HEALTHY DEATH READINESS: DEVELOPMENT OF A MEASUREMENT INSTRUMENT

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To The Provost of the Graduate School:

I am submitting herewith a dissertation written by Roberta McCanse entitled "Healthy Death Readiness: Development of a Measurement Instrument." I have examined the final copy of this dissertation for form and content and recommend that it be accepted in partial fulfillment of the requirements for the degree of Doctor of Philosophy, with a major in Nursing.

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ABSTRACT

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The purpose of this study was to establish whether or not readiness for death, as an indicator of healthy dying, is a measurable concept. A theory of healthy death readiness was derived from the Rogerian Paradigm. The theory related healthy human individual field pattern with healthy death readiness. An instrument, the McCanse Readiness for Death Instrument (MRDI) was constructed which was intended to holistically measure physiological, psychological, sociological, and spiritual indicators of healthy field pattern as death was developmentally approached. The MRDI was a semistructured interview-questionnaire which generated interval-ratio data.

A pilot study was conducted with a sample of nine volunteer patients drawn from a small suburban outpatient hospice. The MRDI was concurrently administered to dying individuals, their primary care givers, and their primary hospice nurses. Correlations between dying individuals' scores and their primary care giver estimates of patient

death readiness, and between patient and primary hospice nurse were very encouraging. A Cronbach's alpha was used to test for internal consistency and was .591. Other tests of reliability and validity were also done. Content validity was addressed by consulting a panel of practicing hospice nurse experts. Construct validity was based on legitimate placement of the concept, healthy death readiness, within the theoretical web which supported it.

The MRDI was then administered to a sample of 31 terminally ill individuals, their care givers and primary nurses, drawn from larger, urban, hospice populations in three geographic areas of the United States. The MRDI was also administered to a contrast group of 39 cardiac impaired individuals who were not terminally ill. Data collection occurred over 5 months. Reliability analysis was conducted using Cronbach's alpha and an alpha of .760 was realized. Four subscales identified apriori were found to be significantly correlated to an overall measure of the concept. Validity analysis included a Pearson's product moment coefficient relating dying individuals' scores with those estimated by primary care givers (.353, $p = .026$), and primary hospice nurses (.525, $p = .002$), and a t-test for difference between

terminally ill individuals' mean scores and cardiac impaired individuals mean scores (f = 2.76, p = .003). A t-test was also done to test for differences between dying individuals' original scores and their retest scores (1.19, p = .769).

As a promising measure of healthy death readiness, the MRDI has implications for the promotion of effective, compassionate, and individualized nursing care of the terminally ill. A death readiness instrument could also be used to evaluate ways in which care settings for dying individuals should be structured. Additionally, right to die issues remain particularly troublesome as nursing moves away from valuing the simple preservation of life toward promotion of quality of life. A measure of healthy death readiness could provide both ethical and legal justification for the controversial passive euthanasia component of hospice care.

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CHAPTER I

INTRODUCTION

When the poet Dylan Thomas urged his father, "Do not go gentle into that good night. Rage, rage against the dying of the light" (Thomas, 1953) he expressed a concern that most humans feel for a loved one who approaches death. Shakespeare's Prince Hamlet speaks of death as a country from which no one comes back to report on its conditions, saying that man is prevented from suicide by his fears of the unknown which lie in that country (Shakespeare, 1604). Poetry and prose fiction alike have always contained expressions of human attitudes toward dying.

In recent years, dying and death have become the participants of other types of writing, especially health care literature. Of prime consideration is the essential conflict between health care givers' mission to restore health, to prevent death, and the need of the terminally ill individual and his family for counseling and support during the transition from life. The concept of hospice care, of care givers who have been especially trained to provide the appropriate counseling and support, is one direct outgrowth of that conflict. Concomitantly, the

idea of "healthy dying" has emerged: some indication of preparedness, of acceptance, or of readiness for death may be present in the dying process which can be termed "good".

Problem of the Study

The present study was concerned with healthy death readiness. Of first importance was the ontological question of whether healthy death readiness exists. If it does, are there observable indicators of its existence? In order to be useful in the identification of healthy dying, death readiness must be a measurable concept. The question proposed for the present study was, "Is readiness for death, as an indicator of healthy dying, a measurable concept?" The purposes of the study were to identify observable indicators of healthy death readiness and create an empirically reliable and valid instrument for measuring healthy death readiness.

Rationale for the Study

Nursing has traditionally dealt with individuals who are not well. Because of nursing's acute care orientation, the patient's physical manifestations of disease have been attended to over, above, and before any psychological or sociological concern. The primary function of nursing is to restore the patient to good

physical health. Psychosocial behaviors are often viewed as related peripherally or in minor ways to the disease processes which the patient exhibits. Patient behaviors, other than physical, are frequently recorded casually into the ill individual's medical history and are often forgotten.

The focus of nursing for the terminally ill has been changing in recent years. With the inflation of costs for acute care and the limitations of diagnosis related groups as well as other economic and practical aspects of modern health care delivery services, dying individuals and their care givers are moving away from institutions and into the homes and communities where the dying individuals have spent their lives. More and more, people are choosing to die at home, and families are becoming the basic unit of care. Gradually society is coming to recognize that there are more normal and comfortable ways in which to die than in an acute care setting.

With a return to caring for the dying outside of institutions and acute care settings, a holistic approach to the care of the terminally ill begins to take hold. Healthy dying must not be considered as a physiological process alone; psychological, sociological, and spiritual aspects of the dying individual and his community must

also be examined. These matters, frequently minor or peripheral in the medical histories of patients being cured, become major components. In harmony with a holistic orientation to care rather than cure, the promotion of "healthy" dying has become nursing's most effective implement in the care of the terminally ill (Fitzpatrick, Donovan, & Johnston, 1980).

In order for care givers to be able to assess whether "healthy" dying attitudes are present, healthy dying readiness must be both measurable and measured. Several assessment tools exist at present; however, no single instrument measures a combination of the several emotions and behaviors which have been identified as being associated, in one way or another, with the various stages of terminality.

An instrument which measures healthy death readiness could be used to assess terminally ill individuals. Based on those assessments, nursing interventions could be planned which would help patients maintain personal or internal control over their lives for as long as they wished to do so (Benoliel, 1975). Additionally, the assessment instrument could assist in promoting normality so that life's developmental tasks might be achieved (Williams, 1982).

A healthy death readiness instrument could also be used to pattern ways in which to administratively structure care settings for the terminally ill. Hospice care, for instance, has been examined and observed to be an economical way in which to care for dying people (Rosen, 1985), but it has not been demonstrated to be more effective than, or preferable to, acute care nursing for the terminally ill.

Additionally, a measure of healthy death readiness has potential value for nursing ethics. The right to die issue remains particularly troublesome as nursing moves away from the simple preservation of life toward promotion of quality of life (Benoliel, 1978; Salmon, 1981). Though nurses are seldom, if ever, consulted in regard to the patient's right to die, physicians have left nurses with almost total responsibility for care of the dying (Fletcher, 1975; Lo, 1984). Allowing the peaceful death of a terminally ill patient who demonstrates a high measure of healthy death readiness might be more easily justified ethically, and perhaps legally, than the passive promotion of the death of a patient who, though obviously suffering, has not been shown to be death ready.

Theoretical Framework

The creation of an instrument with which to measure healthy death readiness was based upon a theory which considered multiple aspects of the human individual holistically. The theory in this research derives from the Rogerian paradigm (Rogers, 1970). The theory relates healthy death readiness among the terminally ill and synchronous, healthy individual field motion.

The Rogerian Paradigm is broad enough to permit a consideration of knowledge which is more than simply empirically valid. There are indeed several paths to knowledge, and nursing, with its intuitive as well as practical roots, makes use of knowledge generated in several ways (Carper, 1978). The McCanse Readiness for Death Instrument (MRDI) generates knowledge that is personal, ethical, and esthetic as well as empirical.

Different kinds of knowledge are credible in different ways (Chinn, 1986). Ethical knowledge begs justification. Personal knowledge invites reflection. Esthetic knowledge is amenable to criticism (Chinn, 1986). However, in the present study, only the empirical knowledge which was generated by the instrument was considered. The credibility of the instrument was determined by a process of validation.

Philosophical Underpinnings of the Rogerian Paradigm

The Rogerian paradigm is an open system, developmental, grand theoretical model which is firmly rooted in a humanistic, idealistic philosophy of life. It presumes belief in both universal consciousness and in the infinite capacity for growth and differentiation (Rogers, 1970). The paradigm is, in this way, in direct philosophical opposition to mechanistic models which limit the growth of any organism according to the presence of stressors which restrict adaptation to some predetermined pattern.

Assumptions of the Rogerian Paradigm Applied to the Healthy Death Readiness Among the Terminally Ill Theory

Rogerian assumptions in regard to man, environment, nursing, and health are the underlying assumptions of the theory proposed for use in this study (Rogers, 1985). Because the paradigm is basically optimistic, as to the nature of man, for instance, so is the theory.

A human being is an individual energy field, ever accelerating, ever differentiating, without boundaries and identified by pattern. Therefore, options for growth and development are unlimited and uninhibited even by death. Dying is viewed as another developmental stage of life.

Pattern is manifested as any and all behavior or emotion exhibited by a human individual. Therefore, the dying stage may be identified by observing behaviors indicative of pattern as it exists during the developmental process of dying (Rogers, 1985).

Environment is also an energy field which is unique to the individual, without boundary, ever accelerating and differentiating, and identified by pattern. Other individuals are part of one's environmental field. Fields, and hence individuals, do not influence one another or cause change to occur in one another. There appears instead to be a tendency for individual field patterns which are less synchronous to become more like patterns which are healthy and synchronous (Rogers, 1985).

Health is culturally defined by those who experience it. Beyond this, it is a manifestation of synchronous pattern. Health represents a state in which human beings are ever involved in change which is directed toward maximizing potential. Endless diversity implies endless choices to be made. When choices are made which are related to synchronous pattern, the state of the individual human being is said to be healthy (Rogers, 1985).

Nursing's main emphasis is service to human beings; thus nursing is intended to help achieve maximum potential as defined as synchronous, accelerated, healthy pattern. Dying, as a developmental stage, is therefore nursing's business and behaviors which represent manifestation of pattern associated with healthy dying and the development of synchronous pattern as individual choices are made are legitimate concerns in nursing.

Theory of Healthy Death Readiness Using Rogers' Paradigm

Based on Gibb's Paradigm, a model of the relationships between the constructs and concepts is depicted in Figure 1. Gibbs (1972) stated that theories ought to be mathematically sound and representable in diagrammatic form. Gibb's classical format is used here to illustrate the relationship between the Rogerian Paradigm and the theory of healthy death readiness which was derived from it.

Intrinsic Definitions:

Axiom 1--Among the dying, the more nearly total acceptance of pending death is at a given moment (T$\emptyset$), the more infinitely differentiated is human field motion, on a four-dimensional plane, at a given moment (T$\emptyset$).

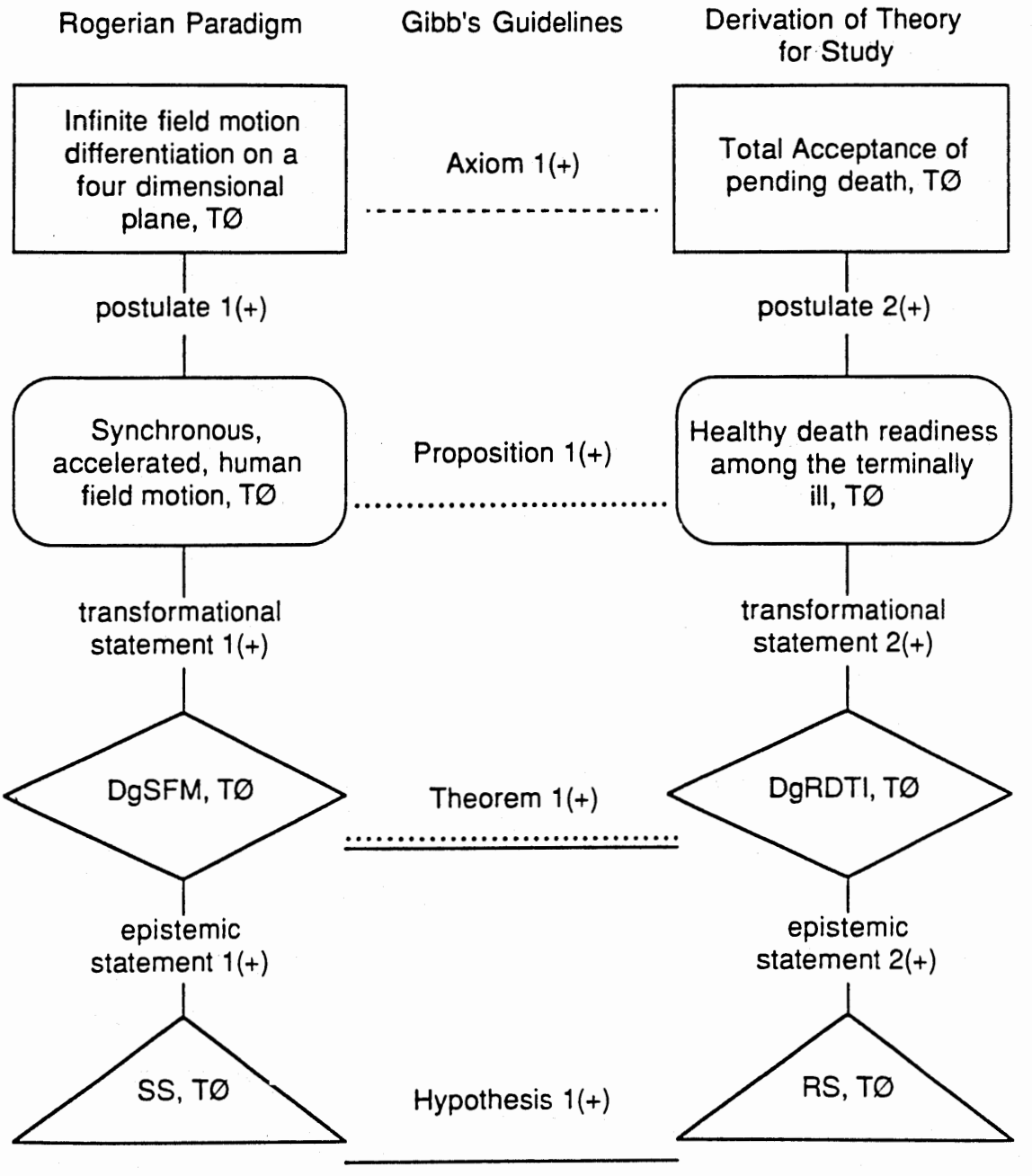

Figure 1. Model of the relationships between constructs and concepts based on Gibb's Paradigm.

Postulate 1--Among human individuals, infinite differentiation is manifested by limitless acceleration in synchronous field motion. The greater the differentiation, the greater the synchronous acceleration.

Postulate 2--Among the terminally ill, acceptance of pending death is represented by healthy death readiness. The greater the degree of acceptance, the greater the degree of healthy death readiness.

Proposition 1--Among the terminally ill, the greater the healthy death readiness at a given moment (TØ), the greater or more accelerated and synchronous human field motion will be at a given moment (TØ).

Transformational statement 1--Among terminally ill individuals the more accelerated and synchronous the individual human field motion, the greater the synchronous field motion (SFM), both at a given moment (TØ).

Transformational statement 2--Among the terminally ill, the greater the healthy death readiness at a given moment (TØ), the greater the readiness for death (RDTI) at a given moment (TØ).

Theorem 1--Among the terminally ill, the greater the healthy readiness for death (RDTI) at a given moment (TØ), the greater the synchronous field motion (SFM) at a given moment (TØ).

Epistemic statement 1--Among the terminally ill, the greater the DgSFM (degree of synchronous field motion) at a given moment (TØ), the greater the SS (synchronicity score) at a given moment (TØ).

Epistemic Statement 2--Among the terminally ill, the greater the DgRDTI (degree of healthy death readiness) at a given moment (TØ), the greater the RS (readiness score) at a given moment (TØ).

Hypothesis 1--Among the terminally ill, accelerated, synchronous, field motion is positively related to healthy death readiness.

Descriptive statement--As the terminally ill individual approaches death, synchronous, accelerated, human field motion and healthy death readiness vary positively together.

Extrinsic Definitions, Substantive Terms:

Acceptance of pending death is a peaceful state in which human individuals feel fully prepared to part with life as it has been experienced. Acceptance of pending death is a dynamic, labile, state evidenced in the terminally ill human individual as death readiness. Total acceptance of pending death is a desirable state in which the terminally ill person is as ready as possible to die at the moment of death.

Infinitely differentiated human field motion is a state of differentiation, existing on a four dimensional plane which places the field beyond time/space limitations. This human field motion is limitlessly accelerated at the time of death.

The terminally ill are people who, because of disease, according to medical prognosis, have 6 months or less to live. Death readiness is a dynamic, labile state achieved by a voluntary, introspective process in turn evidenced by direct and indirect behavioral indicators, wherein a terminally ill individual has recognized and prepared for pending death. Accelerated, synchronous, human individual field motion is that state of field motion which is ever progressively, irreversibly and desirably, being achieved and which is manifested by emotional and behavioral indicators measurable on a tool yet to be developed.

Referential formulas--DgAFM = Σ CDF, where DgAFM equals the sum of scores accumulated as choices (C) are designated (D) on a yet to be developed human field (F) motion tool. DgRDTI = Σ ISMT, where DgRDTI equals the sum of item (I) scores (S) accumulated as the McCanse (M) instrument for measuring death readiness in the terminally (T) ill (MRDI) is administered.

Referents--RS = readiness score as measured on the MRDI, total. SS = acceleration and synchrony score as measured on a tool yet to be developed.

Time units--T$\emptyset$ = any moment in time experienced by the terminally ill individual. No suggestion is made by this theory as to amount of DgRDTI or frequency of DGSFM as death approaches though the Rogerian paradigm implies that field pattern can nought but accelerate. Hence death readiness might be thought to accelerate as well.

Summary of the Theory of Healthy Death Readiness Among the Terminally Ill

$$D = dp \rightarrow \uparrow f \text{ HFSP } (H \lesssim E)$$

That is, dying (D) is a developmental process (dp) characterized by increasingly high frequency (f), synchronous, human field motion pattern (HFSP) wherein there is less and less differentiation ($\lesssim$) between human field (H) and environmental field (E).

$$\uparrow f \text{ HFSP} \rightarrow \uparrow \text{BF(DRTI)}$$

That is, increasing frequency ($\uparrow$f) of high frequency, synchronous, human field motion pattern (HFSP) is manifested as a set of directly observable behaviors (B), and indirectly observable feelings (F), which are together

called an increasing degree of death readiness in the terminally ill (DRTI).

$$\uparrow_{BF} = \uparrow_{DR}$$

Therefore, increased directly observable behaviors (B) and increased indirectly observable feelings (F) together are equal to increased death readiness (DR).

Relationship of the Rogerian Paradigm and the Theory of Healthy Death Readiness to the Question of Healthy Death Readiness Measurement

There is a need for greater synchronization of pattern between man and environment, i.e., a healthy pattern, as one approaches death (Rogers, 1985). How can nursing identify, and hence promote, a synchronous or healthy pattern? The good death must equal maximization of potential. Maximization in turn implies a synchronous, accelerating, i.e., healthy, pattern. Since no measure of synchronous, accelerated, healthy pattern exists, the question then becomes how can healthy ways of dying be identified and, further, how can nursing promote and support healthy dying? Rogers allows utilization of the idea of promotion, not as a causal notion, but as a positive influence on choice as increasing differentiation occurs (Rogers, 1985).

The nature of human field pattern as death approaches is empirically knowable. However, its empirical correlates have not been defined. While awareness of the individuality and diversity of pattern are maintained some measure of the manifestation of accelerated, synchronous pattern must be created so that a degree of healthy death readiness can be tested. The purpose of this study was to develop an instrument which identifies accelerated, synchronous pattern as death approaches. A more general goal was to expand nursing's unique knowledge base for use in service to humankind.

Rogers (1985) suggested that for purposes of the study of phenomena, one may impose imaginary boundaries on field, (i.e., of time and space). Ordinarily, field exists on a four dimensional plane and knows no boundaries either temporal or spatial. The instrument developed in this study imposed temporal boundaries. The instrument and guides for its use promoted the identification of and respect for individual human differences.

Mapping of the Dimensional Components of Healthy Death Readiness

The construct of interest, healthy death readiness among the terminally ill, is drawn from Rogerian Theory. Based on a review of empirical and esthetic literature,

many construct indicators were identified as representative of phenomenon variables or aspects of the whole self.

Emotions referred to and behaviors identified reflected such Rogerian concepts as an altered perception of time, an other than waking state (Rogers, 1985) said to be meditative, or introspective, and the volitional expression of peacefulness. These behaviors and emotions are associated with accelerated, synchronous, pattern (Rogers, 1985). These are presented together with construct indicators identified during review of the literature in the constructural map in Figure 2.

Assumptions

Assumptions made regarding the human aspect of the death readiness theory and regarding the operationalization of constructs for purposes of empirical measurement are as follows.

Assumptions of the Healthy Death Readiness Theory

1. Human individuals are infinite, conscious, fields of energy identified by pattern.

2. Healthy field pattern is synchronous, high frequency, pattern.

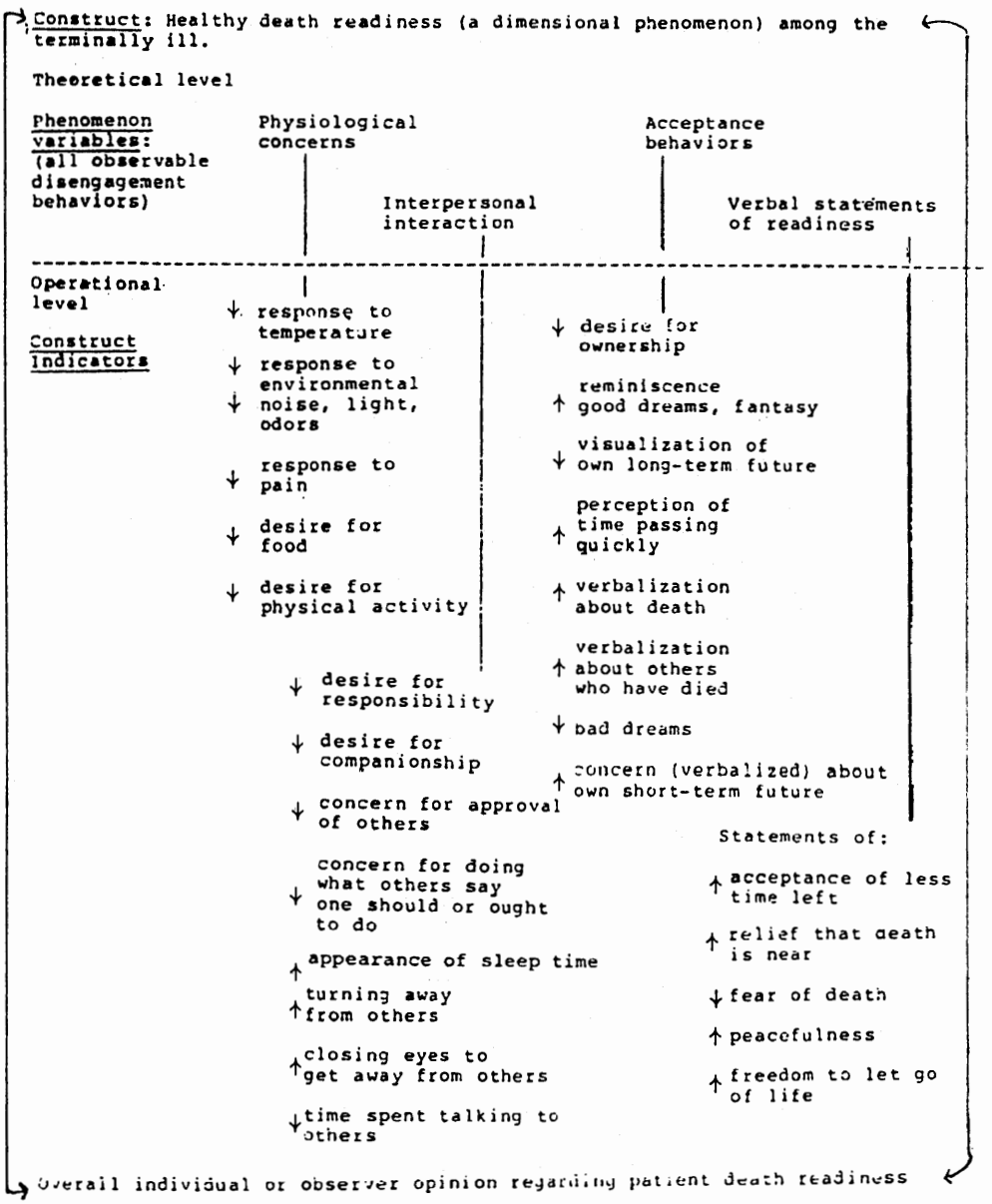

Figure 2. Map of the dimensional components of healthy death readiness.

3. Human individuals have an infinite capacity for development and for creative differentiation and choice.

4. Accelerated change offers infinite choice in regard to the character of individual field pattern.

5. Dying is a developmental phase which offers potential for such accelerated change and choice that creative differentiation may take place on a plane, or in a dimension, which is beyond space and time.

6. Given the existence of choice the character of the dying process and of individual field pattern is largely volitional.

7. Behaviors and emotions which represent a human individual's field pattern are empirically, ethically, personally, and esthetically knowable.

Assumptions Regarding the Operationalization of Constructs for Purposes of Measurement

1. The human individual's field pattern is manifested as observable behaviors and emotions.

2. Death readiness is a positive, voluntarily achieved, state for which empirical indicators exist.

3. Human individuals will honestly report their feelings and behaviors when asked to respond personally.

4. The relationship between healthy death readiness and synchronous, accelerated, human field pattern is

positive, non-linear (except for purposes of measurement) and non-causal.

Hypotheses

Hypotheses relate only to the reliability and validity of the McCanse Readiness for Death Instrument as an empirical measure of aspects of self said to represent death readiness.

1. Healthy death readiness of a terminally ill individual, as measured on the McCanse Readiness for Death Instrument total, is significantly related to decreased environmental interaction as measured by items 1 through 5 (Appendix A).

2. Healthy death readiness of a terminally ill individual, as measured on the McCanse Readiness for Death Instrument total, is significantly related to decreased interpersonal interaction as measured on items 6, 10, 13, 14, 16, 17, 18, and 19 (Appendix A).

3. Healthy death readiness of a terminally ill individual, as measured on the McCanse Readiness for Death Instrument total, is significantly related to increased acceptance behaviors as measured by items 7, 8, 9, 11, 12, 15, 20, 21, and 22 (Appendix A).

4. Healthy death readiness of a terminally ill individual, as measured on the McCanse Readiness for Death

Instrument total, is significantly related to an increase in verbal statements of readiness to die, as measured by items 23 through 27 (Appendix A).

5. Healthy death readiness of a terminally ill individual, as measured on item 28 of the McCanse Readiness for Death Instrument is significantly related to all individual items (Appendix A).

6. Terminally ill individuals' patient scores on the McCanse Readiness for Death Instrument will be significantly related to primary caregiver estimates of terminally ill individuals' scores.

7. Terminally ill individual's scores on the McCanse Readiness for Death Instrument are significantly related to primary hospice nurse estimates of terminally ill individual's scores.

8. Healthy death readiness of terminally ill individuals, as measured on the McCanse Readiness for Death Instrument, is not significantly different from healthy death readiness of cardiac impaired individuals as measured on the McCanse Readiness for Death Instrument.

9. Healthy death readiness of a terminally ill individual, as measured on the McCanse Readiness for Death Instrument, on a given day is significantly related to healthy death readiness of the same terminally ill

individual, as measured on the McCanse Readiness for Death Instrument, 7 to 14 days later.

10. Healthy death readiness of a terminally ill individual, as measured on the McCanse Readiness for Death Instrument, on a given day is not significantly different from healthy death readiness of that same terminally ill individual, as measured on the McCanse Readiness for Death Instrument, 7 to 14 days later.

Definitions

Healthy death readiness within a terminally ill individual--is a positive state of recognition of and preparation for impending death voluntarily achieved by introspective processes of disengagement from physical and human environment and evidenced by varying amounts of direct (behavioral) and indirect (emotional) behavioral indicators.

Decreased environmental interaction--consists of a decrease in physiological concern for temperature, environmental noise, light, odor, pain, food, and activity.

Decreased interpersonal interaction--consists of a decreased desire for companionship, decreased concern for the approval of others and for doing what others say should or ought to be done, a desire for less

responsibility, increased turning away from others, appearance of sleep time and decreased verbal interaction.

Increased acceptance behaviors--consist of a decreased desire for ownership, decreased visualization of one's own long-term future, and increased reminiscence, concern for own short-term future, perception of time passing quickly, verbalization about others who have died and about death in general, and a decrease in bad dreams.

Increased verbal statements of readiness to die--consist of statements of increased acceptance of having less time left, relief that death is near, peacefulness and freedom to let go of life, and decreased fear of death.

Primary care giver--is that individual who has indicated to a hospice that he/she is, and will be, predominantly responsible for care of the terminally ill person.

Primary hospice nurse--defined as that professional nurse self designated as being predominantly responsible for the professional nursing care of the terminally ill person while employed by hospice for that purpose.

Terminally ill individual--is an English speaking human individual over the age of 18 who has a documented medical prognosis of 6 or less months of life.

Cardiac impaired individual--is an English speaking human individual over the age of 18 who has a documented medical diagnosis related to cardiac impairment, who is not terminally ill, and who currently participates in a cardiac rehabilitation program.

Limitations

The limitations of the study are as follows:

1. Access to terminally ill individuals may be very difficult to achieve.

2. A sample of terminally ill individuals large enough to support statistical analysis of the instrument's reliability and validity may be impossible to achieve within time limits imposed by the study.

3. participants and primary care givers and primary hospice nurses to whom the instrument is administered concurrently may collaborate verbally before making individual responses to questions and thus threaten the accuracy of all concurrent estimates of patient healthy death readiness.

4. The length of time necessary for instrument administration may introduce a fatigue factor which may alter the accuracy of participant responses.

5. Some respondents may be denying the participant's terminality and hence be unable to estimate accurately the

extent of the participant's behavioral variables which exist at the current moment.

6. The samples are non-random and self-selected. Self-selection imposes a bias and limits the generalizability of the findings.

Summary

The problem of the present study was to determine whether healthy death readiness is a measurable concept and, if so, to develop a measure of death readiness as an indicator of healthy dying. First, a theory of healthy death readiness was derived by the researcher from the Rogerian Paradigm. The theory related healthy human individual field pattern at a given point in life with healthy death readiness.

Healthy human individual field pattern, as death is approached, is made manifest by physiological, psychological, sociological, and spiritual indicators. These indicators are directly observable behaviors and indirectly observable feelings or emotions which exist to varying degrees within a dying individual. The indicators are therefore measurable within terminally ill individuals and should, together, represent a degree of healthy death readiness.

CHAPTER II

REVIEW OF LITERATURE

A review of literature was done initially in order to justify a healthy death readiness, or acceptance, philosophy. Consensus as to what constitutes healthy dying was determined and then a search for those behaviors which were most frequently said to present healthy death readiness was carried out. Finally, a review of related death and dying research was done.

Justification of a Healthy Death Readiness Philosophy

Our society, with medicine's complicity, denies death and so condemns the dying to a prolongation of the very dying process it would avoid (Cassell, 1974). "Death is unAmerican" (Toynbee, 1968, p. 131). It would be more beneficial to humankind to admit death's certainty and attempt to prepare for it so that death might be more peaceful and dignified. "Our work is to help the dying die 'better' deaths, and live as fully as possible, through our efforts" (Weisman, 1980, p. 67).

The argument that to admit the certainty of death denies the existence of hope has been shown to be fallacious by several authors. Stedeford (1979) stated

that dying patients are capable of conceptualizing both hope and death's imminence at the same time. Soudek (1979) illustrated the existence of both hope and acceptance of death in Tolstoy's "Ivan Illych." Ray and Najman (1974) found death anxiety and death acceptance concurrently present in 206 participants.

That we fear death above all else is a misconception (Weisman, 1978). The idea that life is our most precious possession was countered by Vernon (1979), who pointed out that life has been sacrificed in order to preserve the life of another or one's own dignity and in order to avoid great physical or psychological pain.

Freireich, a physician, argued that to accept death means to accept an inadequate substitute for medical care, i.e., hospice (cited in "Hospice--", 1979). Certain professionals are so committed to preventing death at any cost that they have forgotten why that life force should be maintained; that is, science and technology have become more important than the human whom science and technology were created to serve. According to Thompson (1981),

> humanistic definitions demand that humanity step beyond mechanistic definitions of death into a transcendent world of moral choices that guarantee human dignity and worth by ascribing meaning to life and death. These meanings counter the desecrating fear that something like biologic human might, through something called medical technology, defeat something called fate. (p. 205)

Much has been made of the very limiting theory that people die as they have lived (Tatro & Marshall, 1982; Tolor & Reznikoff, 1967). One's pattern of dying, however, need not be irreconcilably tied to the use of previously exercised defense mechanisms, be they healthy or unhealthy (Hinton, 1967). Hinton believed that although one's view of the end may be influenced by previous manners of adjustment, the likelihood of anxiety as death approaches, for instance, is not related to background. Kemp (1984) would appear to agree. He stated that, among the frail and dying elderly, there is a tendency to evidence choice as to the manner and place of death and that this may well represent a change in the elderly person's previous approach to life. The elderly make these choices regardless of former points of view concerning their own mortality.

There should then at least be options as to the ways in which people approach impending death. It is possible, perhaps desirable, to prepare for death by accepting the inevitable.

Consensus as to What Constitutes Healthy Dying

There is some consensus as to what constitutes healthy dying. Psychologists and psychiatrists have

described the death experience at length. Though, as Weisman (1972) stated, not everyone, stable or unstable, dies with equinimity, he and his colleagues argued that equinimity is desirable. Weisman discussed the concept of safe conduct in which there is relief of suffering and loneliness so that a dignified death may be accomplished. Garfield (1978), reflecting both Jung (1959) and Feifel (1959) believed that acceptance allows a more meaningful, or healthy, death experience.

Grof and Halifax (1977) would promote "transcendence," such as that described in accounts of near death experiences, as an antidote to fear. Cutter (1974) bemoaned the confusion between an unhealthy wish to die and a more preferred "readiness to cease." Such confusion disallows or erroneously negates much current thought in regard to graceful acceptance among the dying. A readiness to cease is certainly similar to acceptance in the form of a "consent to death," discussed by Hinton (1967).

Even Sneidman (1978), whose more morose point of view described Ivan Illych as dying not with acceptance but in a state of resolution, felt that the goal of therapy for the dying should be peace of mind. Here again Jung's (1959) philosophy in regard to the goals of life's

processes are reflected. Life should be seen as fulfilling, for then there will follow an acceptance of death, a state of rest, a return to repose. "Strength must be found . . . to face life's end with serenity, even acceptance" (Schilder, cited in Noyes & Kletti, 1976, p. 375).

Lazarus (1977) suggested that effective coping occurs either directly, in which case anxiety is released as threat is actively opposed, or indirectly, in which case anxiety is reduced as one's perspective of threat is altered. Since death's certainty is unalterable, direct opposition to its reality is a futile exercise. The more positive mechanism is alteration of one's perspective and the restructuring of personal constructs in regard to the meaning of personal experience, that is, accepting and preparing for the inevitable (Neimeyer, Epling, & Krieger, 1982).

Beilin (1981) pointed out that to assert that one is ill, that is, not healthy, is to assert that he/she is not dying. This is true because, according to Parsons (1951), the sick role implies a willingness to try and get well. The logical consequence is a denial of the inevitability of death.

The healthy death is therefore one whose certainty has been acknowledged and accepted. Some degree of readiness of peaceful preparedness may then be achieved.

Behaviors Representing Healthy Death Readiness

It is possible to glean from the literature those patterns of behavior which are thought to represent healthy death readiness. There are options regarding individual action and emotion as death's inevitability is faced. Some rage against the fading light and others suffer isolated grief (Bowlby, 1980) and are perhaps abandoned by loved ones and care givers (Hagglund, 1981). Yet there are many who appear to slip from the state of being into death with the grace of peaceful acceptance.

Kubler-Ross (1969) described peaceful withdrawal from all but one or two significant others during the final stage of dying--acceptance. Hinton (1967) described an approach to death which may be enthusiastic and even ecstatic and which involves separation of self from environmental and interpersonal concerns. Marshall (1983) argued that when patients have achieved a sense of life's cyclicity, they can face the inevitable and sidestep "terror, dependency and other maladaptive responses" (p. 161).

Several other behaviors characteristic of healthy dying are mentioned in the literature. These are remarkably similar especially since so few of the authors appear to have worked closely together. Kubler-Ross' description of the acceptance stage included increased sleep time which precludes social interaction. She discussed an increased preoccupation with self and the wish for one silent companion. Similarily Kemp (1984) described the dying elderly as becoming more and more involved with self as time passed. Rogers (1985) described the increase of the appearance of sleep time, thought to be meditative, as people grow older.

Weisman and Kastenbaum (1968), though they later argued against the existence of Kubler-Ross' stages, discussed a final "phase" of dying in which individuals become less outspoken and appear to withdraw. Patients, they state, appear to be apathetic, less responsive to environment and yet desire "the confident presence of another" (Weisman & Kastenbaum, 1968, p. 44). They clearly believed that this is a developmental phase wherein the dying, especially the elderly, are able to express acceptance and speak of death dispassionately and without fear.

A similar phase was described in children by Nir and Maslin (1982). During "reproachment," death is seen by the child as relief, and when there is increased expression of understanding by others, children fear death less. If others are honest about the child's terminality, the child is less fearful, though he/she may desire minimal companionship. "Children die a thousand deaths when they have to cope with a conspiracy of silence" (Greenham & Lohman, 1982).

Moreover what has been described by some as depression may in reality represent disengagement and healthy death readiness. The decreased physical activity, the withdrawal from social interaction, save for one or two meaningful relationships, the decreased interest in food, and in all things material, commonly associated with depression, may in some dying people not represent depression at all. Death's finality, as well as life's irreversibility, have been faced directly. This voluntary withdrawal from internal and external environment may have been made part of one's armament against the rage, denial and terror which are otherwise occasioned by loss of control and the potential loss of self (Garfield, 1978). Unlike depression, as healthy death readiness progresses,

there are fewer physical complaints and no suicidal statements.

Behaviors associated with death acceptance are very similar, in fact, to the process of disengagement described by Cumming and Henry (1961) whereby elderly people are felt to accept aging developmentally. Cumming and Henry, in their descriptive study of the elderly, noted and named the process of disengagement. During disengagement, a decreasing number of roles are played. There is decreasing interaction with others although a few close kinship relationships are maintained and become more meaningful. The disengaged elderly appear to change social goals, desire fewer things, and begin to give away material possessions.

Those who are disengaging state an appreciation of less responsibility. They seek less approval and love from others, and there is less response to external control. The disengaged state is manifested by a willingness to declare that there is less life left, to assert that there is freedom to refuse to participate in ongoing life and to acknowledge that death is now a logical step (Cumming & Henry, 1961).

Pattison (1977) discussed three phases of dying. The last of these is called "terminal" and is evidenced by

physical and emotional withdrawal though hope remains. Pattison (1977), Hinton (1967), and Hagglund (1981) also cited the occurrence of fantasy, something not mentioned precisely by Cumming and Henry, but believed to be a component of disengagement, or decathexis, by these three nonetheless. A period of separation or isolation was described by Vernon (1979) and Neimeyer, Epting, and Krieger (1982). Vernon said that death with dignity may require a period of reminiscence or daydreaming during which "time is spent re-integrating, reediting, re-interpreting . . . one's life" (Vernon, 1979, p. 85).

There does then appear to be consensus among not only psychologists and psychiatrists but among nurses and philosophers as well that there are healthy ways in which to die. A component of acceptance or readiness is desirable.

Death and Dying Research

Until recently, most death and dying research has been qualitative in nature. Classic studies by Kubler-Ross, Feifel, Hinton, and Glaser and Strauss were descriptive of dying patients and their care givers and were based on observation alone or on interviews which explored the lived experience of dying.

Kubler-Ross collected and presented a synthesis of her very personal work with dying individuals in On Death and Dying (Kubler-Ross, 1969). She described five stages of dying: denial, anger, bargaining, depression, and acceptance. She concluded that all who die do so with acceptance even if this occurs only moments before death. Glasser and Strauss (1965) began by describing care giver behaviors, stating that care givers frequently disregarded the patients' right to know that they were dying. When impending death had been acknowledged, care givers often tried to get patients to die in acceptable or convenient ways. Feifel (1959) concluded that the reality of death gives life meaning, that the dying preferred frankness to deception as this decreased fear of the unknown, and that reaction to impending death depended on several factors including the attitudes of significant others. Hinton (1967) therapeutically interviewed dying people and concluded, in concert with Kubler-Ross, that the moment of death is peaceful and that suffering ends before life ends, though resolution may be quick and momentary.

More recent studies, though still qualitative in nature, more clearly define individual responses to pending death. Pattison (1977) reviewed previous research and then observed dying people in order to describe three

phases of dying: acute (crisis), chronic (living-dying), and terminal (withdrawal). He described the terminal phase as evidenced by both physical and emotional withdrawal from other people, from self, and from hope.

Weisman and Kastenbaum (1968) studied records and conducted interviews about people who had died in order to construct psychological autopsies. They concluded that as death approached, patients become less outspoken, spoke of death dispassionately, were less responsive to environment, and appeared to express acceptance. Weisman (1972) later recommended care of the dying which included control of physical pain, acceptance of the dying person and the use of fantasy in death rehersals. Weisman observed that these interventions decreased psychic pain and promoted acceptance.

Thauberger and Cleland (1979) synthesized, from existential philosophy and direct observation of dying people, several measures of confrontation avoidance of such concepts as death, loneliness, and the meaning of life. Later work with Ruzinsky (Thauberger, Ruzinsky, & Cleland, 1981) included comparison of avoidance of these concepts, and rejection, with stress levels specific to each. No relationship was found between avoidance and

stress, and the authors concluded that awareness and confrontation may be either a good or a bad thing.

Shneidman (1970) constructed a death typology based on his many years of psychotherapeutic intervention with dying people. The typology contrasted termination of life with interruption of life and described three kinds of death, i.e., intentioned, unintentioned, and subintentioned. Each kind of death was illustrated by several personality types such as the death-seeker, the death-darer, the death-fearer, and the death-experimenter.

During the 1970s, several studies were done which described the near death experience. Noyes (1972), based on interviews with mountain climbers who had survived falls from great heights, described phases of the near death experience. The phases included initial resistence (denial and anxiety) and then a tranquil life review followed by calm transcendence (beyond space and time) wherein the victim experienced a sense of truth and insight. In later work with Kletti (Noyes & Kletti, 1976), they concluded that phases of the near death experience were adaptive and that an altered perception of time passing more slowly allowed the victim to respond to danger as though alert and yet emotionally detached. Noyes and Slymen (1978) interviewed people from all age

groups who had suffered near death experiences in different situations. They stated that almost all victims remained aware and alert though detached from body and environment.

The similarity of the transcendent phase of near death experiences, described by Noyes, to the acceptance stage of terminal illness described by Kubler-Ross and Hinton was strengthened by studies done by Greyson (1983) and Grof and Halifax (1977). Greyson (1983) interviewed survivors of cardiac crises and proposed that the out of body experiences which the patients described included a life review in order to promote disengagement from projection into a future life. Grof and Halifax (1977) compared their interviews of accident victims with previous research by Osis (1961) on deathbed experiences and concluded that both the acutely dying and the chronically dying experienced transcendence, an out of body, mystical, dream-like peace which was characterized by pleasant fantasy.

Most recent studies have begun to develop and apply empirical measures of concepts related to the dying process. The experience of time during the crisis of cancer was studied by Fitzpatrick and Donovan (1980), who matched 22 terminal cancer patients with 22 control

participants who were not ill. An interview and a written questionnaire were administered to both groups, including the Time Reference Inventory, the Time Opinion Survey, and the Time Metaphor Test. Terminal cancer patients had shorter time projections and more time pressures. Quinn (1982) administered several tools including Templer's Death Anxiety Scale, a purpose-in-life test, the Time Metaphors Test, and the Ricks-Epley-Wassman Temporal Experience Questionnaire to 145 women aged 60 to 85. Quinn found that increased death anxiety correlated with increased sense of time moving forward and time pressure, and with decreased purposefulness. Those women in better health had less anxiety. A death concern scale was tested for validity by Dickstein (1972), who found a relationship between death concern and anxiety in 160 undergraduate psychology students. The instrument had split half reliability of .86 to .88, but common variance between death concern and anxiety was only 13%.

The Ray and Najman Death Concern Scale was developed in 1972 and combined with the Templer Death Anxiety Scale and the Sarnoff and Corwin California "F" Scale for identifying denial (Ray & Najman, 1973). When administered to 206 psychology students, the Death Concern Scale was found to be highly homogeneous with an alpha of

.58. The index of scale adequacy for the Death Concern Scale was identical to that of the Templar scale at .162, and close to the Sarnoff Corwin scale at .158. A small negative correlation was found between death anxiety and death concern, seeming to indicate that death acceptant people were able to acknowledge some anxiety about death. Denial and death anxiety were also negatively correlated.

Warren (1982) combined the Rainey and Epting Provided-Construct Index with the Dickstein Death Concern Scale, Templer's Death Anxiety Scale, the Sarnoff and Corwin Fear of Death Scale, and the Ray and Najman Death Acceptance Scale. Warren administered these tools in a structured interview to three groups of people thought to be death involved (nurses and funeral directors), at risk (parachutists and hang gliders), and uninvolved. Warren concluded that death acceptance was negatively correlated to death threat, fear of death, death concern, and death anxiety.

Jones (1980) developed a semantic differential composed of four bipolar pairs of adjectives intended to measure death acceptance in children. He administered his tool to 65 children, aged 6-15, whose cognitive functioning and experiences with death had previously been determined. Jones concluded that only two of the four

items on the Death Acceptance Scale were related to cognitive development and to experiences with death.

A qualitative essay was used by Whelan and Warren (1980) to estimate death acceptance in 16 psychology graduate students, 8 of whom had taken part in a death awareness workshop. The Templar Death Anxiety Scale was also administered to all 16 pre and post intervention. Results of this study indicated that the workshop had altered student attitudes toward death and dying, and a 2 month follow-up indicated that the changes in attitude were persistent. Later, Rigdon (1982) administered the Collett-Lester Fear of Death Scale, the Purpose-in-Life Scale, and a threat index to 95 undergraduate students. He found a significant relationship between a positive orientation toward death and optimal life functioning.

Though empirical measures are beginning to be developed for application in the area of research in death and dying, there is a dearth of instruments which measure death concerns (Dickstein, 1972). No measure of healthy dying or healthy death readiness was found in the literature. Measures of death acceptance do not include several components generally agreed to be part of the healthy dying or death acceptance process. No instrument found has actually been administered to dying populations;

most were intended for administration to general or other-than-dying populations. Yet when the rich qualitative base of research concerning death and dying is considered as a whole, it should be possible to create an instrument intended to measure healthy death readiness validly and reliably. Healthy death readiness is, in turn, evidenced by a number of behaviors both directly observable and emotionally implied.

CHAPTER III

PROCEDURE FOR COLLECTION AND TESTING OF DATA

The development of a reliable and valid instrument with which to measure healthy death readiness strongly suggests the use of a methodological design (Kerlinger, 1964). A methodological approach was used in this study. However, the word creation rather than development was sometimes used where the esthetic character of the instrument was in question as opposed to validation of its empirical qualities (Chinn, 1986). A purposive sampling procedure was used rather than random sampling because of the limited or typical character of the population for which more general and eventual use of the instrument was intended (Kerlinger, 1964).

Setting

The research setting was one large midwestern urban area and one large southwestern urban area of the United States. Data were collected in the homes of dying individuals at times convenient to the individual and the individual's primary care giver.

Population and Sample

The four populations used in this study were (a) terminally ill individuals, (b) their primary care givers, (c) their primary hospice nurses, and (d) cardiac impaired individuals. The sampling technique used was availability. The proposed sample consisted of 50 persons in each category. Participants for the sample were obtained through eight major hospice organizations with a total estimated patient census of over 250 and from three southwestern and midwestern outpatient cardiac rehabilitative programs for use as a contrasting group.

Protection of Human Participants

The components of this study fell within the minimal risk category for protection of human participants. The study was reviewed by the human participants review board and received approval before the data were collected (Appendix B). Agency approval was obtained before the instrument was administered (Appendix C). Written consents (Appendix D) were obtained from participants, primary care givers, and primary hospice nurses following a standardized oral explanation of the study (Appendix E) and instrument administration (Appendix E). A more complex consent form was required by two agencies (Appendix D). Individual instruments were number coded to

keep the sets together, and no respondent was identified by name. All participants were assured that they could refuse to answer any or all of the questions and refuse to participate at any point in the study. Approval was also obtained from the TWU graduate school (Appendix F).

Instrument

The instrument developed for the study is the McCanse Readiness for Death Instrument (MRDI) (Appendix A). This instrument was created and developed in the pilot study. A first-person form was used with all participants.

Pilot Study

Instrument Development

Based on a cross disciplinary and cross-genre review of the literature, direct and indirect indicators of healthy death readiness were identified. Indicators were categorized, and together they represented holistically overlapping aspects of the dying individual's physiological, psychological, social, and spiritual self as dying developmentally progresses.

The aspects of self were as follows:

1. Physiological concerns, or those individual human behaviors which indicate awareness of, and interaction with, associated environmental elements;

2. Interpersonal interaction, or that voluntary interplay between individuals indicated by reciprocal engagement behaviors;

3. Acceptance behaviors, or any and all behaviors, including verbal, which indicate voluntary separation of self, and one's own reality, from others on this plane, that is, separation of self from the predominant realities of others;

4. Verbal statements of readiness or those voluntary statements made by human individuals which indicate a positive degree of acceptance of pending death, such as increased peacefulness, decreased fear, and a willingness to part with current realities.

These four aspects of self became the subscales of the MRDI. Items representative of the subscales were created as a result of in depth research in the literature and consultation with other practicing hospice nurses.

The measurement method selected was a norm-referenced, bimodal questionnaire to be administered by an interviewer. Semi-structured interviews were conducted, using the questionnaire concurrently with dying individuals, their primary care giver, and their primary hospice nurse.

The bimodal method selected, questionnaire and interview, was chosen in preference to either questionnaire only or interview only. Death readiness is a very personal and sensitive issue; it was felt that individual and personal contact between the instrument administrator and the respondents would facilitate a genuine and therefore more valid and willing response (Waltz, Strickland, & Lenz, 1984). Additionally the interview has been shown to be therapeutic when used with dying people and their families (Dubrey, 1976; Hinton, 1971, 1981).

Some dying individuals who had achieved a high degree of healthy death readiness were not verbally responsive to the interviewer. They were, however, willing to place a single bar on the response line as each question was asked. If they were totally unresponsive it was anticipated that highly correlated estimates of the individual's healthy death readiness had been obtained from the primary care giver and the primary hospice nurse.

The sequence, content, and wording of the questions were predetermined. It was expected that wording and sequence might be allowed to vary minimally according to the environmental, demographic, and personal determinants of the respondents. This limited loss of structure was

intended to allow the interviewer to use vocabulary appropriate to the respondent's educational, ethnic, or emotional attributes. In practice, variation was not necessary. Vocabulary in the instrument reflected a very basic educational level, and, in the interest of reliability, the wording was usually used as written without problems.

The sequence of questioning placed the most sensitive or emotionally laden items at the end. In no case was it found necessary to alter the sequence so that areas found to be sensitive could be touched on initially and reapproached as better rapport and trust were established. Questions were all phrased in the present tense as current death readiness, assumed to be a labile state, was of interest rather than any more stable personal trait.

The selection of predominantly closed ended types of questions was felt to be justified by the broader allowance for response latitude. An attempt was made to categorize the responses to each instrument according to a five category Likert-type scale, but it was found that many responses fell directly between categories. It was also discovered that every question elicited a verbal as well as a written response from almost all respondents.

This "data leak" was felt to be justified at this point because, as stated in chapter one, only the empirical aspects of the MRDI are in question in this study. Personal, ethical, and esthetic knowledge generated by the instrument will be assessed at a later date. Respondents were cautioned to mark a response to each item before discussing it verbally.

Respondents were asked to indicate the frequency of the relevant patient behavior in each item along a linear scale which ranged from "never" at one end to "always" at the other end. Two questions having to do with the amount of time the dying individual spent sleeping or talking to others used a similar scale ranging from "none" to "all the time." A final item which attempted to measure the respondent's opinion in regard to overall death readiness was scaled from "not at all" to "as much as possible."

Items for aspects, or variables, were both positively and negatively stated. Scores were computed in units consisting of centimeters of line length. Interval/ratio level data were generated (Campbell & Stanley, 1963). Demographic information was generated at the nominal level except for the questions related to number of tasks performed and the number of people close to the patient

who had died, in which case interval-ratio data were generated.

Reliability

Cronbach's alpha was used to test for internal consistency. Cronbach's test was chosen because it measures all possible splits as opposed to the split half test which does not estimate the accuracy of each item. The alpha coefficient was .59132. Because of the small sample size in the pilot study and because the alpha was very consistent for all items, all items which were used in the instrument which was tested in the pilot study were retained as part of the final instrument.

A final item was intended as an overall measure of the individual's healthy death readiness. Scores on this item correlated, within instrument, to a higher degree with some items than with others. All items correlated positively to some degree with this final item, that is from .13 to .80. This tended to support the decision to retain all items. One item regarding good and bad dreams was divided into two because it appeared to represent two distinct behaviors and was, therefore, confusing to respondants. Interrater reliability was not achieved because a single interviewer was used.

Validity

A beginning measure of content validity was obtained by consulting a panel of eight nurses, in three areas of the midwest, considered to be experts in healthy death readiness by virtue of their active hospice nursing practice. The panel was asked three specific questions about the behaviors referred to in items and about the instrument itself:

1. Do you see the behaviors mentioned in the instrument in your dying patients as they prepare for death?

2. What else do you see?

3. Could you administer this tool?

On the basis of panel consensus, all items in the original instrument were retained and seven were added which allowed further differentiation of individual behavioral responses. The panel also achieved consensus that certain behaviors represented in the items tended to occur earlier or later in the dying process. For instance, a tendency to give things away seems to occur early. Giving up responsibility, and its attendant sense of normality, seems to occur later. Whether or not this is true can only be determined by further use of the

instrument with larger samples and perhaps other populations such as the very old.

Avery Weisman, author of many books and articles related to death and dying behaviors, was also consulted as to the instrument's content validity. He stated that the final item, which is intended to encompass the entire concept of healthy death readiness, was most relevant and suggested its singular use.

Because no similar measure of death readiness or acceptance was found in the available literature, no measure of concurrent validity was made. Other instruments considered, such as the purpose in life scales, were found not to measure several of the disengagement behaviors included in the MRDI in a positive manner. Templar's Death Anxiety Scale, Thauberger's Avoidance of the Ontological Confrontation of Death Scale (1981), and Ray and Najmen's Death Acceptance Scale(1974) are intended for use with general populations and not with dying individuals. The Ferrence Human Field Motion tool (Ferrence, 1977), though it purports to measure an emotional manifestation of field motion, does not clearly differentiate healthy pattern from less-than-healthy pattern. Though there may indeed be a positive relationship between high frequency pattern and increased

death readiness, it is not possible to substantiate that either is associated with the synchronisity which Rogers (1985) stated represents healthy pattern.

Construct validity was based, for purposes of the pilot study, on legitimate placement of the concept of healthy death readiness within the theoretical web which supports it (Cronbach, 1955). The theoretical framework was discussed at length in Chapter I.

A principal components factor analysis was not done because of the small sample size of the pilot study. Concurrent administration of the tool to dying individuals, their primary care givers, and their hospice nurses may generate positively correlated estimates of the individual's healthy death readiness. Correlations between .70 and 1.00 would tend to support consistent construct definition or concurrent validity. Indeed, Hinton (1979) found spouse-patient-nurse correlations regarding patient awareness of dying of 0.70.

Sample

The sample for the pilot study consisted of nine volunteer patients, their available primary care givers and primary hospice nurses. Patients ranged in age from 38 to 87. Three were male and six were female. The participants were drawn from the then current census of a

small, though county-wide, suburban outpatient hospice which served between 12 and 20 terminally ill individuals and their families.

Results

Item analysis, discussed above, supported the use of the MRDI as a measure of healthy death readiness in terminally ill individuals. The correlation coefficient between dying individuals' scores and their primary caregiver estimates was .894. The correlation between dying individuals' scores and their primary hospice nurses was .781.

The full-scale study was conducted as follows. Variations in sample size and procedures were frequently based on information obtained in the pilot study.

Data Collection

A sample of 31 terminally ill individuals was drawn from eight large urban, outpatient hospice populations. Participants completed the MRDI as it was concurrently administered by the researcher to their primary care giver, and to their primary hospice nurse. Fourteen participants again completed the MRDI after a period of time consisting of 7 to 14 days.

A contrasting sample of 39 cardiac impaired individuals was drawn from four outpatient cardiac rehabilitation programs. Each participant in the contrasting group completed the MRDI as it was administered by the researcher. A total of 132 instruments was administered over a period of 4 months. Neither the wording or the sequence of the questions were allowed to vary.

Treatment of Data

The demographic data obtained were frequencies analyzed to describe the sample. A Pearson's product moment coefficient was done relating number of tasks performed and number of people close to the patient who had died with overall readiness score. A point biserial was done relating all other demographic items to overall readiness score.

Reliability analysis was conducted on data obtained from the MRDI using Cronbach's alpha. Item to total and individual item (1-27) to final item (28) correlations were also done. Reliability analysis also included a Pearson's product moment coefficient relating terminally ill individuals' scores on the MRDI obtained during initial testing to terminally ill individuals' scores on the MRDI obtained during the second testing.

Validity analysis included a Pearson's product moment coefficient relating dying individual's scores with those estimated by primary care givers and primary hospice nurses. Validity analysis also included a *t*-test relating cardiac impaired individuals' scores with terminally ill individuals' scores.

A *t*-test was used to test for difference between terminally ill individuals' scores on the MRDI obtained during initial testing and scores on the MRDI obtained during the second testing. The difference was used to describe the stability of the construct of healthy death readiness over time.

CHAPTER IV

ANALYSIS OF DATA

The purposes of this study were to identify observable indicators of healthy death readiness and create an empirically reliable and valid instrument for measuring healthy death readiness. A reliable measure of healthy death readiness could be used to assess terminally ill individuals. Nursing diagnoses could then be formulated and nursing interventions could be planned which would help patients achieve developmental tasks and maintain personal control and normality in their lives for as long as they wish. A valid and reliable measure of healthy death readiness could also provide data which would help nurses make ethical and administrative decisions. This chapter discusses the results of data collection and data analysis including a description of the sample, findings, and summary of findings.

Description of Sample

The sample consisted of 31 terminally ill individuals, their primary care givers and primary nurses, and 39 cardiac impaired individuals who were not dying, selected as an availability sample according to criteria specified in Chapter III. The terminally ill participants

were patients in one hospice each in Dallas, Texas; Fort Worth, Texas; and Leavenworth, Kansas; two hospices in Kansas City, Missouri; two hospices and one home health agency in Milwaukee, Wisconsin. The cardiac impaired participants were participants in one cardiac rehabilitation program each in Denton, Texas, and Kansas City, Missouri, and one cardiac rehabilitation program each in Menomonie Falls, and Cudahay, Wisconsin.

Collection of data occurred over a 5-month period of time. Permission was obtained from each agency to conduct the study. Protection of human rights of the participants was maintained by having the protocol for the procedure, and rights of the participant, clearly identified for each agency and clearly explained to each individual potential participant. Participants' permission was given by their signature of consent.

Thirty-one participants were terminally ill individuals. Thirty-one of the terminally ill participants' primary care givers and 29 of the terminally ill participants' primary nurses were also participants. Thirty-nine cardiac impaired individuals were participants used as a contrast group.

Twenty-four of the terminally ill participants' primary care givers were spouses, two were children, five

were siblings, parents, or friends. Demographic data for terminally ill participants and for cardiac impaired participants was not significantly different for the two groups except as presented in Table 1. Of particular note is data which describe 22 (71%) of the terminally ill participants as being of the opinion that they were terminally ill and 24 (62%) of the cardiac impaired individuals as being of the opinion that they were not terminally ill. Seven (23%) of the terminally ill participants and 12 (31%) of the cardiac impaired participants were unsure of their prognosis. Other areas where the samples varied significantly were number of tasks performed in preparation for death, diagnosis (cancer versus cardiac disease), treatment received, educational level, and age. When submitted to chi-square analysis the frequency of levels of education by cardiac impaired participants versus terminally ill participants showed that more terminally ill participants had a grade school or high school level of education and significantly more cardiac impaired participants had a higher level of education, chi-square = 16.15, p = .0028. Demographic data described terminally ill participants and cardiac impaired participants as not significantly different as to gender, race, occupation, religious group membership,

Table 1

Demographic Frequencies for Terminally Ill and Cardiac Impaired Subjects

	Terminally Ill	Cardiac Impaired
Age		
19-35	2	0
36-55	4	9
56-65	3	14
66-84	19	14
85+	3	2
Chi-square = 11.230		
p = 0.0241		
Gender		
Male	16	28
Female	15	11
Race		
White	27	39
Black	4	0
Occupation		
Prof.	13	25
Tech.	3	6

(table continues)

	Terminally Ill	Cardiac Impaired
Occupation (continued)		
Clerical	4	4
Laborer	7	1
Other	4	3
Education		
Grade school	9	2
High school	13	9
Tech. school	4	6
College	3	8
Graduate School	2	14
Chi-square = 16.151		
p = 0.0028		
Religion		
Protestant	26	34
Catholic	5	5
Belief Helps		
Yes	30	34
No	1	5

(table continues)

	Terminally Ill	Cardiac Impaired
Marital Status		
Married	22	32
Single	9	7
Diagnosis		
Ca.	24	1
MS., AIDS	3	0
Other	4	38
Chi-square = 51.435		
p = < 0.0001		
Time Since Told		
Less than 1 year	11	11
More than 1 year	20	28
Who Told		
M.D.	30	32
R.N.	0	1
Family	0	3
Just knew	1	3

(table continues)

	Terminally Ill	Cardiac
Opinion of Prognosis		
Terminal	22	3
Not terminal	2	24
Unsure	7	12
Chi-square = 33.90		
p = < .0001		
Treatment		
Treatment	22	7
No treatment	9	32
No. of Deaths	mean = 4.871	mean = 4.539
Tasks	mean = 2.903	mean = 2.308
t = 2.35		
p = .021		
Words		
Died	27	29
Passed on	5	8
Gone	0	0
Passed	1	0
Asleep	0	2
Other	3	6

helpful religious beliefs, marital status, time since told diagnosis, who told them their diagnosis, the number of close deaths, and works used to describe death.

Of the 31 terminally ill participants who participated in the study, 14 completed the retest 7 to 14 days after initial administration of the instrument. The most frequent reason for not completing the retest was that the terminally ill participant became confused or somulant and was unable to respond to questions on the questionnaire. Nine (29%) terminally ill participants did not complete the retest for this reason. One (3%) terminally ill participant did not complete the retest because they, or family members, refused the researcher further access because they felt the questions were too upsetting. One (3%) terminally ill participant did not complete the retest because the family members or nurses felt the participant was too ill to be disturbed again. Five (16%) terminally ill participants did not complete the retest because they had died before the researcher could return to administer the retest.

Descriptive Data

The McCanse Readiness for Death Instrument, hereafter referred to as the MRDI, administered to terminally ill participants had a range of scores between 167 and 320.5

on first testing and between 212 and 307 on retesting. The mean for first testing was 230.81 and for retesting was 233.84. The standard deviation for first testing scores was 49.84 and for retesting scores was 32.59.

The MRDI administered to primary care giver participants had a range of scores between 163.5 and 347. The MRDI administered to primary nurse participants had a range of scores between 144 and 290. The standard deviation for primary caregiver scores was 38.85 and for primary nurse scores was 32.59.

The MRDI administered to cardiac impaired participants had a range of scores between 170.5 and 291. The standard deviation for cardiac impaired participants score was 30. There were no significant correlations between any of the demographic data and overall healthy death readiness scores of either terminally ill individuals or cardiac impaired individuals who were not terminally ill except for group 1 where readiness correlated with number of spouses lost (.3150, p = .042) and the making of a will (.3285, p = .036) and in group 2 where readiness correlated with educational level (.2875, p = .038) and having one's papers in order (-.2760, p = .044).

Findings

participants were administered the MRDI as planned. The data were analysed according to the hypotheses.

Hypothesis Number One

Hypothesis number one was formulated to describe a relationship between decreased environmental interaction, as measured on items 1 through 5 of the MRDI, and overall healthy death readiness as measured by the MRDI total, which would support the internal reliability of the instrument. To test hypothesis number one, scores of items 1, 2, 3, 4, and 5, as a group, were correlated to MRDI total mean score by calculating a Pearson product moment coefficient. A statistically significant correlation between decreased environmental interaction and total score mean was shown. The Pearson's product moment coefficient for this relationship was .3855 (p = .016).

Hypothesis Number Two

Hypothesis number two was formulated to describe a relationship between decreased interpersonal interaction, as measured on items 6, 10, 13, 14, 16, 17, 18, and 19, of the MRDI and overall healthy death readiness as measured by the MRDI total, which would support the instrument's

internal reliability. To test hypothesis number two, mean scores on items 6, 10, 13, 14, 16, 17, 18, and 19, were correlated as a group to MRDI total mean score by calculating a Pearson's product moment coefficient. A statistically significant relationship was found between decreased interpersonal interaction and total mean scores. The Pearson's product moment coefficient for this relationship was .7130 ($p < .001$).

Hypothesis Number Three

Hypothesis number three was formulated to describe a relationship between increased acceptance behaviors, as measured on items 7, 8, 9, 11, 12, 15, 20, 21, and 22 of the MRDI, and overall healthy death readiness as measured by the MRDI total score, which would support the instrument's internal reliability. To test Hypothesis number three, mean scores on items 7, 8, 9, 11, 12, 15, 20, 21, and 22 were correlated as a group to MRDI total mean scores by calculating a Pearson's product moment coefficient for each pair of scores. A significant relationship was found between increased acceptance and total mean score. The Pearson's product moment coefficient for this relationship was .6836 ($p < .001$).

Hypothesis Number Four

Hypothesis number four was formulated to describe a relationship between an increase in verbal statements of readiness to die, as measured on items 23 through 27 of the MRDI, and overall healthy death readiness, as measured by the MRDI total, which would support the instrument's internal reliability. To test Hypothesis number four, mean scores from items 23, 24, 25, 26, and 27 were correlated as a group to MRDI total mean score by calculating a Pearson's product moment coefficient for each pair of scores. A statistically significant relationship was found between an increase in verbal statements of readiness to die and total mean score. The Pearson's product moment coefficient for this relationship was .7260 ($p < .001$).

Hypothesis Number Five

Hypothesis number five was formulated to describe a relationship between each individual item numbers 1 through 27 of the MRDI, and item 28 of the MRDI, which would support the instrument's internal reliability. Item number 28 was intended to be an overall measure of healthy death readiness. To test Hypothesis number five, terminally ill individuals' mean score for items 1 through 27 was correlated to the mean score for item 28 by

calculating a Pearson's product moment correlation coefficient for each pair of scores. Statistically significant relationships were found between item number 28 and items 11, .4032 (p = .012); 18, .3541 (p = .025); 24, .3586 (p = .024); 25, .4239 (p = .009); 26, .6340 (p < .001); and 27, .6344 (p < .001). No significant relationships were found between item number 28 and any other item. Cronbach's standardized item alpha was .7604.

Hypothesis Number Six

Hypothesis number six was formulated to test the relationship between terminally ill individuals' scores on the MRDI and their primary care giver estimates of their scores. A highly positive relationship would support the instrument's validity as a measure of the concept herein called healthy death readiness. To test Hypothesis number six, terminally ill individuals' scores on the MRDI were correlated with their primary care giver estimates of their scores by calculating a Pearson's product moment coefficient for these pairs of scores. The coefficient between terminally ill individuals' scores and primary care giver estimates of terminally ill individuals' scores was .3527 (p = .026).

Hypothesis Number Seven

Hypothesis number seven was formulated to test the relationship between terminally ill individuals' scores on the MRDI and their primary nurse estimates of their scores. A highly positive relationship would support the instrument's validity as a measure of the concept herein called healthy death readiness. To test Hpothesis number seven, terminally ill individuals' scores on the MRDI were correlated with their primary nurse estimates of their scores by calculating a Pearson's product moment coefficient for these pairs of scores. The coefficient between terminally ill individuals' scores and primary nurse estimates of terminally ill individuals' scores was .5247 (p = .002).

Hypothesis Number Eight

Hypothesis number eight was formulated to test the relationship between terminally ill individuals' scores on the MRDI and the scores of a contrast group of cardiac impaired individuals who were not dying. A significant difference between the mean scores for the two groups would support the instrument's validity as a measure of the concept, herein referred to as healthy death readiness, which is expected to differ between two such groups. Hypothesis number eight was tested by calculating

a t-test to determine if there was a significant difference between the mean score for terminally ill individuals and the mean score for cardiac impaired individuals who were not dying. The t-value for the difference between terminally ill individuals' mean score and cardiac impaired contrast group's mean score was 2.76 ($p = .003$). Cronbach's alpha calculated for terminally ill individuals was .7604 and for cardiac impaired individuals was .3392.

Hypothesis Number Nine

Hypothesis number nine was formulated to test reliability of the MRDI as a measure of healthy death readiness among the terminally ill over a brief period of time. To test Hypothesis number nine, a Pearson's product moment coefficient was calculated between terminally ill individuals' scores and their scores when retested 7 to 14 days later. The coefficient between initial testing and retesting was .2194 ($p = .216$).

Hypothesis Number Ten

Hypothesis number ten was formulated to describe the stability of the concept, healthy death readiness among the terminally ill, over time. In order to test Hypothesis number ten, a t-test was calculated to test

mean differences between terminally ill individuals' initial scores and their scores when retested 7 to 14 days later. The *t*-value for the difference between initial mean scores and retest mean scores was 1.19 (p = .769).

Summary of Findings

Hypothesis number one was supported. Items 1 (response to temperature), 2 (response to noise, light, and odors), 3 (decreased bothersome pain or discomfort), 4 (hunger), and 5 (a wish to be more or less active), as measures of decreased environmental interaction, were significantly related to healthy death readiness scores overall.

Hypothesis number two was supported. Items 6 (concerning a wish for responsibility), 10 (a wish to be alone), 13 (seeking of approval from others), 14 (a wish to do as other wish), 16 (turning away from others), 17 (closing eyes to get away from others), 18 (sleep time), and 19 (time spent talking to others), intended as measures of decreased social interaction correlated significantly as a group with total healthy death readiness scores.

Hypothesis number three was supported. Items 7 (reminiscence), 8 (good dreams), 9 (bad dreams), 11 (thinking about long-term future), 12 (thinking about

short-term future), 15 (a desire to give something away), 20 (time passing quickly), 21 (thoughts about death), and 22 (thoughts about others who have died), correlated significantly with total healthy death readiness scores.

Hypothesis number four was supported. Items 23 (acceptance that life is nearly over), 24 (relief that death is near), 25 (fear of death), 26 (feeling a peace), and 27 (letting go of life), intended as measures of verbal statements of readiness to die, correlated significantly with total healthy death readiness scores.

Hypothesis number five was minimally supported by a significant correlation between item 28 (overall death readiness) and items 11 (thinking about long-term future), 18 (sleep time), 24 (relief that death is near), 25 (fear of death), 26 (peacefulness), and 27 (freedom to let go of life). No other items were significantly correlated with item 28 as a measure of overall healthy death readiness. An overall measure of the instrument's internal reliability was represented by a Cronbach's alpha coefficient relating every item to every other item. The standardized alpha coefficient for all items was .7604, which lends significant support for the instrument's internal reliability.

Hypothesis number six was supported by a significant correlation between terminally ill individuals' scores and primary care givers' estimates of terminally ill individuals' scores. The MRDI'S validity is supported as a measure of some concept, herein referred to as healthy death readiness.

Hypothesis number seven was also supported. A significant correlation between terminally ill individuals' scores and their primary nurse estimates of their scores indicates further support for the MRDI's instrument validity as a measure of a concept called healthy death readiness.

Hypothesis number eight was not supported. Healthy death readiness scores for terminally ill individuals were significantly different from healthy death readiness scores for cardiac impaired individuals who were not terminally ill. The MRDI's validity as a measure of a concept, healthy death readiness, is supported by the difference in scores.

Hypothesis number nine was not supported. Terminally ill individuals' scores at initial testing were not significantly related to their scores at retesting. The MRDI's test-retest reliability was not supported by the positive relationship of initial scores and retest scores.

Hypothesis number ten was supported. There was no significant difference between healthy death readiness scores among terminally ill individuals when first tested and their scores when retested 7 to 14 days later. No significant difference between initial scores and retest scores suggests that the concept, healthy death readiness, is a stable trait or a labile state over a period of 7 to 14 days.

CHAPTER V

SUMMARY OF THE STUDY

This chapter reviews the procedure of the study conducted in relation to the problem of the study and the hypotheses proposed and tested as a method of exploring the problem. A discussion of the findings, limitations, conclusions, implications for nursing and nursing theory, and recommendations for further study are also included.

The problem of this study was to answer the question, "Is readiness for death, as an indicator of healthy dying, a measurable concept?" The purposes of the study were to identify observable indicators of healthy death readiness and create an empirically reliable and valid instrument for measuring healthy death readiness. In order to answer the problem statement and to achieve the purpose of the study, a number of hypotheses were established.

Hypothesis number one: Healthy death readiness of a terminally ill individual, as measured on the McCanse Readiness for Death Instrument total, is significantly related to decreased environmental interaction as measured by items 1 through 5 (Appendix A). This hypothesis was established to verify that decreased environmental interaction was an observable indicator of healthy death

readiness, and to verify the internal reliability of the instrument. A significant positive relationship between items intended to measure decreased environmental interaction and a total mean score for healthy death readiness would support these items as indicators of the overall concept and contribute to the instrument's internal reliability.

Hypothesis number two: Healthy death readiness of a terminally ill individual, as measured on the McCanse Readiness for Death Instrument total, is significantly related to decreased interpersonal interaction as measured on items 6, 10, 13, 14, 16, 17, and 19 (Appendix A). This hypothesis was established to verify that decreased interpersonal interaction was an observable indicator of healthy death readiness, and to verify the internal reliability of the instrument. A significant positive relationship between items intended to measure decreased interpersonal interaction and a total mean score for healthy death readiness would support these items as indicators of the overall concept and contribute to the instrument's internal reliability.

Hypothesis number three: Healthy death readiness of a terminally ill individual, as measured on the McCanse Readiness for Death Instrument total, is significantly

related to increased acceptance behaviors as measured on items 7, 8, 9, 11, 12, 15, 20, 21, and 22 (Appendix A). This hypothesis was established to verify that increased acceptance behaviors was an observable indicator of healthy death readiness, and to verify the internal reliability of the instrument. A significant positive relationship between items intended to measure increased acceptance behaviors and a total mean score for healthy death readiness would support these items as indicators of the overall concept and contribute to the instrument's internal reliability.

Hypothesis number four: Healthy death readiness of a terminally ill individual, as measured on the McCanse Readiness for Death Instrument total, is significantly related to an increase in verbal statements of readiness to die, as measured on items 23 through 27 (Appendix A). This hypothesis was established to verify that increased verbal statements of readiness to die was an observable indicator of healthy death readiness, and to verify the internal reliability of the instrument. A significant positive relationship between items intended to measure increased verbal statements of readiness to die and a total mean score for healthy death readiness would support

these items as indicators of the overall concept and contribute to the instrument's internal reliability.

Hypothesis number five: Healthy death readiness of a terminally ill individual, as measured on item 28 of the McCanse Readiness for Death Instrument, is significantly related to all individual items (Appendix A). This hypothesis was established to verify that each individual item numbered 1 through 27 was an observable indicator of the overall concept, healthy death readiness, and to verify the internal reliability of the instrument. A significant positive relationship between an item's score and the score for an item intended to measure healthy death readiness would support that item as an indicator of the overall concept. A significant positive relationship between all individual items and an item intended to measure overall healthy death readiness would contribute to the instrument's internal reliability.

Hypothesis number six: Terminally ill individuals' scores on the McCanse Readiness for Death Instrument is significantly related to the primary care giver estimates of terminally ill individuals' scores. This hypothesis was established to verify the instrument's concept validity. If terminally ill individuals' scores were highly positively related to primary care giver estimates

of their scores support would be established for the instrument as a measure of the concept, healthy death readiness.

Hypothesis number seven: Terminally ill individuals' scores on the McCanse Readiness for Death Instrument is significantly related to the primary hospice nurse estimates of terminally ill individuals' scores. This hypothesis was established to verify the instrument's concept validity. If terminally ill individuals' scores were highly positively related to primary hospice nurse estimates of their scores, support would be established for the instrument as a measure of the concept, healthy death readiness.

Hypothesis number eight: Healthy death readiness of terminally ill individuals, as measured on the McCanse Readiness for Death Instrument, is not significantly different from healthy death readiness of cardiac impaired individuals as measured on the McCanse Readiness for Death Instrument. This hypothesis was formulated to establish support for the instrument's concept validity. Concept validity will be supported when scores on an instrument said to measure the concept are significantly different between a group of individuals thought to evidence the concept and a contrast group of individuals logically

thought not to evidence the concept. Lack of support for Hypothesis number eight would establish some support for the instrument's validity as a measure of the concept, healthy death readiness. The contrast group chosen for this study was cardiac impaired individuals who, though they may have been chronically ill with a life threatening illness, were not thought to be dying.

Hypothesis number nine: Healthy death readiness of a terminally ill individual, as measured on the McCanse Readiness for Death Instrument, on a given day is significantly related to healthy death readiness of the same terminally ill individual, as measured in the McCanse Readiness for Death Instrument, 7 to 14 days later. This hypothesis was established to verify the instrument's reliability as a measure of the concept, healthy death readiness, consistently over time. A significantly positive relationship between scores obtained at initial testing and scores obtained from the same individuals at second testing would establish a beginning measure of the instrument's reliability.

Hypothesis number ten: Healthy death readiness of a terminally ill individual, as measured on the McCanse Readiness for Death Instrument, on a given day is not significantly different from healthy death readiness of

that same terminally ill individual, as measured on the McCanse Readiness for Death instrument, 7 to 14 days later. This hypothesis was established to describe the stability of the concept, healthy death readiness among the terminally ill, over time. A significant difference between mean scores obtained at initial testing and mean scores obtained at second testing would lend support to description of the concept as a labile state rather than a stable trait.

Summary

In order to test all hypotheses, the McCanse Readiness for Death Instrument (the MRDI) was administered to terminally ill individuals, their primary care givers, and to their primary hospice nurses. In order to satisfy Hypothesis number eight, the MRDI was administered to a contrast population of cardiac impaired individuals. In order to satisfy Hypotheses number nine and ten, the MRDI was readministered, where possible, to terminally ill individuals 7 to 14 days following original testing.

The population for this study was obtained from hospices in Dallas and Fort Worth, Texas; Kansas City, Missouri; Levenworth, Kansas; and Milwaukee, Wisconsin, and from cardiac rehabilitation programs in Denton, Texas; Kansas City, Missouri; and Menomenee Falls and Cudahey,

Wisconsin. Permission was obtained from each institution's human subjects' committee or from the medical director of the program. The population from which the samples were drawn were adult men and women who were terminally ill, their primary care givers, and primary hospice nurses, and adult men and women who suffered cardiac impairment but who were not dying and who participated in a cardiac rehabilitation program. A sample of 31 terminally ill individuals who met specified criteria was obtained. A sample of 31 primary care givers and 29 primary hospice nurses who met specified criteria was obtained. A sample of 39 cardiac impaired individuals who met specified criteria was obtained. The protection of the human rights of the participant was maintained by explaining the research procedure and rights as a participant to the potential participant. Permission of the potential participant was obtained by his or her written signature.

The setting for this study was the terminally ill participant's home or hospital room or the cardiac impaired individual's rehabilitation setting. Standard instructions were given to each participant prior to the administration of the instrument. Terminally ill participants, their primary care givers, and primary

nurses were interviewed concurrently except in three cases where the primary nurse was interviewed separately, at her convenience, on the same day, and in two cases where the primary care giver was interviewed, at his or her convenience, one day later. All participants were cautioned not to discuss the items until all testing had been completed. About 10 to 15 minutes were required to administer the instrument, and about 10 to 20 minutes were usually required to discuss the instrument, and issues it raised, after testing.

Of the 31 terminally ill participants who completed the first administration, 14 completed the second administration. Participants did not complete the retesting for several reasons: participants becoming too confused, somulent, or weak to answer the questions; family or participant refusal to allow retesting; and the death of participants.

Discussion of Findings

Chi-square statistical tests were applied to the frequencies of variables within the sample, variables such as gender, age, race, opinion of terminality, spirituality, and personal experience with the death of others. The chi-square applied to the frequency of the variable of diagnosis manifested a significant difference

between terminally ill individuals and cardiac impaired individuals. This meant that significantly more of the terminally ill individuals had a diagnosis of cancer, multiple sclerosis, or AIDS and significantly more of the cardiac impaired individuals had a diagnosis or other than cancer, multiple sclerosis, or AIDS. This significance was manifested because of the way in which participants were selected, i.e, the contrast population was intended to be a group of people who had cardiac impairments and who were not terminally ill.

The chi-square applied to the frequency of variables of education and life's major occupation manifested a significant difference between terminally ill individuals and cardiac impaired individuals. Significantly more of the cardiac impaired individuals had higher degrees of education and were more often professionals as opposed to the terminally ill participants, who were more often educated at the high school level and who had held technical or clerical jobs. Additionally, there was a wider spread of terminally ill participants across all educational and professional levels. This spread was probably manifested because of the more homogeneous population from which cardiac participants were drawn, that is, they were participants in programs which were

somewhat expensive and which were intended to be educational and strictly restorative. Terminally ill individuals were participants in hospice programs which were not limited as to patient income and which were not particularly intended to appeal to individuals seeking education about their condition or restorative care.

The chi-square applied to the frequency of the variable of age manifested a significant difference between terminally ill individuals and cardiac impaired individuals. Cardiac impaired individuals were more frequently middle aged, i.e., 36 to 55, whereas terminally ill individuals fell more equally into all age categories. This significance was probably manifested because cardiac impaired participants were again a homogeneous group. Those who choose to participate in, and can afford, cardiac rehabilitation programs are likely to be those most interested in maintaining and improving normal function. They are likely to be actively employed and have ongoing financial responsibilities. Terminally ill individuals found in hospice programs are giving up income and responsibilities regardless of age and/or choice.

Demographic data describing terminally ill participants and cardiac impaired participants as not

significantly different as to variables such as gender, race, occupation, and marital status would tend to indicate that the two groups are similar in many external respects except for terminality. Demographic data describing terminally ill participants and cardiac impaired participants as not significantly different as to knowledge of diagnosis, religious group membership, helpful religious beliefs, and number of tasks performed in preparation for death would tend to indicate that the two groups were similar in regard to some internal attributes, such as spirituality and responsibility, regardless of terminality.

Hypothesis Number One

Hypothesis number one was supported with significant internal reliability being manifested. The subscale, decreased environmental interaction, manifested a reliability of .3855 with total readiness. Given the low number of items on the test (28) and the low number of items in the subscale (5), a low reliability would be expected.

Behaviors indicative of decreased environmental interaction may not be as good indicators of healthy death readiness as those behaviors represented by items on other subscales. Additionally, an interaction with internal or

external environment may occur earlier or later during the period before death. As the period of time between testing and actual death varied a great deal among participants, it is difficult to identify, for the group as a whole or for dying people in general, just when a decrease in environmental interaction may occur. Future evaluation of data relating subscale scores to proximity of death may be in order.

Hypothesis Number Two

Hypothesis number two was supported with significant internal reliability being manifested. The subscale, decreased interpersonal interaction, manifested a reliability of .7130 with total readiness. This subscale's reliability is especially significant when the low number of items on the test (28) and on the subscale (8) is considered.

Another factor that contributed to this reliability is that all items were evaluated by a group of hospice nurse experts prior to their inclusion in the instrument. Therefore, some prior reliability had been established before current testing. All hospice nurse experts agreed that as death is approached there appears to be a decrease in interpersonal interaction and that the items in this subscale, as written, represented this behavior. Hospice

nurse experts also agreed that decreased interpersonal interaction appeared to occur later in the pre-death period of life. Again, further evaluation of data relating this subscale to proximity of death would be interesting.

Hypothesis Number Three

Hypothesis number three was supported with significant internal reliability being manifested. The subscale, increased acceptance behaviors, manifested a reliability of .6836 with total readiness. Again, the low number of items on the instrument (28) and the low number of items on the subscale (9) suggest that this subscale's reliability is especially significant.

Behaviors related to increased acceptance of pending death appear to occur at varying points during the period of life just prior to death. Experts such as Kubler-Ross (1969) and Weisman and Kastenbaum (1968) who have defined a "final" stage of dying called acceptance also agree that this stage probably occurs, to different degrees, intermittently as death comes closer. The reliability of the acceptance behaviors subscale across the sample as a whole, regardless of death's proximity, suggests that it is a good overall indication of death readiness. When a

terminally ill individual is experiencing increased acceptance he or she appears to be more death ready.

Hypothesis Number Four

Hypothesis number four was supported with significant internal reliability being manifested. The subscale, verbal statements of readiness, manifested a reliability of .7260 with total death readiness. According to Cattell and Tsujioxa (1964) reliabilities of subscales should be at least .40 or greater to be considered significant. This higher reliability is probably manifested, despite the low number of items on both the test (28) and the subscale (5) because verbal statements of readiness are volitional and are therefore direct indicators of death readiness. Verbalization takes considerable energy at a time when a dying individual may be conserving energy in order to perform only priority tasks. If one is not ready to die, one is not likely to waste breath and energy telling others that he or she is relieved that death is near or that he or she is at peace.

Hypothesis Number Five

Hypothesis number five was supported by significant internal reliability being manifested. Item number 28, intended as a measure of overall healthy death readiness,

manifested a significant reliability with six items: number 11, decreased thinking about long term future (.4032); number 18, increased time spent sleeping (.3541); number 24, relief that death is near (.3586); number 25, decreased fear of death (.4239); number 26, peacefulness (.6340); and number 27, freedom to let go of life (.6344). Cronbach's standardized item alpha was .7604 showing a close relationship among all items. Deleting any item would cause little difference in scale mean (from 219.55 to 227.05), or in the alpha itself (from .7358 to .7714) and this would justify retaining all of the items.

Items which would most positively effect the alpha if they were deleted were item number two, "How often do noises, lights, and odors bother you?"; item number three, "How often do you have bothersome pain or discomfort?"; item number 16, "How often do you turn away from others?"; and item number 21, "How often do you think about death?" Items 2, 3, 15 (a wish to give something away), and 21 negatively correlated with item number 28. In the interest of instrument brevity and increased internal reliability items 2, 3, 15, 16, and 21 might be eliminated from the MRDI.

Hypothesis Number Six

Hypothesis number six was supported by significant validity being manifested. A significant positive relationship was manifested between terminally ill individuals scores and their primary care giver's estimates of their scores (.3527, $p = .026$). Though better evidence of the validity of the MRDI as a measure of healthy death readiness among the terminally ill is desirable, it is interesting to note that care givers are able to estimate terminally ill individual's readiness for death to some degree. In many instances there appeared to be very little verbal communication between patient and care giver at all and yet something of the patient's state of recognition of and preparation for impending death was being conveyed. The degree to which care givers are able to estimate patient death readiness probably does not justify using care giver estimates as legitimate representations of patient death readiness.

It would be interesting to know if care giver estimates increase or decrease as patient scores increase or decrease over time. It may be that care giver estimates of patient scores would improve as death approaches. No care giver was retested in this study.

Hypothesis Number Seven

Hypothesis number seven was supported by significant validity being manifested. A significant positive relationship was manifested between terminally ill individual's scores and their primary hospice nurse's estimates of their scores (.5247, $p = .002$). Again, better evidence of the validity of the MRDI as a measure of healthy death readiness among the terminally ill is desirable.

A significant positive relationship between patient scores and nurse estimates of patient scores is evidence, however, that primary hospice nurses are perhaps as good at diagnosing healthy death readiness as are patient care givers. This is not surprising as, in addition to literary consensus as to what constitutes healthy death readiness, hospice nurse experts helped initially define the concept indicators based largely on their own experience and nursing intuition. Nurses process sets of patient status indicators often without recognizing them individually until they have fallen into conclusive patterns (Smith, 1986). Nurses are, in other words, educated observers who frequently "intuit" patient status without stopping to analyze just what it was that told them a patient was going bad, getting well, coping

adequately, or headed for hard times. A positive relationship of even .5247 is evidence that nurses can and do, at least in this instance, make reasonably good estimates of patient status.

Hypothesis Number Eight

Hypothesis number eight was not supported. A significant difference was found between mean scores on the MRDI for terminally ill individuals and a contrast group of cardiac impaired individuals who were not dying (t 2.76, p = .003). The groups were similar in many respects; i.e., gender, race, occupation, marital status, and so forth. Though the two groups varied significantly as to educational level and age span with the contrast group being better educated and more middle-aged, the differences were clinically minor. The MRDI was intended for possible use with populations who were able to read at a grade school level and with those who could minimally make a single mark on each of 28 lines. Education and age should not be significant factors in determining ability to respond to the instrument. Neither can education and age be said to determine introspectiveness of response to questions such as those included in the MRDI.

Other ways in which the terminally ill group and the cardiac impaired group differed from each other were those

variables on which they were intended or expected to vary. The cardiac impaired group did generally not see themselves as terminally ill whereas the terminally ill group did. Significantly more of the terminally ill group had a diagnosis of cancer, AIDS, or multiple sclerosis, whereas those in the cardiac impaired group had a diagnosis of "other". One terminally ill participant was dying of congestive heart failure and was indeed cardiac impaired, but his prognosis was more similar to that of other terminally ill participants than it was to other cardiac impaired participants. The number of tasks performed in preparation for death by individuals in the two groups varied slightly. The mean number of tasks performed by the terminally ill participants was 2.9032 and the mean number of tasks performed by the cardiac impaired individuals was 2.3077 (t 2.36, p = .024). This task performance is again a factor which might logically be expected to vary between the two groups who were at varying supposed chronological distances from death.

Hypothesis Number Nine

Hypothesis number nine was not supported by significant reliability being manifested. A significantly positive relationship between terminally ill individuals'

mean scores at initial testing and their mean scores at retesting was not found (rxy = .2194, p = .216).

The interval of time between initial testing and retesting may well have been inappropriate for purposes of describing the instrument's reliability over time. A later second testing or multiple retestings over a longer period of time may have manifested greater evidence of the instrument's reliability. Unfortunately, it is very difficult to retest terminally ill people regardless of the length of time between initial testing and retesting. Access to terminally ill patients is very limited and the length of time available for retesting is also often very limited. The intrusiveness of any instrument, no matter how benign, and the limited length of life left to terminally ill participants, also raise ethical considerations when studies are designed which include retesting.

Hypothesis Number Ten

Hypothesis number ten was supported by a lack of significant difference between mean scores for terminally ill individuals at initial testing and a second testing. Because this hypothesis was stated in the null, this means that support is manifested for description of healthy death readiness as a concept which is stable over time.

It may be that the span of time between initial testing and retesting was not long enough for a difference in healthy death readiness to be significantly manifested. Hospice nurse experts and the researcher agree that as patients approach death they do become much more withdrawn and/or somulent, making it very difficult to obtain a response to any item included in the MRDI. Indicators of death readiness which are difficult to measure directly from the patient but which appear to care givers and nurses to vary a great deal toward the end of life are response to pain and hunger and external environmental stimuli. As death approaches patients appear to sleep more and to care less about food and comfort measures. Items reflecting these indicators of healthy death readiness, if measured by care giver or nurse estimate alone over a period of time exceeding 2 weeks, might manifest significant differences and in this way contribute to a description of the concept, healthy death readiness, as a labile trait as opposed to a stable state.

Additionally, the lack of significant relationship between the initial scores and the retest scores combined with a lack of significant difference between these scores may suggest that the concept of healthy death readiness is

a labile state rather than a labile trait. A state, because of its longer standing existance within an individual's personality, is less likely than a trait to be affected by internal or external environmental change. A state may still, however, be labile, perhaps over longer periods of time. In any case attempts to describe instrument stability and attempts to describe concept stability are not the same thing and they probably require different time spans between testing and retesting (Crane, 1986).

Conclusions and Implications

Conclusions drawn from the testing of hypotheses include:

1. That legitimate subscales exist within the MRDI.

2. That behaviors represented by items within the subscales probably occur at different times and in different degrees as death is approached.

3. That individual differences in the ways in which healthy death readiness is manifested among the terminally ill makes this a difficult concept to measure in any generalizable manner.

4. That deleting some items and changing the length of time between initial testing and retesting might increase the instrument's internal reliability.

5. That care giver estimates of patient healthy death readiness are not significantly reliable as measured by the MRDI.

6. That nurse estimates of patient healthy death readiness are significantly reliable though not ideally so, and that nursing intuition may be a factor in the reliability of these estimates.

7. That the MRDI is a valid measure of the concept of healthy death readiness among the terminally ill.

8. That the concept of healthy death readiness may or may not be a labile trait and that its lability or stability is very difficult to measure over a period of time of 7-14 days.

Limitations

Some of the limitations of this study which may have affected the results of the study are: inaccessibility of terminally ill individuals; sample size; the condition of concurrent administration of the instrument to terminally ill participant, primary care giver participant, and primary hospice nurse participant; the length of time necessary for instrument administration; the possibility that primary care giver or primary hospice nurse participants might be denying the terminally ill

participant's terminality; and the non-random, self-selection of all samples of participant groups.

Inaccessibility of Terminally Ill participants

Because ours is a death denying society and because terminally ill individuals are perceived to be fragile and deserving of privacy as they approach death, it is very difficult for a researcher to achieve access to them. Agencies, nurses, physicians, and family members are protective of dying individuals and generally express fear that an interview, however brief, will be intrusive or will cause the patient additional physical and psychological discomfort. Researchers wishing access to terminally ill participants must spend a great deal of time building rapport and trust between themselves and all of those individuals who have the power to deny such access.

Sample Size

The size of the sample, although adequate, did not allow for a factor analysis of all 28 items in the McCanse Readiness for Death Instrument. A factor analysis generally requires a ratio of three participants per variable or item, therefore, 84 participants would have been required to permit a factor analysis. Therefore, the

method for revising and reducing the length of the McCanse Readiness for Death Instrument is limited by the size of the sample. The size of the sample in this study prevents the subscales from being verified or formulated through a factor analysis of all 28 items. A factor analysis would have identified factors or subscales based on the data, aposteriori, rather than factors or subscales being identified prior and correlated to overall readiness for death individually.

Concurrent Administration of the Instrument

Verbal collaboration between terminally ill individuals, their primary care givers and primary hospice nurses did occasionally take place despite researcher cautioning and may have been a factor influencing care giver or nurse estimates of terminally ill individuals' scores. While strict or sternly repetitive prohibition of all verbal response to items on the instrument may have resulted in more accurate care giver and nurse estimates, it may also have occasioned increased anxiety in all respondents. An accurate estimate by the terminally ill individual of his or her own death readiness, as well as accurate estimates by care giver and nurse, might have been inhibited by this anxiety.

Length of Time for Instrument Administration

Length of time for instrument administration can be a factor affecting the accuracy of participant responses to items on an instrument such as the McCanse Readiness For Death Instrument because of participant fatigue or because of care giver or nurse concern about participant fatigue. No participant was unable to complete the instrument because of fatigue. Two terminally ill participants complained of fatigue and were allowed to rest before completing the instrument. Though testing time was almost always 15 minutes or less, a shorter version of the instrument might engender more accurate responses.

Denial of Participant Terminality

No care giver or nurse respondent verbally denied any terminally ill participant's terminality. Three primary care givers did suggest to the researcher and to a terminally ill participant that hope should always be maintained that the patient would not die. Such suggestions of hopefulness could be construed as a denial of terminality on the part of the care giver, whose estimate responses might then be less than accurate. Careful screening of participants, care givers, and nurses, to eliminate all those who feel that the patient

may have more than 6 months to live may ensure more accurate estimate responses.

Non-random, Self-selection of Participants

Because participants were self-selected, several groups of terminally ill individuals with varying degrees of healthy death readiness may not have been included in the study. Most terminally ill participants stated a willingness, if not an eagerness, to talk to the researcher. This was probably true because in many cases their hospice nurses had approached them ahead of time about the study and had selected for inclusion only those patients they felt would be capable of answering the questions without too much physical or emotional distress. No conclusions should be drawn regarding the advisability of use of the instrument with populations of terminally ill individuals, their care givers, or nurses, other than those who are amenable to being interviewed about the participant of death readiness. Administration of the McCanse Readiness for Death Instrument to groups of terminally ill individuals selected regardless of willingness to be included may offer a wider range of response but would be ethically questionable and, therefore, undesirable.

Implications Related to Future Study Design

One implication resulting from the limitations discussed is that a larger, more randomly selected sample of terminally ill participants is desirable. A larger, more random sample would allow a broader application of findings and eventually perhaps increased usefulness of the MRDI for nursing assessment of hospice clients in general.

A second implication resulting from the limitations discussed is that if a sample is desired which will be large enough to allow factor analysis, the instrument should be decreased in size to no more than 20 items. Decreasing the length of the instrument will also decrease the risk of respondent fatigue and the risk of collaboration between respondents. A shorter instrument might be more acceptable to agencies and to individuals who are protective of terminally ill patients. Access to terminally ill patients would then be easier.

A third implication resulting from the limitations discussed is that if a researcher desires access to terminally ill individuals the period of time allowed for data collection must be considerably longer than 5 to 6 months. A great deal of patience and perseverance is necessary when trying to convince agencies and individuals

that little or no harm will come to dying individuals if they are interviewed using the MRDI. Arguments put forth in favor of long term benefit for terminally ill people and those involved in their care frequently are not convincing, especially to physicians and to care givers who are denying a dying person's terminality or who feel that confronting the fact of pending death will somehow lessen their control over pre-death events.

Arguments in favor of the researcher's expertness and experience with dying people are somehow more convincing, especially to hospice nurses and to families and to patients themselves, many of whom welcome the possible opportunity for interaction with and "expert" who is genuinely concerned about dying people. The most convincing argument for continued access to terminally ill individuals is actual observation by nurses and families of positive interaction between a patient and the researcher. Nurses and families who have observed the dying individual relating to the researcher, and the MRDI, in a harmless way become advocates for continuation of the study. This advocacy is also dependent on the researcher's interpersonal skills and ability to allow sufficient time for building good rapport with those involved.

A limitation of the study not recognized prior to conducting the study is that the design did not allow for evaluation of possible relationships between individual items or subscales and the proximity of death among terminally ill participants. When the instrument was evaluated, prior to use, hospice nurse experts repeatedly stated that some behaviors occurred earlier or later as death was approached. Future studies employing the MRDI should include calculation of number of days between testing and patient death so that patient scores in total and scores on individual items and subscales, could be correlated with amount of actual life left.

A related, also previously unrecognized, limitation of the study is that the design did not allow for evaluation of the relationship between patient death readiness scores and care giver estimates of their death readiness scores over time, especially as death became a more proximate reality. A calculation of the number of days between all initial testing and patient death, and calculation of the number of days between retesting of both patient and care giver and patient death, would allow the testing of the relationships between patient scores and care giver estimates over time. Comparisons of the relationships between patient scores and care giver

estimates of patient scores over time between different patients would be inappropriate, however, because it is assumed that healthy death readiness is an individually manifested trait or state and that one person's healthy death readiness cannot be compared to another person's healthy death readiness. The ethical and practical issues surrounding the retesting of dying people may preclude retesting in any case.

A final limitation, not recognized prior to conducting the study is that the length of time between initial testing and retesting of terminally ill individuals may not have been enough for a significant difference in healthy death readiness to be manifested. It is still possible that death readiness is a labile state or trait over a period of time exceeding 7 to 14 days. Likewise, retesting over a different period of time might allow for greater manifestation of test-retest reliability (and ethical liability).

Nursing Implications

Findings reported for Hypothesis one, two, three, four, and five suggest a first nursing implication; i.e., that behavioral indicators exist for the concept of healthy death readiness. Though the instrument's internal reliability was not quite enough to support clinical use

of the MRDI the researcher feels that nurses may use it to diagnose degrees of healthy death readiness among their terminally ill patients. Implied nursing concerns beyond diagnosis consist of developing interventions to help terminally ill patients, as individuals, achieve greater degrees of healthy death readiness.

Findings reported for Hypothesis six suggest a second implication; that primary care givers are sometimes not aware of the terminally ill patient's emotional preparedness for death. Because the MRDI brings to the surface issues which are quite sensitive and personal, administration of the MRDI appears to promote increased communication between patient and care giver or family. When retesting is not an issue of concern for purposes of testing the instrument's reliability such communication could be therapeutically enhanced by the nurse administering the instrument. It is possible that enhanced communication is not only of therapeutic benefit to patient and family but is also of value in providing better data upon which to make nursing judgments in regard to nursing care.

A third nursing implication is that though healthy death readiness is not a concept whose measurement is intended for use in the comparison of individuals or

groups it may be in nursing's interest to compare degrees of healthy death readiness among terminally ill populations in different settings. Nursing administrators may be interested in knowing which settings most economically and effectively promote healthy death readiness.

Because nurses are frequently left with most of the responsibility for care of the terminally ill, their ability to diagnose a degree of healthy death readiness may have important ethical and legal implications. The dying individual who has evidenced increasing death readiness might be allowed to die a peaceful death instead of being subjected to traumatic life-saving procedures. A measurable degree of healthy death readiness could provide both ethical and legal justification for the controversial passive euthanasia component of hospice care.

A final nursing implication is that nursing intuition as a basis for determining concept indicators of healthy death readiness among terminally ill patients is of value. Nursing knowledge extends well beyond what is empirically measurable and the nursing profession should not be shy about asserting this.

Theoretical Implications

Nursing's emphasis is on service to human beings. The MRDI has been shown to have a beginning measure of reliability and validity and is intended for use with human individuals so that individual variations in a desirable degree of death readiness may be measured. Applied to the Rogerian Paradigm indicators of healthy death readiness are behaviors and emotions also indicative of pattern which represents healthy individual energy field. Evidence of healthy individual energy field pattern, such as that provided by the MRDI, is therefore useful to nursing and will promote nursing's therapeutic purposes.

Recommendations for Further Study

Based on the findings for this study, further research is recommended in these areas:

1. Replication of this study with a larger sample so that a factor analysis of the MRDI could be performed manifesting inherent factors or subscales within the instrument from the data obtained.

2. Performance of a similar, ethically structured, study which would allow longer periods of time between initial testing and retesting, and which would include concurrent retesting of care givers so that further

support for the instrument's reliability may be established and so that clearer concept definition may be achieved.

3. Replication of this study using an abbreviated instrument of perhaps 20 items instead of 28 so that further support for the instrument's validity and reliability could be manifested.

4. Performance of a similar study using samples from a population of the oldest old or prisoners awaiting execution so that support for the instrument as a valid and reliable measure of healthy death readiness in other similar, death imminent, populations might be manifested.

5. Performance of studies which would evaluate the ethical, personal, and esthetic knowledge generated by administration of the MRDI so that support for the theoretical relationship between healthy death readiness and synchronous, accelerated human field motion might be established.

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APPENDIX A

Measurement of Healthy Death Readiness

Measurement of Healthy Death Readiness

Instructions to Interviewer:

1. Please choose a time and place for the interview which is convenient for the respondents and free of environmental distraction for at least 40 minutes.

2. Assure the respondent that he/she may refuse, at any time, to answer any or all questions. Explain that no patient or respondent name will appear on any form and that any other mark which may identify the respondent will be destroyed as soon as the data have been processed.

3. Please do not alter the wording or the sequence of questions unless it is absolutely necessary to insure that the respondent understands the question.

4. Do not suggest respondent consideration of patient behavior over a period of time other than here and now, i.e., at this time in the patient's life.

5. Be prepared to spend time with the respondent after the interview discussing and perhaps resolving issues of concern which may surface as a result of exposure to the instrument.

6. Begin by reading the instructions for response to the respondent. Make sure that he/she understands how to record his/her answers. Try the example question.

7. Please refer to the patient by name, or appropriate pronoun, where a blank line indicates this, i.e., as in the third person form of the MRDI.

8. Read each item aloud to the respondent(s). Repeat the item if necessary. Allow time for the respondent(s) to answer each item.

9. Caution respondent(s) not to discuss any question until the entire instrument has been administered.

10. After final administration of the instrument, ask the respondent for demographic information.

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9. Caution respondent(s) not to discuss any question until the entire instrument has been administered.

10. After final administration of the instrument, ask the respondent for demographic information.

MRDTI, first person form, an interview-questionnaire for use with dying or elderly individuals

"I am going to ask you some questions about yourself. Please show me on the answer sheet how often you do or feel the following things. Do this by marking a bar (/) wherever you think best on the line next to the number of each question I ask you."

Example: How often do you answer the telephone?

1. How often are you too hot or too cold?

2. How often do noises, lights, or odors bother you?

3. How often do you have bothersome pain or discomfort?

4. How often do you not want to eat?

5. How often do you wish you could be more active.

6. How often do you wish you could be more responsible for things you used to take care of or do?

7. How often do you reminisce about your past life?

8. How often do you have good dreams or fantasies?

9. How often do you have bad dreams?

10. How often do you wish to be alone or with only one or two familiar people?

11. How often do you think about your life two or three years from now?

12. How often do you think about your life a few days or weeks from now?

13. How often do you seek the approval of others?

14. How often do you feel as though you no longer want to do what others say you should or ought to?

15. How often do you wish to give something away?

16. How often do you turn away from others?

17. How often do you close your eyes to get away from others?

18. How much time do you seem to spend sleeping?

19. How much time do you spend talking to others?

20. How often do you feel as though time is passing more quickly than it used to?

21. How often do you think about death?

22. How often do you think about others who have died?

23. How often do you feel as though you have accepted that life is nearly over?

24. How often do you feel relieved that death is near?

25. How often do you feel afraid of death?

26. How often do you feel at peace?

27. How often do you feel free to let go of life?

28. Overall, how ready for death do you think you are?

Date:_____ Patient#_____

Respondent:

_____ (1) Patient
_____ (2) Spouse
_____ (3) Child
_____ (4) Parent
_____ (5) Sibling
_____ (6) Friend
_____ (7) Other

Patient Information:

Age:

_____ (1) Birth to 18 yrs.
_____ (2) 19 to 35 yrs.
_____ (3) 36 to 55 yrs.
_____ (4) 56 to 65 yrs.
_____ (5) 66 to 84 yrs.
_____ (6) 85 yrs. and older

Gender:

_____ (1) Female
_____ (2) Male

Race:

_____ (1) White
_____ (2) Black
_____ (3) Hispanic
_____ (4) Oriental
_____ (5) Other
_____ (6) American Indian

Life's major occupation:

_____ (1) Professional
_____ (2) Technical
_____ (3) Clerical
_____ (4) Laborer
_____ (5) Other

Highest educational achievement:

_____ (1) Grade school
_____ (2) High school
_____ (3) Technical school
_____ (4) College degree
_____ (5) Graduate degree

Religious group membership:

_____ (1) Protestant
_____ (2) Catholic
_____ (3) Jewish
_____ (4) Other
_____ (5) None

Are religious beliefs helpful to the patient?

_____ (1) Yes
_____ (2) No

Date:_____ Patient #_____

Current marital status:
_____ (1) Married
_____ (2) Single
_____ (3) Widowed

Primary medical diagnosis:
_____ (1) Cancer
_____ (2) MS
_____ (3) AIDS
_____ (4) Other

How long ago was patient told?
_____ (1) 1 day to 2 weeks
_____ (2) 2 weeks to 6 months
_____ (3) 3 to 6 months
_____ (4) 6 months to 1 year
_____ (5) more than 1 year
_____ (6) Never told

By whom was patient told:
_____ (1) Physician
_____ (2) Nurse
_____ (3) Family
_____ (4) Other
_____ (5) Knew though never told

Patient opinion of prognosis:
_____ (1) Terminal
_____ (2) Not terminal
_____ (3) Unknown or unsure

Treatment received within the last year:
_____ (1) Radiation
_____ (2) Chemotherapy
_____ (3) Surgery
_____ (4) Radiation/chemotherapy
_____ (5) Radiation/surgery
_____ (6) Chemotherapy/surgery
_____ (7) Radiation/chemotherapy/surgery
_____ (8) None

How many people close to the patient have died? _____

Who were they and how many of each?
_____ (1) Spouse
_____ (2) Parent
_____ (3) Child
_____ (4) Sibling
_____ (5) Friend
_____ (6) Other

Do not ask patient. Please indicate here what words the patient and/or care giver use to describe death.

_____ (1) Died
_____ (2) Passed on
_____ (3) Gone
_____ (4) Passed
_____ (5) Asleep
_____ (6) Other

Date:_____ Patient #_____

Which of the following tasks have you, the patient, completed?
_____ (1) Selection of grave site of other disposition
_____ (2) Funeral arrangements
_____ (3) Making a will
_____ (4) Making sure insurance and other papers are in order

Date of death:_____

Date:_____ Patient#_____

The MRDI, response sheet

Instructions: After each question is asked, please mark a bar (/) on the numbered line at a place between "Never" and "All the time." The mark should indicate how often you think the behavior asked about in each item occurs. With the interviewer, try the example question on the first line, below.

Never All the time

Ex. _____

Never All the time

1. _____

2. _____

3. _____

4. _____

5. _____

6. _____

7. _____

8. _____

9. _____

Never All the time

10. _____

11. _____

12. _____

13. _____

14. _____

15. _____

16. _____

17. _____

None All the time

18. _____

19. _____

20. _____

21. _____

22. _____

23. _____

Never All the time

24. _____

25. _____

26. _____

27. _____

Not at all As much as possible

28. _____

APPENDIX B

Research Review Committee Approval

JUN 1 6 1986

TEXAS WOMAN'S UNIVERSITY
Box 22939, TWU Station
RESEARCH AND GRANTS ADMINISTRATION
DENTON, TEXAS 76204

HUMAN SUBJECTS REVIEW COMMITTEE

Name of Investigator: Roberta P. McCanse Center: Denton

Address: P.O. Box 22871, TWU Date: 6-17-86

Denton, TX 76204

Dear Roberta McCanse,

Your study entitled The Development of an Instrument for the Measurement of Healthy Death Readiness

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

Please be reminded that both the University and the Department of Health, Education, and Welfare regulations typically require that signatures indicating informed consent be obtained from all human subjects in your studies. These are to be filed with the Human Subjects Review Committee. Any exception to this requirement is noted below. Furthermore, according to DHEW regulations, another review by the Committee is required if your project changes.

Any special provisions pertaining to your study are noted below:

_____ Add to informed consent form: No medical service or compensation is provided to subjects by the University as a result of injury from participation in research.

_____ Add to informed consent form: I UNDERSTAND THAT THE RETURN OF MY QUESTIONNAIRE CONSTITUTES MY INFORMED CONSENT TO ACT AS A SUBJECT IN THIS RESEARCH.

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

_____ Other:

_X_ No special provisions apply.

cc: Graduate School
Project Director
Director of School or
Chairman of Department

Sincerely,

Chairman, Human Subjects
Review Committee

APPENDIX C

Agency Permissions

TEXAS WOMAN'S UNIVERSITY
COLLEGE OF NURSING

AGENCY PERMISSION FOR CONDUCTING STUDY*

THE Southern Y M.C.H

GRANTS TO Roberta P. McCANSE

a student enrolled in a program of nursing leading to a Doctoral Degree at Texas Woman's University, the privilege of its facilities in order to study the following problem.

Development of an instrument for the measurement of response to life threatening illness.

The conditions mutually agreed upon are as follows:

1. The agency (may) (may not) be identified in the final report.
2. The names of consultative or administrative personnel in the agency (may) (may not) be identified in the final report.
3. The agency (wants) (does not want) a conference with the student when the report is completed.
4. The agency is (willing) (unwilling) to allow the completed report to be circulated through interlibrary loan.
5. Other _____

Date: _____

Signature of Agency Personnel

Bobbi McCanse

Signature of student

Patricia M. Mahon, PhD

Signature of Faculty Advisor

* Fill out & sign three copies to be distributed as follows: Original - Student: First Copy - Agency; Second copy - TWU College of Nursing.

TEXAS WOMAN'S UNIVERSITY
COLLEGE OF NURSING

AGENCY PERMISSION FOR CONDUCTING STUDY*

THE Community Memorial Hospital of Meramec Hills, Inc. (agency)

GRANTS TO ROBERTA P. McCANSE

a student enrolled in a program of nursing leading to a Doctoral Degree at Texas Woman's University, the privilege of its facilities in order to study the following problem.

The conditions mutually agreed upon are as follows:

1. The agency (may) (may not) be identified in the final report.
2. The names of consultative or administrative personnel in the agency (may) (may not) be identified in the final report.
3. The agency (wants) (does not want) a conference with the student when the report is completed. *
4. The agency is (willing) (unwilling) to allow the completed report to be circulated through interlibrary loan.
5. Other * The student should provide the agency with a copy of the final report

Date: 10-21-86

Signature of Agency Personnel

Bobbi McCanse
Signature of student

Patricia M. Mahon, PhD
Signature of Faculty Advisor

* Fill out & sign three copies to be distributed as follows: Original - Student: First Copy - Agency; Second copy - TWU College of Nursing.

TEXAS WOMAN'S UNIVERSITY
COLLEGE OF NURSING

AGENCY PERMISSION FOR CONDUCTING STUDY*

THE ANNA'S HAVEN HOSPICE

GRANTS TO ROBERTA P. MCCANDLE
a student enrolled in a program of nursing leading to a PhD. ~~Master's~~ Degree at Texas Woman's University, the privilege of its facilities in order to study the following problem.

READINESS FOR DEATH AMONG THE TERMINALLY ILL.

The conditions mutually agreed upon are as follows:

1. The agency (may) (may not) be identified in the final report.
2. The names of consultative or administrative personnel in the agency (may) (may not) be identified in the final report.
3. The agency (wants) (does not want) a conference with the student when the report is completed.
4. The agency is (willing) (unwilling) to allow the completed report to be circulated through interlibrary loan.
5. Other _____

Date: 11-12-85

Adrian Anderson
Signature of Agency Personnel

Roberta P McCandle
Signature of Student

Carolyn A Tanner RN PhD
Signature of Faculty Advisor

*Fill out & sign three copies to be distributed as follows: Original - Student; First copy - Agency; Second copy - TWU College of Nursing.

TEXAS WOMAN'S UNIVERSITY
COLLEGE OF NURSING

AGENCY PERMISSION FOR CONDUCTING STUDY*

THE Leavenworth Hospice

GRANTS TO Roberta P. McCANSE

a student enrolled in a program of nursing leading to a Doctoral Degree at Texas Woman's University, the privilege of its facilities in order to study the following problem.

The conditions mutually agreed upon are as follows:

1. The agency (may) (may not) be identified in the final report.
2. The names of consultative or administrative personnel in the agency (may) (may not) be identified in the final report.
3. The agency (wants) (does not want) a conference with the student when the report is completed. — not necessary but would like a copy.
4. The agency is (willing) (unwilling) to allow the completed report to be circulated through interlibrary loan.
5. Other _____

Date: 8-20-85

Signature of Agency Personnel
Patient/Family Care Coordinator

Signature of student

Patricia M. Mahon, PhD
Signature of Faculty Advisor

* Fill out & sign three copies to be distributed as follows:
Original - Student: First Copy - Agency; Second copy - TWU College of Nursing.

TEXAS WOMAN'S UNIVERSITY
COLLEGE OF NURSING

AGENCY PERMISSION FOR CONDUCTING STUDY*

THE Good Samaritan Project

GRANTS TO Roberta P. McCasse

a student enrolled in a program of nursing leading to a Doctoral Degree at Texas Woman's University, the privilege of its facilities in order to study the following problem.

Healthy Death Readiness among the Terminally Ill.

The conditions mutually agreed upon are as follows:

1. The agency (may) (may not) be identified in the final report.
2. The names of consultative or administrative personnel in the agency (may) (may not) be identified in the final report.
3. The agency (wants) (does not want) a conference with the student when the report is completed.
4. The agency is (willing) (unwilling) to allow the completed report to be circulated through interlibrary loan.
5. Other They would like a copy of the results of the study -

Date: 8/14/86

Signature of Agency Personnel

Roberta P McCasse, RN, MA
Signature of student

Patricia N. Mahon, Ph.D.
Signature of Faculty Advisor

* Fill out & sign three copies to be distributed as follows: Original - Student: First Copy - Agency; Second copy - TWU College of Nursing.

TEXAS WOMAN'S UNIVERSITY
COLLEGE OF NURSING

AGENCY PERMISSION FOR CONDUCTING STUDY*

THE _

GRANTS TO Roberta McCasse

a student enrolled in a program of nursing leading to a Doctoral Degree at Texas Woman's University, the privilege of its facilities in order to study the following problem.

DEATH READINESS AMONG THE TERMINALLY ILL.

The conditions mutually agreed upon are as follows:

1. The agency (may) (may not) be identified in the final report.
2. The names of consultative or administrative personnel in the agency (may) (may not) be identified in the final report.
3. The agency (wants) (does not want) a conference with the student when the report is completed.
4. The agency is (willing) (unwilling) to allow the completed report to be circulated through interlibrary loan.
5. Other _____

Date: 7/1/86

Signature of Agency Personnel
Director Hospice Program

Roberta P. McCasse
Signature of student

Patricia N Mahon, PhD
Signature of Faculty Advisor

* Fill out & sign three copies to be distributed as follows:
Original - Student: First Copy - Agency; Second copy - TWU College of Nursing.

TEXAS WOMAN'S UNIVERSITY
COLLEGE OF NURSING

AGENCY PERMISSION FOR CONDUCTING STUDY*

THE Milwaukee Hospice Home Care.

GRANTS TO Roberta McCance

a student enrolled in a program of nursing leading to a Doctoral Degree at Texas Woman's University, the privilege of its facilities in order to study the following problem.

The conditions mutually agreed upon are as follows:

1. The agency (may) (may not) be identified in the final report.
2. The names of consultative or administrative personnel in the agency (may) (may not) be identified in the final report.
3. The agency (wants) (does not want) a conference with the student when the report is completed.
4. The agency is (willing) (unwilling) to allow the completed report to be circulated through interlibrary loan.
5. Other _____

Date: 5/29/86

Nancy Kostka BSN.
Signature of Agency Personnel

Roberta P. McCance
Signature of student

Patricia M. Mahon, PhD
Signature of Faculty Advisor

* Fill out & sign three copies to be distributed as follows: Original - Student: First Copy - Agency; Second copy - TWU College of Nursing.

TEXAS WOMAN'S UNIVERSITY
COLLEGE OF NURSING

AGENCY PERMISSION FOR CONDUCTING STUDY*

THE

GRANTS TO Roberta McCause

a student enrolled in a program of nursing leading to a Doctoral Degree at Texas Woman's University, the privilege of its facilities in order to study the following problem.

Death Readiness among the Terminally Ill

The conditions mutually agreed upon are as follows:

1. The agency (may) (may not) be identified in the final report.
2. The names of ~~consultative~~ or administrative personnel in the agency (may) (may not) be identified in the final report.
3. The agency (wants) (does not want) a conference with the student when the report is completed.
4. The agency is (willing) (unwilling) to allow the completed report to be circulated through interlibrary loan.
5. Other _____

_____

_____

Date: 7-14-86

_____
Signature of Agency Personnel

Roberta P. McCause, RN
Signature of student

Patricia N. Thacker, Ph.D
Signature of Faculty Advisor

* Fill out & sign three copies to be distributed as follows:
Original - Student: First Copy - Agency; Second copy - TWU College of Nursing.

St MICHAEL HOSPITAL
2400 west villard avenue milwaukee, wisconsin 53209 tel (414) 527-8000

MEMORANDUM

September 29, 1986

TO: Roberta P. McCanse, RN, MAPHC

FROM: Peggy L. Wagner, RN, CNS/Cardiovascular
Chairperson, Protection of Human Subjects Committee

SUBJECT: Protocol #27: Development of an Intrument for the Measurement of the Response to Life-Threatening Illness

Your study has been approved by the Protection Of Human Subjects Committee with the following conditions:

1) That the name of the Protection of Human Subjects Committee Chair on the Consent Form be changed from Peg Wagner to Margaret Meyer, RN, Director of Nursing.

2) That it be stipulated that data will be locked separately from the code list.

Implementation of your study will be facilitated by Patti Schroeder, RN, MSN. Please contact her at 527-8276 for assistance.

PLW:gw

ST. MARY'S HOSPITAL
M·I·L·W·A·U·K·E·E

October 16, 1986

Ms. Roberta P. McCanse
3339 North Cramer Street
Milwaukee, WI 53211

Dear Ms. McCanse:

Thank you for presenting your proposal to our Nursing Research Committee. I am pleased to inform you that it has been approved by the committee for study at St. Mary's Hospital.

Please contact Janet Lotegeluaki, RN, MSN, Director - 7th Floor/Hospice, at 225-8070, to make arrangements to begin your study. She will be available to you for any assistance you might need throughout your study.

A copy of the final report must be sent to me, as committee chairperson, at the conclusion of the study. If the study continues for over one year, an interim report should be submitted.

Please feel free to also call me for any assistance.

Sincerely,

Delores Parsons, RN, CCRN
CNS/Supervisor - SICU

DP:sa
enclosure

2323 North Lake Drive • P.O. Box 503 • Milwaukee WI 53201-0503 • Phone 414-225-8000
Member Daughters of Charity Health System – East Central

APPENDIX D

Consent Form

TEXAS WOMAN'S UNIVERSITY
HUMAN SUBJECTS REVIEW COMMITTEE

CONSENT FORM B

Title of Project: Dealing with Terminal Illness

Consent to Act as a Subject for Research and Investigation:

I have received an oral description of this study, including a fair explanation of the procedures and their purpose, any associated discomforts or risks, and a description of the possible benefits. An offer has been made to me to answer all questions about the study. I understand that my name will not be used in any release of the data and that I am free to withdraw at any time. I further understand that no medical service or compensation is provided to subjects by the university as a result of injury from participation in research.

_____ _____
Signature Date

_____ _____
Witness Date

Certification by Person Explaining Study:
This is to certify that I have fully informed and explained to the above named person a description of the listed elements of informed consent.

_____ _____
Signature Date

_____
Position

_____ _____
Witness Date

One copy of this form, signed and witnessed, must be given to each subject. A second copy must be retained by the investigator for filing with the chairman of the Human Subjects Review Committee. A third copy may be made for the investigator's files.

Informed Consent

Development of an Instrument for the Measurement of Response to Life Threatening Illness

I request your participation in helping me develop a questionnaire with which to measure how people best respond to life threatening illness. I am asking hospice patients, their caregivers and nurses, and cardiac rehabilitation patients to participate in this study. Before you decide whether or not to participate, you have the right to obtain complete information about this study in non-medical language.

Participation in this study is voluntary. If you decide not to participate, your care will not be affected in any way. Your name will not be identified at any time. If you decide to withdraw, information collected up to that point would be destroyed, if you request.

If you participate I will ask you 28 questions about things patients do or feel. I will also ask you questions about your age and things that have happened to you during your life. In a week or two I would like to come back and ask you, the patient, the original 28 questions again.

It will take about 10 to 15 minutes to answer all of the questions each time. If you become too tired to answer all of the questions we will stop. You may refuse to answer any or all of the questions at any time.

There will be no risk associated with participation in this study, only the inconvenience of the time it takes for you to answer the questions. Some of the questions are more sensitive than others. Some questions may make you feel anxious or sad.

We will have time to talk about any feelings you have after you have answered the questions. The researcher is a nurse educator and has been a hospice nurse and is capable of helping you discuss any issues you may wish to raise or questions you may wish to ask. It is hoped that the questionnaire will eventually help nurses find out how to give better care and support to patients with life threatening illnesses.

This study has been approved by the St. Michael Hospital Nursing Department Protection of Human Subjects Committee and by the Texas Woman's University Human Subjects Review Committee. Participation will not affect the cost of your care in any way.

Although this study could have been done only with people close to patients, and not with patients themselves, it was felt that the most accurate information would be obtained directly from those who are ill. Caregivers and nurses are also being asked to answer the questions so that we can see how closely they will estimate patient responses. If the estimates are very good the questions may eventually be asked only of the caregiver and nurse when the patient is too ill to be disturbed.

Your name will not be used in any way. I will not release any of the information you share to anyone in any way that could identify you.

2476n/433C/1
9/86

Informed Consent (continued)

After the study is completed, in about six months, you may obtain a copy of the results by contacting the researcher. A summary of the study may be published in the nursing literature without identifying any names.

If you have any questions regarding the study, I will be happy to answer them now or later. It is important that you understand completely your role in the study before you decide whether or not to participate. If you have any questions about the study, please call or write:

Roberta McCanse, R.N., M.A.
University of Wisconsin-Milwaukee
School of Nursing
Box 413
Milwaukee, Wisconsin 53201
414-963-6237 (weekday mornings)

If you have any complaints about this study, please call or write:

Margarette Meyer, RN, Director of Nursing
Chairperson, Protection of Human Subjects Committee
St. Michael Hospital
2400 W. Villard Avenue
Milwaukee, Wisconsin 53209
414-527-8276
Hours: 8:00 a.m. to 4:30 p.m.

Your concern will be held in confidence, although Ms. Meyer will ask for your name.

Thank you for consideration of this request.

I have received an explanation of the study. I have carefully read this consent and understand that I may withdraw at anytime without penalty, and agree to participate.

Signature of participant Date

Signature of researcher who obtained this consent from participant Date

2476n/433C/1
9/86

Informed Consent

Development of an Instrument for the Measurement of Response to Life Threatening Illness

I request your participation in helping me develop a questionnaire with which to measure how people best respond to life threatening illness. I am asking hospice patients, their caregivers and nurses, and cardiac rehabilitation patients to participate in this study. Before you decide whether or not to participate, you have the right to obtain complete information about this study in non-medical language.

Participation in this study is voluntary. If you decide not to participate, your care will not be affected in any way. Your name will not be identified at any time. If you decide to withdraw, information collected up to that point would be destroyed, if you request.

If you participate I will ask you 28 questions about things patients do or feel. I will also ask you questions about your age and things that have happened to you during your life. In a week or two I would like to come back and ask you, the patient, the original 28 questions again.

It will take about 10 to 15 minutes to answer all of the questions each time. If you become too tired to answer all of the questions we will stop. You may refuse to answer any or all of the questions at any time.

There will be no risk associated with participation in this study, only the inconvenience of the time it takes for you to answer the questions. Some of the questions are more sensitive than others. Some questions may make you feel anxious or sad.

We will have time to talk about any feelings you have after you have answered the questions. The researcher is a nurse educator and has been a hospice nurse and is capable of helping you discuss any issues you may wish to raise or questions you may wish to ask. It is hoped that the questionnaire will eventually help nurses find out how to give better care and support to patients with life threatening illnesses.

This study has been approved by the St. Mary's Hospital Nursing Department and medical staff Protection of Human Subjects Committee and by the Texas Woman's University Human Subjects Review Committee. Participation will not affect the cost of your care in any way.

Although this study could have been done only with people close to patients, and not with patients themselves, it was felt that the most accurate information would be obtained directly from those who are ill. Caregivers and nurses are also being asked to answer the questions so that we can see how closely they will estimate patient responses. If the estimates are very good the questions may eventually be asked only of the caregiver and nurse when the patient is too ill to be disturbed.

Your name will not be used in any way. I will not release any of the information you share to anyone in any way that could identify you.

2476n/433C/1
10/86

Informed Consent (continued)

After the study is completed, in about six months, you may obtain a copy of the results by contacting the researcher. A summary of the study may be published in the nursing literature without identifying any names.

If you have any questions regarding the study, I will be happy to answer them now or later. It is important that you understand completely your role in the study before you decide whether or not to participate. If you have any questions about the study, please call or write:

Roberta McCanse, R.N., M.A.
University of Wisconsin-Milwaukee
School of Nursing
Box 413
Milwaukee, WI 53201
414-963-6237 (weekday mornings)

If you have any complaints about this study, please call or write:

Jan Loteluaki, Director
St. Mary's Hospice Unit
2320 N. Lake Drive
Milwaukee, WI 53211
414-225-8025

Your concern will be held in confidence, although Ms. Loteluaki will ask for your name.

Thank you for consideration of this request.

I have received an explanation of the study. I have carefully read this consent and understand that I may withdraw at anytime without penalty, and agree to participate.

Signature of participant Date

Signature of researcher who obtained this consent from participant Date

2476n/433C/1
10/86

APPENDIX E

Explanation of Study

THE UNIVERSITY OF WISCONSIN—MILWAUKEE/P.O. Box 413, Milwaukee, Wisconsin 53201

SCHOOL OF NURSING (414) 963-4801

Dear Cardiac Rehabilitation Participant:

My name is Bobbi McCanse. I am a graduate student in nursing at Texas Woman's University and I teach nursing at the University of Wisconsin-Milwaukee. I am doing research about the ways in which people deal with serious illness. I would like to ask you some questions about who you are and then 28 questions about things you do or feel. It takes about 10 minutes to answer the questions. By answering the questions you will help nurses learn more about the feelings of seriously ill people so that we may give them better care.

Because the questions were originally intended for use with terminally ill people some of them may seem inappropriate to you. I am trying to find out if the questions are answered differently by dying people and people like you who are not dying. Some of the questions are more sensitive than others. Some questions may make you anxious or sad. We will have time to talk about these feelings, if you like, after you have answered the questions. You may refuse to answer any or all of the questions at any time. Your participation is voluntary and will not affect your participation in the Y.M.C.A.'s program in any way.

I will ask you not to put your name on any page of the questionnaire. I may use a number code to keep your questionnaire together with those of other rehabilitation program participants. No ones name will ever appear in any data or in my papers or in any publication related to this study.

Thank you for considering whether or not you would like to participate in my study.

Bobbi McCanse, RN, MA, Ph.C.

BMcC/wb
9/86

Dear Hospice Patient and Care giver:

My name is Bobbi McCanse. I am a graduate student in nursing at Texas Woman's University and I have been a hospice nurse. I am doing research about the ways in which people deal with serious illness. I would like to ask both of you, and your hospice nurse, 28 questions about things you do or feel. By answering the questions you will help nurses learn more about the feelings of seriously ill people so that we may give them better care.

In a week or two I would like to come back and ask you the same questions again. It will take about 10 to 15 minutes to answer all of the questions each time. Some questions are more sensitive than others. Some questions may make you feel anxious or sad. We will have time to talk about these feelings after you have answered the questions. If you become too tired to answer all of the questions, we will stop. You may refuse to answer any or all of the questions at any time. Your participation is voluntary and will not affect your care from the hospice or their services to you in any way.

No names will ever appear in any data or in my papers or in any publication related to this study. I may use a number code to keep all of your questionnaires together.

Thank you for your time and for considering whether or not you would like to participate in this study.

Bobbi McCanse, R.N., M.A., PhC.

APPENDIX F

Graduate School Permission to Conduct Study

TWU Texas Woman's University
P.O. Box 22479, Denton, Texas 76204 (817) 898-3400, Metro 434-1757, Tex-An 341-3400

THE GRADUATE SCHOOL

August 28, 1986

Ms. Roberta L. McCanse
Box 22871 - TWU Station
Denton, TX 76204

Dear Ms. McCanse:

I have received and approved the Prospectus for your research project. Best wishes to you in the research and writing of your project.

Sincerely,

Leslie M. Thompson
Provost

ay

cc: Dr. Patricia N. Mahon