or became too weakened and retreated to a point where simply trying to feel better, during these times deriving comfort from the hospice environment was their main focus. This focus left the residents with unresolved issues and concerns for trying to make sense of dying.

Some of the residents invested the emotional and spiritual time in trying to make sense of dying. This was met with or without success, they felt that *trying to understand* was important.

I don't really feel in charge of my life right now.

The situation is basically one of trying to deal with it. When it hurts, I let it go by. I wish I had tried to get past it earlier and went [sic] on with my life. I didn't, so I have to deal with it now. It's hard to explain.

Living with Purpose. This aspect of the process was exhibited by residents who had a strong image of themselves as PWAs who were members of the hospice culture and whose social and occupational focus was living while dying of AIDS. These residents recognized that hospice presented an opportunity to develop a new occupational focus concerned with managing how time was spent living and dying in the hospice. A key to the transition involved developing a lifestyle in which, to the extent possible, time was set aside and managed for dealing with a variety of quality-of-life concerns. Part of the routines involved trying to carry out activities which challenged and satisfied the individual, such as preparing food, learning new things and receiving important visits. Time for these activities was balanced with working on trying to understand. Separate time

was set aside to feel better by integrating and relaxing in the hospice.

The element of living with purpose also included addressing family relationships and trying to obtain closure on the part of both the family and the PWA. The availability of family and significant others to visit with the PWA was not only important for providing comfort, but it was also essential to providing the opportunity to work on closure. A lack of visiting opportunities led to frustration and reduced motivation to focus on the hard work of coping with dying.

The residents who established a sense of working on it did not necessarily resolve their concerns related to trying to make sense of dying. Nevertheless, they recognized that they were trying to organize their remaining lives to include the issue of working on understanding, and they were able to obtain some spiritual well being from the activity of working on it. Rewards, for example, came through overcoming bitterness and anger at their fate, and realizing that they were continuing to live as fully as possible.

Allan, who had been living at the hospice for the last 4 weeks stated:

A typical day for me at Happy Haven is work. I have never worked as hard before now. I study languages and I sketch like I used to when I was a commercial artist. I work from early in the morning until 4 in the afternoon, then I relax and watch a little TV. In the evening, I eat junk food or cook, and watch more TV or movies. When I don't feel well, I take time to meditate and pray. When I do this, He [God] takes my pain away. He [God] is my surgeon and healer. I love visiting, also, and have been fortunate to have my family spend a lot of time with me.

Evelyn, a college prepared executive assistant, shared her thoughts of life at the Hospice:

Nothing has prepared me for what I am going through now. I wish I could tell people what it's like.. and how this place helps you work to make a transition to whatever it is.

On a later day Evelyn said:

At first I was bitter and angry about catching AIDS, then I thought about it and how I have nobody to blame and I'm not bitter towards life. I have it [AIDS] and I just go day by day.

Another resident, Bob, who has been living in the hospice for 5 days shared: "I grew up Methodist and still believe in my own way of communing which involves thinking of nature and walking in the woods. It's the closest I can get to it".

Getting it Together. In one or two cases, the residents succeeded in reaching a state of control in which they were at peace and were able to manage their pain or prospect of dying without suffering. These individuals understood their situation and felt in control of the work of managing the quality of their remaining lives. This state was achieved by the residents who adapted to the hospice and saw it as an environment in which they could effectively address many of their quality-of-life concerns and work positively to make sense of their dying time. One

indicator was recognizing they were free to control emotional and spiritual outlook and how they spent their time. These individuals felt that they managed and controlled their pain. They felt at peace with their circumstances and indulged in hope that they could maintain their physical and emotional state up to the point of their death.

Evelyn stated her thoughts concerning her ability to get it together:

Since becoming partially immobilized and having to go the hospital and the Happy Haven, I have come to see things have always been there for me and that I am truly blessed with a good family, and things have turned around for me.

Allan shared:

Since coming to Happy Haven, I feel fine. There is no pain. God took it away so I could listen and have a clear mind to hear. I feel in charge of my life right now. I have freedom of choice which is important to my Indian background, and I hope I

have more time when I can live doing things I love like walking and eating, and that I keep my nice Indian hair.

I feel the Lord is in charge now, and that's alright with me. He has always been. Before, when I had pain, I took pills. It took something like this to make me feel closer to the Lord. I wish I had tried to get this close before and got past this sooner.

Summary of Quality-of-Life Concerns

An objective of this study was to understand the meaning of quality of life based on the residents' perceptions of their ability to exert meaningful control over the illness situation they viewed as relevant (Ragsdale, Kotarba, & Morrow, 1992b). There are two analytical elements to this concept: the residents' inventory of practical problems to address and the processes residents undergo to manage the practical problems.

The process model of working on living while dying of AIDS is intimately related to a conceptual view of quality-

of-life concerns of the PWAs (see Appendix D, Figure 7). In this model, the PWA is at the center of an environment of approaching death due to AIDS. The PWA within this environment must deal with a number of concerns that are related to quality-of-life dimensions. These dimensions include:

1. Physical and functioning ability due to disease.

This dimension is primarily influenced by the disease process and presents the patient with concerns over reduced functional ability, pain and physical self-image. These concerns are related to the current situation and to the uncertainty over the rate at which the disease process could worsen the situation.

2. Relationships with family and significant others.

This dimension focuses on the PWAs dealing with family and significant others. Areas of concern include stress for others, sorrow, desire for familial contact, appreciation, caring, and closure.

3. Satisfaction with social and occupational environment. These concerns involve PWAs, dealings with

other individuals such as care givers, with treatment satisfaction, and with the ability to derive meanings from daily activities and the surrounding environment. For example, an environment might be perceived as feeling like home, from which a sense of peace can be derived.

4. Emotional and spiritual well-being. This dimension focuses on the PWAs' ability to develop emotional and spiritual outlooks to achieve positive well-being despite the difficult situation being faced. Developing a feeling of being in control is a way of achieving same sense of well-being. Achieving progress in this dimension can assist in addressing concerns associated with other quality-of-life dimensions. A spiritual level might be achieved, for example, that allows a PWA to transcend concerns of physical pain.

The conceptual model indicates that a PWA individual emotional and spiritual well-being may interact with other quality-of-life dimensions. Well-being in this domain affects, and is affected by, progress in dealing with problems in other domains.

Summary of Findings

Analysis of interview transcripts with PWAs living in a hospice culture yielded a model of the process of living while dying of AIDS that was experienced by the hospice residents. The process model was grounded in the empirical data; it consisted of a set of conceptual stages which represented shifts in perspective or complexity involved with the process. The purpose of the model was to provide a framework for describing how the experience occurs within its cultural environment and understanding its meaning. Contemplation of the model stages and their descriptive categories led the researcher to the following summary description:

The experience of hospice residents living while dying of AIDS involved working on a process which led to committing to entering the hospice, adapting to the hospice culture and choosing to work on managing dying. The patient-directed process was centered on addressing quality-of-life concerns that included physical and functioning ability, family-type relationships, social and environment

satisfaction and individual emotional and spiritual well-being.

The core variable was "working" on the process of living while dying of AIDS. Each PWA sensed approaching death and struggled with the problems it presented as the process unfolded. The work involved a process that consisted of three stages. The first stage led to entering the hospice, followed by a second stage of adapting to the hospice culture. The final stage was managing dying. At each stage, the quality-of-life concerns addressed by PWAs differed, and the work required by the individual changed. The resulting view of living while dying of AIDS was patient-centered. At the same time, due to the changing circumstances of approaching death, the PWAs' experiences also reflected the dynamic nature of the work involved.

The initial process stage of entering the hospice was characterized by a period of struggling with concerns over reduced physical functioning, strain on close relatives and significant others who provided support, and the degree of treatment satisfaction associated with home, hospital or

hospice care alternatives. The work of deciding to choose the hospice alternative occurred, for some of the PWAs, in the midst of struggling under the guidance of health care professionals. For others, the hospice choice was planned, and the work of deciding involved gauging if the time was right. The outcome of the PWAs' decision process was a commitment to enter the hospice to live their remaining time. The commitment involved a mix of emotions ranging from regret to acceptance of the hospice as the best place to work on living while dying.

The process stage of adapting to the hospice involved dealing with being sick while trying to get comfortable and make a daily life in the hospice. Feeling sick was an amorphous concern related to feeling unwell due to weakness and physical or emotional pain. Most of the PWAs worked to obtain relief from feeling sick by trying to derive comfort from the home-like environment of the hospice and from the helpful volunteers. The residents also worked to establish daily living routines within the limitations of their capabilities. These routines included interactive, restful

and relaxing activities to reduce the strain of feeling unwell and the stress of approaching death.

The process of managing dying was characterized by an underlying need to try to understand the emotional and spiritual aspects of dying of AIDS. The PWAs invested varying degrees of effort in trying to understand their approaching death. Some of the residents came to shape their hospice lives with a purpose and occupational focus based on working on managing dying. This focus involved balancing their lives with activities that provided a sense of accomplishment and closure in the face of impending death. In a few cases, the residents who followed this path were able to get it together, i.e., to establish a sense of peace of mind and feeling of being in control of the pain of dying.

Present throughout the process was a consistent set of quality-of-life concerns. Reduced physical functioning triggered the sense of struggle which led to entering the hospice. This reduction in physical functioning ultimately controlled the PWAs' capability to work on adapting to the

hospice and on managing dying. Concern over close relationships was an important factor in committing to the hospice. This concern set emotional limits on the degree of comfort derived from hospice daily living and on the sense of closure in managing dying. Increased social and environmental satisfaction were regarded as important outcomes derived by the hospice residents through committing and adapting to the hospice. As the process unfolded, progress was made in managing concerns. PWAs were able to focus on trying to achieve a more complete emotional and spiritual well-being and an increased strength to work on the difficult task of managing dying.

CHAPTER 5

SUMMARY OF THE STUDY

Persons with AIDS (PWAs) approaching death face a number of problems that must be effectively managed in order to minimize suffering and to increase the quality of their remaining lives. Nurses and other health care providers need to gain insight into the experiences of PWAs who are in the final stages of living while dying of AIDS and to understand the human experience in order to implement holistic care for PWAs as they approach death. Increasingly, PWAs are choosing to spend the last days of their lives in hospice environments, where the philosophy of patient-centered holistic care is particularly relevant. The purpose of this study was to explore and to describe the perceptions of PWAs residing in a hospice setting.

An qualitative approach using grounded theory methodology were used to gain an understanding of perceptions of residents of an AIDS hospice called, "Haven Hospice". Theoretical sampling resulted in a sample size of

10 residents. The sample size was determined through the process of saturation as data were being collected.

Informed consent was obtained for study inclusion as well as for audiotape permission.

Participants were interviewed using a semi-structured interview guide (see Appendix B). Field notes were recorded immediately after the interview. Interviews began with general questions, such as, How are you feeling? in order to encourage residents to explore their experiences fully. Each interview was audiotaped and then transcribed. Data were reduced, coded and categorized in order to uncover emerging themes.

A common theme emerged, i.e., working on managing living while dying of AIDS. Additionally, applying grounded theory techniques further uncovered a process model entitled, "Living while Dying of AIDS," which described conceptual stages of the PWAs' hospice experience. The initial stage of the process, *Entering the Hospice*, included the conceptual elements of *struggling*, *deciding*, and *committing* as descriptions of the work related to developing

a commitment to entering the hospice. The next stage of the process, *Adapting to the Hospice*, included the elements of *feeling sick, getting comfortable and making a daily life at the hospice*. The final process stage, *managing dying*, involved conceptual elements categorized as *trying to understand, living with a purpose, and getting it together*.

During the steps of entering and adapting to the hospice, the PWAs worked on addressing quality-of-life concerns related to physical functioning ability, relationships with family or significant others, and social and environmental satisfaction. Successful outcomes strengthened the PWAs' capability to work on individual emotional and spiritual well-being concerns during the stage of managing dying. Credibility of the study was reinforced through validating findings and interpretations with the care givers who were other members of the research team (Lincoln & Guba, 1985).

Discussions of Findings

The PWAs residing in the hospice shared commonly accepted quality-of-life concerns that have been summarized

in the literature and studied for other types of ill patients. Cella & Tulsky (1990), provide a listing of ten quality of life dimensions derived from 30 different studies. These dimensions include: (1) physical concerns, (2) functioning ability, (3) treatment satisfaction (including financial concerns), (4) family well-being, (5) emotional well-being, (6) future orientation, (7) spirituality, (8) social functioning, (9) occupational functioning, and (10) sexuality (including intimacy and body image). These dimensions are similar to the categories of physical and functioning ability, relationships, social environment satisfaction and individual emotional and spiritual well-being, which were found to summarize the quality-of-life concerns expressed by the hospice PWAs involved in this study.

The PWAs dealt with these quality-of-life concerns in the form of practical problems; these problems differed between individuals, based on their circumstances, and changed at different points in time. This finding illustrates the difficulties cited in the literature in

attempting to measure quality-of-life as a dependent variable at a point in time and assuming that quality of life could be changed by medical interventions. This study conceptualized quality of life as a patient's ability to exert meaningful control over affective, cognitive, social and medical aspects of the illness situation perceived as relevant (Ragsdale, Kotarba, & Morrow, 1992a); it provided a more effective operational framework for understanding the experience of the PWAs residing in the hospice (Ragsdale et al, 1992a) used quality-of-life as a multi-dimensional concept that involved the patient's inventory of problems. This study breaks new ground in extending this concept to gain understanding of the experiences of PWAs in a hospice. The process model of *Living while Dying of AIDS* presents a multi-dimensional view of the PWA's hospice experience that shows how their ability to deal with an inventory of quality-of-life problems changes with time and circumstances. The core variable involved with the process was work, a finding that is consistent with Strauss (1975), who states that persons with any chronic illness must work

hard to manage their illness. He uses the term work to refer to a set of tasks performed by an individual or couple, alone or in conjunction with others, to carry out a plan of action designed to manage one or more aspects of their illness and the lives of ill people and their partners" (Corbin & Strauss, 1988, p.9). Previous studies involving this work have focused on the problems of managing living, including a study of hospitalized PWAs by Ragsdale et al.(1992b). This study found that the concept of work extends to managing dying, a new, yet not surprising, revelation.

Stage One: Entering the Hospice

The decision to enter a hospice involves formally recognizing that death is near and that a change is necessary in health care perspective and environment. Deciding to enter the hospice was a difficult task for the PWAs, their families and significant others. This finding is consistent with the statement by Elizabeth Kubler-Ross (1987) that an important "goal has been, and still is, to educate healthcare professionals to become more familiar

with the needs, concerns, fears and anxieties of individuals and their families who face the end of their lives" (p. 1).

"When science and medicine has done all it can, patients can either sign themselves into a palliative care unit or hospice where the quality-of-life is emphasized and not the prolongation of dying (suffering)" (Kubler-Ross, 1987, p.4). This study found that the decision occurred during a period of struggling with intense concerns over physical functioning, family well-being and treatment satisfaction. As a result, the process of entering the hospice was a traumatic experience for the PWAs that involved a dynamic interplay between *struggling*, *deciding* and, finally, *committing*.

The PWAs in this study were driven to the decision to enter the hospice in order to relieve their sense of struggling and to exercise control over their immediate situation. Control is another aspect of work described by Corbin and Strauss (1988). Strauss (1975) assesses control as preventing and managing medical crisis, managing regimes, controlling symptoms, reordering time and becoming socially

isolated. Preventing and managing medical crisis is a primary activity of which control is a central issue. The process of entering the hospice allowed the PWAs to overcome a sense of indecision or crisis and to exercise control over their situation.

In addition, this study found that several of the PWAs had distressing hospital care experiences with health care professionals; these experiences were major factors in their decision to enter hospice. This supports the conclusions of Foley and Fahs (1994), who found that responses from hospitalized PWAs, who were interviewed for their study, suggested themes of communication deficits and depersonalizing behaviors. They recommended further research to help healthcare professionals develop sensitivity to patient perspectives and evaluate and improve the experiences of patients during hospitalization for AIDS (Foley & Fahs, 1994).

Other PWAs who preferred to keep their situation as private as possible were unprepared for the severe difficulties that can be encountered in a home-care

environment. Not only do people with AIDS have to go through stages of dying, but they also are faced with issues the world has never had to deal with to such an extent, in such massive numbers, and from all ages and populations (Kubler-Ross, 1987). Discrimination from all facets of the community ranges from refusal to deliver food, share books or visit a PWA's home, to insurance policy cancellation and burial restrictions. These experiences may distinguish AIDS patients from other chronically ill patients who ultimately face decisions on choosing hospice care.

The literature does not reflect the linkage found in this study between the perceptions of immediate crisis experienced by the PWAs and their decision to enter the hospice. This study found that many patients were confused or without clear information on the meaning of hospice care. The result may have been late entry into the new setting, so they were too weak or lacked the time to work effectively on the remaining stages of adapting to the hospice and of managing dying.

Stage Two: Adapting to the Hospice

This study found that the PWAs were able to adapt to the hospice by achieving an improvement in quality of life in terms of their ability to exert meaningful control over practical problems of feeling sick, getting comfortable and making a daily life. A study of PWAs in hospital by Ragsdale et al. (1992b) found these patients worked on similar problems which were described as: (1) a sense of control, (2) physical pain, (3) comfort and security, and (4) everyday life on the unit.

Adapting to the hospice was viewed by the PWAs in this study as a unique and distinct problem that was separate from the more difficult process of "managing dying." This study found that the PWAs worked within the hospice environment to establish a sense of control over their daily lives. This finding is consistent with hospice care mission and philosophy, i.e., establishing a home-like, comforting environment where palliative care is provided and quality of life is emphasized. The finding in this study that the PWAs choosing hospice derived comfort and treatment satisfaction

supports the national trend that hospice is a viable health care alternative for dying PWAs.

Stage Three: Managing Dying

This study found that managing dying was characterized by an underlying need to work on the emotional and spiritual aspects of dying. This finding is consistent with the classic stages of dying discussed in *Death and Dying*, by Kubler-Ross (1969). Over 20 years ago, these stages were explained as denial and isolation, anger, bargaining, depression and acceptance. These 5 stages describe major emotional reactions that patients and family go through upon discovery of a terminal illness. These stages still hold true today, as cancer is joined by AIDS as a leading cause of terminal illness. Kubler-Ross (1969) identified that the stages did not need to be sequential, and in this study, hospice residents were found to be dynamically working at several stages concurrently.

The process model stage of *managing dying* identified three conceptual categories that showed how the hospice PWAs attempted to deal with the emotional and spiritual aspects

of approaching death. This need to manage dying included understanding the meaning of having AIDS, an area of work requiring special effort that was also identified by Ragsdale et al.(1992) as a major issue for hospital PWAs. Through support from others, and individual efforts, many of the hospice PWAs overcame feelings of isolation, guilt and depression over dying of AIDs. This step involved establishing a self-identity independent of being a PWA and working on living with a purpose focused on managing dying. In all cases, the PWAs appeared anxious to discuss their situation, either to build understanding or to reinforce their sense of living with purpose. Two of the hospice residents achieved a conceptual category termed *getting it together*, where they appeared to have dealt with dying and were freed to live their remaining time with a unique peace of mind as physical death approached. This step in the experience of managing dying is not discussed in the scientific literature and, yet, it clearly represents a quality of life state which care giving should assist dying persons to achieve.

Conclusions and Implications

Conclusions from the study include the following:

1. PWAs residing in AIDS-dedicated hospice settings engage in a process to improve the quality of their remaining lives.
2. PWAs engage in a process of living while dying that includes a great deal of work involved in overcoming crisis and taking control of their lives.
3. Caregivers, nurses or volunteers take on the roles of family members to support the work involved in living while dying of AIDS.
4. Dedicated AIDS hospices provide the support needed to increase quality of life among the residents.

The following implications are drawn from the findings of the study:

1. Quality of life is important to PWA hospice residents. Nursing care should be designed to support this patient-centered perspective.
2. PWAs expend energy while managing dying in the hospice. Nurses can be instrumental in supporting these work

activities.

3. Health care and other personnel should have educational programs to assist them in supporting hospice residents who are at different points in the process of managing dying. This includes residents who are trying to understand dying as well as residents who, in a spiritual sense, have died, and are able to focus on living as physical death approaches.
4. Nurses and supportive personnel who care for the residents need protocols based on the process of living while dying of AIDS.

Recommendations for Further Study

The following recommendations for further research are based upon the findings from this study:

1. Quality of life issues should be compared for AIDS versus non-AIDS patients in a hospice setting.
2. Research is needed to explore differences in quality-of-life experiences for those residents who are nurse care-managed up to hospice admission as compared to those residents who are self-directed to hospice

settings.

3. Nursing-directed research should be conducted to develop tools to assess the stage at which a client is working in the process of living while dying of AIDS, implement protocols to support the work phase and evaluate impact of supportive activities on quality of life.
4. Research is also needed to evaluate interventions to assist and support not only the PWA but also the PWAs' family. Although health care provider- directed support groups and bereavement plans are often used as an intervention method, the effectiveness of these approaches has not been consistently validated through research (Halm, 1990).
5. Quality of life, as defined in this study, provides a useful perspective to investigate issues that are important to PWAs in hospice. The work of managing dying is a dynamic process which includes trying to understand the meaning of having AIDS. PWAs are willing to share these experiences and provide nurses with data

to develop holistic, patient-centered care strategies.

6. Further research should investigate a comparison of quality of life work activities between PWA's and other residents with assorted diagnoses who live in hospice settings.

References

Aamodt, A.A. (1982). Examining ethnography for nurse researchers. Western Journal of Nursing Research, 4, 209-221.

Aamodt, A.A. (1983). Problems in doing nursing research: Developing a criteria for evaluating qualitative research. Western Journal of Nursing Research, 5, 398-402.

Aamodt, A.A. (1991). Ethnography and epistemology: Generating nursing knowledge. In J.M. Morse (Ed.), Qualitative nursing research: A contemporary dialogue (pp. 40-53). Newbury Park: Sage.

Agar, M. (1986) Speaking of ethnography. Qualitative research methods. Vol 2. Beverly Hills, CA: Sage.

Andrews, F.M., & Whithey, S.B. (1976). Social indicators of well-being: American perception of life quality. New York: Pelam Press.

Anderson, H., & MacElveen-Hoehn, P. (1988). Gay clients with AIDS: New challenges for hospice programs. Hospice Journal, 37-54.

Babbie, E. (1979). The practice of social research. Belmont, CA: Wadsworth.

Benoliel, J.Q. (1984). Advancing nursing science: Qualitative approaches. Western Journal of Nursing Research, 6, 1-8.

Berg, R., Hallauer, D., & Berk, S. (1976). Neglected aspects of quality of life. Health Services Research, 11, 391-395.

Bogdan, R.C., & Biklen, F.K. (1982). Qualitative research for education: An introduction to theory and method. Boston: Allyn and Bacon.

Bolen, J.S. (1996). Close to the bone: Life threatening illness and the search for meaning. New York: Scribner Publishers.

Boyd, C. (1990). Qualitative approaches to research. In G. LoBiondo-Wood & J. Haber (Eds.), Nursing research: Methods, critical, appraisal, and utilization (pp. 181-208). St. Louis: Mosby.

Brink, P., & Wood, M. (1988). Basic steps in planning nursing research. Boston: John and Bartlett.

Campbell, A., Converse, P.E., & Rodgers, W. L. (1976) The quality of American life. New York: Russell Sage Foundation.

Cantril, H. (1966). The pattern of human concerns. New Brunswick, NJ: Rutgers University Press.

Castles, M.R. & Murray, R.B. (1979). Dying in an institution: Nurse/patient perspectives. New York: Appleton-Century-Crofts.

Cella, D., & Tulsky, D. (1990). Measuring quality of life today: Methodological aspects. Oncology, 4, 29-38.

Centers for Disease Control (1996). Summary of cases of specified notifiable diseases. US cumulative week ending October 25, 1996.

Centers for Disease Control (1992). The second 100,000 cases of AIDS US: June 1981-December 1991. Morbidity and Mortality Weekly report, 41(2), 28-29.

Centers for Disease Control (1993). Summary cases of specified notifiable diseases, US cumulative week ending February 13, 1993. Morbidity and Mortality Weekly Report, (2), 30.

Centers for Disease Control. (1991). The HIV/AIDS epidemic: The First 10 years. Morbidity and Mortality Weekly Report.40. 357-365.

Corr, A., & Corr, D. (1983). Hospice care: Principles and practice. New York: Springer.

Corbin, J., & Strauss, A. (1990). Grounded theory research: Procedures, canons, and evaluative criteria. In Qualitative sociology. 13(1), 3-21.

Corbin, J., & Strauss, A. (1988) Unending work and care: Managing chronic illness at home. San Francisco, CA: Jossey-Bass.

Durham, J., & Cohen, F. (Eds.) (1991). The person with AIDS nursing perspectives. New York: Springer.

Elliot, C., & Elliot, B. (1991). From the patient's point of view: Medical Ethics and the moral imagination. Journal of Medical Ethics, 17, 173-178.

Fairbain, G. (1991). Enforced death: enforced life. Journal of Medical Ethics, 17, 144-149.

Ferris, F.D., Flannery, J.S., McNeal, H.B., Morissette, M.R., Cameron, R. & Balley, G.A. A comprehensive guide for the care of persons with HIV disease. ISBN 0662 22924-L.

Field, P.A., & Morse, J.M. (1985). Nursing research: The application of qualitative approaches. Rockville, MD: Aspen.

Foley, M.E. & Fahs, M.C. (1994). Hospital care ggrievances and psychosocial needs expressed by PWAs: an analysis of qualitative data. Journal of Association of Nurses in AIDS Care. 5(5) 21-9.

Frake, C. O. (1983). Ethnography. In R.M. Emerson (Ed.), Contemporary field research: A collection of readings (pp. 60-67). Boston: Little, Brown & Co.

Gallman, L. (1988). Caring: A concept within nursing (pp. 179-189). New York: National League of Nursing.

Gaskin, S., Sowell, R., & Gueldner, S. (1991). Overcoming methodological barriers to HIV/AIDS nursing research. JANAC, 2, 4.

Germain, C. (1982). Ethnography: The method. In P. Munhall and C. Oiler (Eds.). Nursing research: A qualitative perspective (pp. 147-162). Norwalk, CT: Appleton-Century-Crofts.

Glaser, B.G., & Strauss, A.L. (1965). Awareness of dying. Chicago: Aldine Publishing Co.

Glaser, B., & Strauss, A. (1967). The discovery of grounded theory: Strategies for qualitative research. New York: Aldine Publishing Company.

Guidotti, T. (1976). Five levels of interaction. The Western Journal of Medicine, 11, 395.

Halm, M. (1990). Effects of support groups on anxiety of family members during critical illness. Heart and Lung, 19(1), 62-71.

Health and Public Policy Committee of American College of Physicians and the Infectious Diseases Society of America (1988) The acquired immunodeficiency syndrome (AIDS) and infection with the human immunodeficiency virus (HIV). Annals of Internal Medicine. 108, (3), 460-469.

Hurt, D. (1992). An ethnography of an AIDS hospice. Unpublished M.A. thesis, Department of Sociology, University of Houston.

Hutchinson, S. (1986). Grounded theory: The method. In P.L.F. Munhall & C.J. Oiler (Eds). Nursing research: A qualitative perspective (pp. 111-130). Connecticut: Appleton-Century-Crofts.

Katz, S. (1987). The science of quality of life. Journal of Chronic Diseases, 40, 459-463.

Kirk, J., & Miller, M. (1986). Reliability and validity in qualitative research. In Sage University Paper Series on Qualitative Research Methods, Vol. 1. Beverly Hills, CA: Sage.

Koff, T. (1980). Hospice, a caring community. Cambridge, MA: Winthrop.

Kohut, J., & Kohut, S. (1984). Hospice: Caring for the terminally ill. Springfield, IL: C.C. Thomas.

Kubler-Ross, E. (1969). On death and dying. New York: Macmillan.

Kubler-Ross, E. (1987). AIDS: The ultimate challenge. New York, NY: Macmillan.

Larson, R. (1988). Nursing research and AIDS. Nursing Research, 37(1), 60-62.

Larson, R., & Ropka, M. (1990). HIV epidemic: Nursing in HIV infection: Prevention and care. National nursing research agenda. Developing knowledge for practice: Challenges and opportunities. United States Department of Health and Human Services, Washington, DC: Government Printing Office.

Lasher, A.T., & Ragsdale, D. (1989). The significant other's role in improving quality of life in persons with AIDS dementia complex. Journal of Neuroscience Nursing, 21(4), 25-55.

Leininger, M. (Ed.) (1985). Qualitative Research Methods in Nursing. New York: Grune & Stratton.

Lewis, F.M. (1986a). How adults with late stage cancer experience personal control. Journal of Psychosocial Oncology, 4, 27-42.

Lewis, F.M. (1986b). The impact of cancer on the family: A critical analysis of the research literature. Patient Education and Counseling, 269-89.

Ley, D. (1988). The Casey house model. Journal of Palliative Care, 4, 111-115.

Liehr, P., & Marcus, M. T. (1994). Qualitative approaches to research. In G. Lobiondo-Wood & J. Haber (Eds.) Nursing research: Methods, critical appraisal and utilization (3rd ed.). St. Louis: Mosby.

Liu, B.C. (1975). Quality of life indicators in the U.S. metropolitan areas. Kansas City: Midwest Research Institute.

Lincoln, Y., & Guba, E. (1985). Naturalistic inquiry. Beverly Hills, CA: Sage.

Magno, J.B. (1990). The hospice concept of care: Facing the 1990's. Death Studies, 14,(2), 109-121.

Miles, M.B., & Huberman, A.M. (1984). Qualitative data analysis: A sourcebook of new methods. Beverly Hills, CA: Sage.

Mocroft, A., Johnson, M.A., & Phillips, A.N. (1996). Factors affecting survival in patients with the acquired immunodeficiency syndrome. AIDS, 10(10), 1057-1065.

Moore, R. D., Keruly, J.C., & Chaisson, R. E. (1996). Duration of the survival benefit of zidovudine therapy in

HIV infection. Archives of Internal Medicine 156(10), 1073-1077.

Moore, R., Hidalgo, J., Sugland, B., & Chaisson, R. (1991). Zidovudine and the natural history of the Acquired Immunodeficiency Syndrome. New England Journal of Medicine, 324, 1412-1416.

Moinpour, G., Hayden, K., Thompson, I., Feigl, P., & Metch, B. (1990). Quality of life assessment in Southwest oncology group trials. Oncology, 4, 79-89.

Morse, J. (Ed.). (1991). Qualitative nursing research: A contemporary dialogue. Newbury Park, CA: Sage.

Mukherjee, R. (1989). The quality of life valuation in social research. Newbury Park, CA: Sage.

Munhall, P.L., & Oiler, C.J. (1986). Philosophical foundations of qualitative research. In P.L. Munhall & C.J. Oiler (Eds.) Nursing research: A qualitative perspective (pp. 47-63). Norwalk, CT: Appleton-Century-Crofts.

Newman, M. (1991). Quality of life of persons with HIV disease. Unpublished manuscript, Texas Woman's University, Houston.

Oiler, C. (1982). The phenomenological approach in nursing research. Nursing Research, 31, 118-131.

Oleson, M. (1990). Subjectively perceived quality of life. Image, 22(3), 187-190.

Omery, A. (1983). Phenomenology: A method for nursing research. Advances in Nursing Science, 5(2), 49-63.

Parse, R., Coyne B., & Smith, M. (1985). Nursing research: Qualitative methods. Bowie, MD: Brady Communications.

Patton, M.Q. (1990). Qualitative evaluation and research methods. Newbury Park: Sage.

Polit, D., & Hungler, B. (1987). Nursing research principles and methods. Philadelphia: Lippincott.

Ragsdale, D., & Morrow, J.R. (1990). Quality of life as a function of HIV classification. Nursing Research, 39, 6.

Ragsdale, D., Kotarba, J., & Morrow, J. (1992a). Quality of life of hospitalized persons with AIDS: An ethnographic analysis. Image, 24(4), 259-265.

Ragsdale, D., Kotarba, J. & Morrow, J. (1992b). Work-related activities improve quality of life in HIV disease. Janac, 3, 1.

Ragsdale, D. (1993). A Call for help: Collaborative nursing research. Janac, 4, 2.

Sadler, H., & Grausz, H. (1976). Medicine and the quality of life. The Western Journal of Medicine, 11, 393-394.

Sandelowski, M. (1986). The problem of rigor in qualitative research. Advances in Nursing Science, 8(3), 27-37.

Scitovsky, A. (1989). Past lessons and future directions: The economics of health services delivery for HIV-related illness. In W.N. LeVee (Ed.) New perspectives on HIV-related illnesses: Progress in health services research. Conference Proceedings, Miami, FL. National Center for Health Services Research and Health Care Technology Assessment. Washington, DC: U.S. Government Printing Office, 21-33.

Seidel, J.V., Kjolseth, R., & Seymour, E. (1988). The ethnograph (Version 3.0). Littleton, CO: Qualis Research Associates.

Shaw, A. (1977). A formula without numbers: Defining the quality of life. Hastings Center Report, Institute of Society, Ethics and Life Sciences, 7-11.

Smith, A.D. (1989). The ethnic origins of nations. New York: Basil Blackwell.

Solomon G., & Temoshok, L. (1987). A psychoneuroimmunologic perspective on AIDS research: Questions, preliminary findings and suggestions. Journal of Applied Psychology, 7, 286-308.

Spradley, J. (1979). The ethnographic interview. New York: Holt, Rinehart and Winston.

Stern, P.N. (1985). Using grounded theory method in nursing research. In M.M. Leininger (Ed). Qualitative research methods in nursing, (pp. 149-160). Philadelphia: Saunders.

Strauss, A. (1975). Chronic disease and the quality of life. St. Louis: C.V. Mosby.

Strauss, A.L. (1987). Qualitative analysis for social scientists. New York: Cambridge University Press.

Swanson-Kaufman, K.M. (1986). A combined qualitative methodology for nursing research. Advances in Nursing Science, 8(3), 58-69.

Taylor, S. J., & Bogdan, R. (1984). Introduction to qualitative research methods: The search for meanings. New York: Wiley.

U.S. Department of Health and Human Services (1994)
Public Health Service, Agency for Health Care Policy and
Research, NO.94-0572.

Watson, H.S. (1985). Research in nursing. Menlo Park:
Addison-Wesley.

Wolcott, D., Fawzy, F., & Pasnau, R. (1985). Acquired
immunodeficiency syndrome (AIDS) and consultation-liaison
psychiatry. General Hospital Psychiatry, 10, 280-293.

Woods, N.F., & Catanzaro, M. (1988). Nursing research
theory and practice. St. Louis: C. V. Mosby.

Vachon, M.L.S., Lyall, A., & Freeman, S.J.J. (1977).
The final illness in cancer: The widow's perspective.
Canadian Medical Association Journal, 117(11), 51-54.

Vachon, M.L.S. (1987). Occupational stress in the care
of the critically ill, the dying and the bereaved. New
York: Hemisphere.

Appendix A.
Consents and Approvals

TEXAS WOMAN'S UNIVERSITY
DENTON DALLAS HOUSTON
HUMAN SUBJECTS REVIEW COMMITTEE - HOUSTON CENTER

HSRC APPROVAL FORM

Name of Investigator(s): Diane Ragsdale and Elizabeth Ames

[REDACTED] and [REDACTED]

Name of Research Advisor(s): Diane Ragsdale

Address: Texas Woman's University

1130 M D Anderson

Houston, TX 77030

Your study entitled: Quality of Life of Persons with AIDS in Hospice

Settings: An Ethnographic Study

(The applicant must complete the top portion of this form)

has been reviewed by the Human Subjects Review Committee - Houston Center and it appears to meet our requirements in regard to protection of the individual's rights.

Please be reminded that both the University and the Department of Health and Human Services regulations typically require that signatures indicating informed consent be obtained from all human subjects in your study. These are to be filed with the Human Subjects Review Committee Chairman. Any exception to this requirement is noted below. Furthermore, according to HHS regulations, another review by the HSRC is required if your project changes or if it extends beyond one year from this date of approval.

Any special provisions pertaining to your study are noted below:

_____ Add to informed consent form: "I understand that the return of my questionnaire constitutes my informed consent to act as a subject in this research".

_____ The filing of signatures of subjects with the Human Subjects Review Committee is not required.

_____ Other: see attached sheet.

_____ No special provisions apply.

Sincerely,

Anne Young
Anne Young, Ed.D.
Chairperson, HSRC - Houston Center

2/25/91
Date

Oral Description of the Study

You are being asked to participate in a study conducted in the Nursing Department of Texas Woman's University. This study is designed to explore the meaning of quality of life as you see it, while you are in . This is necessary so that volunteers, families and health care personnel will know how to give the best possible care to persons with AIDS (PWAs).

If you agree to participate, you will be asked questions relating to your quality of life. Your answers to these questions will be audiotaped so that they may be transcribed for analysis. This interview will take no longer than one hour.

Your interview will be conducted by a trained researcher. A possible risk is that you may experience some anxiety or have questions during the interview. To alleviate any possible anxiety, the entire interview will be conducted in this room with the door closed. Adequate time will be allowed for you to ask questions or to discuss any concerns. You will be free to interrupt the interview at any time, either to rest or to terminate the interview. If you wish any rest period, the interview will be stopped until you wish to continue. The researcher will remain in the room after the interview is completed to answer questions or to discuss any other concerns. Additionally, if you have any questions, please call Dr. Diane Ragsdale at 794-2146 during business hours. She will be happy to answer your questions.

The indirect benefit from participating in this study is that this information will be used to identify what aspects of life are important to PWAs. This information can then be used as the basis for planning the type of care that is most relevant to PWAs.

We are conducting no similar study at this time in which you could participate. You are free to participate or not to participate. The choice is yours. If you choose to join the study, you may withdraw from the study at any time without penalty. Your care will not be affected in any way if you do or do not participate. There will be no penalty or loss of benefits.

Confidentiality will be assured. Only a number will be placed on each form and audiotape. This is necessary to keep your data separate. No names will appear on any data forms or audiotapes. Neither you nor any other person caring for you will be identified anywhere in this research study. The name and location of this hospice will remain confidential as this information will not be included in this research study. All audiotapes will be destroyed no later than two years after the completion of the study. Findings from this study will be published only in scientific and medical journals, and presented at professional meetings.

No injury is anticipated as a result of your participation in this study. However, Texas Woman's University is not able to offer financial compensation nor to absorb the costs of medical treatment. First aid care will be provided as necessary.

Thank you for your time and interest,



Diane Ragsdale, RN, EdD
Professor
College of Nursing
Texas Woman's University

Consent Form

I hereby authorize Dr. Diane Ragsdale, or one of her research associates to ask me some questions about myself and my feelings or perceptions of quality of life. I was informed that my answers to these questions will be audiotaped. It is my understanding that this interview will take no longer than one hour.

I understand that the entire interview will be conducted in this room with the door closed. I also understand that a possible risk to me is that I may experience some anxiety during the interview. I know that if I experience some anxiety or have questions during the interview, that adequate time will be allowed for me to ask these questions or to discuss any concerns. I am free to interrupt the interview at any time, either to rest or to terminate the interview. If I wish any rest period, the interview will be stopped until I wish to continue. I understand that the researcher will remain in the room after the interview is completed to answer questions or to discuss any other concerns. Additionally, if I have any questions, I may call Dr. Diane Ragsdale at 794-2146 during business hours.

I understand that the indirect benefit from participating in this study is that this information can be used to identify what aspects of life are important to PWAs. This information can then be used as the basis for planning the type of care that is most relevant to PWAs.

I was informed that the researchers are conducting no similar study at this time in which I could participate. I understand that I am free to participate or not to participate. The choice is mine. If I choose to join the study, I may withdraw from the study at any time without penalty. My health care will not be affected in any way if I do or do not participate. There will be no penalty or loss of benefits. I was also told that the findings from this study will be published only in scientific or medical journals, and will be presented at professional meetings.

I was informed that confidentiality will be assured. Only a number will be placed on my data forms and audiotape. I know that this is necessary to keep my data separate. I further understand that my name will not appear on any data forms or audiotapes. Neither myself nor any other person caring for me will be identified anywhere in this research study. The name and location of this hospice will also remain confidential. I understand that all audiotapes will be destroyed no later than two years after the conclusion of the study.

I understand that no injury is anticipated as a result of my participation in this study. However, Texas Woman's University is not able to offer financial compensation nor to absorb the costs of medical treatment. First aid care will be provided as necessary.

An offer to answer all my questions regarding this study has been made. If alternative procedures are more advantageous to me, they have been explained. A description of possible discomfort or risks reasonably expected have been discussed with me.

Participant's Signature

Date

Witness

Date

Appendix B.
Demographic Data Sheet

Demographic Fact Sheet

Respondent I.D.: _____

Biographical Data:

Gender: _____

Age: _____

Residence: _____

Work: _____

Leisure: _____

Primary relationships: _____

Education: _____

Ethnicity: _____

Belief System: _____

Appendix C.

Semi-Structured Interview Guide

Semi-Structured Interview Guide

Everyday life at hospice

How do you feel?

Length of current stay at hospice

How long have you been here?

Where were you before?

Why did you choose to come here?

Typical day (pace and engagement of self)

Was yesterday a typical day? What was it like?

What is an example of an unusual day?

Health care activities

What kind of health care activities do you do?

Medicines, exercise, diet, meditation?

Sense of control over the management of one's illness

(therapies, insurance, physicians, nurses, prognosis)

Do you feel you are in charge of your life right now?

Are things going the way that you want them to go?

Comfort and security of the hospice as an environment.

What do you feel about your situation here at Haven

Hospice? How do you feel about visitors?

Pain Management

What do you do when you are hurting? Is this different for you than what you would have done a year ago?

Self identify relevant to AIDS

Trace your career for me. What was your life like then and how did you feel about yourself then? What was it like when you were diagnosed? How did you come to terms with the diagnosis? Who or what became important to you? Was there a change in the primary relationship?

Ability to integrate past, present, and future biography relevant to AIDS.

The meaning of AIDS

What does having AIDS mean to you?

What do you think about having AIDS?

Is there anything else that you wish to tell me of your feelings about having AIDS?

Appendix D.

Figures 1-7

Figure 1

WORKING ON LIVING WHILE DYING OF AIDS

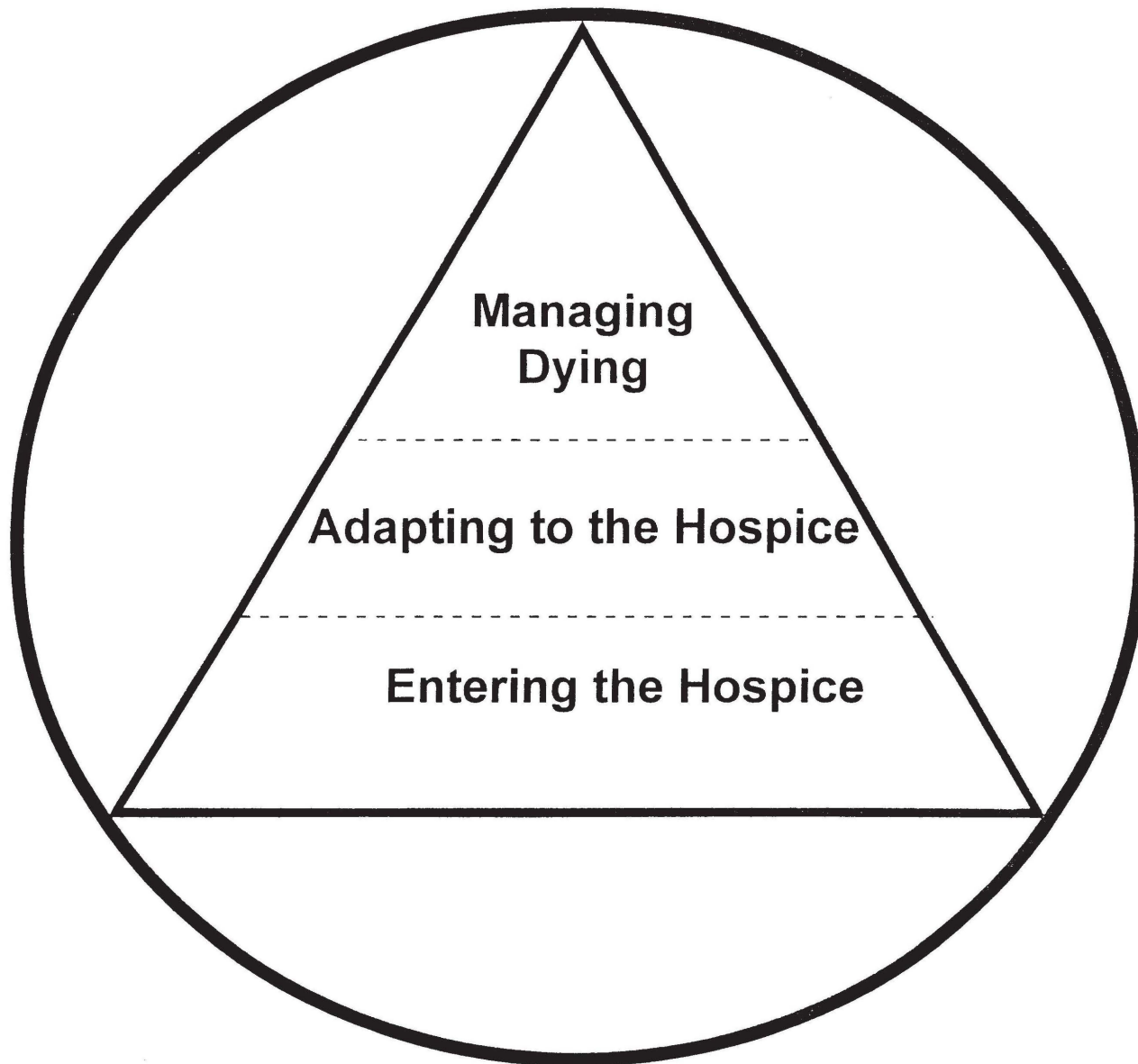


Figure 2

WORKING ON LIVING WHILE DYING OF AIDS AND PWA'S QUALITY OF LIFE CONCERNS

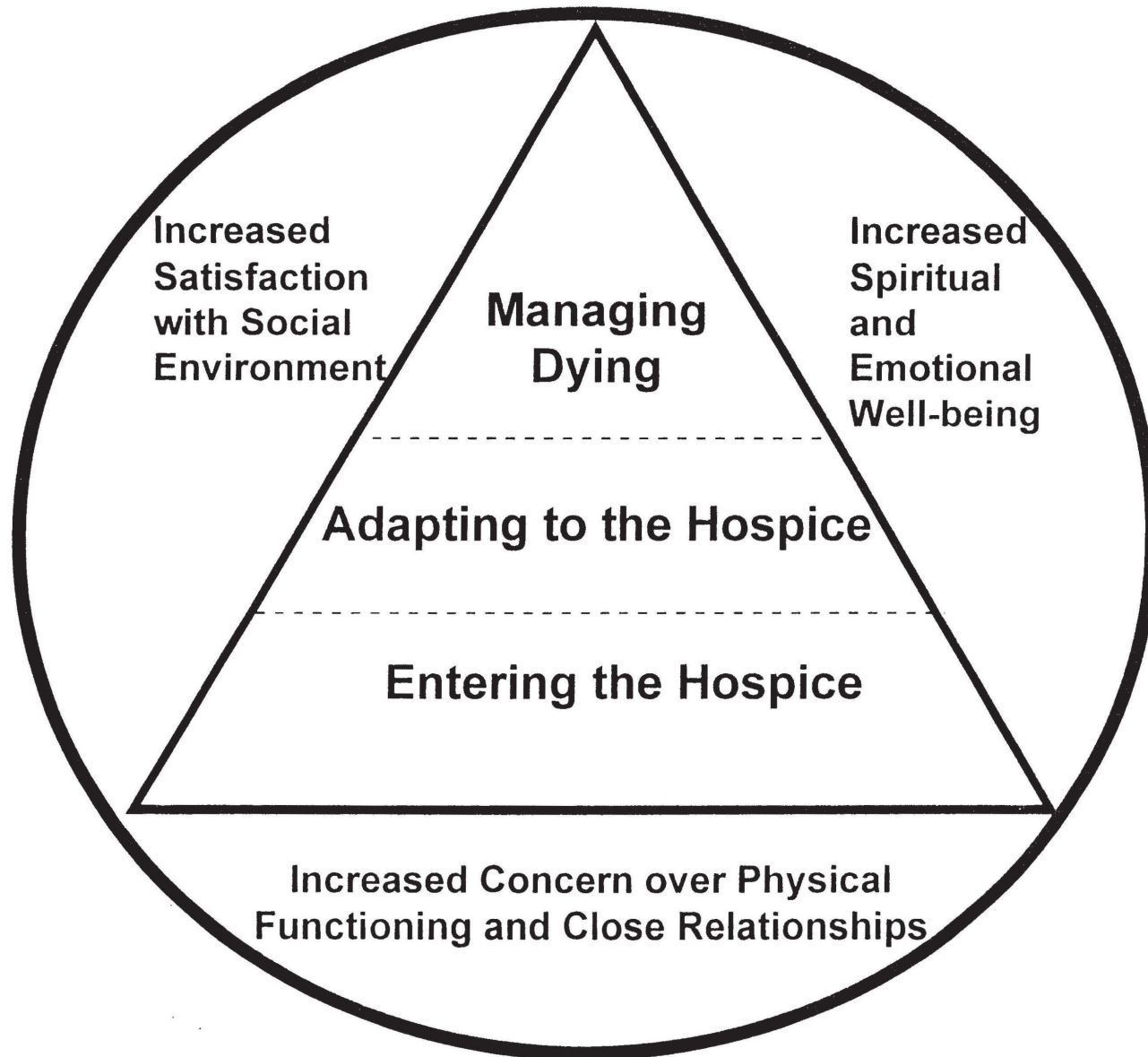


Figure 3

PROCESS MODEL OF LIVING WHILE DYING OF AIDS

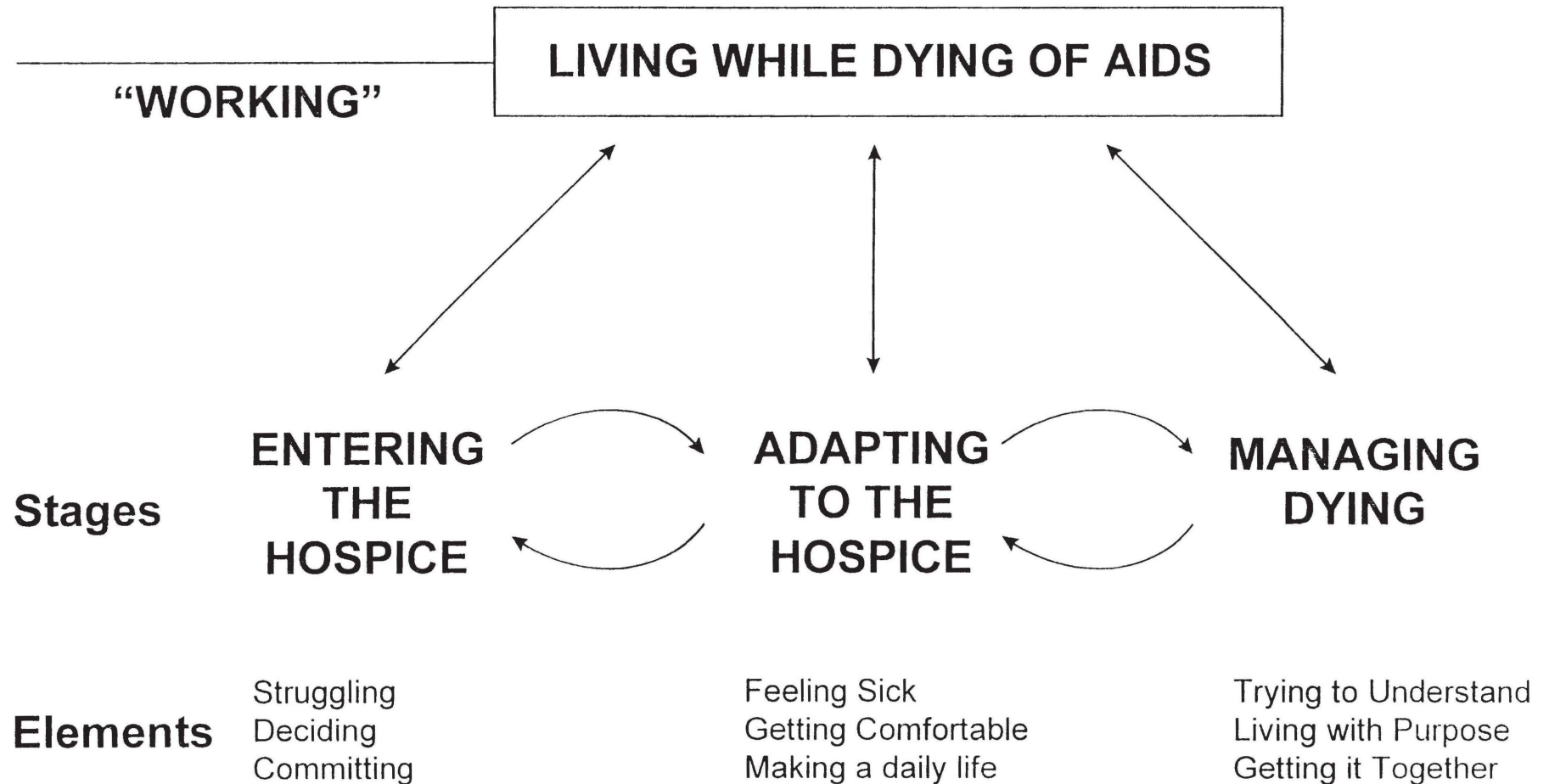


Figure 4

ENTERING THE HOSPICE

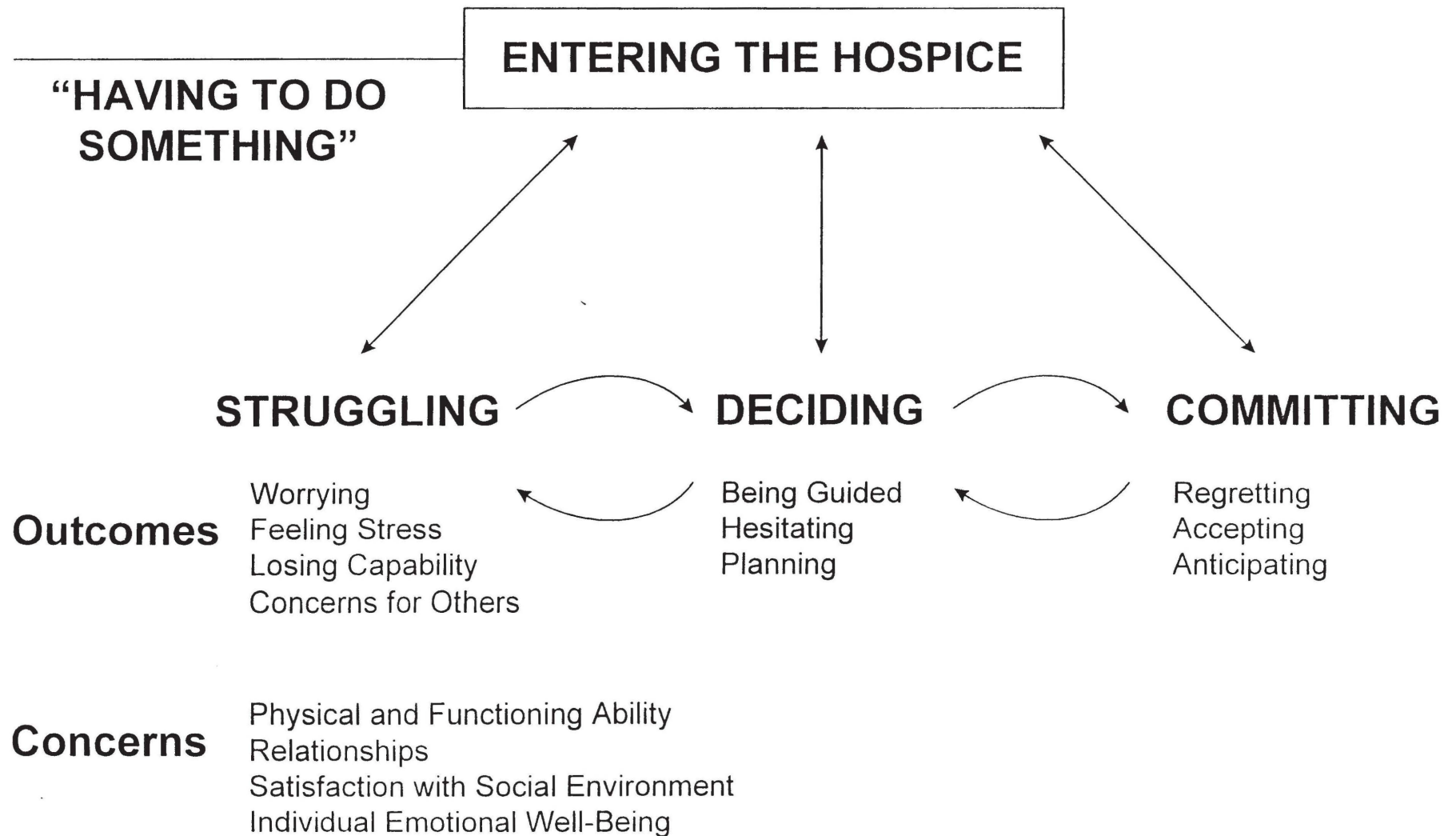


Figure 6

MANAGING DYING

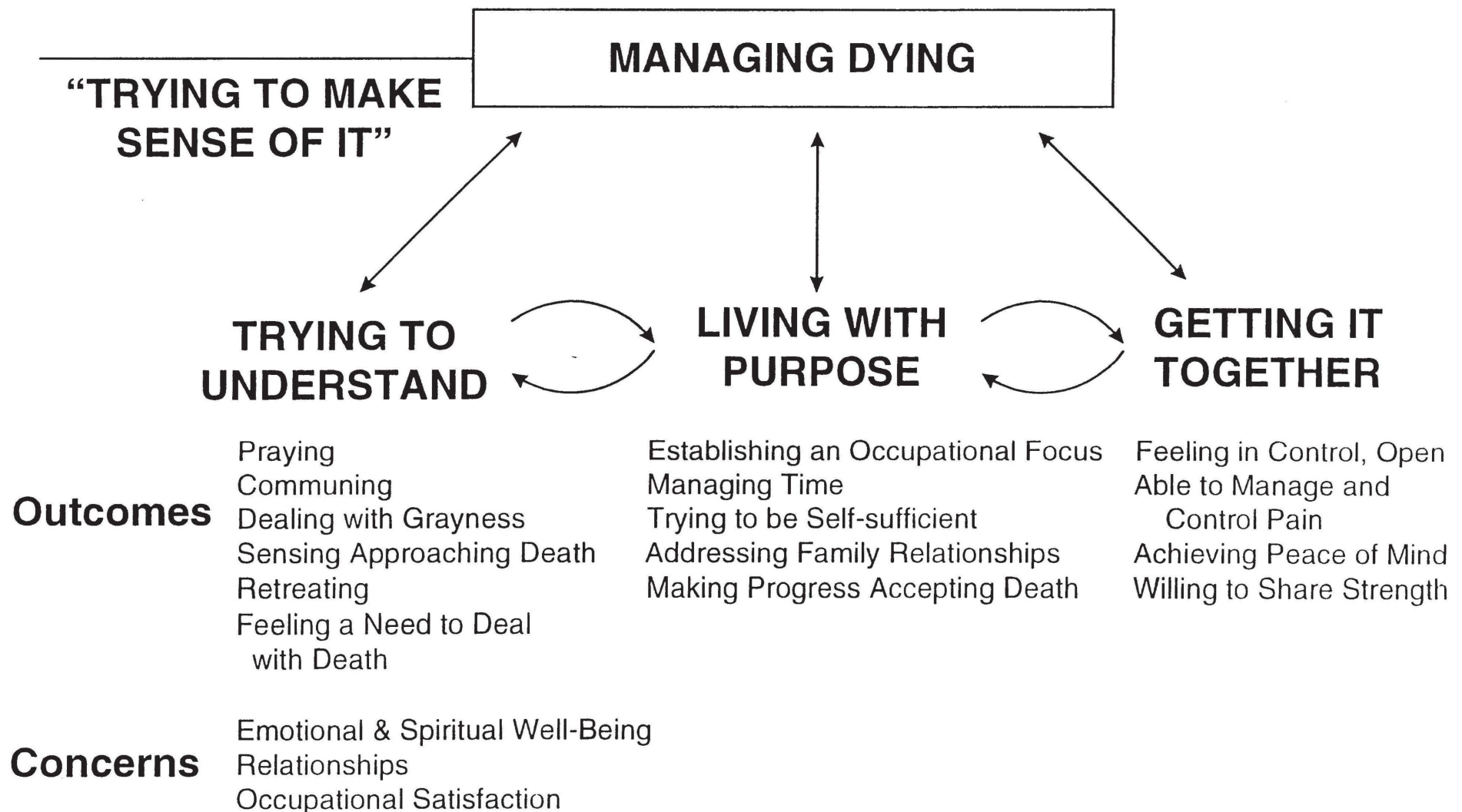


Figure 7

QUALITY OF LIFE CONCERNS

