

The University of Manitoba

APPROPRIATE DYING: SOME PHENOMENOLOGICAL ASPECTS
OF THE DYING PROCESS

by

Donna L. Stephen

A thesis
submitted to the Faculty of Graduate Studies
in partial fulfillment for the degree
Doctor of Philosophy

Department of Psychology
Winnipeg, Manitoba

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Abstract

Twenty terminally ill cancer patients participated in an exploratory study which had three aims: to suggest some ways of viewing the construct *appropriate dying*; to provide a method for investigating the concept; and to show the importance of idiosyncratic variables in understanding the dying process.

The concept of "appropriate death" was introduced by Avery Weisman in 1970 and elaborated in subsequent publications (cf. Weisman, 1972, 1974, 1979). The present study reasoned that in order to avoid judgements based exclusively upon one's own interpretations of "appropriateness", it is important to ask others what is important for them. Therefore subjects were asked to elaborate upon what sorts of things they would like to see happen--what goals and expectations they might have, as they approached their own deaths.

Subjects were twelve male and eight female hospice patients with a diagnosis of cancer and a prognosis of at least six weeks. In order to obtain idiographic information, data collection employed a phenomenological method. Three interviews occurred typically over a six week period. At the first interview subjects were asked about their agendas, expectations, and goals, and, at subsequent interviews, whether or not these agendas were perceived as fulfilled. Three self-report scales--The CES-D (Radloff, 1977), the Anxiety Scale (Ware, Snyder & Wright, 1976), and the McGill Pain Questionnaire (Melzack, 1975) were also administered (verbally) at the second and third interviews.

Thirty-seven agendas were reported for all 20 subjects over t1, t2 and t3. Twelve agendas were categorised as actions or activities, 10 as interpersonal, and 15 as intraindividual using *a priori* descriptive categories. Fifty-six percent of those agendas were perceived as fulfilled. Few agendas were added or rejected over time. Post-interview assessments revealed that most individuals had numerically few agendas, that

an incongruity frequently occurred between stated agendas and actual activities, and that most agendas were reality bound. In addition, activity level was not necessarily predicted by the number of agendas reported. Varying investments, priorities, and meanings attributed to agendas were noted between subjects.

Subjects reported little or no pain on the McGill Pain Questionnaire, a tribute in some cases to the pain management techniques used by this hospice. Although ranging widely, depression scores were elevated in this group but anxiety scores were in the normal range. Test scores were uncorrelated with number of agendas or whether agendas had been perceived as fulfilled.

A review of the hospice literature and psychological aspects of terminality occurs. Theoretical aspects of the concept *appropriate dying* and suggestions for clinical practice are discussed.

Introduction to Chapter 1

The consummating death I show unto you, which becomes
a stimulus and a promise to the living...In your dying shall
your spirit and your virtue still shine like an evening after-
glow around the earth; otherwise our dying hath been un-
satisfactory.

Friedrich Nietzsche, *Thus Spake Zarathustra*
(Chapter XXI)

The idea of better and worse endings is certainly not new. Socrates advised us in meeting death to "Keep quiet and be brave." (*Phaedo*, p. 521). Likewise for Aristotle, facing death bravely was the epitome of rational courage: "Now death is the most terrible of all things; for it is the end, and nothing is thought to be any longer good or bad for the dead. But the brave man would not seem to be concerned even with death in all circumstances e.g., at sea or in disease" (*Ethics*, p. 1115).

Around the middle of this century popular works such as Jessica Mitford's The American Way of Death (1963) began to point out the rather elaborate deceptions which had become routine around the topic of death. Most North Americans would probably agree with Aristotle that "...death is the most terrible of all things..." (*Ethics*, p. 1115) but the "virtue" of facing death is not apparent in an age in which death has been called the new taboo (Gorer, 1965).

Many people in our society are faced with a protracted period of dying. Each year in the United States there are over 400,000 cancer deaths alone (cf. Noyes, 1981) and a new fatal epidemic--AIDS--is amongst us. A wave of interest in the topic of death and dying in the last few decades has resulted in a plethora of material both in

professional journals and in the popular media. Of special significance, Elisabeth Kübler-Ross (1969) formulated her observations of the terminal process as five stages of dying and her ideas gained widespread acceptance. And, with inspiration from Cicely Saunders in Great Britain, hospices offering palliative care for the dying began springing up in North America in the mid 1970's.

Avery Weisman, a Harvard psychiatrist, introduced his theoretical concept, *appropriate death*, in 1970 and elaborated his ideas in subsequent publications (cf. Weisman 1972, 1974, 1979). The present study attempted to operationalise some components of this felicitous concept asserting that its important core is idiosyncratic in nature, or, what is appropriate for one individual is not necessarily appropriate for another, thus the phenomenological emphasis of the current study.

Individuals who participated in this effort were cancer patients enrolled in a hospice programme. To provide a context for understanding the population of interest, the literature review is organised around the concept of hospice. In fact, as will be seen later, a substantial portion of Chapter 1 is devoted to a discussion of hospice. In this sense hospice was used as the impetus for presenting theoretical, ethical, and treatment issues of import for the whole area of death and dying. Some general notions are presented which become increasingly specific with each successive topic.

The selective review begins with a broad introduction to hospice, enumerating its aims and ideals, in somewhat abstract terms, as evolving from a need to provide specific care for dying persons. Included in this section is an outline of pertinent medical approaches to the treatment of dying persons--pain and symptom control--which are integral not only in understanding hospice, but also in understanding what constitutes adequate care. Then, St. Christopher's Hospice is described as the hospice most frequently considered prototypical. Some comments on hospice in Britain are followed a discussion of the origins of hospice in Canada and in the United States. The

hospice section of the review concludes with a few notable contrasts in implementation between Canada and the United States and a review of the evaluative literature.

It will be seen that a hospice population (which in the United States is biased toward homecare) was chosen for the present study, among other reasons, to ensure a certain level and continuity of care both within and across individuals. Continuity of care is deemed vital from both practical and ethical perspectives. It is unlikely that individuals who do not have certain resources (e.g., 24 hour pain and symptom management) available could be amenable to research and the ethics of proceeding in the absence of such resources should be questioned. An effort was made to hold constant some features which would intuitively contribute toward a "better" death. However, initial evaluations have not reported the unequivocal superiority of hospice treatment despite positive anecdotal evidence. Also, it appears that there is a conspicuous lack of professional psychological input--whether theoretical or practical--on any level of hospice care.

It is following from the above shortcomings that psychological aspects of the terminal process are introduced in the second section of Chapter 1. And, it is suggested that psychological findings have *also* been prematurely reified. The emphasis early on in thanatology was to discover facts about the dying process--to determine what it is like. However, in reaction to certain stage theories some theorists began placing more emphasis on individual reactions to dying. From this point of view the dying process may be considered a misnomer. It is suggested instead that individuals die as they have previously lived--which is almost a tautology.

The idea presented in Chapter 1 is that the two positions need not be mutually exclusive i.e., some features specific to the unique threat of terminality as well as some "idiosyncratic" features may be apparent. From a methodological perspective appropriate dying can be amenable to investigation on both nomothetic and idiographic levels.

In the final section of Chapter 1 the theoretical concept of appropriate dying is discussed followed by a description of the present study which emphasises the patient's own perceptions. It is reasoned, in order to avoid judgements based exclusively upon one's own interpretations of "appropriateness", i.e., what would be appropriate for oneself, it is important to ask others what would be appropriate for them. One way of partially operationalising some of the idiosyncratic aspects of "appropriateness" is to ask individuals what things are important for them. Thus, while previous efforts have largely been retrospective in nature, the present study utilises a prospective method in which idiographic information is obtained.

The essential thesis is that too little attention has been directed toward describing and understanding the individual's own view, given the threat of impending death. While it is not possible, or in some senses desirable, to observe individuals in isolation, i.e., removed from a societal context, it may be that some of our observations of the dying process have been artifacts of our own values and assumptions. A small effort away from this particular bias might be to ask individuals about *their own* experiences. This is the direction the present investigation has taken--a direction which should have utility for those (e.g., hospice staff) who work with terminally ill persons.

The importance of such an approach became apparent to the present investigator as a result of a longstanding interest and experience with treating some terminally ill cancer patients. It was noted that the intense emotional reaction to the topic of dying by those involved with seriously ill persons tended to obscure clear thinking--after all, death has intimate significance for everyone. One's own fears and assumptions, particularly pertaining to values, seemed too easily projected onto the dying person. Thus it could be hypothesised that formulae have in part developed as a way of handling our own fears and insecurities around the topic of dying.

It seemed to this investigator that, in treating seriously ill individuals, personal agendas emerged which were not immediately apparent and that it was these unfulfilled

agendas that were principal sources of emotional disturbance. Based upon these observations, individuals in the study were asked to provide standards for judging their own behaviour and to respond to a series of self-report measures of pain, depression, and anxiety.

Chapter 1

Review

The special difficulties associated with finding oneself dying in a society which considers death to be an affront--a dreaded symbol of failure, a subject to be avoided, denied, repressed at any cost--have been well documented (Becker, 1973; Feifel, 1959; Gorer, 1965; Weisman, 1972). A few of the more interesting revelations in this regard include Feifel's hypothesis that physicians tend to have greater death anxiety than the general population (Feifel, Hanson, Jones, & Edwards, 1967); Kübler-Ross's puzzlement at being told that there were no dying patients at her place of employment--a large general hospital (1969); and Le Shan's finding (Bowers et al, 1964) that nurses take a longer time to answer the bells of dying patients than those who are not dying. On the whole, the dying have been depicted by early thanatologists as a group suffering from inordinate pain and isolation and abused by unconscious ideologies (cf. Glaser & Strauss, 1965; Kastenbaum & Aisenberg, 1976; Kübler-Ross, 1969; Sudnow, 1967).

One humane reaction to our collective abandonment of the dying has been the hospice movement (cf. Buckingham & Foley, 1978). The goal of a hospice is to provide comprehensive care for patients who have limited prognoses. Proponents of this model argue that the prospect of terminality does not eliminate the necessity for useful and appropriate medical care. It is not simply the case that medicine has nothing to offer the dying but that physicians must substitute palliative for curative goals in order to address what needs to be accomplished (Saunders, 1981, 1982).

Essential to the theory of hospice is a holistic attitude toward care which advocates responding to all the needs of persons whether they be physical, emotional, social, psychological, or spiritual. Many authours who have written on the history of the movement attempt to convey the essence of hospice by touching upon the etymology of the word itself, derived from the Latin *hospes* meaning host (and its logical consequence hospitality) and the use of the word for Medieval way stations for

crusaders, travellers, and the ill in order to create images of compassionate and responsible caring (cf. Stoddard, 1978). The aim of hospice is to improve the quality of life for the terminally ill by providing an emotionally supportive milieu (cf. Gardner, 1976; Saunders, 1976; Woodson, 1978). While components of the milieu may be discussed and analysed at length, it has been emphasised repeatedly in the literature that adherence to, for instance, a particular philosophy of pain management is not sufficient (Saunders, 1981). The word *community* has been used to convey what hospice proponents see as vital for creating a supportive atmosphere. "What the caregivers can provide dying patients fosters the patients' sense of self-worth and their role in the community even if that community has shrunk to include only family members" (Kutscher & Kutscher, 1983, p. xiii).

The hospice team is interdisciplinary and typically includes physicians, nurses, social workers, nutritionists, physical therapists, a psychiatric or psychological consultant, clergy, and scores of volunteers. Although the actual disciplines may vary from hospice to hospice, the philosophy of care is definitely one of a team approach which may or may not be headed by a physician. Most hospices consider the family (kith and kin) essential caregivers and the patient's wishes as paramount (Cohen, 1979; DuBois, 1980; Gardner, 1976; McNulty & Holderby, 1983; Mount, 1978; Munley, 1983; Rossman, 1977).

There are several characteristics of the modern hospice: The staff-to-patient ratio is usually very high; care is delivered 24 hours a day seven days a week; visiting hours are unlimited, i.e., family and friends may arrive at any time and stay as long as they like; small children and pets are not excluded; and efforts are made to provide as much freedom as possible for the patient and his or her support system (cf. Gardner, 1976; Stoddard, 1978). It is easy to see how this freedom--the element of choice--may be in conflict with more traditional hierarchical health delivery systems.

In addition to a supportive milieu which allows individuals to live as normally and fully as possible it may be asked what can actually be done medically for dying persons? The goals of palliation are pain and symptom control.

Pain and Symptom Management

On the issue of pain, the aim is abolition of it. Although there is no reliable epidemiological data on the incidence of cancer pain (Noyes, 1981), it has been estimated by some researchers (e.g., Saunders, 1976) that in about 50% of all cancer deaths there is little or no pain. However, for many, pain may be very severe in the advanced stages due to bone destruction, infiltration into organ capsules and nerves, occlusion of blood vessels, and so forth (Mount, Ajemian & Scott 1976; Murphy, 1973). Of course, emotional distress may exacerbate any existing pain regardless of how clearly definable the physical etiology (cf. Turk & Rennert, 1981).

It has been claimed that physicians seem disinterested in the topic of cancer pain (Bonica, 1979; Noyes, 1981). Others claim that cancer pain is frequently poorly managed and that patients suffer unnecessarily (cf. Noyes, 1981). Cancer pain can, for the most part, be adequately controlled with the proper administration of drugs. In advanced situations when severe pain is evident the choice of analgesic is usually one of the narcotics (Mount et al, 1976). Indeed, the term Brompton Cocktail or Brompton Mixture has become almost synonymous with cancer pain management. The mixture originally consisted of diamorphine (heroin), cocaine to sustain vitality, and a phenothiazine, all in liquid form with some alcohol and syrup to disguise the bitterness of the narcotic (cf. Twycross, 1979). Morphine has routinely been substituted for heroin in North America where the latter is illegal. While the comparative efficacy of these two narcotics has not been systematically evaluated, there is good evidence to suggest that, in most cases (with oral administration), morphine is an adequate substitute in adjusted dosages (Twycross, 1979). Nevertheless, a bill entitled the Compassionate Pain Relief Act (H.R. 5290) being considered by the U.S. Congress

would allow medically supervised use of heroin for cancer patients who cannot find relief through any other analgesic (Angell, 1984). Although the debate continues, heroin seems to have some advantages over morphine when administered parenterally due to more rapid absorption and the requirement of a much smaller dosage (Angell, 1984; Saunders, 1981).

Still, there is a prejudice against all narcotics, a prejudice partially rooted in the fear of addiction (cf. Angell, 1982). Evidence suggests that addiction occurs in less than .1% of those who receive narcotics for pain (Porter & Jick, 1980). General misinformation about narcotics seemed widespread in a study of house physicians by Noyes (1981) which showed physicians typically underestimated the effective dose range, overestimated the duration of action, and exaggerated the dangers of addiction even when treating patients with a terminal diagnosis. As result, 32% of patients in the study who were treated with narcotics reported experiencing severe pain (Noyes, 1981).

Narcotics have a soporific effect and need to be carefully titrated in order to maintain alertness in patients. However, stupor need not occur in most cases. It is claimed by Mount (1978) "After the initial 48 hours, sustained sedation suggests that the narcotic dose is excessive. However, if the physician fearful of narcotics has delayed their introduction until the final days or weeks of life, the patient may be more drowsy and less communicative when the pain is finally controlled" (p. 204). Cocaine is no longer used to combat stupor because it does not seem to have an effect on sustained alertness (Saunders, 1981). Its use is also called into question due to the frequent side effect of hallucinations (Twycross, 1979).

Those who advocate use of some variation of the Brompton Mixture emphasise that "The results are best when the cocktail is used within the context of general emotional support for the patient and his family" (Twycross, 1979, p. 297). A study by Melzack, Ofiesch and Mount (1976) showed some evidence for this assertion by

demonstrating that pain was successfully controlled in 90% of hospice (Palliative Care Unit) patients with the use of the Brompton Mixture. It controlled pain (in a comparable sample) in 75-80% of cases on other wards.

In general, it is thought that it is not so much *what* is administered to cancer patients as *how* it is administered. Specifically, hospices prefer a fixed interval approach to routine medication administration rather than one based on "when needed" (p.r.n.) schedules which are inappropriate when treating chronic pain (Saunders, 1981). Medication is usually given every four hours. Most of those requiring morphine can be maintained on 5 to 20 mg. per dose (Mount, Ajemian & Scott, 1976). As stated earlier, the aim is to control pain totally whenever possible. By this philosophy it makes no sense for patients to suffer pain in order to get relief which is what occurs on a p.r.n. schedule. It is easy to comprehend how "when needed" schedules could reinforce psychological dependence and maintain pain behaviours (Mount, 1976; Saunders, 1981; Turk, 1978).

Symptom control, as with pain management, requires careful, continual evaluation and total team input is an important part of this ongoing assessment. Typical symptoms which are to varying degrees amenable to intervention include nausea, vomiting, anorexia, dysphagia, dry mouth, hiccoughs, dyspnea, insomnia, constipation, fungating growths, and so on (cf. Mount, 1978). Traditional treatments with palliative aims such as radiotherapy, chemotherapy or nerve blocks are legitimate tools in specific appropriate cases (cf. Saunders, 1981). Symptoms such as anxiety, depression, and insomnia are considered on psychological and medical levels and the impact of psychological variables on other symptoms are certainly regarded as part of the total evaluation (Mount, 1978).

St. Christopher's Hospice

St. Christopher's in south London established in 1967 is considered the modern prototypical hospice (DuBois, 1980). However, it was not the first institution to give

priority to care for the dying. Sandol Stoddard (1978) has traced the hospice movement beginning in Syria A.D. 475 to several institutions existing in North America and Great Britain at the turn of the century. At one of these institutions, St. Joseph's, Dame Cicely Saunders did much work in pain management. This work determined the philosophy of care propagated later at St. Christopher's, which she founded. After almost twenty years of planning, St. Christopher's was established as a free standing institution. It consists of 54 inpatient beds for the terminally ill, a wing of 16 beds for well elderly residents (most of whom are related to staff), an outpatient programme, and a domiciliary service (Saunders, 1982).

The Domiciliary Service is designed to bring hospice principles and care into the individual's home. Nurses are available 24 hours a day in this programme which is paid for by the (British) Department of Health (Saunders, 1982). Most subsequent hospice programmes have incorporated home care into their services for patients who are able and wish to remain in their usual surroundings.

Outpatients may attend clinics at St. Christopher's in order to obtain control over particular medical or emotional problems. There is no limitation on the amount of time a person is allowed to spend as an outpatient. Other important functions of St. Christopher's include research and teaching, and, pertaining to the latter, St. Christopher's has about 100 resident visitors each year (Saunders, 1981).

The nature of care at St. Christopher's is typified by the customary admitting procedure at the hospice. Each patient is greeted at the ambulance bay by the senior nurse on duty. The patient is then transferred to his or her own (moveable) bed which has been warmed with hot water bottles, and then is escorted immediately to the ward in company of the family and personal possessions (Saunders, 1982). The patient is therefore settled in before being visited by the physician on duty.

Apparently the stability of elderly residents and the omnipresence of staff members' children creates a unique ambience. Add to this the physical and

environmental considerations, (e.g., cozy, well-lighted rooms, gardens, a communal dining room) and the hospice philosophy of care and St. Christopher's has often been described in almost idyllic terms (cf. Lamberton, 1980; Rossman, 1977; Smyser, 1982; Stoddard, 1978).

From the patient's point of view it is apparently not unusual to hear testimonies such as the following:

'...I am alive and enjoying myself. Every single person in the whole world should have a place like St. Christopher's to go when things get out of hand. I was absolutely howling with pain when I came in here, 48 hours ago. Hadn't been able to keep food down for nearly two weeks. This morning I ate like a horse...They know what they are doing here you see. They do miracles, I assure you, but not as result of floating about in a sort of euphoric trance praying and all that sort of thing--not if I mind if they do it at this point--but it's all the result of absolutely tremendous discipline. And the moment you come in here you feel you are the only pebble on the beach. That in itself is the most incredible lift.'

(Stoddard, 1978, p. 132).

On the issue of funding, Dame Cicely was originally bequested the amount of 500 pounds which grew through additional gifts and grants to the amount of 500,000 pounds. The National Health Service pays for about three-fourths of the costs for patient care and most of the funding for research, the outpatient programme and teaching. The deficit is covered by donations (Saunders, 1982). There are currently 55 hospices in Great Britain which operate in a manner similar to St. Christopher's (Saunders, 1982), although a trend now exists in Great Britain to build independent units on the grounds of general hospitals. Typically they are built by the National

Society for Cancer Relief and then are turned over to the National Health Service (Lamberton, 1980). A highly successful example of this trend is the Sir Michael Sobell House on the grounds of Churchill Hospital in Oxford. This hospice has managed to maintain a homey quality with care comparable to St. Christopher's. The director, Dr. R.G. Twycross, was previously head of pharmacology at St. Christopher's (Stoddard, 1978).

Hospice in Canada

Results of a questionnaire distributed in the early 1970's to 1600 staff members and terminally ill patients at Royal Victoria Hospital in Montreal indicated that "It was indisputably clear that the hospital was deficient in meeting the needs of the terminally ill. The recommendation that a hospice unit or palliative care unit be established to better meet these needs was a natural outcome of the compiled data." (Wilson, Ajemian & Mount, 1978, p. 6). Thus, in January of 1975 a 12-bed unit within the hospital was established as a two year pilot project. The Palliative Care Unit (PCU) is an important component of the Palliative Care Service which also consists of a hospital based home care programme, a consultation team, and a bereavement follow-up group. The consultation team serves a useful educational as well as practical function in offering the principles of palliation to patients on other wards throughout the hospital. This is to say the consultation team offers assistance in instigating and maintaining a programme of palliative care. Bereavement follow-up is a standard part of the care plan as it is on the PCU unit itself.

In addition to the patient and his or her family, the PCU team consists of physicians, nurses, volunteers, a social worker, chaplain, physiotherapist, and the unit coordinator. All team members are trained from a hospice perspective and key staff members have visited St. Christopher's. The nursing staff is not rotated off the unit.

While Wilson, Ajemian and Mount (1978) list several advantages to a unit within a general hospital, the decision not to build an independent free standing unit seems

largely evolved from economic considerations. Stoddard (1978) comments favourably upon the PCU at Royal Victoria which she says is "...somewhat reminiscent of St. Christopher's in miniature..." (p. 236) and yet she points out the difficulty of achieving a sense of community unless there is psychological and physical distance between hospice and hospital. It seems Stoddard is referring to an incompatibility between aims of palliation versus acute care. However, the translation of the hospice concept as manifested by the Royal Victoria Hospital is considered a salubrious one which has become the model of palliative care in Canada. There are now about a dozen such services across Canada (Cohen, 1979).

Dr. Balfour Mount, founder and director of the PCU at Royal Victoria Hospital, recognises the incongruity in the two philosophies--palliative versus acute care--and cites this as a justification for a *separate* unit within hospital.

The Bereavement Follow-up programme entails close assessment of the styles in dealing with the impending loss of the significant others, an encouragement of anticipatory grieving, and identification of individuals (survivors) considered particularly at risk. Those deemed at risk are followed after the death. Others may or may not be followed. Follow-up itself includes a telephone call at two weeks, a visit by a staff member at one month, and a letter at one year. Family members are also brought together periodically for group meetings (Wilson et al. 1978).

The Hospice Movement in the United States

Hospice in the United States has followed divergent paths. The early examples of hospice represented three different models. Hospice, Inc. in New Haven was designed after the principles of St. Christopher's. Its medical director, Dr. Sylvia Lack, was trained at St. Christopher's. It is a 44-bed facility which received support for a two and a half year period from the National Cancer Institute (NCI) as a demonstration project for the hospice concept (Stoddard, 1978). Another pilot began in New York City in

1975 at St. Luke's Hospital as an in-hospital hospice team. This is to say that hospice principles are carried to terminally ill persons wherever they are in hospital--a separate and distinct unit does not exist. The Marin County (California) hospice founded in 1975 represents the third type of hospice in that it is essentially a Home Care Agency and has been licensed as such by the state. Of the three models, the bias in the United States is currently toward the home care model (Kutscher & Kutscher, 1983).

Tehan (1982) believes that hospice may function effectively within an existing home care agency, given a strong administrator who is willing to be an advocate for the concept, as well as to ensure principles are really being implemented. She comments, though, that the whole team must be dedicated to, and supportive of, all features of hospice, e.g., bereavement care as well as pain and symptom management. In addition, an agency's commitment to the concept should be challenged if 24-hour care is not available. "An inherent danger in establishing a hospice program in an existing agency is offering several, but not all, of the components of hospice care" (Tehan, 1982, p. 13).

It has been argued by Rossman (1977) that there really is no unitary hospice model which is appropriate to the variety of settings in the United States i.e., each community must assess its own needs. By now it can be seen that hospice is first and foremost a *philosophy* of care (e.g., Saunders, 1981; Buckingham, 1982) and, in theory at least, it is conceivable that this philosophy can be carried to wards of a general hospital as it is at St. Luke's. However, the difficulties inherent in doing so should not be overlooked. To reiterate, hospice requires a tenacious dedication to creating a special ambience as well as to the principles of medical palliation. Regardless of principles and regulations which are set in place, DuBois (1980) has reminded us:

...the appropriate management of death involves both science
and art. Hospice care, in the end, is only as good as the services
the staff can provide, and that in turn depends upon the quality

of personnel, the quality of training they have received, the quality of interactions among staff members, the support the staff receives from the administration, and the relations the staff enjoys with the surrounding community (p. 67).

Despite the emergence in the United States of literally hundreds of agencies offering hospice care, the movement has not yet received widespread societal support (Kutscher & Kutscher, 1983; McNulty & Holderby, 1983) nor has it been integrated into the health care system (Dooley, 1982; McNulty & Holderby, 1983). Part of the reason for the latter is the fragmentation of care which exists in the United States.

In August 1982 the "Hospice Bill" section 122 of the Tax Equity and Fiscal Responsibility Act of 1982 was passed by the U.S. Congress. The effect was federal recognition of hospice as a separate and distinct provider of service (Cassileth & Donovan, 1983). Also, Medicare was extended to those Medicare eligible home-care patients and in-patients with a prognosis of six months or less for a trial period beginning November 1, 1983 and ending October 1, 1986 (Smyser, 1982). Cassileth and Donovan (1983) noted that the guidelines are broad in order to accommodate different hospice programmes and to allow for innovation. However, they suggested vigilance against extremes: over-regimentation and insensitivity on one hand; and the degeneration into a too subjective "how one ought to die" attitude on the other. Paradis (1984) reported an increased tendency toward integration of hospice programmes into the traditional medical establishment with the advent of third party payment. She claimed that this integration has resulted in some loss of idealism and decreased programme flexibility. However, her survey did not indicate that quality of care or patient satisfaction with care had decreased (Paradis, 1984).

Dooley (1982) claimed that hospice is a threat to the traditional medical network. In many states, prior to Medicare approval, hospice philosophy had not been congruent

with existing regulations and some hospice organisations had already ended up sacrificing ideals for survival. Some had chosen to affiliate with existing services rather than follow tedious and uncertain steps toward licensure. Although this relationship of convenience can be workable, Dooley commented, "Instead of a hospice program, the result may be traditional health care service with hospice overtones" (1982, p.38).

Aiken and Marx (1982) also warned of the potential dangers of institutionalisation and urged a careful look at the lessons of the nursing home movement as a benevolent notion gone wrong. They reminded us that nursing homes were a by-product of the Social Security Act of 1935 which intended to give elderly sufficient money to support themselves so that almshouses could be closed. Unfortunately, the fact that elderly persons are also frequently infirm was not given proper consideration, resulting in an increased demand for institutions. Subsequently the nursing home came into existence. After tens of thousands of people were involved, payment could not be discontinued even given low standards of care. "Thus, legislation designed to phase out substandard institutions actually served to accelerate the growth of proprietary interests. Care of the elderly became a profitable business" (Aiken & Marx, 1982, p. 1273). The implication is that a rigorous investigation of options and outcomes needs to accompany good intentions if a similar dire consequence is to be averted in the hospice movement.

Mount and Scott (1983) have been very outspoken on some differences they see between how hospice is practiced in the United States and how it is typically practiced in Great Britain and Canada. As alluded to above, hospice in Great Britain and Canada developed within a health care system in contrast to the situation in the United States which was more the result of a grass roots movement. Mount and Scott stated that the latter case has resulted in less physician involvement. They were critical of this trend, arguing that greater, not less, need for physician involvement in terminal care is

evident. In addition, they pointed out that innovative pain and symptom management techniques in the early hospices resulted from intensive physician involvement.

Another difference, also discussed above, is that hospice is largely home care oriented in the United States. For many individuals, home care may be undesirable or impossible. Along with the economic considerations i.e., home care is cheaper than in-patient care, there seems to be widespread acceptance of the idea that individuals want to die at home. It could be argued that to assume this is what all individuals want is to discriminate against those who do not want it or those for whom it is not appropriate e.g., those who live alone. Mount and Scott believe that hospice ought to be capable of providing for the needs of these patients. Another difficulty with programmes based exclusively on home care is that without in-patient facilities respite for kith and kin is much more difficult. If the patient ends up hospitalised, disruption of care can have dramatic medical and psychological consequences.

American hospices require a prognosis of no more than six months for admission. Mount and Scott claimed first of all that such a specification is both arbitrary and difficult to ascertain. About 20% of patients at Royal Victoria Hospital live longer than six months and this projection is not used as the criterion for admission (Mount & Scott, 1983). They believe "Hospice care becomes relevant not when the patient 'has 6 months to live', but when further treatment aimed at cure or prolongation of life is no longer appropriate" (Mount & Scott, 1983, p. 732). Within this context months left to live is arbitrary and as such would exclude some individuals who would be eligible by the former criterion. It may be that a difference in philosophy of treatment influences when patients are perceived as eligible for hospice. This could be the case if American physicians are generally less willing to pronounce prolongation of life as an inappropriate goal. On the other hand, there is no particular hard evidence that American physicians are satisfied making decisions to include or exclude patients based upon the criterion of time left to live.

Mount and Scott also objected to the usual practices of ensuring that the patient and family know the prognosis and that there be a principal care giver (PCG) available for the patient. The latter is an obvious reflection of preference for home care and seems to discriminate similarly. Patients may simply live alone or not have family or friends willing to take on the task. Pertaining to the former point, the authours feared the effects of legislated medical communications. By way of example, the patient may be forced to see hospice as an alternative to care rather than a continuation of care (Mount & Scott, 1983). In general, according to Mount and Scott, some substantial and important differences exist between Canadian and American implementation of the hospice concept.

Butterfield-Picard and Magno, both of the National Hospice Organization have been critical of the principal care giver requirement arguing that, while 70% of hospice patients are over sixty-five, 65% of the elderly population in the United States is comprised of women who are over 65 years of age and live alone. Therefore, the PCG requirement excludes the typical older adult (Butterfield-Picard & Magno, 1982). Supplemented by the fact that 67% of U.S. hospices require a PCG available 19 hours a day (Butterfield-Picard & Magno, 1982) fears of elitism are not unrealistic.

"There is good reason to think...that the hospice presents to our society and to the medical profession a moral crisis of the most profound nature" (1984, p. 4). So remarked Gibson in a recent issue of "The Gerontologist". One consequence of hospice philosophy according to Gibson is that cost-effective utilitarianism has been substituted for the sanctity of human life. While there are frequent references to cost savings in the literature, to assume that this is a primary motivation is quite another matter. An alternative explanation is the recognition by those involved with hospice that beneficent notions are not accepted on their merits alone. It obviously helps to be cost effective (cf. Aiken & Marx, 1982). This is pragmatic but not necessarily utilitarian. And, as of now, there is no agreement that hospice *is* cheaper. The

question should be, cheaper compared to what? For example, it is certainly more expensive than "ordinary" home care (Tehan, 1982).

Hospice Evaluation

Efforts to evaluate hospice effectiveness have not been numerous. Early exceptions include an evaluation of the New Haven Hospice Home Care programme and a descriptive report compiled by the Royal Victoria Hospital PCU. The former study concluded that hospice patients and their families exhibited less psychological trauma and greater satisfaction with social activities than did non-hospice patients and their families. In addition to descriptive data, Royal Victoria reported a small bereavement follow-up study which concluded that PCU interventions promoted "normal recovery" from grief (Godkin, Krant & Doster, 1983). However, due to methodological shortcomings, conclusions from both these early studies should be considered tentative (Godkin et al, 1983).

With the approval of Medicare, evaluation of hospice effectiveness is now mandated i.e., a congressional review of Medicare occurred in the Fall of 1986 (Mount & Scott, 1983). A result of this mandate is the National Hospice Study implemented by the Health Care Financing Administration, the Robert Wood Johnson Foundation and the John A. Hartford Foundation (Vandenbos et al., 1982). The study which involved 26 hospices in the United States (Vandenbos et al, 1982) employed a time series design with two comparison groups. Data were collected for (a) hospice patients in hospital, (b) home-care hospice patients and (c) patients receiving conventional care at one to two week intervals (Dush & Cassileth, 1985). Even before reports of the results had been published (Dush & Cassileth, 1985), criticism had already emerged.

Dush and Cassileth (1985) have pointed out the potential bias of statistical regression with non-equivalent groups as well as the difficulty of inferring causation with any quasi-experimental design. More dramatically, Mount and Scott (1983) questioned the representativeness of the study by suggesting that the best examples of

hospice may not have been included in the sample. The question of what has been measured is certainly an important one. On a more specific level, Mount and Scott challenged the use of a modified Spitzer Quality of Life Index which is the chief measure of that variable as having poor content validity for the seriously ill. While demonstration of validity remains to be seen, Mount and Scott asserted, "It may be that excellence in hospice evaluation must await the development of new out-come measures" (1983, p. 734).

Also on a global scale Buckingham and Lupu (1982) have compared various hospice services in the United States. This study did not evaluate effectiveness (e.g., in outcome or implementation) but results may have implications for the concerns voiced by Mount and Scott above. Questionnaires were mailed to hospices. Participating hospices were asked to select 5 staff members and 5 volunteers who would each complete a questionnaire. It is not known if those selected differed from other staff or volunteers. The sample was a rather unorthodox aggregate composed of 15 hospices selected randomly and 9 hospices selected because they were considered established models in the field. Apparently the two groups did not differ significantly on important variables.

Results showed the emergence of two types of programmes. Programmes which were independent of hospitals tended to make extensive use of volunteers, had a wide variety of professional staff offering diverse psychosocial services to home care patients, but often had major funding problems. On the other hand, institutionally based hospices provided in-patient care with more emphasis on medical and nursing care and fewer types of psychosocial services offered by fewer staff and volunteers. This type of programme tended not to have major funding problems.

Buckingham and Lupu identified three factors as essential to holistic, comprehensive care: (1) medical and social services; (2) use of volunteers; and (3) availability of both in-patient and home-care services. On the whole their survey

showed hospices act on the first two precepts. The third requirement has not been fully implemented. Only 10 hospices offered in-patient care and almost 40% had no physician on staff. The authours recognised the limitations of their study, but concluded that it was their subjective impression that wide differences existed in the *quality* of hospice programmes (1982). This assessment was based upon their criteria of care and more specifically National Hospice Organization standards. (see Appendix A).

Recently, a few studies have appeared in the literature which have evaluated components of hospice programmes. Godkin et al. (1983) did a retrospective analysis of a particular hospice's impact on spouses. The questionnaire attempted to elicit information about perceived effectiveness of care, the impact on the patient's functioning, the spouse's psychological well-being while on the service, preparedness of families for death of the patient, and bereavement outcomes. Basically, the questionnaire was designed to evaluate effectiveness of hospice care from the point of view of the significant other i.e., spouses were asked to compare hospice services to previous care.

Of 100 questionnaires mailed, 58 responses were returned. Ninety-one percent of those who responded rated hospice care as "excellent". Nine percent rated overall care as "good". Previous care was rated "excellent" by 36%, "good" by 30%, "fair" by 16% and "poor" by 18%. Families also felt supported and were "very well" or "reasonably well" prepared for the death of their loved one. Feelings of loss were perceived as large or major problems in 51% of the respondents.

The researchers concluded "...that a service unit set up to improve terminal care of cancer patients and their families, is well received by bereaved spouses who appear to experience considerable relief of many emotional and behavioral dimensions of the terminal period" (Godkin et al., 1983, p. 164). It should be pointed out that a substantial number of targeted subjects did not respond to the questionnaire and

objective measures of variables were not employed (Godkin et al., 1983). While satisfaction with care is certainly important, it is not known if this service affected the survivor's morbidity (Godkin et al., 1983).

Brescia, Sardof, and Barstow (1984) examined the records of 50 patients who died in a home care programme within a 6 month period. They were interested in determining differences between those who died at home as opposed to those who were in-patients when they died. The programme evaluated did not have provisions for in-patient care. They found that 48% of their sample required hospitalisation at one point or other after enrollment in the home care programme. Most often pain was the symptom which necessitated hospitalisation. However, among patients who died at home no symptom complex was perceived as unmanageable by the patient's family, the nurse, or the physician. In general, Brescia et al. were unable to predict which patients would die at home (1984). The high number of patients requiring hospitalisation suggests the importance of providing both types of care. It is ironic that patients should be hospitalised on a general ward for symptoms which are "specialties" of hospice care.

Also in an attempt to determine where patients die, Bass, Pestello, and Garland (1984) analysed data from records of 146 home care hospice patients for a one year period. As in the previous study, data were compiled from one programme which does not provide in-patient care. The study hypothesised that the greater support patients received, the greater likelihood they would be able to cope with their situation. The implications are that satisfaction with care and adequate hospice care should preclude hospitalisation. As was mentioned earlier, this assumption may be challenged on theoretical grounds. Nevertheless, the study found that 43% of patients chose to return to a facility rather than remain on the home care programme and eventually died as inpatients.

Unlike Brescia et al. (1984) a few variables were found to significantly correlate with hospitalisation. These were: (1) length of time enrolled on the programme, (2)

race (Black or White), (3) number of visits from hospice nurse and (4) intensity of contact with hospice nurses. Bass et al. suggest that patients enrolled in the programme for a long period of time may be in relatively good shape upon admission and remain stable for some time. Sudden deterioration may be difficult for staff and significant others to deal with and long term care may drain resources increasing the likelihood of hospitalisation. As for race, Blacks may have different attitudes toward death which results in hospitalisation or alternatively, interactions with non-Black staff may inhibit rapport (Bass et al., 1984). The correlations with number and intensity of contacts demonstrates the importance of non-medical care (Bass et al., 1984) i.e., it is assumed that those patients with fewer nurse contacts had adequate medical attention.

Unique in the hospice outcome literature is the UCLA Hospice Evaluation study which began in 1980 and was completed in 1983. In an effort to attend to the problem of selection bias, the researchers used a randomised control trial design assigning informed subjects at a VA hospital to either hospice or conventional care. This is to say that "During the study, no subjects were admitted to the hospice programme except through this process of informed consent and randomisation" (Kane, Wales, Bernstein, Leibowitz and Kaplan, 1984, p. 890). More specifically, patients were identified by their primary physicians as being potentially eligible on the basis of having cancer with a terminal prognosis (two weeks to six months). Patients who had been informed of their prognosis were invited to participate, at which point hospice and random assignment were explained. After receiving consent from the patient and one significant other, assignment occurred.

Patients and their significant others were then interviewed at fixed intervals until the patient's death or until a predetermined number of interviews had been completed. The treatment group, composed of in-patient and home care patients, numbered 137. There were 110 patients in the control group who continued to receive care from their primary physicians (Kane et al., 1984).

Interview content consisted primarily of a number of instruments chosen for their established validity with the terminally ill. Instruments showed good test-retest reliability but were also short so as to minimise fatigue. Response format was of the multiple choice type in order to facilitate quantification, and, once again, to prevent over-burdening subjects (Wales, Kane, Robbins, Bernstein & Krasnow, 1983).

It was expected that the hospice group would show less pain, depression, anxiety, and anger than the controls, as well as fewer symptoms, more satisfaction with care, and an increase in activities. The significant others likewise were predicted to show less affective disturbance (as measured by the scales), more satisfaction with care, and less morbidity than controls (Wales et al., 1983; Kane et al., 1984).

The results were something of a surprise. In general, the predicted differences (which would show greater effectiveness of hospice care) were not obtained. For example, no significant differences in pain were observed between groups over time, and, more dramatically, no difference in mean pain score was found at any interview time point. There were no differences in symptom scores or in anxiety. Control subjects had consistently higher depression scores but the difference between groups was not significant. Hospice patients did express more satisfaction with care than did control patients (Kane et al., 1984). A cost comparison study was also conducted which yielded no significant differences between hospice and conventional care (Kane et al., 1984).

On the basis of these findings and the strength of the experimental design, Kane et al concluded: "Since our findings suggest no substantial difference in cost or effectiveness, we suggest that hospice care should be available as a matter of choice" (1984, p. 893).

No difference in complaint of pain or symptoms is certainly surprising given hospice philosophy and practice as discussed earlier. However, it may be, as the researchers suggest, that conventional care is becoming more effective due to the

dissemination of hospice techniques and philosophy throughout the general hospital. Others (e.g., Dush & Cassileth, 1985) have also suggested this possibility. It is now not unusual to find articles exhorting care as proposed by hospice by those formally outside of the system. For example, Geyman (1983) encouraged family practitioners to be supportive of the dying patient in ways which respect the patient's individuality. Further, he defined the physician's responsibility as not ending with the death of the primary patient. Given increased morbidity in survivors "...it is essential to see the spouse or other appropriate family members at periodic intervals thereafter" (Geyman, 1983, p. 130). It should also be remembered that part of the hospice ideal is education and many institutions offer formal consultation both within their own systems as in the cases of hospice within hospital settings, or to the community at large (cf. Lattanzi, 1982).

There are at least two limitations of the Kane study: (a) applicability, given VA patients may not be typical of the rest of the population; (b) number, in that only one hospice was studied (Kane et al., 1984).

Dush and Cassileth in a thorough review of theoretical issues of programme evaluation (1985) argued that the question, "Is hospice effective?" is analogous to asking, "Is surgery effective?" In this context, no single study is sufficient to answer the question, no matter how well that study may be designed. "Rather than studying 'the hospice effect', the more important question would seem to be what kinds of terminal care interventions, by whom, in what combinations, form, and amount, for what kinds of patients and families with which types of concerns, work best under a particular set of circumstances?" (Dush & Cassileth, 1985, p. 56).

As implied above, many levels of evaluation exist and the questions are different at each level. By way of example, the issue pertaining to the possible proliferation of hospice techniques is an important question of impact evaluation. More specifically, one might ask what impact, if any, specific hospice pain management approaches have

had on general medical attitudes towards cancer care. Dush and Cassileth (1985) assert a general need to begin at the beginning and evaluate contexts (needs assessments, programme goals, etc.) and implementation, or the degree to which programmes do what they say they are going to do. In this way, one may be more confident that observed effects are related to what actually happened in patient care. In short, much more careful and well defined research needs to occur on many levels of hospice evaluation (Dush & Cassileth, 1985).

Summary of the Hospice Literature

The above discussion of the modern hospice began with the idea that this philosophy of care evolved from an acknowledgement by professionals and laypersons that an adequate system did not exist to deal with the problems of the dying (Stoddard, 1978; Wilson, Ajemian & Mount 1978). There may be many reasons for this but, in general, it was thought that there was an increasing awareness that North American society had become pervasively death denying.

Theoretically, a holistic interdisciplinary approach was advocated (e.g., Cohen, 1979; Gardner, 1976; Munley, 1983; Rossman, 1977) which, from a medical perspective, emphasised palliative rather than curative treatment (Saunders, 1981). It was suggested that prevalent attitudes about the dying have, in the past, resulted in an unnecessary amount of physical pain and emotional distress for terminal patients (Bonica, 1979; Kübler-Ross, 1969; Noyes, 1981). Implicit in hospice is the assumption that a supportive milieu can decrease distress (Melzack, Ofiesch & Mount, 1976).

Hospice, in practice, has generated much research resulting in improved patient care in areas such as pain management techniques. And some myths, for example that all terminal cancer patients experience pain or that the administration of narcotics results in addiction, have been demonstrated to be inaccurate. Although a unitary phenomenon, *hospice*, may often be presupposed to exist, this is not in fact the case. While the core

philosophy remains the same, there are key differences in British, Canadian, and American translations of this philosophy. In the United States three different models arose at once but the current bias is toward home care (Kutscher & Kutscher, 1983). Even within this model there are wide divergences in the services offered and in how well hospice philosophy is implemented (Buckingham & Lupu, 1982). The discussion of hospice evaluation has shown the importance of carefully identifying and defining the problem of interest for research.

Psychological Aspects of Terminality

The role of the clinical psychologist in providing services for the terminally ill patient, especially within hospice systems, has not yet been clearly delineated. As of now, mental health training for hospice workers is not systematised (Garfield, 1982) and psychologists have been conspicuously absent. For example, only 21% of hospices employ psychologists in any capacity (Liss-Levinson, 1982). In an article which makes several proposals in this regard, Carr (1983) suggested research activities as one particular skill that psychologists may bring to a field which has not received much of this sort of attention--a fact which was seen from the prior discussion of efforts to evaluate hospice efficiency. As an aside, pain management is another area (among many) in which psychologists may make significant contributions.

While the proponents of a hospice approach advocate comprehensive care, there can be limitations inherent in specific hospice structures (e.g., hospices without in-patient facilities) which can compromise the level of care. Some authours have voiced concerns over bureaucratic and proprietary trends in American hospices which already may have contributed toward a weakening of the ideal. And research efforts have not unequivocally shown the superiority of the hospice approach. All these factors contribute toward a greater urgency for evaluation and research on many levels. Attending to psychological and social needs of individuals (and significant others) must

be an integral part of caring for dying persons. Surely how well that care can be carried out is dependent, in part, upon the current state of knowledge in the field and how well that knowledge has been promulgated.

It could be suggested that the importance of accountability has increased as hospice has grown and been identified as a primary specialist in care for dying persons. Without this accountability, a possible scenario which could develop is a too comfortable confidence in hospice's skills and a growing rift with research in the area. It is imaginable that a premature acceptance of research "facts" could have some detrimental effects on terminally ill patients. In a similar way it has been seen that, in the past, medical care for the terminally ill had been limited by the level of medical knowledge. So, it is proposed that hospice and research in death and dying be seen as interdependent. An important question then, assuming this interdependence, is to ask about the state of the research.

In the discussion below, some early efforts are reviewed which were primarily nomothetic in design. Perceived limitations with this approach has led to a greater emphasis on "idiosyncratic" variables. The idea is presented that research in this area need not be framed as an either/or proposition i.e., nomothetic or idiographic. Next, appropriate dying is introduced as a theoretical construct which can be investigated on many levels of observation and also has implications for treatment. It is argued that the core of this concept respects individual differences and thus may be of considerable importance to those, such as hospice advocates, who stress individualising care for the dying.

Carr (1983) claimed that much of what is known in thanatology *in general* has been prematurely accepted as fact. This is especially evident in discussions of psychological variables thought to be manifest in the dying process. The most widely propagated and generally accepted description of psychological components of terminality has been Kübler-Ross's (1969) enumeration of the five stages of dying.

While recognising that individual reactions to stress can vary, Kübler-Ross asserted that there exist common stages which she labelled: (1) denial; (2) anger; (3) bargaining; (4) depression; and (5) acceptance.

According to Kübler-Ross, patients do not necessarily proceed through all of these stages but at times may become "fixated" at a particular stage. It is also possible that two of the stages can occur simultaneously (Kübler-Ross, 1974). Despite variations, the stages are used as progressive indicators of where persons are psychologically in relationship to the physical process which is dying. Kübler-Ross views the fifth and final stage, acceptance, not only as the most desirable--in that it promotes peace and dignity--but also as a sort of natural consequence of the dying process. It may be asked then why some individuals do not reach this stage. According to Kübler-Ross the answer seems to be that others, especially those involved in the patient's care, interfere with the process. She has said, "I think most of our patients would reach the stage of acceptance if it were not for the members of the helping professions, especially the physicians, who cannot accept the death of a patient" (1974, p. 37).

Social conditions certainly may influence how an individual interprets his or her illness or at least what is thought to be safe to reveal in particular situations. For example, Glaser and Strauss (1976) describe a hospital scenario in which the patient and the medical staff (or a significant other) agree (tacitly) to pretend the patient is not dying even though they "know" otherwise. Such occurrences, called *mutual pretense*, are typically instigated when the patient picks up cues from the staff concerning their unwillingness to talk about or deal with the patient's death. Should the patient attempt to talk about his/her eventual demise in direct terms, staff may respond in a manner which makes clear a desire to continue the pretense by ignoring, minimising or directly repudiating the intent of the patient's comment. If the patient then agrees to adopt the staff's position the pretense may be reinitiated.

Similarly, Stein (1984) suggests that our "observation" (of stages) may reflect an imposed rather than intrinsic process which evolves from a middle-class attitude toward death. Such an attitude assumes a linear approach to problem solving which is probably culture bound. On a slightly different level of social influences, Jankofsky and Stuecher (1984) hypothesise stages to be a reaction to dying *per se*. They reason that a sick role removes motivational forces in life and leaves the individual with feelings of failure and guilt. Given such reactions, anger and depression would not be unusual or unexpected responses.

Kübler-Ross's early descriptions abound with staff members' inability to deal with death (cf. 1969) and it makes sense particularly in an autocratic system that this inability, or lack of acknowledgement, would influence what is communicated by patients. Nevertheless, these occurrences do not address the issue of whether a stage of acceptance is a natural consequence of the terminal process or whether the aforementioned stage process occurs at all.

Kübler-Ross's theory has become very popular, especially with hospital personnel (Kalish, 1978) and the hospice movement (cf. Hare, 1983). Still, there has been growing opposition to the stage approach by other thanatologists who reject or question the notion (Feigenberg, 1980; Kastenbaum, 1975; Shneidman, 1973) as well as a failure by other researchers to verify it (Kalish, 1978; Schulz & Aderman, 1974). There is a lack of systematic research which either clearly contradicts or substantiates Kübler-Ross's formulation (Kalish, 1978).

Part of the difficulty is that the stages are not operationally defined. What does it mean for example for an individual to be in or at the stage of acceptance? Schulz and Aderman (1974) have attempted to review the concept by comparing the apparently contradictory conclusions arrived at by Hinton using a method (of unstructured interviews) comparable to Kübler-Ross's. According to Schulz and Aderman almost 60% of Hinton's sample appeared to not know about or were denying their impending

deaths while Kübler-Ross asserts that all her patients were aware. This disparity is pointed out as good reason to question Kübler-Ross as Hinton's sample should have been approaching "acceptance".

In addition to the problem of assuming comparability of samples and methods, Schulz and Aderman seem to assume an equivalence between awareness and acceptance. While such difficulties will inevitably arise without definitional agreement, it seems that Kübler-Ross does not wish to equate the two. Acceptance means more for her than awareness of one's terminality i.e., a sort of equanimity is implied. For example, an individual may be aware and depressed but the stage of depression is ideally a psychological position to be moved out of in the progression toward acceptance. Left to intuitive assumptions about words, confusion results. On a more serious level, assumptions are made about how individuals ought to die which has had the consequence of professionals urging patients through stages (Hare, 1983; Liss-Levinson, 1982). The issue of what does occur and what ought to occur--the latter being a therapeutic judgment--have become muddled. If theoretically Kübler-Ross's stages do not occur, what features do characterise the dying process?

Schulz and Aderman (1974) state there is some consensus among researchers that depression is apparent shortly before individuals die. Shneidman states his position this way:

Rather than the five definite stages discussed above, my experience leads me to posit a hive of affect, in which there is a constant coming and going. The emotional stages seem to include a constant interplay between disbelief and hope and, against these as background, a waxing and waning of anguish, terror, acquiescence and surrender, rage and envy, disinterest and ennui, pretense, taunting and daring and even yearning for death--all these in the context of bewilderment and pain (1973, p. 7).

Weisman (1972) claims that denial characterises the dying process. Use of the word denial can be problematic from a definitional point of view and in understanding what reference is intended. Cohen and Lazarus assert, "When we speak of denial, avoidance and other intrapsychic coping processes, it is as though we know clearly what these processes are and how they are to be assessed. Such clarity however, does not exist, and in practice their assessment is filled with ambiguity and confusion" (1979, p. 226). Cohen and Lazarus point out that denial and avoidance are often confused when denial is inferred from what may be the deliberate avoidance of a topic. They also feel that an over-emphasis has been placed on the trait position so that denial is seen in a static sense and not as a *process*. In this way, people become labelled "deniers". (Cohen & Lazarus, 1979). This labelling may be clearly evidenced in literature which treats denial strictly as a defence mechanism. For example, Bahnsen and Bahnsen (e.g., 1966) have attempted to account even for the etiology of cancers by implying that such individuals have regressive ego defences i.e., make persistent and excessive use of denial and repression.

Various degrees of denial which seem characteristic of the terminal process were elaborated by Weisman following interviews with 350 patients. Some patients were seen only once, but 25 were seen at least 12 times and 50 others provided in depth information. Recognising that "There is no certain method for assessing the proportion of denial or acceptance that anyone actually experiences" (1972, p. 93), Weisman observed three psychosocial types of denial which corresponded to the physical staging in the course of a fatal disease--Primary Recognition, Established Disease, and Final Decline.

First order denial pertains to primary facts of the disease, that is, around the diagnosis. The tendency upon suspecting serious illness is (as Weisman referred to first order denial) denial (e.g., of symptoms) and postponement. Once the disease is

clinically established, denial which alters the implications of the disease is typical. For instance, an individual may attribute further signs of disease to something other than cancer. Weisman called this stage mitigation and displacement. Third order denial is characterised by denial of extinction.

These stages are fluid and it is not possible to categorise all manifestations of denial. As Weisman asserted,

The path from primary recognition of disease to incipient death is highly idiosyncratic. Only when we stand at a distance does human behaviour seem subject to laws and to prediction. Nevertheless it is possible to recognise and describe general phases of terminal illness without imposing sterility or an artificial stereotyped version of threatening events (1972, p. 97).

Extrapolating from a case consultation, Stein (1984) proposed that determining the source of denial may not be an easy task and may be present in many parts of the patient's network. In the case Stein discussed, what was assumed to be solely the patient's intrapsychic defence turned out to be bolstered by defences in the family, cultural differences, and by the institution. As for institutional reinforcement of denial, an example was given previously in the description of mutual pretense. What Stein reminds us is that a systems approach to problem solving is too frequently not taken into consideration when dealing with the problems of the dying (Stein, 1984).

Weisman uses the term denial to refer to a process which is by necessity interpersonal i.e., what was thought to be shared reality is repudiated. In addition to avoiding perceived danger, denial serves to maintain significant relationships and may be manifest to varying degrees depending in part on external circumstances. In an article which defends denial as socially useful, Beilin (1981) suggested physicians should be sensitive to the patient's needs to deny. Beilin claimed "The threat of death

is a threat to the future of the relationship in question. In unthreatened relationships, members are available to one another for support, validation and emotional sustenance. The imminence of death of one member jeopardizes this social support" (1981, p. 26). In addition to preserving relationships Beilin asserted it may preserve life. For example, if a prognosis is dire at the time of diagnosis, a possible scenario which could develop is that of a patient giving up and not complying with a suggested medical regimen which could possibly have positive effects. A popular advocate for patients taking more responsibility for their recovery is Norman Cousins (1979) who survived a diagnosis which, if correct, was deemed to be fatal.

Denial then may not always be a negative process to be "broken through" but may be adaptive from time to time. However, Hackett and Weisman (1964) have demonstrated pervasive denial to be more effective in coping with illnesses where there is a greater chance of recovery--for example myocardial infarction--rather than terminal cancer. The implication is that it is improbable that an individual remain well defended in a situation which is chronic and severely debilitating without giving up reality testing altogether (Weisman, 1972). Such factors would not preclude intermittent denial serving a useful purpose.

There is some opposition to the idea that denial may be potentially beneficial. Noyes and Clancy (1977) have claimed that denial in terminally ill patients results in an unwarranted drain on medical and family resources. Therefore patients should be confronted with their impending non-existence. The intention is to encourage patients to relinquish the sick role and adopt a dying role with rights and obligations distinct from the former role. While it is correct as Noyes and Clancy have asserted that an individual who is sick and dying, in some sense, violates the constraints of the sick role (because such patients do not get well), it could be claimed that they were attempting to lend more clarity to human behaviour in dire situations than can actually exist. More

important than theoretical considerations are the ethical implications of presuming such a paternalistic stance toward another's life and illness.

In contrast to the idea that universal stages exist, some (e.g., Hinton, 1975; Shneidman, 1977, 1980; Thompson, 1984) have claimed that the dying process is idiosyncratic. For example, Shneidman has stated "People live differently; people die differently--much as they have lived during previous episodes in their lives that were, to them, presages of their final dying period" (1980, p. 112). Periods which are especially predictive for behaviour of dying persons are those incidents which are comparable in the sense of being stressful and bleak (1977). Essentially this thesis asserts that previous patterns of coping with failure, if they could be known in sufficient detail, would illuminate current functioning in the dying process (Shneidman, 1977).

Hinton, studying 60 married terminally ill cancer patients, investigated whether or not correlations existed between "...descriptions of patient's personalities before they were ill and their state of mind during their last illness" (1975, p. 96). Information about the patient's previous personality was gathered retrospectively by interviewing the patient's husband or wife while information about current functioning was gleaned from interviews and assessments of mood with the patient, nurses who filled out rating scales, and husband's or wives's opinions about how the spouse (patient) was feeling.

Eight factors were studied in all, four of which pertained to the patient's character i.e., the ability to face problems, degree of decisiveness, neurotic traits, and life satisfaction. Two factors pertained to the marriage (harmony and degree of dominance) and two to religion (religious practice and belief in immortality). Current psychological states assessed included depression, anxiety, anger, and degree of withdrawal.

In general, Hinton found that previous manner of living influenced the way people die. Interestingly, there was no significant difference in depression and anxiety manifest between "stable" and "nervous" individuals (Hinton, 1975). This occurrence

had been observed earlier by Weisman who commented, "We are led by our prejudices to assume that how a person dies will be determined by how he has lived, a proposition that scarcely anyone can dispute. However, if this maxim leads us to expect that only 'stable personalities' will endure fatal illness without serious fluctuations of hope and despair, it is patently incorrect" (1972, p. 116).

Hinton recognised some problems with his method of investigation. For example, he found that spouses described reactions of their husbands or wives in a manner which corresponded more with their own expectations than with actual events (1975). It seems that, at best, spouses could only be expected to convey their own perceptions. In addition, biases exist due to the retrospective nature of the judgements being made and the fact that spouses are participants in the drama. One might expect these last two factors to have a strong interactive effect. Nevertheless, the difficulties associated with assessing premorbid functioning should not be minimised.

The thesis that an idiosyncratic approach is necessary for understanding how individuals die need not exclude the possibility that some common features exist. Runyan (1984) suggested a solution to the either/or dilemma (nomothetic versus idiographic) which entails understanding the problem as reflecting various levels of observation based in part on Kluckhohn and Murray's dictum: "Every man is in certain respects (a) like all other men, (b) like some other men, (c) like no other man" (1953, p. 35). It is asserted that each level of investigation is semi-independent. While they are all necessary for understanding the Gestalt, "The solution of problems at one level of analysis will not necessarily solve problems at the other levels" (Runyan, 1984, p. 9). For instance, group studies would have inherent limitations for understanding and predicting the behaviour of individuals in specific circumstances. The answer to this limitation would seem to be to study individuals. Runyan enumerates about half a dozen systematic methods of doing so which have appeared in recent literature. In



order to be distinctly idiographic, studies must look at relationships within the individual case.

A recent example of this approach was a study by Mages and Mendelsohn which examined the effect of having cancer on individuals' lives through the use of intensive interviews (1979). In essence, the individual is the basic unit not a set of variables, so that "...its end product is an integrated description of a unique pattern of functioning" (1979, p. 256). Examples of methods in addition to the case study approach include efforts to correlate variables within a single individual and configural analysis. The latter recognises stable and changing states within the individual which may be identified in both nomothetic and more idiographic terms. Runyan gives the example from Horowitz of a set of phenomena which could be described either as "depressed mood" or in the words of the subject, "hurt and not working" (Runyan, 1984). "Hurt and not working" then may be anchored to other states or conditions in the individual's life.

The most prevalent objection to idiographic studies is that generalisation is difficult. Runyan claims that this criticism assumes that the only goal of personality psychology is to generate higher and higher levels of abstraction. Secondly, the criticism is inappropriate to the idiographic level of analysis. "To the cry of 'How can you generalize from that idiographic study?' an equally appropriate response could be 'How can you particularize from that group or population study to the individual?'" (Runyan, 1984, p. 172). To the criticism that the study of individual cases is useful for generating hypotheses but not testing them, Runyan answers that this assumes there are only general laws i.e., not laws pertaining to particular cases. In fact, specific experimental designs and statistical methods exist for testing hypotheses on the level of individual cases (Runyan, 1984).

The implication of emphasising levels of observation and analysis for the study of the dying process is to recommend an acceptance of analysis on all these levels of

observation and a recognition that study on one level not be perceived as precluding efforts on other levels. In the next section, a concept which has treatment implications as well as potential for generating hypotheses on varying levels of observation will be explored.

The Concept of Appropriate Death

Countering the view that death is always an unmitigated evil, Avery Weisman claims death "...can arrive in a seemingly appropriate and timely manner" (1970, p. 68). This assertion reflects the observation (e.g., Weisman & Hackett, 1961) that some patients, when confronted with the prospect of their own imminent deaths, manifest relative equanimity. In this same article (1970) Weisman argues against the taboo nature of death which forbids discussion and promotes avoidance in hope that death may be magically vanquished. Instead, Weisman urges communication because, "Death with dignity and open awareness is more harmonious than death accompanied by a conspiracy of silence, deception, denial and censorship" (p. 68). It seems, then, that Weisman uses the potential for better and worse endings (e.g., a death which shows some equanimity and resolution as opposed to a totally degraded and fearful ending) to justify promotion of a humanistic goal--death with dignity.

Continuing the argument of humane care giving, Weisman elaborates the concept of an appropriate death in On Dying and Denying (1972). "An appropriate death, in brief, is a death that someone might choose for himself--had he a choice" (p. 41). Further, an appropriate death is purposeful and acceptable. However, not all purposeful deaths are necessarily appropriate and what is acceptable for one individual may not be so for another. Appropriate deaths then, are idiosyncratic. So Weisman advocates (thanatological) interventions to help individuals achieve an appropriate death without imposing someone else's phantasies. On this point he is emphatic, "To tell another person what he ought to do, think, or be is an affront at any time; but to do this when he nears the end of life is sanctimonious cruelty" (p. 36).

In a later publication (1979) Weisman indicates that an appropriate death has four characteristics: awareness; acceptability; propriety; and timeliness. He lists six prerequisites for an appropriate death--care, control, composure, communication, continuity, and closure. These prerequisites are further explained by a set of ten instructions or guidelines for reaching an appropriate death. For example, research indicates that denial may be effective in cases where the possibility of a positive outcome is real (e.g., in myocardial infarction) but not so with terminal cancer (Hackett & Weisman, 1964). Therefore, given a terminal prognosis, Weisman advises, "Avoid avoidances. Denial is effective only to a limited degree" (p. 100). The other nine guidelines are tenets which are also thought to reflect "good coping".

Intuitively, the idea of a better death seems plausible. That is, it is possible to imagine instances when loneliness, pain and anxiety are minimised, when coping is for the most part effective and personal agendas are pursued with some degree of satisfaction. This general scenario can certainly be considered better than one of isolation and loneliness. Conversely, it should be pointed out that to contemplate better and worse ways of dying does not necessitate admitting that death in and of itself is good, obfuscating the fact that "Death--being dead--is total cessation, personal naughtment, individual annihilation" (Shneidman, 1971, p. 10). Shneidman claims "There is (or ought to be) a reasonable difference between experiencing justifiable pride in what one has been and is and has created, on the one hand, and, on the other hand, feeling an unwarranted equanimity when one reflects that he will soon no longer be" (1971, p. 13).

An appropriate death is a better death. There is a danger that appropriate should become synonymous with "good coping", a danger because coping is only one component (albeit an important one) in an appropriate death. An additional danger is that what is "good" or "bad" may become a static judgment. It is recognised that the reluctance which is being expressed to equate good/bad death with

appropriate/inappropriate (i.e., as one and the same set of phenomena) is essentially a philosophic distinction. However, there is utility in the distinction if a static judgement is avoided. By the use of the word *appropriate* it is hoped that some understanding of the phenomenological view of others is implied in addition to common sense judgements of better or worse endings. The idea of a good death though is certainly not new. In the Middle Ages, for example, the art of dying (*ars moriendi*) provided exemplary standards of virtuous and heroic (sacred and secular) death based upon societal--religious and political--standards. (cf. Jankofsky & Stuecher, 1984).

One may question why a static judgement is unreasonable on theoretical grounds. A reason is that there seems to be little evidence for the position that there is consistency in modes of coping from one situation to another (Cohen & Lazarus, 1979). And, even within the same stressor (e.g., illness), different modes may be observed in the same individual. Not ignoring common, core or reoccurring features, a static judgement does not allow for unique patterns of functioning over time.

A good argument could be developed for uniqueness of a life-threatening threat i.e., there may be no equivalent stressor. In a broader sense (when the prognosis is not necessarily dire) Mages and Mendelsohn claim, "For most patients cancer presents a set of adaptive demands that are outside of their previous experience" (1979, p. 268). Similarly, one might also question the use of the word *cope* itself insofar as a "successful resolution" is what is implied by coping. Again, this speaks to the most basic and distinctive nature of the problem one has with death. By way of illustration, it is imaginable that a suicidal crisis can be successfully resolved. This means in favour of life. However, when the threat is a terminal disease, the fact of impending death is not altered no matter what one does. It is how one lives and is sick (given the dire fact of terminal illness), that defines better and worse dying.

A clear distinction should be made between the process of dying and the state of being dead: death. Perhaps the term "appropriate dying" would more concisely convey

the idea than does "appropriate death" in that it reflects everything which leads up to the event, including individual needs and expectations, patterns of functioning, relationships to significant others, and so forth.

Since Weisman's introduction of the term, appropriate death has become an important part of the parlance of the thanatologist. It is commonly used to refer to the way people die and also to describe thanatological therapeutic goals. However, with the exception of two instances (both efforts by Weisman) no attempts have been made to systematically explicate components of the concept. The first effort (Weisman, 1974) employed the "psychological autopsy" method. Essentially, features of a single case were reviewed after the death of the individual to determine to what extent the death had been appropriate. The definition of appropriate was inferred from the individual's past life history which was then compared to aspects of the individual's illness and decline i.e., the individual's behaviour and stance toward his illness. In the discussion of this case Weisman commented that key components of appropriate death are synonymous with those of successful coping.

The idea was presented above that appropriate dying should not be seen as equivalent to good coping but rather coping should be viewed as an aspect of the concept. If it were true that coping is synonymous with appropriate dying it would of course be sufficient to judge whether successful coping had occurred or not (based upon some external standard) to apply the label of appropriate. It does not seem, though, that Weisman really meant to be implying this because earlier in that same discussion he said "Deciding that one death is appropriate and another not depends upon distinguishing between what would be appropriate for us and what would be appropriate for the other person" (1974, p. 148). At this point then, the idiosyncratic component is reasserted.

In a later effort (Weisman, 1979) components of the concept were enumerated. In the actual study, judgements were made pertaining to "good" and "bad" deaths, not

appropriate dying. According to Weisman, "While it was not possible to do more than conjecture about appropriate death, there was evidence for judging whether a good, bad, or equivocal death had occurred" (1979, p. 101). So, in the latter effort a judgement of good, bad, or equivocal death was made, while the former study entailed a judgement of consistency with previous (premorbid) functioning. Perhaps the most important question to be raised at this point is whether it is possible to define appropriate death meaningfully so that the judgement rests on a more substantial ground than conjecture. But first a summary seems in order.

Previous efforts have considered the concept of appropriate death as a clustering of three components: (1) consistency in functioning; (2) idiosyncratic views of appropriate; and (3) features which contribute toward a better death. Consistency in functioning pertains to the type of judgments which were made using the psychological autopsy method. According to this view, it is assumed that patterns of functioning within individuals which are discordant with past functioning or with one's view of oneself, or with a significant other's view, contribute toward an inappropriate death. The implication is that such incongruities are troublesome i.e., accompanied by perturbation or emotional disequilibrium for both the patient and significant others. This notion is typified by Thompson (1984) who, noticing the tendency to prejudge and claiming that individuals were coerced into restricted death styles, suggested more of an individual approach to working with the dying which would help individuals achieve a "death style" which is compatible with the individual's life style. She reasoned, "Since dying is the living we do at the end, people should be encouraged when possible to die the way they live" (Thompson, 1984, p. 224).

In that appropriate dying is a phenomenological notion, the essence of the definition must pertain to the second component listed i.e., what would be appropriate from the individual's own point of view. What is given is that one is dying from a terminal illness. This fact cannot be altered. Therefore, it should be remembered that

appropriate dying is being elaborated within a particular, albeit unfortunate, context. As such, this is different from imagining the best possible death given a person's previous life history and personality. The option of dying peacefully in one's sleep in the distant future is excluded.

Given this imposed limitation, determining what is appropriate necessitates knowing what is important for each individual. In an effort to avoid speculation on this issue, individuals themselves should be asked what would be appropriate. This approach would require each individual to provide his or her own standard for evaluating appropriateness. Behaviour then could be compared to the standard that each individual provides. With multiple measurements over time, patterns across individuals, as well as patterns within individuals, could be observed. In this way conjecture can be minimised.

The third component, "better death", refers to some of the features Weisman has called prerequisites. These features are so called because it is difficult to imagine how one could die appropriately wishing an unnecessary amount of pain and discomfort and inadequate care. In that most individuals would ideally like relief from pain, the variables which contribute toward a judgement of "better death" are viewed as common goals for all patients.

Concerning the notion of appropriate death, Shneidman said, "It is illuminating, elevating, just right, and on the humanitarian side of things" (1973, p. 25). What is it specifically about this concept which is important? One could argue that if appropriate death by definition has a component which is truly idiosyncratic, this is an important variable in that it respects individual differences and forces a phenomenological view of life. The concept is a reminder that while group trends towards more adequate care of dying persons (e.g., the hospice movement) have been benevolently motivated, that one answer may be not sufficient for all. One possible, though admittedly extreme, outcome of feeling as though the problems of dying are "under control" is an attitude

toward the problem which is overly rigid or too predictable. This sort of attitude could be manifested, for example, in an unnecessary adherence to a set of "stages" of dying for which there is little proof of correspondence to reality.

The Present Study

The present study was primarily concerned with the second consideration of appropriateness enumerated above--namely the phenomenological aspects. As was hinted in the previous section, we could do more than conjecture about dimensions of appropriateness if we knew what was appropriate for individuals. Rather than making inferences from some predetermined samples of behaviour or asking another's opinion (e.g., a significant other) it made good sense that individuals themselves would be in the best position to provide these dimensions. So, it was proposed, why not just ask individuals what would be appropriate? In this way individuals would be able to provide dimensions which are specific to their own viewpoints and needs. Such a method would have the potential for obtaining phenomenological information without unduly imposing the researcher's prejudices.

However, the pith of the problem needed some elaboration. On a practical level, some individuals may not have an intuitive understanding of the word *appropriate*. In addition, for an individual who is in fact suffering from what is thought to be a terminal illness, the juxtaposition of *appropriate* to dying may easily be perceived as threatening and intrusive. If for no other reason than it would be unethical to ask the question, as it stands, the term needed to be framed in another manner. There also were important reasons to do so from a theoretical perspective. As has been seen, the term appropriate has been used previously to refer to a clustering of components thought intuitively to be of importance. No attempt has been made to elaborate what specifically is meant by its idiosyncratic core. What does appropriate mean in the sense elaborated above? The term remains to be defined in an operational way.

Appropriate dying is a theoretical construct posited as a way of viewing a process-dying. As a construct, it does not exist in the sense of being a readily observable or naturally occurring phenomenon. By way of contrast, it is definitely not being suggested, for example, that dying in a certain manner is an inherent or learned propensity. It *is* being suggested, though, that the concept may imply a context for "observing" the process of dying. The value of such a context is that it may resolve some of the problems of attributing too much (i.e., in the way of generalities) to particular individuals. This method may also result in amassing data which could be subject to verification on particular (idiographic and nomothetic) levels of observation. However, the concept itself is *not* amenable to verification in this same manner. How then can such a term be operationalised?

The answer for this study has been one of logical analysis i.e., a rational approach. It was reasoned that some clarity might be given to the concept by understanding what expectations individuals might have in terms of appropriate dying. The importance of individual expectations was based upon previous experience with terminally ill patients in which this investigator observed that personal agendas emerged which were not obviously apparent. In that these expectations, agendas, goals and so forth seemed to have an impact upon the patient's emotional equilibrium, it made sense that these issues would be important (e.g., for therapists) in understanding the patient's perspective, or what is appropriate. So, when some phenomenological aspects of appropriateness are referred to, what is meant, for these purposes, are the subjects' responses to the question or questions: "What sorts of things would you like to see happen, what goals or agendas do you have?" In that this study was intended to be exploratory, the usefulness and meaningfulness of asking such a question is largely determined by the results.

Returning now to the method, the data obtained was considered phenomenological because every effort was made to understand responses from the

perspective of the context provided by each individual subject. Pivotal to this approach was a prospective method in which the individual provided essential data. Idiographic features were carried even further by asking subjects to make assessments of the data they themselves had provided. (This point will be clarified in greater detail below.) Thus, while retrospective analysis may still be possible, it was not essential.

As was seen in the discussion of appropriate dying, previous efforts have employed a retrospective method. While neither method is objectively better, a prospective approach has some advantages in a study which emphasises the patients' views. Most obvious is the greater potential certainty attached to asking an individual about his or her own views rather than relying on inference from material such as documents or asking someone else's opinion. After all, it is not as if some "objective" information was being sought. The intention instead was to understand the perspective of each subject. Following from this point, another advantage to this method was the potential for each subject to clarify his or her own view until it is understood by the investigator. In fact, each individual was asked to provide standards for judging his own her own behaviour.

Asking individuals to provide standards for judging their own behaviour is congruent with some trends in the personality and assessment literature. For example, from an interactionist perspective, Pervin (1977) in an attempt to study multiple situations in persons' lives elicited details about specific life situations from the individuals themselves. Groups of subjects might be asked to describe in detail situations occurring in their lives at the present. These descriptions would include how the person feels in a particular situation as well as how he or she acts. Behaviour could then be checked objectively, e.g., by observation. However, it is not just the situation which is important but also the individual's *perception* of the situation (Pervin, 1977). His approach is similar to Brunswik urging representative rather than systematic research designs (1947).

A study which employs some idiographic or phenomenological features need not take one particular form. As discussed above, for the present study, the data and method of collecting these data have been called phenomenological. However, the resultant material could be analysed in different ways. For example, comparisons could be made between some features of the data such as numbers of agendas, types of agendas or some correlation between other variables. This type of study could be nomothetic because it intends to generalise to some or all individuals even though the *input* has been idiographic. Or, perhaps more clearly, the design has been representative rather than systematic.

In order for a study to be truly idiographic, the intent needs to be one of analysing variables within (rather than across) individuals. As examples, these sorts of attempts would include case history methods, single case experimental designs, intraindividual correlational methods, assisted autobiography, narrative methods and so forth (Runyan, 1984). The focus of this study has been on the individual. Only the subject (hospice cancer patient) was interviewed e.g., significant others, hospice staff did not participate. In a way (which will be explained further), each subject was used as his or her own control. From this perspective the study has been idiographic.

Therefore, the present study proposed: (1) to operationalise some features of the idiosyncratic aspect of appropriate dying, (2) gather information pertaining to these features through the use of semi-structured interviews, and (3) to administer some self-report scales which measure pain, depression, and anxiety.

The rationale for operationlising the term was explained above. Pertaining to the second point, it was proposed that this phenomenological information be gathered by enquiring about what expectations, agendas, and goals one has for oneself given a dire prognosis. It was imagined that some individuals would like to take certain actions such as engaging in a particular pastime or hobby. Others might have interpersonal agendas

such as a desire to communicate something of significance to another. Still others might have intrapsychic or philosophic agendas.

Once agendas and so forth were stated it might have been possible to seek some "objective" information, for example, as to whether these agendas and expectations were in fact obtained or fulfilled. However, the intention was to follow through as far as was possible with an idiographic approach because this would most accurately reflect the theoretical implications of appropriate dying as pertaining to its idiosyncratic component. Not that an "objective" approach is unimportant, but rather, what is essential from an idiographic approach are the subjects' own perceptions not only in enumerating goals, agendas and expectations, but in whether or not they are perceived as fulfilled. Hence, subjects themselves were asked at subsequent interviews whether or not agendas were fulfilled. It could be the case that particular agendas are not perceived as fulfilled but are no longer important to that person or that they are still important but are just not yet fulfilled. Similarly, new agendas may emerge or existing agendas may be altered in some way.

While the primary aim of the study was to elaborate agendas specific to individuals, it was also proposed that it might be convenient to group agendas which have some common features. Eight *a priori* categories were then proposed as a tentative suggestion for one way of organising the data. No hypotheses pertaining to these categories were made, but, it was hoped that they would prove to be mutually exclusive and exhaustive (cf. Holsti, 1969; Lazarsfeld & Barton, 1971). Roughly, agendas were distinguished as primarily actions or activities, intraindividual or interpersonal. It should be emphasised that they were proposed as one possible logical organisation of the material and were not intended to interfere with any *post hoc* analysis or discussion of the material. They should be seen as a convenience and not as a central or stereotyping tenet of the study. A further discussion of these categories may be found in Appendix D.

In order to obtain some information about the emotional equilibrium of subjects as reflected in the variables depression, pain and anxiety, three self-report scales were administered. These scales, Center for Epidemiological Studies-Depression (CES-D), the McGill Pain Questionnaire, and the Anxiety Scale were chosen for their reliability and validity with hospice cancer patients. These scales are discussed in greater detail below.

A hospice population was chosen for a number of reasons. First, it was assumed that concerted efforts would be made to manage patients' symptoms and pain and to deal with psychosocial issues. Hospice patients would be guaranteed efforts on their behalf by virtue of being enrolled in a programme. One could question whether patients who do not have these basic needs met as well as resources to call upon would be psychologically prepared to deal with more sophisticated issues. Not ignoring differences in how the system is used by individuals, a potentially better level of functioning than what might have occurred is assumed. Given a multidisciplinary team approach where information and suggestions for care are shared, a second assumption is that some uniformity of care would exist--a situation which would not obtain in the general community. Third, medical recognition of terminality is clear in that this judgement is necessary for referral and acceptance into the programme. Most patients had been told in various fashions (which it was not feasible to control for) that curative treatment was no longer appropriate. Referral to hospice may originate with the patient, family or physician but ultimately the patient must decide whether or not enrollment will occur. And, acceptance of hospice principles is a prerequisite for enrollment. This does not preclude patients manifesting varying stances toward their illness e.g., "dying", "not dying", "dying in two or three years". A final consideration was ease of referral and opportunities for follow-up which would occur working within a system.

Chapter 2

Method

Subjects. Twenty terminally ill cancer patients participated in this study. At the time of the initial contact all subjects were enrolled as homecare patients in a southern California hospice. They were at least partially ambulatory and had been receiving hospice care for a minimum of one week. Eight women and twelve men participated. Ages ranged from 50 to 92 years. The mean age was 64 years. Sixteen subjects were White, three Black and one Hispanic. Two subjects were European immigrants; all spoke English fluently. Most (16) were married. The majority of subjects were skilled or semi-skilled labourers. Table 1 indicates the sex, age and diagnosis of the subjects.

This fully staffed hospice was primarily oriented toward homecare although an in-patient component also existed. Fifteen beds were used for initial admissions or transfer from homecare; three beds were reserved for emergencies. Homecare patients could be temporarily transferred to in-patient status in order to provide respite for the family. Patients could also be admitted if they did not wish to die at home, or if sufficient home help did not exist. Follow-up interviews (when appropriate) sometimes occurred while subjects were in-patients.

For a number of reasons, approximately 70 patients were excluded as potential subjects. Most of these patients had too short a prognosis. Others were confused or had brain metastases. Still others were incapable of speech or did not speak English. A few were AIDS patients. A few others were considered too unstable for reasons other than the above. Eight patients out of the initial pool declined to participate. Most of these either felt too weak, too sick, or were too busy. Two subjects died before the first interview.

Measures. Assessments of agendas, expectations and goals were obtained during tape recorded semi-structured interviews. Follow-up information (e.g., whether or not

Table 1

Description of Subjects by Type of Cancer, Age, and Sex

Sex	Age							
	50-59		60-69		70-79		80 +	
	M	F	M	F	M	F	M	F
Type								
cervical/ ovarian		4						
endometrial				1				
esophageal		1			1			
lung	2	1		1		1		
melanoma						1		
pancreas			1					
prostate			1		1		1	
renal			2					
sarcoma		1						

agendas were perceived by subjects as fulfilled) was also obtained using the same method. Basically, interviews began with an open-ended discussion of issues which were of importance to subjects such as explaining their medical predicament to the interviewer. Due to the potentially sensitive nature of such a question, each subject was asked what sorts of things he or she would like to see happen--what goals and agendas they might have had at a point in the interview which was thought by the interviewer to be appropos. This was dependent upon subjective cues concerning such factors as subject openness, trust, and degree of comfort. Once subjects began to respond to the question the interviewer could ask for elaboration (dependent upon the nature of the individual response) which provided greater information about each subject's perspective. Points which were unclear were queried and information validated by the subject's own confirmation. In general, an attempt was made to minimise the interviewer's influence on content which was revealed (cf. Stones, 1985).

Subjects were frequently quite ill by the second interview which often limited the amount of information which could be obtained. Given the frailty of the sample, follow-up interviews were restricted to a specific enquiry as to whether or not agendas, which had been reported in the first interview, were perceived as fulfilled and whether subjects had any additional agendas.

A descriptive organisation of the idiographic material obtained involved assigning each agenda to one of 8 categories. This determination was based upon the central characteristic of agendas as assessed by two independent judges (neither of them the present investigator) following an inspection of verbatim material. The purpose of such categorising was to minimise investigator bias in providing a preliminary, *objective* organisation of the data. Agendas were also rated by the judges as fulfilled or unfulfilled by an inspection of verbatim material. Further assessment focussed on a subjective *post hoc* inspection of qualitative features by the investigator. Whenever possible, responses were presented and interpreted emphasising the subjects' own

views. The format which guided the assessment of agendas is reflected in Figure 1 (p. 79).

Anxiety, depression, and pain were measured by three self-report instruments which were administered verbally. Instruments included the Center for Epidemiologic Studies-Depression (CES-D), the McGill Pain Questionnaire and the Anxiety Scale. These instruments were chosen because they have all been used previously with terminally ill and hospice populations. Most recently Wales et al. (1983) administered these scales (and others) to 240 terminally ill patients in order to show validity and reliability of the instruments, and to evaluate hospice effectiveness. Two of the instruments (The McGill Pain Questionnaire and the Anxiety Scale) had been used with similar populations prior to the UCLA hospice evaluation study. Secondly, the scales are short which has the advantage of minimising fatigue in physically ill subjects. Test-retest reliability scores range from .86 to .93 for the same interviewer (see Wales et al. 1983). Third, the instruments are paper and pencil tests (which may be administered verbally) and have close-ended multiple choice formats which should also minimise fatigue for the subject, and are easily quantifiable by the investigator.

An instrument developed by the Center for Epidemiologic Studies (CES-D) was used to measure depression. This scale is a 16 item self-report symptom rating instrument which was compiled for use in the general population (Weissman, Sholomskas, Pottenger, Prusoff & Locke, 1977). It has been used in several survey studies sponsored by CES (e.g., Comstock & Helsing 1973, 1976; Radloff, 1975, 1977). Validation studies used a random community sample of over 3800 subjects and samples from five psychiatric populations (Weissman et al. 1977). The scale was shown capable of detecting depressive symptoms in normal as well as psychiatric populations and to discriminate depression from other psychiatric symptoms. Items were obtained from several previously existing scales, for instance, Beck (1961), Zung (1965), and Raskin (1967) on the basis of their content validity. CES-D scores

correlated highly with scores from other depression scales such as the Raskin Depression Scale (Weissman et al., 1977).

Previous to the study by Wales et al. (1983) the CES-D had not been used with a terminally ill/hospice group. Use of the scale here was justified due to its established validity (a high correlation with other depression scales) and reliability across diverse populations, as well as its high test-retest reliability coefficient which was shown to be .86 with a terminally ill sample (Wales et al., 1983).

The McGill Pain Questionnaire was used to assess pain. This questionnaire was developed as a result of a study (Melzack & Torgerson, 1971) which showed that words describing pain experience could be classified as evaluative, sensory, or affective. It was also found that within these subgroups words could be ranked according to their intensity. A high degree of agreement was found between persons with varying educational, socioeconomic, and cultural backgrounds on the words belonging to each subset as well as the intensity of various descriptors (Melzack, 1975). As a result of these consistencies, a quantifiable measure of subjective pain experience was developed which specified three indices of pain: the pain rating index (PRI); the number of words chosen (NWC); and the present pain intensity (PPI).

Subjects are asked to respond to 20 descriptive subsets. Only words which describe present pain experience are to be chosen, i.e., not all subsets are pertinent. From this information, the NWC may be calculated as well as the PRI. The latter is the sum of the rank positions for words chosen. The PPI is a number from 1 to 5 which corresponds to the words: mild, discomforting, distressing, horrible, excruciating.

Generally, the questionnaire has been shown to be a reliable, multidimensional measure of immediate pain (Graham et al., 1980). Wales et al. (1983) found the test-retest reliability to be .93. Melzack (1975) found changes in pain as indicated by PPI and PRI scores are very consistent. Thus the scale provides reliable information

concerning changes in pain experience across time. In addition, it is capable of distinguishing cancer pain from other types of pain (Dubisson & Melzack, 1976). The questionnaire has been used on a number of occasions with cancer patients. For example, Melzack, Ofiesh, and Mount (1976) used the scale to show the relative effectiveness of the Brompton mixture. Graham, Bond, Gerkovich, and Cook (1980) and Kremer, Atkinson, and Ignelzi (1982) investigated psychometric properties of the questionnaire relative to cancer patients. Graham et al.(1980) found the consistency in descriptors reported by Dubuisson and Melzack (1976) although the set Graham's sample described was slightly larger than the set described by Dubisson and Melzack's sample. Graham et al.(1980) also investigated differences in administration (oral versus written) and use of the scale to summarise past pain. They found no differences between methods of administration, but concluded the scale is best used as a measure of immediate pain. Kremer et al. (1982) found differences in the way cancer patients select pain descriptors. Cancer patients assign a reliably greater *affective* component to their experience than do those patients with benign pain. The authors suggest that, while cancer patients are systematic in their use of affective descriptors, these descriptors may reflect overall dimensions of their illness rather than affect specifically related to pain (Kremer et al, 1982).

The Anxiety Scale is a five item anxiety measure developed and validated by Ware et al. (1976). It is a subscale of the Ware General Well-Being Scale which has been shown to be predictive of stress at home and on the job and to correlate highly with depression. Wales et al. obtained a test-retest reliability coefficient of .92 (1983).

Procedure. Potential subjects were identified during weekly staff presentations. The following criteria were used: (1) diagnosis of cancer (e.g., AIDS patients were excluded); (2) an estimated survival of at least six weeks; (3) alertness--ability to handle the task and to understand informed consent; and (4) medical approval for participation. A staff person then either called or visited potential subjects and asked if they would

like to participate in a research project which would entail two or three sessions talking about themselves with a graduate student. If the patient consented, the investigator telephoned to confirm an interest in participation, to answer any questions which may have arisen and to arrange a home visit at the subject's convenience. Home visits were not scheduled during the first week of hospice care so that patients would have a chance to get used to hospice procedures and philosophy and to stabilise medically.

At the beginning of the home visit, the aims and requirements of the study were explained to the subject:

I am doing a study which involves trying to understand some ways in which people are similar and ways in which they differ. Most of all I am interested in your attitudes-- how you understand things. And, I will be asking you specific questions about some things. Today I would first like to spend some time getting to know you. If you feel O.K. about our visit today, I would then like to see you again in two weeks to ask you a few more questions. If you have no objection, I would also like to tape record our conversations so I do not have to take notes.

It was then explained to the subject that written consent is necessary to participate in a research project and the consent form was reviewed (see Appendix C). After any questions the subject might have had were answered, the form was signed and the tape recorder was turned on. Subjects were encouraged to inform the interviewer if they wished to stop for any reason or if they would like the tape recorder turned off.

Subjects sometimes began talking right away but usually the investigator said, "Tell me something about yourself". Most subjects then immediately launched either into a life review or an description of their present condition. At any rate, all subjects

talked about how they understood their illness and usually made spontaneous favourable comments about hospice. The purpose of the first part of the interview was to establish rapport and to give the subject control over what was revealed. Once they began discussing a topic of personal interest most subjects relaxed.

The second part of the interview was primarily concerned with obtaining the subject's assessment of his or her goals and expectations. Typically the interviewer said: "What sorts of things would you like to see happen? Do you have any goals or agendas?" After an agenda was mentioned the subject was asked to specify any details which might not be clear and to give guidelines for how such a goal might be fulfilled. If the subject mentioned only one goal he or she was asked, "Are there any other things you would like to see happen?" Then, those subsequent goals would be clarified. Finally, the interviewer summarised the agendas and their criteria for fulfillment and the subject either agreed or corrected the interviewer's perceptions.

At the end of the interview the interviewer asked for feedback about the exchange and made tentative plans to call for the second interview. Subjects were assured that their participation was helpful and valued. Between visits tape recordings were transcribed and agendas were extracted by the investigator. Supplemental information pertaining to the participant's age, sex, occupation, diagnosis, race, marital status and religious preference was compiled and some descriptive notes were made.

At the beginning of the second interview the interviewer said, "Today I would like to begin by asking you some specific questions about how you have been feeling while I record your answers. Is that O.K.?" If the subject said "Yes", the interviewer continued by asking the first question: "Are you presently experiencing any discomfort or pain?" If the subject replied, "No" the response was noted and the rest of the McGill Pain Questionnaire was not administered. If the subject said that he or she was currently experiencing some discomfort the interviewer replied, "I would like to ask you some questions about how strong your pain is. Here is a card with a series of

statements describing pain. Please use one of these descriptions to answer the following questions." The subject is then asked three questions (see Appendix B). Continuing, the interviewer said (after handing the subject the appropriate response card) "Some of the words I will read to you from this sheet may describe your present pain. Choose only a single word in each appropriate group--the word that applies best. Leave out any word group that doesn't apply."

Next, the depression scale was administered and the interviewer said, "Please use the words from this card (handed appropriate card) to answer the next series of questions about how you have been feeling during the past week. Please try to be as honest as you can."

The Anxiety scale was the final instrument administered. After handing the subject the appropriate response card the interviewer said, "I have a few more questions to ask you about how you might have felt or behaved during this past week. As I read the statements to you, tell me which response most accurately describes how often you felt or behaved this way during the past week."

Following administration of the instruments the investigator said, "If you are not too tired, I would now like to ask you some questions about some of the things we talked about last time". If the subject consented--as all did--the tape recorder was turned on and the interviewer said, "Last time we talked about some of the things that are important to you and some of the things you would like to see happen. As I recall you mentioned _____. How do you feel about that now?" If the previous agendas were still important to the subject he or she was asked, "How are you doing with that goal?" After reviewing each agenda in a similar manner, the interviewer asked about any new agendas following the procedure described above.

The procedure for the second interview was repeated in two weeks for the third and final interview. Thereafter subjects were followed informally in staff meetings and

by periodic telephone contacts. Data collection occurred over a period of almost one calendar year--fifty weeks to be exact.

Two judges both graduate students with a background in clinical psychology, neither of them the experimenter, independently categorised all agendas in terms of eight categories and rated them as either fulfilled or unfulfilled. Instructions to judges may be found in Appendix D. Judges were exposed to agendas only. They did not have access to test scores or any supplemental material.

Chapter 3

Results

Synopsis: A total number of 37 agendas were reported for all 20 subjects over t1, t2, and t3. Using *a priori* descriptive categories, 12 agendas were initially categorised as actions or activities, 10 as interpersonal, and 15 as intraindividual. A reliability coefficient of .90 was obtained for assignment of these agendas to categories by two independent judges. The criteria for assignment to categories and instructions to judges may be found in Appendix D. Further *post hoc* assessments of agendas described below are diagrammatically represented by Figure 1.

Nineteen out of 20 subjects reported having had at least one agenda at the time of the first interview. The average number of agendas at t1 was $M = 1.8$ with a range from 0 to 5. The mode, 1, accounted for half the subjects. Thirty-five agendas were reported.

At the second interview ($N = 14$) a total of 56% of agendas were perceived as fulfilled, or 15 out of a total of 24 items. One "activity" and one "interpersonal" agenda were added by one subject. Another subject rejected an "interpersonal" item. Agendas for all other subjects remained stable over time. One hundred percent agreement occurred between the two judges who rated the agendas as fulfilled or not fulfilled based upon criteria elaborated in Appendix D. Six subjects had dropped out by t2; one was too confused to be interviewed, 2 declined to continue, and 3 died.

Only 5 subjects participated at t3. Subjects had either died or were too ill to continue (either semi-comatose or confused). Fourteen agendas occurred. Nine were perceived as fulfilled. Three out of 5 subjects fulfilled all of their agendas by t3. See Appendix E for a comparison of raw data at t1, t2, and t3. Agendas themselves are enumerated in Table 2 and summarised in Appendix E.

Eleven subjects reported no pain. The mean depression score was 10.9 with a standard deviation of 6.3. The range of depression scores was 0 to 22. The mean

Table 2 Agendas.

I Actions/Activities

- S3 (2) I love to gamble now--only thing I can think of that I'd like to do. (F)
- S4 (1) I want to do some painting. (UF)
 (2) I want to work in the garden. (F)
 (3) I want to work with the lung association. (UF)
 (4) I want to go fishing. (UF)
 (5) ...cook meals and help with the house. (F)
 (6) I want to put together this scrapbook. (A,F)
- S5 (1)* I just have the urge to go somewhere. I don't know where yet.
- S12 (2) ...would like to go to the racetrack. (F)
- S14 (1)* I'd like to take a trip.
- S20 (1) I've got this garden here to take care of.
 (2) ...and I'd like to sew.

II Interpersonal

- A.
- S1 (2) I would certainly like my children to continue liking me. (UF)
- S6 (2) I want to visit my aunt and uncle. (F)
- S15 (1) Continuing to be open and spend time with my family.
- S16 (1)* Not anything special...just to keep track of my family. I want to...see my sister...talk to my brother. (F)
- S17 (1)* I'd like to see her (daughter) settled in her new house. (UF)
- C.
- S4 (7) I want to go out and meet people. (A, UF)
- D.
- S1 (3) Naturally, I would like to see every American prosperous. (R)
- S8 (1)* Well, the main thing I want is to see my family taken care of.
- S12 (1) If I'm gone that everything works out here...with my wife and mother. (F)
- S18 (2) I'd like to see everyone get well.

III Intraindividual

A.

- S1 (1) I'd like things to be quiet so I can go on and finish out...I would like to live peacefully--so to speak. (UF)
- S2 (1) ...I don't want to say anything or commit anything that's ever going to cause any pain. (F)
- S6 (1) I want to be helpful. I do not want to leave this world without being a help to somebody. (F)
- S9 (1)* I just want to have a pleasant time--that's all! (F)
- S11 (1)* Ask the Lord to show me how to be a good person. (UF)
- S13 (1)* I'd like to have a good time as long as I can. (F)
- S15 (2) ...well, if I can wake up in the morning, look out the window and thank God.
- S19 (1)* Try to be pleasant. I think that's the best. (F)

B.

- S3 (1) ...get my pre-funeral need straightened out. (F)
- (3) I want to get my finances in order. (F)
- S20 (3) I've got a whole mess of things to do...my will is there and has to be finalised.

C.

- S2 (2) I'd like to be able to pull a cord. (UF)
- S6 (3) I guess my goals are must maintaining myself, being able to say no... that's the hardest thing to do. (F)
- S10 (1)* I wished I could get well--that's all I'd like to be up and well and at work. (UF)
- S18 (1) I'd like to figure out how to do things that I'm supposed to do.

Note. S = subject number; () = agenda number; * = only agenda; F = fulfilled; UF = unfulfilled.

anxiety score was 9.4 with a standard deviation of 3.2. The range for anxiety was from 5 to 15.

Description of qualitative data: By way of reminder, an agenda was defined as "things individuals would like to see happen"--expectations and goals--given a current understanding of their own medical status. In most cases very clear comments were made by subjects pertaining to an understanding of this status. While some diversity of interpretation occurred, the majority of comments revealed that death was thought to be imminent or would happen in the relatively near future e.g., "I'm at the hospice because I'm terminal now"; "I won't be around very long"; "Well, first of all I have to recognize that I'm dying". Of course there was variability in how this information was stated: at least one individual showed no apparent understanding that he was dying; another, seemingly more conflicted, individual revealed her understanding in more ambiguous and covert ways than others e.g., by attributing illness to other causes, referring to threats in the past tense and by the use of allegory to reveal a clearer acknowledgement in the present. The fact of imminence no matter how clearly stated and understood did not necessarily exclude hope for change e.g., "I do believe it is possible for it to be altered. I take it one day at a time."

During the course of interviews several generalisations pertaining to agendas emerged: (1) most individuals had few agendas; (2) an incongruity frequently occurred between stated agendas and actual activities; (3) most agendas were reality bound.

(1) The average number of agendas per individual was M = 1.8. Ten subjects had only one agenda. Of the 12 activities which were reported to be agendas by subjects two included taking trips. This was the only agenda reported by these two subjects. Gambling (cards and horseracing) and gardening were also listed as agendas by two subjects. One of the subjects interested in gardening also wanted to do some sewing; the other listed 5 additional activities which will be enumerated below.

Interpersonal agendas (10) were stated in both global and specific terms. As an example of the latter, one individual said, "I want to visit my aunt and uncle" while another commented, "I'd like to see her (daughter) settled in her new house". By way of contrast (3) other subjects said, "I would certainly like my children to continue liking me"; "...continuing to be open and spend time with my family" and "Not anything special just to keep track of my family." No apparent pattern emerged in how these agendas were stated (globally or specifically) and whether or not they were perceived as fulfilled or unfulfilled. Four subjects had agendas *for* others, e.g., "Naturally, I would like to see every American prosperous" and one reported wanting to initiate new relationships: "I want to go out and meet people." No subject reported wanting to resolve an interpersonal problem (category IIb) as an agenda.

Fifteen agendas were scored as intraindividual. Of those who wanted to maintain or initiate a particular stance or attitude, two subjects said having a good time was their primary, and in fact, only agenda. For both these subjects having a good time was predominately an attitude both wished to maintain toward life i.e., what actually occurred was secondary to how their lives were perceived. What was especially pleasurable for one subject was interacting with people while the other was most happy when immersed in sketching and painting. The latter individual elaborated: "I would like to just scoot along--like we are now. If I can just paint a little bit, you know. That's about all. I have a good time painting." Seven others wanted to be pleasant, helpful or good, to express gratitude, or to live peacefully. Three agendas were categorised as unfinished business e.g., "...get my pre-funeral need straightened out" and four as reflecting intraindividual conflicts or problems.

It was observed in this sample that activity level could not be accurately predicted by the number of agendas reported. In other words while some constriction, lack of motivation and so forth was apparent, the mode (1) did not, as will be seen below, necessarily reflect an absence of activities. This was particularly evident in those four

out of the ten individuals with one agenda and four individuals with more than one agenda, who reported wanting to maintain or initiate a particular stance or attitude toward the world in general, or their daily activities in particular. It is logically possible for an individual who, for example, reports "wanting to have a good time" to be relatively inert, or, at the other extreme, to demonstrate frenetic activity. This is to say that when an agenda reflects an attitude a certain activity level should not be implied. Of course, this activity level (whatever it is) would also be independent of whether or not the agenda of "having a good time" is perceived as fulfilled. So, a paucity of reported agendas may be deceptive if any one of those agendas reflects an attitude. Still, *numerically* few agendas were reported by most subjects.

An exception to this was a 56 year old woman who had seven agendas by t2. It would be difficult to say for sure what, if anything, made this subject different than the others. Most of her agendas pertained primarily to actions or activities e.g., painting, working in the garden, putting a scrapbook together and her anxiety scores (t2: 12; t3: 13) were moderately high. She had a good deal of pride around seeing herself as very instrumental in the world and was oriented toward achievement. There were also metaphysical conflicts concerning her own role in her illness ("I really can't blame myself too much...") and reported feelings of guilt when she was not busy ("I have been sitting here doing nothing which is not good"). Most of her agendas had an aesthetic component and she spent some time during interviews conversing about her concern and caring for people and nature. In general, she gave the impression of striving after missed opportunities or racing against time.

(2) It was stated above that a low activity level in subjects should not automatically be inferred from the fact of few stated agendas due, in part, to the nature of some agendas. It was also observed that an incongruity frequently existed between stated agendas and actual activities of subjects' lives. Accurate numbers cannot be quoted because individuals were not systematically asked about their daily activities.

However, this point is most dramatically illustrated by the one subject who differed from the others in reporting that he had absolutely no agendas. This subject was a 66 year old man with seemingly good family and social supports. He was seen for the purposes of the study in June but had been told his cancer was terminal the previous February. He told the investigator that his initial reaction to this news was to plan his funeral and he commented in retrospect, "I assumed that it was over." Concerning agendas he said, "I used to be a doer; I'm a deader now. I don't want to do anything." Interestingly, this comment was in really striking contrast to the actual activities of the subject's life. In fact, he travelled to a resort city bi-monthly, had luncheon dates with friends, and went to the movies. In that it was not obvious that this subject differed from the others along other dimensions (i.e., other than reporting no agendas), a more detailed analysis of factors which possibly influenced him occurs below in "suggestions for futher research." Still, this apparent incongruity between reported agendas and actual activities was not unusual in other subjects possibly reflecting a decreased emotional investment in some of their actual agendas and activities, or a higher investment in stated agendas. Some hypotheses concerning these relationships are explored later.

(3) The third general feature common to most agendas pertained to reality orientation. With the notable exception of one individual whose only goal was to get well and another who wanted everyone to get well, agendas were for the most part reality bound. That is, whether or not agendas were fulfilled, or were perceived as fulfilled, they were mostly within the realm of possibility. For example, those who wished to take trips could have done so. At the other extreme, it was not uncommon for subjects to reject ideas which might have been agendas. One individual wanted to go to Las Vegas but rejected the idea as "silly." Another wanted to go fishing and had the means to do so but did not want to be a "burden" to his friends. Still another felt it was not proper to be (deathly) ill in public so rejected the idea of taking a trip.

As was described in the "method section" and shown in Table 2, each agenda was objectively placed in one of 8 categories for descriptive purposes and ease of inspection. In addition agendas were assessed in a subjective *post hoc* fashion according to some general guidelines which are diagrammatically represented by Figure 1. The narrative which follows is a result of that analysis.

It is possible for an individual to engage in a number of activities and yet be emotionally distanced from them as was evidenced by the description of the subject with no agendas. Such a phenomenon, a sort of closing off, has been observed in a terminally ill population previously (e.g., Kübler-Ross, 1974; Weisman, 1972). However, a paradox presents itself when it is recognised that the present sample did report some satisfaction with activities. This conflict is demonstrated by a subject who said, "It's different...having no motivation for what you're doing" and then juxtaposed to this comment added enthusiastically, "Oh yeah, I'd say the last few weeks have been good." In addition, all 20 subjects were at least somewhat interested in participating in a research project. Whatever research may have meant for them, they were still willing to form a new, albeit limited relationship, very near the end of their lives. Therefore this generality--a complete emotional distancing--seems a too narrow explanation and does not account for the divergences observed in this sample.

Prioritising: The fact that the sample was for the most part comprised of individuals very near the end of their lives suggests some hypotheses. A limited amount of energy--physical and emotional--seems obvious. Prioritising would not be unexpected. In fact, some subjects began a discussion of agendas with some reference to prioritising: One said, "There are a few goals--very few. Most of them mean to be giving to someone else." This subject had other agendas which were important to her but her priority was to be giving, e.g., "I do not want to leave this world without being a help to somebody," Another, referring back in part to his goal of living peacefully said, "I'd like to see us all live comfortably and in prosperity--that is all. I don't have any

aspirations." Therefore, it is possible that agendas in some cases reflect this prioritising.

Given the proximity of death, it is possible that other agendas may have occurred earlier (in the terminal phase) for some individuals and may have already been perceived as fulfilled. Also reflecting the ordering mentioned above, "usual" activities may have become less important because of this proximity. Of course, variability occurred in the length of the terminal period, how the message of terminality was conveyed and processed, whether or not the individual was sick prior to this period, and so forth.

Varying investments and meanings: Stated agendas may reflect a greater emotional investment, although this need not be the case. While many agendas seemed to reflect an intense investment by subjects, others seemed only of moderate or negligible importance. In some cases of moderate or negligible investment this was the only agenda reported or on the other hand, an attitude common to all of their agendas. For others, varying investment was reflected in the apparent prioritising or ordering which was observed. For some, the fulfillment of an agenda was a great relief, e.g., "You'd be surprised how much of a relief that is. I was always...didn't want to...every so scared of dying before I got all of that stuff done."

Varying investment was noted between individuals with superficially similar agendas which suggests the importance of different motivations and meanings attached to agendas. By way of illustration, one subject said; "I've got a whole mess of things to do. For example, my will is there (points) and has to be finalised...dying is a pain in the neck--let me tell you--all the things you have to do." Another subject had a similar agenda, namely, to wrap up his financial affairs (his will) and take care of issues pertaining to his funeral. However, the level of emotional investment was entirely different and needs to be understood within the broader context of the individual's life. This subject's financial abilities and the fact that he had managed to accrue a substantial amount of money, in bonds and so forth, was one of the greatest sources of pride in his

adult life. Clearly, this agenda had a different meaning for him than for the former individual who saw wrapping up affairs as a necessary nuisance--something one ought to do.

Phantasies: In addition to the fact that most agendas were fairly reality bound subjects spontaneously distinguished between what they intended to be actual agendas and what were wishes or phantasies. Here are some examples: When one subject was asked if there were other goals or things she would like to see happen she said, "Oh nothing that is under my control. I would like to see M (step-son) finish college." In response to the same question another subject said: "I would like to but they are not things that are going to happen. Naturally, I would like to see a better world than we have, but I don't expect the world to change to accommodate my situation." Reflecting a desire for conditions to be otherwise on a much more personal level, a 60 year old man said: "I would love to go back to work. I'm still on the payroll. I would like to go back to work, work a couple of years and then retire. But it doesn't look like I'm going to be that privileged--because we had planned to go all over the U.S. and Canada in our motorhome. And of course, that is a disappointment." On a much lighter note a 58 year old woman commented, "No...(laughter) I'd like to win a lottery and leave my family with money. I've got so many of those tickets it's not even funny. I've got a stack of them that big...I buy two or three at *least* every day."

Goals: "No I'm going by Grace Kelly. She says don't plan nothing when you're facing the inevitable. Face it gracefully and don't plan nothing. So, I'm not planning anything..." While all but one individual had agendas and engaged in various activities, an interesting stance toward the notion of goals emerged. The subject who listed seven agendas said, "That's a good question. I don't know. I don't really have any goals--I really don't. I guess I would say, short term goals." For most individuals in the sample, the idea of goals was seemingly incompatible with a shortened future. Even those who had a clearer perception of themselves living longer than six months did not

report agendas in terms of goals. One subject implied that nearly 80 was too old to have goals. Another said, somewhat similarly, "So that's about it--for goals I mean. How much of a goal can you have? I don't know. I can't plan anything long, I'm 93. I don't know how far you can go. I might last another three, four or five years--something like that."

Motivation: Some subjects reported a decreased motivation and interest in the present because of this shortened future. "I don't really care...I've lost that what you might call future pleasures. I lost my future. That's a hell of a thing to say. You don't have nothing to look forward to." Another subject said "You see, you're not going to get better. This is what's hard to face. You're not going to get better." For this subject, that realisation was, as she put it, "very odd" and resulted, for her, in a marked decrease in motivation. She explained it to the interviewer this way: "You see that's it. You have no goals. You have no--well like my sister says, 'Why don't we go and get you something different to wear?' Why? I have a closet full of clothes now I'll probably never wear...I don't feel motivated at all." Now, it would not have to be the case that this lack of motivation ruins all or most *present* pleasures, although for some it appeared to do so. Specific to this subject, it could be that this individual did not ever find shopping pleasurable and this activity may now remind her of her medical status. Another subject also mentioned this lack of motivation but the consequences of this condition were for him somewhat different: "I know I haven't got the ambition I used to...like I told A (wife), if I don't get that done today, I'll get it done tomorrow...No, I never put my sight that far ahead. The spur of the moment, that's when you have more fun than planning it." That is, while this subject recognised his life had changed and he was somewhat judgemental about this change ("I know I haven't got the ambition I used to"), his enjoyment of the present was not totally spoiled. This subject's attitude toward his predicament was a solution many subjects (7) reported, namely, to "live one day at a

time." Similarly, another subject claimed that the perception of his own death as imminent, heightened his appreciation of life.

Efforts to change: At least two individuals very clearly stated agendas which related to efforts to change. A 53 year old woman said, "I don't want to leave this world without being a help to somebody." Throughout her time on the hospice programme she made concerted efforts to help other people, to be giving, and so forth, and was generally very pleased with the progress she made.

A 66 year old man reported:

I've got a big love for people now. I don't want to say anything or commit anything that's ever going to cause any pain or--I'm not talking about physical pain. I'm talking about discomfort, embarrassment, social embarrassment to people. In other words, I want to feel that if I can't say something nice about people, I don't want to have it said--not just myself. I don't want to be a part of it--people gossiping and criticising...it just really turns me off. No, I don't want to be a part of it, which is quite a change in my particular case anyway. But, I think those things are important later...life's too short.

Pain, depression and anxiety: Very few subjects (3) reported any pain at t2 or t3. This may, in part, be due to pain management techniques. Evidence for this hypothesis is suggested by the fact that many patients reported having been in pain prior to enrollment, or at the beginning of enrollment, on the hospice programme, and patients were not seen during the first week of hospice care. In one instance, when pain was reported, it was clear that proper maintenance of medication schedules had not been adhered to by the subject, most likely due to confusion resulting from alcohol induced

blackouts. Once the subject controlled her drinking and the proper regimen was adhered to, she no longer complained of pain.

A wide range of medications and dosages were represented in the sample. Some subjects took no pain medications while others took only tylenol. Stronger analgesics ranged from tylenol with codeine to 40 mg. of morphine every 4 hours. Other medications included ativan and valium.

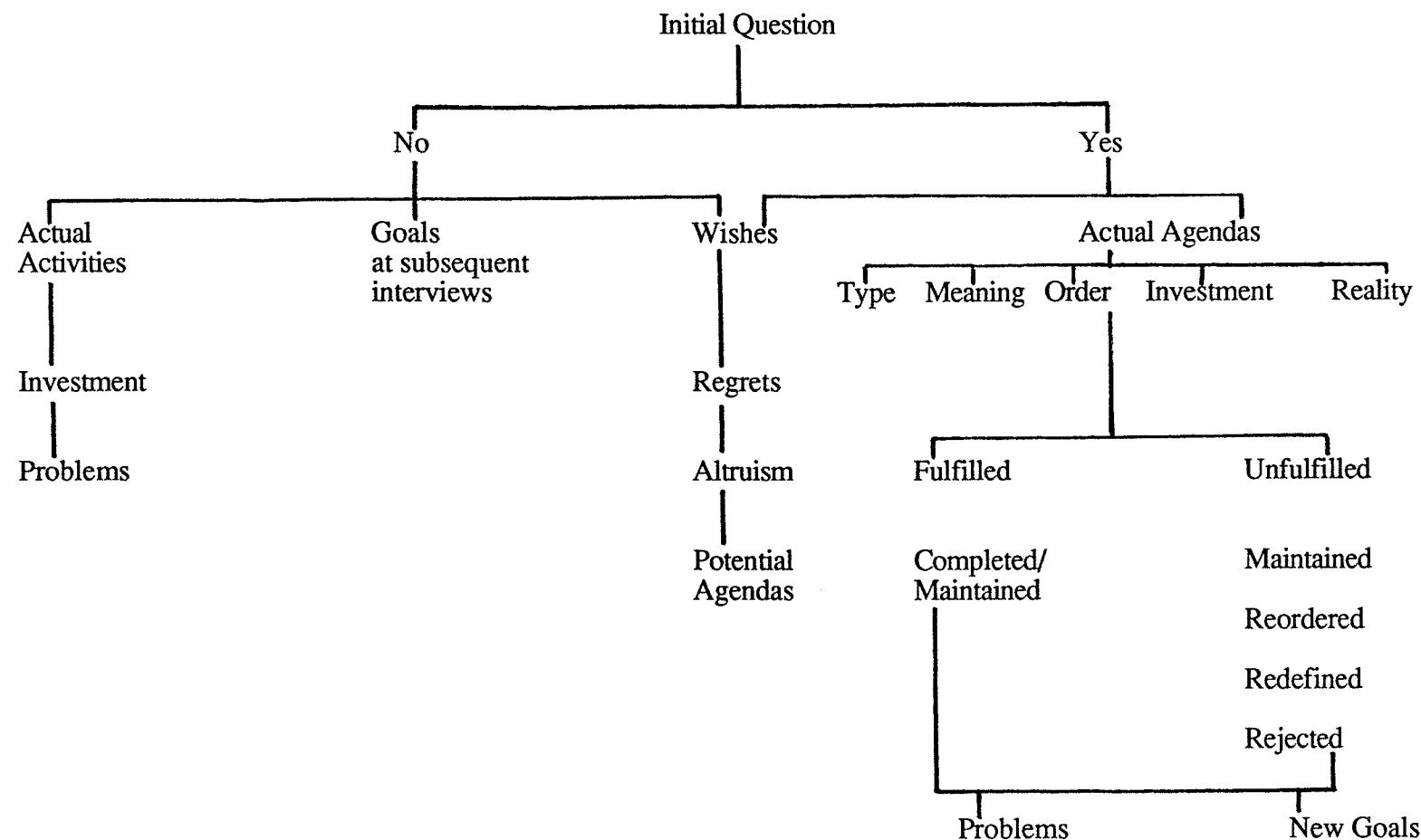
The mean depression score for all subjects was quite high ($M = 10.9$), although, three subjects had scores of 3 or less. On the other hand, two subjects who fulfilled their agendas (100%) had depression scores of 17. It may be that the particular content of the agenda could offer some explanation. In one case an individual was very depressed by her environment (which was objectively dreadful) and over which she had little control. It is probably also the case that terminally ill patients in general show more depression than individuals not seriously ill. This could be a function of various aspects of their diseases. In the case of the individual mentioned above, increased debility would limit her ability to deal with a "bad" (e.g., unsafe) environment.

Anxiety scores were far less elevated than depression scores. Five subjects showed mild or no anxiety and no subject reported extremely high anxiety. One subject reported no anxiety and had no agendas which were fulfilled while another fulfilled 100% of his agendas but manifested an anxiety score of 15--moderately high. The former subject's only agenda was to get well, and, it was apparent he was in a fair amount of denial which might have accounted for an absence of anxiety. The latter subject suffered from lung cancer and had been having a particularly difficult time breathing. Problems with breathing may intensify feelings of anxiousness.

As was stated above, there are many factors which could account for elevated anxiety in a terminally ill patient. One such factor might be a medical crisis which interrupts a period of relative stability. For instance, during the course of the study, one subject had a traumatic episode of bleeding from the lungs which resulted in a temporary

change of status (one day) from homecare to in-patient. The incident occurred during the week the subject was seen for the second interview (t2). In responding to the Anxiety Scale, the subject was asked to answer with the previous week in mind. While the subject's present anxiety did not seem high, her score (10) may have partially reflected this isolated incident. The subject's depression score was very low (2).

Figure 1. Diagram of Post-Interview Assessment of Agendas



Chapter 4

Discussion

In discussing the agendas which were reported by subjects in this study some general remarks seem to be in order. One factor of probable significance pertains to characteristics of the subjects themselves. Subjects did not (with some exceptions) tend to be particularly introspective and many were not highly verbal. Such factors could have influenced the quantity and richness of idiographic material obtained. Also of probable importance is the fact that some subjects had less than ideal living circumstances (e.g., substandard ghetto housing in high crime rate areas) and others had more than one severe loss (e.g., death of a step-child) or recent trauma to cope with in addition to their own illnesses.

Many factors may contribute toward the difficulties of coping with the issues of serious illness and the level of emotional distress which is reported. Individuals are faced with increased weakness and debility sometimes necessitating dramatic losses and changes in life-style and body image. To point out the obvious, these individuals were sick and often had a post-surgical or post-treatment (e.g., chemotherapy) status. One subject complained that he had not had pain until following his recent surgery.

Some (but not all) subjects were faced with losing their favourite or most important activities as a direct result of their medical conditions. One subject reported losing the privilege of driving as well as the loss of her home. Others were unable to play golf or bowl, which were both very important pursuits for these subjects. For another, dancing had been a real passion and not merely a pastime: "I had a hell of a good retirement, let me tell you, until this thing hit me. Oh, I had a marvelous time. Did what I wanted to do. Not what anyone else wanted me to do. People like to travel and all that junk, but I had my own ideas. I like to dance and that's what I did. I was a good ballroom dancer." The subject with the passion for painting did not lose the ability

to engage in this activity while the subject who liked dancing most of all could no longer do so. It has already been hypothesised that further agendas could have been reported earlier in the terminal process i.e., in a sample with a longer prognosis. Also, a life-long agenda may already have been perceived as fulfilled prior to the advent of illness, as was apparent in an individual who said, "I guess I reached my goal--my childhood dream. I guessed I reached that...when I passed the \$100,000 mark--I realised I had reached a childhood goal. That's about the only goal."

One subject very clearly stated the importance of the threat of imminent death in intensifying his appreciation of life and in providing perspective as to issues of importance. Although other subjects may not have been as articulate on these themes, some activities such as fishing, gardening and painting reflected definite desires to convey an aesthetic appreciation of life. A similar effort toward appreciation was reflected in some interpersonal agendas and in agendas with altruistic components. For some subjects then, these sorts of priorities were manifested in agendas either explicitly or implicitly.

As has been stated earlier, diminished motivation was more problematic for some than others such as the individual who was quite interested in conveying the peculiar quality of recognising that "You are not going to get well." It was apparent for this individual that some members of her support system did not truly understand what an "odd" realisation this was for her. She seemed frustrated in her attempts to convey the meaning of this change of status to others.

Somewhat surprisingly, no subject reported wanting to resolve an interpersonal conflict as an agenda. As was seen many subjects rejected ideas which might have been agendas. In one instance, an individual wished to resolve some issues with friends but this was not an agenda for him due to fear of rejection and censure. There was no other indication of such wishes in other subjects.

Findings in general may be a product of the relatively short prognoses of subjects. It is also possible that this sample was biased in some unknown ways. An expectation for a higher number of agendas reflecting, for instance, activities or efforts to wrap up business may assume a high achievement orientation. Many individuals (8) reported wanting to maintain or initiate particular attitudes. This could have been the result of characteristics specific to subjects. On the other hand, one subject clearly attributed causality to the situation he found himself in when he said, "I've got a big love for people now...But, I think those things are important later...life's too short."

Perhaps the most important feature of stated agendas was their apparent dissimilarity. Even agendas which appeared superficially similar have diverged on important variables such as personal meaning and investment. At least for this sample, very few generalities or obvious correlations were observed. For this reason the usefulness of general categories was probably limited to a descriptive function in that there seems to be compelling reasons to urge an idiosyncratic context for understanding agendas. Further demonstrations of this point are seen in the individual case illustrations which occur below.

Clinical Impressions and Implications for Practice

Some observed features of agendas strike the present investigator as having importance for clinical practice. First, agendas frequently emerged which were not immediately apparent. Secondly, some of these agendas were accompanied by dysphoric mood and reflected problem areas for the subject. Third, some agendas reflected content which would usually be considered "socially unacceptable."

Pertaining to the first observation, there were, on more than one occasion, subjects who would have said that they did not have goals but, with some qualifications, revealed an investment in pursuing some activity or they had some interpersonal or intraindividual aim. This suggests the importance of asking the question but caution in *how* it is asked. As was seen, it was apparent that some individuals had difficulty with

the word "goal" but resonated, for example, to "agenda". Others used "goal" themselves in what seemed to be a usual sense while some others qualified its reference. It could be that goals in general have very different connotations for the terminally ill than for the well. In addition, a theme which was dominant in the results section should be reiterated i.e., too broad a generalisation about types of agendas, numbers of agendas, or even the meanings of stated agendas may obscure important individual differences.

The second observation has important implications for intervention. While innumerable small incidents occurred both around the subject's elaborations of agendas and in the content of agendas themselves, there were cases which were quite dramatic. As an example of such a case, a 78 year old man living alone--after having been widowed two and a half years previously--presented himself as a charming, intelligent individual with a wry sense of humour. Given the fact of a terminal prognosis, this individual had many superficial advantages over some other patients. For example, he lived in a large, familiar, and comfortable apartment in a neighborhood he knew well. He was weak and anorexic but had a good appetite (he enjoyed eating and playing the host) and remained ambulatory until the day he died. He reported absolutely no pain and took no medications. Even though one of his daughters was present for the first interview, one would probably assess his chief complaint as loneliness. Some loneliness would be expected, and, given this subject's demeanor and obvious delight with company, it is unlikely that he would be assessed as needing psychological intervention i.e., he did not present himself as depressed or distressed in any significant manner.

While acknowledging that his life would be better if his wife had not died, he said about agendas: "I'd like things to be quiet so I can go on and finish out--that's all...For life to go on, I am contented...I would like to live the rest of my few years, whatever they are, without any disturbances. Naturally, you are bound to run into things here and

there that are unpleasant. I would like to live peacefully so to speak." He reported spending most of his time reading (he lived across the street from the local library), playing chess, reminiscing, thinking and enjoying food. Living peacefully, whatever time is left, seems an admirable agenda and again, superficially, he probably would have been assessed by an observer as achieving this goal. However, at the second and third interviews the subject reported anything but peace. He said at t2: "I'm more depressed. Questioning that eternal question a little more sharply: What the hell is it all for? I still don't get the answer--that's the difficulty." And at t3: "I haven't had it easy lately...there's always a whirlwind in there (points to head) conjures up questions for you: What the hell is it all about? That kind of stuff but there's not a damn thing you can do about it." It is evident that this subject experienced a great deal of emotional discomfort around some plaguing existential issues which were masked by his demeanor and assessed as loneliness. For this subject, asking about agendas, goals, and expectations and whether or nor they were fulfilled provided a format for discussing some issus which were from his own point of view not only significant but problematic.

This example also demonstrates the importance of *perceived* fulfilled agendas. An additional illustration of this point was a subject who wished to be able to take care of herself and told the interviewer with great pride how she had managed to successfully settle her financial affairs. It turned out after her death that her estate was in fairly bad condition. Nevertheless, she had been happy with her accomplishment. In a sense, it is not so important whether agendas are objectively fulfilled or not. To have been objective with this patient would have meant imposing *our* agendas.

A very pleasant and likeable 67 year old man, living with his wife, said to the interviewer at t1 "I'd like to be able to pull a cord. That would be better. Unfortunately, it isn't acceptable and everything. Yeah, that's the way I think I'd like to go." He elaborated the ambivalent side of this wish by telling the interviewer that the previous day he had been absolutely convinced he was going to die. He attributed the incident to

anxiety and was glad to be alive. He said, somewhat tearfully, "I wasn't prepared." Then he brightened and said with some determination, "I don't know if you ever could be, but, I think if you worked on it--if you picked out a Tuesday and said, 'God damn it, Friday would be a good day--it's fish day and what not'. So just go ahead and plan on something. Yeah (he said with further conviction) you've got everything taken care of as well as can be taken care of and then just let it go at that." Then he added humourously, "Call up the mortician and say, 'God damn it, you promised less than \$1,000 and it's going to be that way.' You know, go ahead and wrap it up." Clearly, being able to control--pull the cord for himself--was an agenda for this individual but probably not a very socially acceptable one. While the agenda had suicidal-like overtones, "it isn't acceptable and everything" the intent was not to kill himself but to have control over the time and conditions of his death.

At t2 the agenda persisted and by that time he was spending quite a lot of emotional energy attempting to figure out the "problem" of controlling his own death. His experience had also acquired mystical overtones. He felt people touching him when there was no one in the room and was having moments of peace and contentment. He said, "...two or three times I've been quite peaceful laying down--man this is comfortable. You know you'd like to be able to take the light switch and boom--that's it." Interviewer: "At that point when you feel peaceful." "Yeah, right then everything is so smooth and man this feels good. And, just to punch a button and say that's over with and be gone." To dismiss the above as drug effects or to over-react to the wish to die would have been to deny a good deal of this dying person's experience, and, to exclude a very logical explanation and context for understanding his behaviour. The next series of events demonstrate the latter point.

Six days after the second interview the patient convinced staff to hospitalise him. This was distressing to his wife who could not understand why he wanted to be hospitalised. When he saw the interviewer approaching, he smiled and said quite

excitedly, "You know what we talked about? I found out I could will myself to die." Shortly thereafter the patient was discharged and died four days later. His death came as a surprise because he was not thought by staff to be preterminal.

Another issue which has obvious implications for clinicians is the apparent decreased motivation which was observed. As was noted earlier, it may be that some kinds of changes in motivation are more troublesome for subjects than others i.e., interest in the present may be more or less impacted upon. It would be important to assess this difference.

Many subjects in the present study seemed motivated to participate out of a desire to be helpful or to make a contribution and reported enjoying interview sessions. As was seen in the review of the literature, Jankofsky and Steucher (1984) have hypothesised that observed emotional reactions in the seriously ill may, in part, mirror a loss of meaning and feelings of uselessness imposed by society. One might wonder how much of the closing off which is observed is socially or culturally reinforced. Some subjects in the sample appeared to have notions about what was proper or improper behaviour for someone with their particular medical status. On the other hand, some did not. Jankofsky and Steucher (1984) suggest that altruistic activities may increase the patient's sense of personal value. The present study seemed also to affirm that structured efforts to provide altruistic opportunities could have utility for increasing patients' feelings of usefulness.

In general, asking what agendas and expectations are important to individuals may be useful for a number of clinical reasons. The question respects individuality and conveys an interest in the patient's own thought processes. Secondly, it often seems to generate comments about the patient's understanding of and attitudes toward his or her illness. And, it appears to be useful for identifying problem areas, and for providing information which could help ameliorate those problems on individual, family, and systems levels.

Restatement of the Problem

The present study began with two essential premises. The first was the idea that the theoretical construct *appropriate death/dying* (Weisman, 1970) could inherently avoid some of the difficulties which evolved in the literature investigating the psychological aspects of terminality. To reiterate, one of these difficulties has been a premature acceptance of data as fact (Carr, 1983). This would include an endorsement of Kübler-Ross's stage theory by the medical and hospice communities (cf. Hare, 1978; Kalish, 1978). Other problems are a confusion about how terms should be operationalised--as was evidenced by the discussion of denial (e.g., Cohen & Lazarus, 1979); the assertion that some of our observations may have been clouded by social bias (Janofsky & Steucher, 1984; Stein, 1984); the reliance upon retrospective methods (e.g., Hinton, 1975); and the apparent tendency to view a particular level of observation e.g., the nomothetic, as logically excluding other levels such as the idiographic (cf. Runyan, 1984).

The potential for avoiding some of these difficulties lies in directing the focus of the investigation away from significant others, staff members, and so forth, and back to the individual dying person. It makes intuitive sense that what is appropriate for one individual is not necessarily appropriate for another. Therefore, the present investigator has claimed that the essence of appropriate dying is idiosyncratic.

A second premise was that the term, appropriate dying, could be usefully operationalised in a way which would minimise static judgements by investigators, or those involved in treatment. A suggestion was made to ask dying persons themselves something about idiosyncratic variables by operationalising the term (in part) as the expectations, goals, and agendas one has for one's self given a dire prognosis. So, unlike Weisman's claim about his concept that we could do little more than conjecture

about "appropriateness" (1979), the present study has asserted that conjecture can be minimised by seeking the dying person's own perceptions.

In practice, this meant the collection of descriptive, idiographic material through a phenomenological method which attempted to minimise the influence of the interviewer (e.g., Stones, 1985). This trend was maintained by asking subjects themselves whether or not their "agendas" were maintained, altered, or rejected, and whether or not those agendas were perceived as fulfilled or unfulfilled. Interpretation of data was connected as closely as possible to the perceptions and experiencing of the subjects themselves. Theoretically, attention to the subject's own perspective should minimise judgements which pertain to underlying philosophic assumptions of the investigator.

One importance of such an approach has been in avoiding speculation through a prospective rather than retrospective method. By way of illustration, it has been shown how retrospection was a problem for Hinton (1975) in relying upon significant others' interpretations of patients' past personalities, and for Weisman (1979), in restricting "appropriateness" to the notion of "good coping".

Results have appeared to show some evidence for the importance of accepting each subject's frame of reference. It has been seen from a clinical point of view that serious problems which would probably have remained undetected, have been expressed. And it seems that patients' perceptions about, for example, whether agendas are fulfilled are more important than "facts" about these agendas. At least for this sample, very few generalities could be imposed. In a sense, the most important feature of agendas was their apparent dissimilarity.

In summary, the empirical aspects of the study are consistent with the view that data should be interpreted from the perspective of the individual subject--basically a phenomenological approach in the tradition of Stones (1985) which does not exclude dissimilar events for the purpose of theory construction. The descriptive aspects are also consistent with some studies in the personality and assessment literature (e.g.,

Pervin, 1977) which have incorporated the subjects' perceptions of situations as pivotal data. Theoretical components of the study developed from two premises: (1) that the construct *appropriate dying* is inherently capable of dealing with some of the problems in the thanatological literature; (2) that the idiosyncratic component of appropriate dying can be operationalised in a practical manner.

In the sections which follow, limitations are enumerated and suggestions for further research are discussed in some detail.

Limitations

A minimum N of 30 was proposed. However, this did not turn out to be feasible. The small sample size was a product of both limited access and resources and the frailty of the subject pool in general. The average survival time for the year in which data was collected was M = 39.4 days--substantially less time than was predicted (four to six months). This factor accounted for over 70 potential subjects being screened out. The former problem could be overcome with greater available resources. A study of this nature is bound to be an enormous emotional strain on the experimenter. Therefore, economic, institutional, and research assistance would be desirable prerequisites.

With a considerably larger sample size, it is possible that more frequent measurements over time could have been employed. Perhaps a greater number of measurements would have been a more accurate reflection of specific details of agendas and of emotional equilibrium. However, the possible benefits would have to be weighed against the danger of intrusiveness. While two to three interviews did not seem to be intrusive, it is likely, given the short survival time of subjects obtained, that more frequent interviews might have been problematic from this point of view. Also, in retrospect, given the apparent stability which emerged i.e., very few agendas were added, altered or rejected, it is unlikely that much more information pertaining to agendas would have been forthcoming.

Greater frequency of interviews would also contribute toward experimenter bias. Even given fewer measurements, experimenter bias must exist to some extent with an interview method; this may be problematic from the point of view of replication. Still, the benefits in terms of richness of material obtained justify the risk. It also seems to the present investigator that an interview method is a more humane approach to research involved with individuals this ill, i.e., subjects not only had terminal prognoses but, in many cases, were within weeks of their deaths.

The essential theme of the study emphasised the nature of agendas occurring within a terminally ill hospice sample. The intent was exploratory. Secondarily, the study intended to gather some information about emotional disequilibrium. Conversely, the intent was not, for example, to explore the nature of depression in a terminally ill population. In other words, there might have been other variables which could have as easily or perhaps more accurately reflected this disequilibrium. For example, pain did not turn out to be a potentially good variable for distinguishing between those who were more or less disturbed, or those with fulfilled or unfulfilled agendas. The theoretical reason for choosing this variable pertained to the nature of pain. It was reasoned that pain would be correlated to depression and anxiety i.e., that emotional disturbance increases pain experience. What could not be accurately predicted was the level of effectiveness in pain management techniques. This leads to another bias.

The particular hospice was in itself a bias. As was seen from the review a good deal of variability is manifest in not only how the philosophy of hospice is translated but also how *well* it is translated. It may be questioned: Does a particular hospice do what it purports to do? And, how effectively are those activities carried out? While recognising that experimental evidence does not exist for this statement, it could be speculated that this particular hospice team was very effective in controlling pain. This might account for the majority of subjects reporting no pain. At any rate, the sample could not be said to be representative of hospice patients in general.

Another bias which needs to be considered concerns the issue of self-report measures of depression and anxiety. It is possible for halo effects to occur with this type of scale. One way of dealing with this issue would be to use other types of measures in addition to those with self-report response formats. For example, a behavioural check-list or rating instrument could provide some objective measures of particular variables. Such ratings could be made by hospice staff members, e.g., nurses. The difficulties inherent in implementing such ratings should not be minimised. First, total institutional cooperation would be required. And secondly, staff members would have to be carefully trained and monitored. Both of these requirements were beyond the realm of possibility for the present study.

Suggestions for Further Research

It was observed by the present investigator that terminally ill individuals are not only interested in participating in research for altruistic and personal reasons but also find the opportunity to express their own views appealing. Despite the emotional intensity of material which sometimes emerged, subjects in the present study reported enjoying interview sessions. One subject, who was not sure at the first visit how much time she had to spend, said after one and a half hours (considerably longer than most interviews) "Do you need to go? I'm all right." When the interviewer commented to another subject that over an hour had passed, he said, "I enjoyed every minute of it." Others said, "I hope I've been helpful. I love people to visit me." Still others noting indirect therapeutic effects, said, "It's been helpful for me."

It is certainly possible that the present study be replicated on a larger scale. However, some caveats are in order. It is this investigator's opinion that prior experience with seriously ill individuals is essential. Secondly, and following from the first point, a good deal of sensitivity to the needs and wishes of subjects as well as research flexibility is required in order to deal with the special problems of the terminally ill. There will be occasions when research goals clash with situations presented by

subjects. From an ethical point of view, there is no question as to the appropriate response. Researchers not willing to make this sacrifice should not investigate this population.

Research design can be rigorous but cannot always be rigorously followed, even given the best of circumstances (i.e., assuming accurate prognoses, unpredictable events will occur). For example, one subject in this study had a stroke and died approximately one week following the first interview. He had been receiving good medical care prior to this event. His death at that point in time and in that way was totally unexpected.

In replicating the present study a number of improvements could be made. Pertaining to the interview, subjects with more than one agenda might be requested to prioritise their lists. Also, more specific questions could be asked about the personal meanings of agendas and the level of emotional investment. Parallel to this line of enquiry, more formal information might be obtained about actual activities in subjects' lives.

While something like a structured interview theoretically could be developed for exploring the sorts of things individuals would like to see happen, it is the present investigator's opinion that the need for flexibility with individual subjects should be heeded. There seems to be value for avoiding intrusiveness in letting subjects maintain a good deal of control over the interview. And, as was mentioned previously, the richness of material obtained has been a positive feature of the study.

The interviewer is always a bias. However, assuming that the interview is progressing well i.e., the subject is willing to talk about him or herself, it would seem that for the purposes of a phenomenological study of the present nature, that interviewer bias would be preferred to the biases inherent in most structured tests. For example, subjects were not prompted by structured questions to offer material they would not have thought of on their own. Subjects were not asked questions like, "Do you have any unresolved business with a significant other?" Such a question could influence the

subject's response in either direction i.e., subjects might then offer material they would not have otherwise in order to please the interviewer or, if the question is perceived as intrusive or threatening, material may not emerge which might have if the subject had more control over how and when such information is revealed.

Assuming for the sake of argument though, that some sort of structured interview will eventually be desired, an interview schedule would ideally contain many options for questions--perhaps something like a taxonomic key, with choices being dependent upon the responses of the subject. The development of such an interview schedule is probably premature at this point. To develop a questionnaire or even a structured interview too soon in the empirical process could mean making assumptions on insufficient data which could have the result of narrowing information obtained and obscuring the perspective of the subject. Instead, further post-interview assessments of agendas are recommended.

A systematic method could be developed for such assessments. Perhaps a beginning in this direction has been made (see diagram on p. 79). Another approach (or in some cases a supplementary approach) could be to use judges to make post-interview assessments. Similarly, some phenomenological studies (e.g., Stones, 1985) have advocated the use of independent judges to validate both idiographic and nomothetic descriptive outcomes: "Since the hallmark of any scientific endeavor is that there should be consensual validation of the outcome, a panel of judges should be used to determine whether the specific descriptions and the general descriptions are true to the phenomenon" (Stones, 1985 p. 71). That is, attempts could be made to discover variables which have importance for understanding individual agendas, or independent judges reviewing the data could attempt to sort out common features occurring across subjects.

Pertaining to the former, configural analysis has already been suggested as one way of examining and systematising within-subject variables. It might be recalled that

an example from Horowitz (cited in Runyan, 1982) was used to demonstrate this method. It was claimed that an experience such as depression might be described as depression or it could be anchored to more personal interpretations of the experience such as "hurt and not working".

This sort of approach might be useful in understanding attitudes about agendas. By way of illustration, the one subject who said, "I don't have any goal or agenda now" not only engaged in a number of activities but also reported some pleasure with activities. On the other hand, some activities did not seem to be pleasurable. So, it might be asked what sorts of thoughts, emotions or environmental markers might be correlated with a shift from pleasure to displeasure for this subject?

He said, "When I came back (from surgery) I didn't have any desire really to do anything and I'm still *much* that way." He gives us some clues which may help differentiate between pleasurable and unpleasant states: "I read the paper and I find some interest in politics. I'm still interested enough to read the paper and to skim ten magazines." So when does a pleasurable activity for this subject shift to displeasure or disinterest? He said: "I don't have the same interest when they say something is *going to happen*. 'In the year 2004 the population is going to be...'" Thus, one shift may occur when references are made to "times when I won't be alive." Events which focus on the immediate experience may be pleasurable e.g., "I had a very pleasant evening. We went to a movie and we ate out and went to friends." Potentially, each component of these activities could be analysed from the subject's point of view to determine what features are salient for "having a pleasurable time."

Simply focussing on the present, though, does not appear to be a complete explanation for this subject in that an activity such as staying at his condo in a resort city is reported as being not pleasurable. "When we go (to the resort city) it's hard on me." It turns out that the subject feels hurt and excluded from activities such as swimming

which others assume he is not capable of pursuing. "Hurt and excluded" appears to be another state for this subject which precludes pleasure.

Thus, activities which (1) begin to lose focus on the present or (2) pertain to activities he is excluded from, may be markers for a change in attitude. It would be possible to test such within-subject hypotheses with a more intense involvement with one subject. With more data, precise explanations would develop pertaining to transitions for this subject from pleasurable to not so pleasurable states.

Runyan (1982) suggested, based upon Horowitz's study, that reliability may be established by having more than one judge review material i.e., states such as "hurt and excluded" could be reliably demonstrated if a similar conclusion could be reached by independent observers.

Another topic for further research are the descriptive *a priori* categories used in the study, which were intuitive i.e., they were not empirically defined. Thus, it is not possible to do more than conjecture about whether or not the categories are truly exhaustive or if further distinctions are necessary within categories and so forth. In order to evaluate meaningfulness, the categories should be employed with larger numbers. Some hypotheses about types of agendas could be made. For example, there may be reason to believe, based upon the present sample, that a greater than average number of activity agendas is correlated with high anxiety. This would be expected with high pressure to achieve, given one's medical status.

The need for other measures of affective variables has already been pointed out. Even though the CES-D shows excellent reliability, and has been validated with a number of populations, the concept of depression may need to be redefined for the seriously ill. For example, it is possible to imagine instances when terminally ill patients are clinically depressed. Such individuals may be depressed in reaction to their medical conditions or the depression could have had a premorbid onset. Certainly, it would be important to distinguish these individuals from those showing a "normal" amount of

depression. However, the issue may be more than simply developing norms or cut-off points--although this could be helpful. While it may be useful and important to hypothesise that terminally ill cancer patients show more depression than those not ill, it makes intuitive sense that some kinds of sadness would be a normal reaction to their terminal condition. Further, this sadness may be qualitatively different than depression shown in those not ill. It may be that no meaningful method currently exists for measuring or evaluating emotional disequilibrium for this group. This objection is similar to that of Mount and Scott (1983). Specifically, that adequate measures i.e., with good content validity, for "quality of life" do not yet exist for hospice patients. By way of illustration, it was not uncommon for subjects to show relatively high depression scores yet also report some feelings of satisfaction. One subject in particular had a high depression score (15) and yet said, "Since my notification that I'm down the tube, you might say I've been more contented in that 60 to 90 days than I ever have been in the previous 66 years." The interviewer, curious about this attitude, asked the subject why he thought this was so. He quickly responded: "Oh, that's very simple--appreciation." While this subject was one point away from the cut-off for clinical depression, it is unlikely he would have been assessed as depressed. So for future research there would be value in exploring concepts such as depression as it relates *specifically* to the terminally ill. This activity could result in a depression scale for this group.

Another suggestion for research is to test group hypotheses. The small numbers obtained in the present study precluded testing between subject hypotheses. In the introduction to Chapter 1, it was commented that part of the intuitive importance of fulfilled or unfulfilled agendas was that these variables have seemed to have had an impact on the emotional equilibrium of dying persons. While it has also been noted more than once in the previous text, that there are many factors which could affect, for example, the level of depression and anxiety reported by an individual with a life threatening illness, perceived fulfilled or unfulfilled agendas may be a significant enough

variable to account for some general differences between subjects. Using an idiographic method such as the one described in the present study, significant correlations could help demonstrate the importance of information which was obtained.

A number of hypotheses such as the generalities observed in the sample may be tested using between-subjects designs. To reiterate, it was observed that most individuals had few agendas, that an incongruity existed between stated agendas and actual activities and that agendas were largely reality bound. Prognoses were for the most part very short in the present sample. A comparison between a comparable group and a group with longer prognoses may reveal a greater number of agendas or perhaps types of agendas.

Summary

The present study, which was largely exploratory, has had several aims: to suggest some useful ways of viewing the construct appropriate death; to provide a method for investigating this concept; and to show the importance of idiosyncratic variables in understanding the dying process.

A logical approach was applied to the first problem. The consequences of this approach included a substitution of the term appropriate death with *appropriate dying* and a suggestion for operationalising what was called by the present investigator the idiosyncratic components of the concept. It was argued that the distinctive value of the concept from research and clinical perspectives is this idiosyncratic core. And, it was shown that in order to avoid speculation, it seemed important to somehow gain access to individuals' perspectives.

Next, a phenomenological method of *data collection* was proposed which was prospective in nature. The emphasis on such a method was in avoiding the problem of speculation which had hampered previous efforts. The intention was to collect data which could have the potential for analysis in either an idiographic or nomothetic manner. Some suggestions for both within and between subject designs were made.

Data itself has included each subject's response to the question of what sorts of things they would like to see happen--what sorts of goals and agendas they might have as well as scores from quantifiable measures of pain, depression and anxiety. The phenomenological thread was maintained by asking individuals whether any alterations in those agendas had occurred and whether or not they were perceived as fulfilled or unfulfilled.

It was found that most subjects reported few agendas; that these agendas remained fairly stable over time; and that activity level was not necessarily predicted by the number of agendas reported. The fact that an incongruity existed between stated agendas and actual activities suggested a number of individual explanations and hypotheses: Stated agendas sometimes explicitly or implicitly reflected prioritising. However, varying investments--from intense to negligible--were apparent not only among two or three agendas reported by individual subjects, but also in subjects reporting only one agenda. In addition to priority and investment the meaning of various agendas differed between subjects.

Although exceptions occurred, agendas were, for the most part, bound by constraints of reality. Subjects spontaneously distinguished between what were intended to be agendas and what were wishes or phantasies. For a variety of reasons, some activities which might have been agendas were rejected as such.

A decreased motivation for pursuing usual activities was noticed in many subjects and due to this decrease, or change in motivation, various effects were noted between subjects. Some other observations were also discussed. For example, aside from the explicit content of agendas, some additional agendas emerged which were problematic for subjects and were often accompanied by dysphoric mood. Other agendas revealed content which could be considered socially unacceptable. Still others represented constructive efforts to change or manifested altruistic motivations.

The contribution to the concept of appropriate dying, as the investigator sees it, has largely been one of methodology i.e., rather than emphasising other's impressions or some set of *a priori* judgments, individuals themselves were asked to provide their own standards. In essence, an effort has been made toward developing an approach which does not rely on retrospection. For theoretical reasons (e.g. only a portion of the concept was operationalised--the whole notion of coping, for example, was not explored) systematic efforts were made to avoid referring to a particular individual's dying as appropriate or inappropriate. However, the therapeutic value of understanding a dying individual's goals and agendas when one's own aim as a therapist is to promote appropriate dying, was elaborated in the section of the discussion referred to as clinical impressions.

In general, it is hoped that the present effort will provide some evidence of not only the feasibility but the usefulness of a phenomenological approach with the seriously ill from both research and treatment perspectives.

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Appendix A
Standards of a Hospice Program

A Hospice is a program of palliative and supportive services which provides physical, psychological, social and spiritual care for dying persons and their families. Services are provided by a medically supervised interdisciplinary team of professionals and volunteers. Hospice services are available in both the home and an inpatient setting. Home care is provided on a part-time, intermittent, regularly scheduled, and around-the-clock on-call basis. Bereavement services are available to the family. Admission to a Hospice program of care is on the basis of patient and family need.

Hospice affirms life. Hospice exists to support and care for persons in the last phases of incurable disease so that they might live as fully and comfortably as possible. Hospice recognizes dying as a normal process whether or not resulting from disease. Hospice neither hastens nor postpones death. Hospice exists in the hope and belief that, through appropriate care and the promotion of a caring community sensitive to their needs, patients and families may be free to attain a degree of mental and spiritual preparation for death that is satisfactory to them.

1. The hospice program complies with applicable local, State and Federal law and regulation governing the organization and delivery of health care to patients and families.
2. The hospice program provides a continuum of inpatient and home care services through an integrated administrative structure.
3. The home care services are available 24 hours a day, seven days a week.
4. The patient/family is the unit of care.
5. The hospice program has admission criteria and procedures that reflect:
 - a. The patient/family's desire and need for service.
 - b. Physician participation.
 - c. Diagnosis and prognosis.
6. The hospice program seeks to identify, teach, coordinate, and supervise persons to give care to patients who do not have a family member available.

7. The hospice program acknowledges that each patient/family has its own beliefs and/or value system and is respectful of them.
8. Hospice care consists of a blending of professional and nonprofessional services, provided by an interdisciplinary team, including a medical director.
9. Staff support is an integral part of the hospice program.
10. Inservice training and continuing education are offered on a regular basis.
11. The goal of hospice care is to provide symptom control through appropriate palliative therapies.
12. Symptom control includes assessing and responding to the physical, emotional, social and spiritual needs of the patient/family.
13. The hospice program provides bereavement services to survivors for a period of at least one year.
14. There will be a quality assurance program that includes:
 - a. Evaluation of services.
 - b. Regular chart audits.
 - c. Organizational review.
15. The hospice program maintains accurate and current integrated records on all patients/families.
16. The hospice complies with all applicable State and Federal regulations.
17. The hospice inpatient unit provides space for:
 - a. Patient /family privacy.
 - b. Visitation and viewing.
 - c. Food preparation by the family.

Appendix B

Instruments.

Present Pain Intensity

1. Which description tells how strong your pain is right now?	Not at all strong	1
	Mildly strong	2
	Moderately strong	3
	Very strong	4
	Extremely strong	5
2. Which description tells how strong your pain is at its worst?	Not at all strong	1
	Mildly strong	2
	Moderately strong	3
	Very strong	4
	Extremely strong	5
3. Which description tells how strong your pain is at its least?	Not at all strong	1
	Mildly strong	2
	Moderately strong	3
	Very strong	4
	Extremely strong	5

1	2	3	4
Flickering Quivering Pulsing Throbbing Beating Pounding	Jumping Flashing Shooting	Prickling Boring Drilling Stabbing Lancinating	Sharp Cutting Lacerating
5	6	7	8
Pinching Pressing Gnawing Cramping Crushing	Tugging Pulling Wrenching	Hot Burning Scalding Searing	Tingling Itchy Smarting Stinging
9	10	11	12
Dull Sore Hurting Aching Heavy	Tender Taut Rasping Splitting	Tiring Exhausting	Sickening Suffocating
13	14	15	16
Fearful Frightful Terrifying	Punishing Grueling Cruel Vicious Killing	Wretched Blinding	Annoying Troublesome Miserable Intense Unbearable
17	18	19	20
Spreading Radiating Penetrating Piercing	Tight Numb Drawing Squeezing	Cool Cold Freezing	Nagging Nauseating Agonizing Dreadful Torturing

Center for Epidemiological Studies Depression (CES-D) Scale

During this past week:	Never or Rarely (less than one day)	Some of the time (1-2 days)	Occasionally (3-4 days)	Most or all of the time (5-7 days)
1. I was bothered by things that usually don't bother me.	0	1	2	3
2. I felt I could not shake off the blues --even with help from my family and friends.	0	1	2	3
3. I felt that I was just as good as other people.	0	1	2	3
4. I felt depressed.	0	1	2	3
5. I felt everything I did was an effort.	0	1	2	3
6. I thought my life had been a failure.	0	1	2	3
7. I felt fearful.	0	1	2	3
8. I was happy.	0	1	2	3
9. I talked less than usual.	0	1	2	3
10. I felt lonely.	0	1	2	3
11. People were unfriendly.	0	1	2	3
12. I enjoyed life.	0	1	2	3
13. I had crying spells.	0	1	2	3
14. I felt sad.	0	1	2	3
15. I felt that people disliked me.	0	1	2	3
16. I could not get going.	0	1	2	3

Anxiety Scale.

	None of the time	A little of the time	Occasionally or moderatey	Most of the time	All of the time
During this past week:					
1. Were you bothered by nervousness or your nerves?	1	2	3	4	5
2. Were you under or felt you were under, any strain, stress or pressure?	1	2	3	4	5
3. Were you anxious, worried or upset?	1	2	3	4	5
4. Were you generally tense or did you feel any tension?	1	2	3	4	5
5. How much of the time during the past week, did you feel relaxed and free from tension?	1	2	3	4	5

Appendix C
Consent Form

CONSENT FOR PARTICIPATION

I hereby authorize Donna L. Stephen, M. A. to include me in a study of the various stages of the life cycle.

I understand that participation may include several tape-recorded interviews with Ms. Stephen and that I may be asked some questions about my feelings and mood and my degree of comfort or discomfort.

I understand that these audiotapes will be used only for research purposes and that my identity will not be disclosed. Any subsequent publication or release of information will be such that all identifiable information will be protected to the limits allowed by law.

I understand that I may withdraw consent for participation at any time without prejudice to my present or future treatment.

Subject's signature:

Date:

Witness:

Appendix D

Instructions to Judges and Schedule Form

Instructions to judges:

Below are several forms called schedules. The first column contains descriptions of one or more agenda (indicated numerically) and the criteria for fulfillment. The second column contains verbatim responses pertaining to whether or not items (agendas) are perceived as fulfilled.

I. Each agenda should receive a numerical code (1-3 and any appropriate subcode) in column 3--"category"--based upon a congruence between the description of the item (column 1) and the categories below.

1. Actions or activities: Any behaviour with reference to self or self and others which is not problematic or does not imply a conflict i.e., expressed goals or agendas implying doing/action. Examples might include reading a book, going to lunch with a friend, taking a trip.
2. Interpersonal relationships: Any wish or behaviour with a primary focus on a relationship issue.
 - a. maintain: To spend time with an individual, to keep close ties, to receive a phone call or a visit from an individual.
 - b. restore: Any problem or conflict with a primary focus on relationship issues.
 - c. initiate: e.g. "I wish I had someone to talk to."
 - d. goals for others: Any wish with a focus on another person e.g., " I would like my grandson to go to college."
3. Intraindividual:
 - a. stance: An expression of beliefs or attitudes toward illness, self or the world. A desire to initiate, maintain or change a stance. Examples might be: "I want to have a good time"; be a better person"; "I don't want to think about the future."

- b. unfinished business: Personal affairs and agendas implying a desire for completion or resolution but which are not problematic i.e., just undone.
- c. conflicts/problems: Wish to resolve or figure out problems with a focus on the self (does not pertain to relationship issues).

II. They are also scored as fulfilled or unfulfilled using a plus or minus rating. This determination is made by comparing the response column to the description column using the rating criteria explained below.

- Plus (+) (1) Agenda is reported as completed (e.g., "I was able to go fishing" or "I have got this figured out"). Or:
- (2) Agenda is retained by individual at follow-up and a. some satisfaction with progress is verbalised (e.g., "I feel pretty good about that") or b. the individual is unequivocal, "Yes I feel fine about that."
- Minus (-) (1) is reported not completed (e.g., "No, I have not done that.")
- (2) Individual is not optimistic about progress: "I have not done very well with that."

Subject number

SCHEDULE

Description and Criteria	Response	Category	Rating + or -

Appendix E

Raw Data

Raw Data for All 20 Subjects

<u>S</u>	<u>#A</u>	<u>A/R</u>	<u>AF2</u>	<u>DP2</u>	<u>AX2</u>	<u>PA2</u>	<u>AF3</u>	<u>DP3</u>	<u>AX3</u>	<u>PA3</u>
01	3	1r	0	08	10	0	0	22	13	0
02	2	0	1	15	10	0	-	-	-	-
03	3	0	3	17	15	0	-	-	-	-
04	5	2a	2	09	12	0	4	07	13	-
05	1	-	-	-	-	-	-	-	-	-
06	3	0	3	12	08	4	3	03	08	0
07	0	0	-	12	12	3	-	-	-	-
08	1	-	-	-	-	-	-	-	-	-
09	1	0	1	03	05	0	1	02	05	0
10	1	0	0	12	05	0	-	-	-	-
11	1	0	0	15	10	3	-	-	-	-
12	2	0	2	08	06	0	-	-	-	-
13	1	0	1	0	07	0	1	01	05	0
14	1	-	-	-	-	-	-	-	-	-
15	2	-	-	-	-	-	-	-	-	-
16	1	0	1	02	10	0	-	-	-	-
17	1	0	0	22	14	0	-	-	-	-
18	2	-	-	-	-	-	-	-	-	-
19	1	0	1	17	07	0	-	-	-	-
20	3	-	-	-	-	-	-	-	-	-

Note. S=subject number; #A=number of agendas at t1; A=added, R=rejected;

AF=number of agendas fulfilled at t2 or t3; DP=depression; AX=anxiety; PA= pain.

Summary of Schedules

1. Items on original schedule: 35, M = 1.75
2. Items added: 2
3. Items amended or rejected: r = 1 a = 0
4. Total number of items: 37, M = 1.85
5. Number of items fulfilled (+): 17 (t2: 15; t3: 17)
6. Equivocal: 1 (scored -)
7. Total % fulfilled: 56
8. Categories:

I. Actions/Activities: 12

II. Interpersonal: 10

a. 5

b. 0

c. 1

d. 4

III. Intraindividual: 15

a. 8

b. 3

c. 4

Appendix F

Transcripts

The following are three abridged transcripts which correspond to interviews occurring at t1, t2 and t3. The interviews took place over a seven week period.

The subject was a 53 year old woman with a diagnosis of squamous cell cancer with cervical and esophageal primary sites. She lived alone having been widowed two years previously. The subject had worked as a bookkeeper.

Upon calling to confirm an interest in participation the subject said she would be happy to see me, that she loves to talk to people and wanted to be helpful.

First interview:

I: You were saying just before we turned the tape recorder on that you have been on the hospice programme about two months.

S: Yes...it is just so helpful to me. You know, friends are friends and people care. But they have their own lives and sometimes they just don't have time for you. And, I always know that the hospice programme is right there in case I get into an emergency. And before that when Dr. R. told me the cancer was incurable I was considering suicide very seriously. But I searched my own mind and I don't believe in things like that so I decided to ride it through.

I: What was the thought, what went through your mind at the time?

S: Just to get out of this because I've been throwing up for two years now.

(tears...) Dr. R. says I have a right to cry once in a while.

I: I should say so.

S: It just gets miserable when all you can do is lie in bed with a towel throwing up blood and throwing up--you can't eat. And I was working two jobs...

I: What were you doing?

S: Oh, office manager, bookkeeper. You name it...And I thought after my ankle had been broken--as you can see here, I have an eight and a half inch metal thing down my leg and a two and a half inch screw on this other side. And, that happened just about a week before my husband died. And, I kept going down to see him...he died in 1983...I

just--well, possibly I shouldn't be smoking (*lights cigarette*) but it seems to soothe my throat a little bit. And at this point what can they tell me that it's going to kill me? (*laughs*) Oh, I still have my sense of humour and--that's what our marriage was based on--a sense of humour. And when he got sick I just didn't really know what to do and I knew I was sick then too. I started throwing up before that you know, the choking sensation and everything? And I know that that is one of the first signs of cancer, difficulty in swallowing. I was so concerned about him and it felt like just a cold with postnasal drip or something? So, I wouldn't do anything about it. I finally went to the doctor after I had taken on three jobs and was throwing up in the wastepaper basket (*at work*)...But as long as I take my time and it might take me three hours--maybe a whole day to eat a meal--but I'm going to do because, by darn, I'm going to take on everything and anything as long as it takes me.

I: What sort of food do you enjoy?

S: Oh, you'll laugh--Chinese food--and watermelon. (*S talks at some length about favourite foods*).

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S: This thing has to run its course and I may beat it yet. They told me when I was 25 that I had cancer of the uterus in the fourth stage...the doctor had me all set up for the hospital and I said, 'I'm sorry, I don't have time for it. I have two children to support.' They are now grown...one lives three blocks from here. I called him when I knew--that this was terminal--but I'm still not convinced that it is terminal. (*laughs*)

I: You sound like a survivor.

S: I am a survivor. I have been through hell and back--went through 18 years of being beaten half to death. One son came back and said 'Mom I don't see how you ever stood it' So, this thing is a piece of cake compared to that (*laughter*). Well, I have the ability to forgive--maybe not forget completely--but the ability to forgive. And, I just don't

believe that there is any retribution that I should do in this life because God is my only adversary.

I: Tell me about that...

S: Well, it's hard to explain, you just get a sense of peace, that everything is going to be O.K. no matter what. (*relates life after death experience at age four*). I kept the incident secret for many years. That's why I have no fear of death now. But I am not going to commit suicide because I feel that--because it would be wrong. And, God has his own purposes for me and I don't know what they are.

I: Celia, what about yourself, what sorts of things would you like to see happen?

S: You mean to me?

I: Yes.

S: There are a few goals--very few. Most of them mean to be giving to somebody else. And, that's the only way I can see it. I want to go visit my Aunt and Uncle--just have people visit me once in a while. And, most of my friends just--they can't stand the idea of death. They really can't. And, so they kind of stay away. But, I guess my goals are just maintaining myself through this period. That is my main concern--being able to take care of myself. And, I want to be helpful. I don't want to leave this world without being a help to somebody.

I: Let's see if I've got this straight. You would like to have people visit you and you have a specific plan to visit someone else.

S: Right.

I: Also, you would like to be able to take care of yourself and to be helpful to someone. Is that correct?

S: Yes it is. My first priority is friendship and loving and caring for people. That's really all I need--I want people around me to know that I'm alright--that I'm doing O.K...I have already disseminated my jewelry and things like that. (*S elaborates about will, finances and so forth.*)

I: Do you have any other goals or agendas right now?

S: Oh, nothing that is under my control I would like to see A. (step-son) finish college. (*S. talks at some length about own education, pride in her achievements and her intellect.*)

I: You have a lot to be proud of.

S: Yes, I think I've done pretty well--considering.

I: We've been talking for some time would you like to quit for now?

S: Yes, I think so.

I: You've been very helpful. Thank you for spending time with me.

S: You are very welcome.

I: Could we meet again in two weeks?

S: Sure anytime--just give me a call in the morning.

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At the time of the second interview the subject was at home in a considerable amount of pain and was having difficulty with nausea, but really wanted to try to proceed with the interview anyway. I told her that she should just let me know if she did not feel up to continuing that we could stop at any time.

The subject was somewhat tired after completing the self-report scales so the follow-up interview was quite short.

Second interview:

I: Celia, when we met last time you said that it is important to you to be giving to people

S: It is. I'm not one of these people who can just sit around and take. In fact, I'll sit here and not ask for help when sometimes I should. Because I feel that everyone else

has their own life and they do as much as they can and unless I really have a need I don't like to ask. (*Some discussion of hospice and medication regimen occurred at this point.*
S. was given support for asking for help).

I: Returning to your agenda of being helpful to people, do you feel you've been able to be helpful to people in the last few weeks?

S: Yes, I think so, that is so important to me.

I: You also said you would like to have visitors and you had planned--

S: I made a visit to my Aunt and Uncle which I thoroughly enjoyed. E. took me over. I really appreciate her visits because we sort of give to each other. She gives me encouragement. (*S asks for a glass of water*)

I: I want you to know you are being a tremendous help to me. I really appreciate it.

S: You're quite welcome.

I: I am sorry you are feeling so distressed today...

S: It has been this bad for the last...ever since I started having problems with my kidneys. My urine was a better colour this morning so maybe with enough water today--because that's primary--I'll feel better tomorrow.

I: I certainly hope you do.

S: I do want to be able to take care of myself, but I'm not sure how much longer that's going to last. I am much worse than I was even two weeks ago.

I: So, you are able to take care of yourself right now, but it is very difficult.

S: Yes that's right. That is why this distresses me so much--to be dizzy. And, I hate to even have the housekeeping service in but I'm saving my strength a little bit that way. I've got to get up and around more though. I try to sit up as much as I can but then I usually have to take a towel in there with me because I start these sieges of vomiting. I mostly just lie here with the fan on all the time. If that's all I can do--that's all I can do.

I: That's right. I think you're doing wonderfully well. You look pretty tired...

S: Yeah, I think I am going to have to stop. Do you have any other questions?

I: No, we did really well. I'll call in a few days to see how you're feeling.

S: Thank you.

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By the third interview the subject was much weaker but not in pain. Her symptoms also were controlled and her mood much improved. The interview occurred while the subject was an in-patient.

Third interview:

I: So you're happy to be here...

S: I sure am. It's just wonderful. I guess a lot of people maybe fight against it thinking by the time they get here it's the end of the road. Well, it's a lot better end of the road here than it is in that lonely apartment not being able to take care of myself very well. I just don't know what people do without things like this. (*interruption*)

I: You were saying you don't know what people do without it but some might not want to be here.

S: They're denying death. And, they think that it's just going to go away if they stick their heads under the covers. And, it just isn't.

I: That is a very realistic attitude.

S: It is so much better to be happy than sit around and cry.

I: You look happy. The stress has gone out of your face.

S: I am--well I was just really having a hard time.

I: One of the things you said was important to you was taking care of yourself.

How are you feeling about that?

S: As long as I could. I still think I'm doing very well at it. I think I have a very fortunate--if you want to call it that way but that's the way I look at it--a very fortunate type

of cancer. And that is, that it hasn't affected my mind. It's affected my body. But just because the old bod goes doesn't mean the intellect has to go. So, I'm able to take care of my affairs--my financial affairs. I've worked everything out. (*S elaborates financial details*) So, I'm very fortunate in that way that I'm able to carry on and not just be a vegetable. I would hate that. I didn't know how readily help is available. They (*hospice*) had six people at my doorstep. And it took them two sentences to convince me to come in here. But I just felt I wasn't bad enough yet. Well, how bad do you have to get?

I: So you gave yourself a break.

S: Umhm, I deserve it. It just wasn't working and that is no way to live and I'm going to live until the end.

I: You've had visitors.

S: Oh yes! Everyone has been wonderful...I have so much fun doing so many different things. I forget things so easily these days. But I don't think that's too unusual with all the medication and everything. I am just--I feel like I'm in heaven. I really do. A beautiful view with a nice garden outside.

I: Another thing we talked about last time was your desire to be helpful to people.

S: Umhm and there are all kinds of ways you can be helpful. And it does not necessarily mean money. It's like getting M. through this with a good attitude and able to face up...22 is not too young. And he's really been on the right track... I got the nicest letter. Perhaps you'd like to read it.

I: I'd love to. (*thank you letter from her best friend*). It sounds like you are finding lots of ways to fill that need to be helpful--lots of ways you can do that.

S: Oh yes, very many ways.

I: Are there any other things you would like to see happen?

S: Well, just other than the hospice becoming well publicised and better known--I am just so very pleased with the way everything is going. I am just so grateful to be comfortable.

I: It looks like time for lunch so let's quit for today. Is there anything you would like to add?

S: No, other than just that I'm available at any time. As I get worse I may not make a lot of sense or whatever but whenever you need me I'll be here.

I: That is very generous of you.