Montanas voices on end of life decisions
by Diane Lynn Jones

A thesis submitted in partial fulfillment of the requirements for the degree of Master of Nursing
Montana State University
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Abstract:
The purpose of this qualitative research study was to identify the values, opinions and attitudes of a
sample of rural Montanans in the area of end-of-life decisions. Understanding the values, opinions and
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Die with Dignity (Tyler, Perry, Lofton & Millard, 1997). The grounded theory method was used in this
study as a means to obtain and analyze data in discovery of the perspectives of a rural Montana sample
about end-of-life decisions. Two focus group interviews were conducted with participants from one of
three remote rural counties in Montana. A convenience sample of a total of 19 adults was utilized.
Collection of data occurred through semi-structured focus group interviews and observations.

The major outcome of the study was the development of a conceptual model entitled “End-of-Life
Decisions: Rural Values and Perspectives”. The natural world view was the core variable of the study
and contained the properties of unpretentiousness, a natural life-death cycle, and an ideal place and way
to die. Other variables included free choice; family advocacy and responsibility; trust in local provider;
mistrust of health care system; and barriers to end-of-life care which contained the properties of lack of
resources, distance and isolation, lack of knowledge, and coping abilities.

The research results can be used by health care professionals to better understand the rural people of
Montana in the area of end-of-life decisions. Implications of the study include (a) recognizing the value
of the provider/patient relationship as a trusting partnership from which end-of-life decisions can be
made, (b) the need to incorporate advance care planning into family practice, (c) the importance of
recognizing individual values and perceptions when planning end-of-life care, (d) the need for further
research regarding how to provide resources for end-of-life care in the rural setting.
MONTANA’S RURAL VOICES ON END-OF-LIFE DECISIONS

by

Diane Lynn Jones

A thesis submitted in partial fulfillment of the requirements for the degree of Master of Nursing

MONTANA STATE UNIVERSITY-BOZEMAN
Bozeman, Montana

May, 2000
APPROVAL

of a thesis submitted by

Diane Lynn Jones

This thesis has been read by each member of the thesis committee and has been found to be satisfactory regarding content, English usage, format, citations, bibliographic style, and consistency, and is ready for submission to the College of Graduate Studies.

Dr. Janice Buehler  
(Signature)  
5/2/00  
Date

Approved for the Department of Nursing

Dr. Lea Acord  
(Signature)  
5/10/00  
Date

Approved for the College of Graduate Studies

Dr. Bruce McLeod  
(Signature)  
6-7-00  
Date
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Date  5/4/2000
This thesis is dedicated to Montana's rural voices.
ACKNOWLEDGMENTS

The continuous encouragement from my husband Bob, children Jennifer and Christopher, sister Nancy, and friend Leta were deeply appreciated. I especially thank my husband for his devoted support during periods of immense transition. My family and friends brought humor and hope to an often intense process.

A heartfelt thanks is extended to the 19 participants of the study whose openness and willingness to share their values, perspectives and time provided the rich basis for this study and revitalized my belief in humanity. I also wish extend my appreciation to Bev Tyler, one of the authors of the national study, *The Quest to Die with Dignity* (1997), for allowing me to replicate the study on a rural level, and for her assistance in the early development of this study.

My thesis committee members were Dr. Jan Buehler, Dr. Vonna Koehler and Jean Ballantyne. Thank you all for your guidance, patience and expertise. I am especially grateful to Dr. Buehler for introducing me to the world of qualitative research which has allowed me to gain new insight into the complexities of the human condition.

Finally, I want to thank the physicians and nurses from my home town who believed in my abilities over the years and who continue to demonstrate what it is to be truly caring professionals.
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ABSTRACT

The purpose of this qualitative research study was to identify the values, opinions and attitudes of a sample of rural Montanans in the area of end-of-life decisions. Understanding the values, opinions and attitudes of the sample provides insight regarding how to communicate with rural people regarding end-of-life issues and decisions.

This study was a replication of a national study entitled *The Quest to Die with Dignity* (Tyler, Perry, Lofton & Millard, 1997). The grounded theory method was used in this study as a means to obtain and analyze data in discovery of the perspectives of a rural Montana sample about end-of-life decisions. Two focus group interviews were conducted with participants from one of three remote rural counties in Montana. A convenience sample of a total of 19 adults was utilized. Collection of data occurred through semi-structured focus group interviews and observations.

The major outcome of the study was the development of a conceptual model entitled “End-of-Life Decisions: Rural Values and Perspectives”. The natural world view was the core variable of the study and contained the properties of unpretentiousness, a natural life-death cycle, and an ideal place and way to die. Other variables included free choice; family advocacy and responsibility; trust in local provider; mistrust of health care system; and barriers to end-of-life care which contained the properties of lack of resources, distance and isolation, lack of knowledge, and coping abilities.

The research results can be used by health care professionals to better understand the rural people of Montana in the area of end-of-life decisions. Implications of the study include (a) recognizing the value of the provider/patient relationship as a trusting partnership from which end-of-life decisions can be made, (b) the need to incorporate advance care planning into family practice, (c) the importance of recognizing individual values and perceptions when planning end-of-life care, (d) the need for further research regarding how to provide resources for end-of-life care in the rural setting.
CHAPTER 1

INTRODUCTION

As a director of nursing, and later administrator, of a rural Montana hospital and nursing home, I worked to raise awareness in my community regarding end-of-life decisions and advance directives. I presented talks about the issues at local community groups, discussed the Patient Self-Determination Act with professional staff, and set policies in accordance with federal requirements at my workplace. I felt frustrated that no one, including myself, seemed to fully understand the complicated, and sometimes vague, language and procedures presented in the documents “Durable Power of Attorney” and “Living Will.” It occurred to me that the health care documents related to end-of-life decisions were jargon-ridden and were difficult for not only the general population to understand, but for health care professionals to utilize as well. Confusion frequently arose in deciphering the medical/legal terms into a language that could be understood by people unfamiliar with such specialized vocabulary. In addition, and most importantly, I had the impression that neither health care professionals nor local lay persons felt comfortable communicating about end-of-life issues, no matter what the language.

The concept of end-of-life issues has become a more pertinent and widespread social concern in recent decades. By the 1950s, advances in medical technology allowed terminally ill and permanently unconscious persons, who in earlier decades died quickly
from complications or from an inability to eat and drink, to be kept alive dramatically longer than ever before. The new-found capability of medical science brought difficult end-of-life issues into the lives of many dying patients. In situations where the course of nature once seemed unalterable, physicians, patients and families suddenly needed to make decisions about when a life should end.

For nearly twenty years advance directives have been required in America, yet signing rates are far from universal (Doukas, 1999). The Patient Self-Determination Act was enacted in December 1991. The purpose of the Act was to ensure that clinical care was in keeping with the preferences of the patient when the patient had become incapable of decision making. Although implemented in the early 1990s, the Act has not had a major impact on patient awareness, understanding or use of advance directives. Fewer than 40 percent of hospitalized patients have advance directives (Emanuel, Weinberg, Gonin, Hummel & Emanuel, 1993). Advance directives remain under utilized and evidence suggests postponing discussion of these issues until the patient is hospitalized and seriously ill may prove too late for any beneficial effect. According to a study done by Nolan and Bruder (1997), almost all of the hospitalized subjects studied expressed a preference of issuing advance directives when healthy, prior to hospitalization.

**Background of Study**

A national study entitled *The Quest to Die with Dignity* (Tyler, Perry, Lofton, & Millard, 1997), approached the importance of end-of-life issues from a grassroots level.
Funded by the Robert Wood Johnson Foundation, the study sought to analyze American values, opinions and attitudes concerning end-of-life care. Data collection for the research was accomplished through the use of focus groups. The researchers believed the focus group setting provided an atmosphere in which participants could talk about personal experiences and consider decisions that had moral implications. Three hundred eighty-five individuals participated in 36 focus groups around the nation. Four of the focus groups were identified as “rural.” However, the population of those rural communities ranged in size of 15,000 to 50,000 (U.S. Census Bureau, 1999). None of the designated “rural” communities in the national study were as sparsely populated as Montana’s rural population.

By applying the same methodology used in the national study to a rural Montana sample, a platform for discussion would be established to allow rural dwellers to explore and reflect about what was important to them when life ends. Understanding the values and perspectives of the sample may provide insight about how to communicate with rural people regarding end-of-life issues and decisions. The resulting information from the rural study could then be used to increase patient awareness of advanced directives and to provide a mechanism which would allow the patient to make decisions before becoming gravely ill or facing terminal illness.
Purpose of Study

The purpose of this study was to identify the values, opinions and attitudes about end-of-life decisions of a sample of rural Montanans. Through this study, it has been possible to identify the language that those rural Montanans used to communicate their understanding of end-of-life decisions, their viewpoints toward death and dying, and how they want to be treated as the end of life draws near.

Theoretical Perspective

The qualitative method of grounded theory was used in this study. Grounded theory provides a means of understanding behavioral patterns from the perspective of the participants (Buehler, Malone & Majerus, 1998). Likewise, grounded theory provides a useful approach to gain understanding of social processes and problems. The examination of values, opinions and attitudes about death and dying, as a complex process of human expression, lends itself to the grounded theory approach. Grounded theory allows for the direct examination of the world of rural residents in a naturalistic way (Schatzman & Strauss, 1973).

Grounded theory has its philosophical roots in the symbolic interactionist perspective and was developed by Barney Glaser and Anselm Strauss (1967). The symbolic interactionist perspective provides a useful approach to understanding interaction and human behavior. Symbolic interactionists view human behavior as a
process whereby the individual interprets events to derive meaning. Perceived meaning then serves as a guide to action (Chenitz & Swanson, 1986).

Identification of the values, opinions and attitudes about end-of-life issues and decisions of a rural Montana population was the goal of this study. Through identification of those values, opinions and attitudes, an understanding of what the sample perceived as important in regard to end-of-life issues and decisions was achieved.

**Complexity in Defining Rural**

The definition of rural has been a struggle for all who have tackled defining the term including researchers, policy makers and the U.S. Census Bureau. The great diversity in rural America causes the concept of, and operationalization of, the term to be quite diverse (Lee, 1991). The word “rural” evokes images of agriculture, rustic countryside, and simple living. Lee observes rural may mean “a place to get away from”, and yet for others it may mean “a place to get away to” (Weinert and Boik, 1998, p.449).

The U.S. Census Bureau defines urban as comprising all territory and population in urbanized areas. Urban includes places of 2,500 or more persons living outside urbanized areas. Rural is defined as places of less than 2,500 people. Rural consists of areas outside incorporated places and rural portions of extended cities. Furthermore, rural population is subdivided into “rural farm”, containing those households on farms; and “rural non-farm”, consisting of the remaining rural areas (U.S. Census Bureau, 1995).
Rural Montanans: The Population of Interest

Being "rural" in Montana has a more specific meaning. In 1900 there was a ratio of 1.67 inhabitants to the square mile in Montana (Malone, 1999). There are now an estimated 870,281 people living in Montana, or 5.5 inhabitants per square mile (U.S. Census, 1999), continuing to give Montana its well earned designation as a rural state. Forty-seven percent of the Montana population lives in communities with 2,500 or less inhabitants. Scharff (1998, p.21-22) states: “Being rural means being a long way from anywhere and pretty close to nowhere. Being rural means being independent or perhaps just being alone...knowing rural means knowing that what one knows may be all one has.”

Definitions of Terms

For purposes of this study the definitions of urban, rural and remote rural were used based on those developed by Koehler (1998).

Urban. Urban was defined as a community with a population of 50,000 or greater. An urban community contains at least one hospital of 100 beds or more and has at least two medical clinics containing a variety of practicing physicians, including a full selection of medical specialists available for referral and consultation.

Rural. Rural was defined as a community with a population no larger than 10,000, located at least 15 miles away from a city with a population of 50,000 or greater. Rural communities have a local hospital, and at least one practicing medical provider residing in the community. Small communities that do not have a local hospital, or
resident medical provider but lie within a 15- to 39-mile radius of an adjacent urban community were also defined as rural.

**Remote Rural.** Remote rural was defined as a community with a population of 2,500 or less located 40 miles or further from a city with a population of 50,000 or greater (Koehler, 1998). Remote rural communities may or may not have a hospital or medical provider in residence. Counties with inhabitants of less than 2 people per square mile are also considered remote rural (U.S. Bureau of Census, 1999). The remote rural area is the setting where the research study was located, in two counties in Montana with less than 2 people per square mile.

**Advance Directive.** An advance directive is an oral and/or written instruction about a person’s future medical care in the event he or she becomes unable to communicate. There are two types of advance directives: a living will and a durable (health care) power of attorney (Aitken, 1999).

**End-of-Life Decision.** The process (rather than a single consultation or the signing of a statutory document) of discussing end-of-life care with the patient and developing a valid expression of the patient’s wishes regarding future medical care (Aitken, 1999).

**Patient Self-Determination Act.** The federal law that requires health care facilities receiving Medicaid and Medicare funds to inform patients of their right to execute advance directives.
Assumptions & Limitations

It was assumed that the grounded theory approach would facilitate new insight into the “rural Montanan” perspective regarding end-of-life matters. It was not the purpose or intent of this study to define or describe the entire value and belief systems of the sample regarding end-of-life decisions. No general conclusions or inferences can be made regarding values of the sample as a whole. Instead, comparisons are made to detect areas of similarity and difference between the findings of the national study *The Quest to Die with Dignity* (Tyler et al., 1997), and those of the rural sample in order to provide a greater understanding which may lead to improving the death and dying process for rural Montanans.
CHAPTER 2

REVIEW OF LITERATURE

Historical Background

Advanced directives began to unfold in the United States in the 1970s and 1980s following the highly publicized cases of two women, Karen Quinlan and Nancy Cruzan, who were kept alive in vegetative state for a number of years, against the wishes of their families. In years prior to the 1970s, end-of-life decisions were made by physicians who knew the patient and the family. Now, people who die in hospitals are often treated by specialized physicians who may not know them. The changing physician-patient relationship has been accompanied by advances in technology and increased longevity. Subsequently, there are an increased number of people who are living to a serious, debilitating state.

The President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research (1983) supported the principle of shared decision making between patient and health care provider and reported that an advance directive was a statement by a competent person indicating his wishes in the event of future incompetence. An early article by Davidson and Moseley (1986) cited the major reasons medical professionals were reluctant to use advance directives during this time were because of procedural difficulties rather than theoretical defects with advance directives.
Confusion over types of directives and ambiguous language found in the directives were cited as reasons for lack of completion.

In an effort to support and protect the rights of patients at the end of life, the Patient Self-Determination Act (PSDA) was passed by Congress in 1990. The Act, implemented in December of 1991, requires hospitals, health maintenance organizations (HMOs), home health agencies, hospices, and skilled nursing facilities receiving Medicare and Medicaid reimbursement to educate patients, staff, and the local community about advance directives; retain patient advance directive documents in the patient record; and develop written policies regarding advance directives (Omnibus Budget Reconciliation Act, 1990).

The purpose of the act was to educate health professionals and consumers regarding the rights of health care consumers to make decisions in advance of what life sustaining measures they might want in the event of a terminal illness when they are no longer able to speak. Additionally, the act delineated the right of the health care consumer to designate someone to make end-of-life decisions, in the event that he/she was unable to do so, by preparation of a durable power of attorney.

**Efficacy of the Patient Self-Determination Act (PSDA)**

With the deadline of December 1, 1991, looming ahead, initial literature in regard to the PSDA was directed toward hospitals and preparation for compliance with the new federal law on advance directives. Hospitals would be required to ask whether every patient admitted had an advance directive, e.g., a living will or a durable power of
attorney (Hudson, 1991). Follow-up studies of patient attitudes were conducted to
determine whether patients were receiving information regarding end-of-life care options
from their physicians while in the hospital, nursing home or outpatient setting (Hare &
Nelson, 1991; Terry & Zweig, 1994). In general, these studies found although patients
were receiving information about end-of-life care options, completion of an advance
directive was far from universal. The importance of physician/patient communication in
regard to formulating advanced directives was reinforced.

Attitudes and knowledge levels of physicians and health care professionals in the
area of advance directives was studied repeatedly throughout the 1990s to gain
understanding of barriers to completion (Dimond, 1994; Doukas & Brody, 1992; Fade,
1994; Singleton, Dever & Donner, 1992; Watt, 1995). Although health care provider
attitudes about advance directives were positive, most commonly cited reasons for failure
to discuss the issue with patients included lack of proper forms or a place to refer the
patient. Reluctance by physicians, except in limited life threatening illness, to initiate a
dialogue about advance directives was also a contributing factor (Brunetti, Carperos &

A 1993 study by Robinson, DeHaven and Koch explored the effects of the
Patient Self-Determination Act (PSDA) on hospitalized patient knowledge and behavior.
The study results showed the measures employed by the hospital to meet the PSDA
requirements increased patient awareness of living wills. However, those measures
failed to increase the number of patients who acted on the awareness. The study found
that simply informing patients about their right of self-determination was insufficient to meet the intended goals of the PSDA legislation.

Repeatedly, the theme of communication among physicians, nurses and patients when confronting life-threatening or terminal illness was a focus of study (Hanson, Tulsky & Danis, 1997; Virmani, Schneiderman, & Kaplan, 1994; Palker, & Nettles-Carson, 1995). Although some health facilities and organizations launched aggressive patient education campaigns concerning advance directives, the number of patients reporting that they had issued advance directives ranged from 0.4% to 30% (Rubin, Strull, Fialkow, Weiss, & Lo, 1994; Reilley, Wagner, Ross, Magnussen, Papa, & Ash, 1995; Gilligan, & Jensen, 1995; Perry, Nicholas, Molzahn & Dossetor, 1995). Studies examined the impact that content and timing of advance directive information had on the frequency of directive selection. For example, oncology patients indicated a preference that advance directive information be provided prior to hospitalization (Haisfield, McGuire, Krumm, Shore, Zabora, & Rubin, 1994). Findings in another study indicated that most primary care patients thought discussions concerning advance directives should be initiated by the provider, before the patient reached the age of 50 years, early in the disease process and in an outpatient setting (Johnston, Pfeifer, & McNutt, 1994).

A well-publicized controlled trial to improve care for seriously ill hospitalized patients was published in *The Journal of the American Medical Association* (SUPPORT Principal Investigators, 1996). The Study to Understand Prognoses and Preference for Outcomes and Risks of Treatment (SUPPORT) was the first large scale, prospective study of dying patients in the United States and had broad implications for care of
patients near the end of life. The study was conducted in five major medical centers and focused on specific diagnostic categories. Data from the SUPPORT trial provided a picture of the failure to address the needs of dying patients. The four-year, two-phased study included 9,105 seriously ill patients. The phase one observational component of the study confirmed substantial shortcomings in care for seriously ill hospitalized adults. The phase two intervention failed to improve care or patient outcomes (SUPPORT, 1996; Doukas, 1999).

According to a study by Jacobson, White, Battin, Francis, Green, & Kasworm (1994), 302 randomly selected patients were interviewed to determine understanding of advance directives. Although 90% of the patients were aware of the living will, only one-third selected the correct definition or the correct circumstances in which it applied. Less than 20% of patients had completed a directive and those who had did not demonstrate better understanding of these documents.

Barriers other than information and access to documents appeared to be involved in completion of advance directives. Dr. Wendy Adams, a physician from Omaha, Nebraska wrote:

One possible explanation for our inability to change clinical outcomes through better documentation of advance directives has been the language in which the documents are written. Despite painstaking efforts to reduce hospital do-not-resuscitate policies (advance directives) to their bare minimums, housestaff and attending physicians alike often find the policies cumbersome and difficult to interpret. These policies are made more obtuse by language that attempts to cover every contingency but is too vague to serve as a guide in any particular situation. Appropriate patient care remains an issue that often frustrates and leads to unwanted and costly treatments (1997, p. 4).
Rural Studies

Although numerous studies, linked to health care agencies, have been conducted regarding end-of-life issues and decisions, few were found in the literature to have focused specifically on the perspective of rural dwellers. A study completed in a rural county in North Carolina focused on elderly persons living in the community regarding their knowledge, attitudes and behavior regarding advance directives. Fifty-two percent of the 75 ambulatory elderly persons studied said they were familiar with living wills. When asked about preferences for medical care in the setting of a terminal illness, eighty-six percent stated a desire to receive basic medical care or comfort care only. Of the 75 participants, none had signed the living will available in North Carolina and only two had discussed a living will with their physician (Gamble, McDonald, & Lichstein, 1991).

Two communities of 50,000 in the United States are undertaking separate community wide advance directive education projects. In LaCrosse, Wisconsin, a program called “Respecting Your Choices” has been developed out of the LaCrosse Area Medical Center Task Force on Advance Directives. The components are locally developed patient education materials; access to and availability of the advance directive materials throughout the community; training and resources for educating a large core group of non-physician educators; common policies and practices for maintaining and using advance directive documents, including broad physician involvement; and documentation of advance directives in the patient’s medical record with systems in
place to ensure the information travels with the patient across care settings (Hammes & Rooney, 1998).

In Missoula, Montana, Dr. Ira Byock has developed a collaborative community wide effort called the Missoula Demonstration Project (MDP) with the objectives to study and transform end-of-life experience and care. Local hospitals, nursing homes and home health providers in Missoula are actively participating, along with many of the town’s physicians and nurses, healthcare aides, social workers and emergency medical technicians. Initially MDP focused on research and now is employing research findings to achieve success in providing broad spectrum quality end-of-life care for the entire community (Byock, 1999).

In summary, many studies have been conducted to identify the barriers to completion of advance directives. Barriers include procedural difficulties and the vague language found in advance directives. Attitudes and knowledge levels of health care professionals, patients and families are also reasons for lack of completion of directives. Recent studies have focused on the need for shared decision-making and increased communication between health care provider and patient. Community wide efforts to increase public awareness of advance directives and care at the end of life are current areas of study.

Long and Weinert identified that “many health care needs of rural dwellers cannot be adequately addressed by the application of nursing models developed in urban or suburban areas but require unique approaches emphasizing the special needs of this population” (1998, p. 3). Although rural nursing theory development is on the increase,
no literature was found specific to end-of-life care and decision-making of the rural resident. Further study of the values, opinions and attitudes of the rural dweller is needed to increase understanding of their perceptions surrounding end-of-life care and to identify if other studies are applicable to end-of-life planning and care of this population. The purpose of this study is to identify the values, opinions and attitudes about end-of-life issues and decisions of a rural Montana sample.
CHAPTER 3

METHODOLOGY

Introduction

The grounded theory method was used in this study as a means to obtain and analyze data in the discovery of the perspectives of a rural Montana sample about end-of-life decisions. Because qualitative methods focus on the whole of human experience and the meanings ascribed by individuals living such experiences, broader understanding and deeper insight into complex human behaviors can be obtained. In recognition of the multidimensional nature of human beings, nursing research has as its goal to advance knowledge and understanding of human responses to health and illness within the context of the sociocultural experience of the individual or family (Koehler, 1998).

There is a scarcity of information in the literature in the area of end-of-life care and the rural dweller. Grounded theory lends itself well to the discovery of the rural perspective and development of ideas to address the potential end-of-life needs and desires of this population. This chapter includes an overview of the method, sample, data collection, and analysis used in the study.
Grounded Theory Method

Barney Glaser writes:

Grounded theory is ideational; it is a sophisticated, careful method of idea manufacturing. The conceptual idea is its essence. The best way to produce is to think about one's data to generate ideas. The relative emphasis when generating is on thinking as opposed to learning. It is assumed that the analyst can learn well, has learned a great deal in the past, and will continue to learn in the future. Focusing on generating ideas that fit and work the data takes considerable thought (1978, p. 7).

Grounded theory asks two formal questions: 1) What is the chief concern or problem of the people in the substantive area, and what accounts for most of the variation in processing the problem? 2) What category or what property of what category does this incident indicate? These questions are asked by the researcher while constantly comparing data, incident to incident. Soon through this effort, categories and their properties emerge which fit and work and are of relevance to the processing of the problem. Grounded theory allows the relevant socialpsychological organization of the people studied to be discovered (Glaser, 1992). The interpretive researcher aims to discover the unarticulated problem and process.

The researcher must study what is to be studied without preconception of what should be in advance of its emergence (Glaser, 1992). In order to do this, I identified any of my own personal biases about the phenomenon of interest to clarify how my personal experiences and beliefs might color what was heard and reported. I put aside my personal biases, by “bracketing” them, when engaged with the participants.
The participants for this study were from one of three remote rural counties in south central Montana where the population per square mile was 1.7, 1.6, and 0.8 persons respectively (U.S. Census, 1992). A convenience sample of 19 adults was utilized and most subjects were known to me. I believed them to be articulate members of the remote rural population. Two of the subjects were recommended to me by other participants of the sample. Sample selection included individuals who had resided in Montana for 20 years or more on a farm, ranch or rural area. The sample was Caucasian, indicating under representation of minorities and possibly emphasizing the remoteness of the population studied from urban areas or other minority groups in the state. The participants included a mixture of individuals with various incomes, education levels and gender. Specific income data were not obtained.

Human Subjects

An ethical issue unique to focus groups arises from the fact that the material that participants share with the researcher is inherently shared with other participants as well (Morgan, 1988). This raised invasion of privacy issues and human subject rights for the sample that were protected by the following procedure. An initial phone contact was made with each participant which provided information about the study and was used to obtain verbal consent (see Appendix A). A consent form was then sent to each participant for signature and included the purpose of the study, a right to withdraw.
consent at any time during the interview and assurance of confidentiality (see Appendix B). A stamped return envelope was provided each recipient to return the written consent to the researcher.

At the start of each focus group, each informant was provided a copy of the signed consent form and reminded of their rights. In addition, the duration, benefits and risks, and the voluntary nature of participation was shared. Permission for audiotape recording the interview was included in the written consent. The written consent also included benefits and risks.

No benefits to study participants were promised. However, through participation in the focus groups, participants had an opportunity to share and identify their values, opinions and attitudes about end-of-life issues and decisions. Potential risks associated with the study included emotions that might have been triggered by questions contained in the interview. The researcher endeavored to serve as an interested listener for the study participants who wanted to discuss their feelings about end-of-life issues and decisions. Should any participant have become emotionally distraught, the interview would have been stopped, and the individual given opportunity to discontinue participation. The interview approach allowed the participants to share as much or as little as desired.

The study was approved by the College of Nursing Human Subjects Review Committee of Montana State University, Bozeman, Montana. Due to the sparse population of south central Montana and the small sample size, no specific locations were mentioned in order to protect the identities of informants.
Data Collection

Historically, focus groups have had their roots in business and the social sciences and have been used as a self-contained means of data collection and as a component of larger research programs. Focus groups are now widely used in qualitative studies in nursing as well as in the social behavioral sciences and marketing. Focus groups serve well as a basis for grounded theory development. The primary advantage of focus groups is the use of group interaction to produce data and insights that may not be as accessible without the interaction of the group members (Morgan, 1988).

Subjects were organized into one of two focus groups. A convenient time and place for meeting was agreed on by members of each focus group. The first focus group met at the home of one of the participants. The second focus group met in the community hall of a local community. The focus groups were semi-structured group interviews. Reliance was on interaction within the group, based on open-ended questions that I, as facilitator, supplied for discussion. Each focus group had 9 or 10 participants. Data were recorded from focus group discussions through tape recording. The groups were staggered so that data could be analyzed from the first group. This allowed for the use of theoretical sampling in which hunches about emerging categories and themes were verified, utilizing members of the second focus group for further concept development.

I became aware of the national study, *The Quest to Die with Dignity* (Tyler et al., 1997) through the hospice organization with which I work. I had heard an audio tape of
a presentation of the study made by Beverly A. Tyler, Executive Director of Georgia Health Decisions. I contacted Ms. Tyler who was one of the authors of the national study by phone and received permission to replicate the study. Ms. Tyler sent me a copy of the national study and the focus group moderator’s guide from which to draw my open-ended questions (see Appendix C) for the semi-structured focus group interviews. Not all of the questions in the moderator’s guide were used in the focus groups due to limitations of time.

Demographic questions were asked to elicit data particular to the remote rural population versus the more urban populations studied in the above mentioned study (see Appendix D). An aspect of demographics considered was the distance and time to travel for emergency care. Distance to emergency care is one measure of rurality because in an emergency, the nearest source of assistance is sought (Weinert & Boik, 1998). Informants were asked to write down the number of miles and approximate travel time one way to reach emergency care.

Data Analysis

The grounded theory approach was used in this study to analyze the qualitative data through constant comparative analysis. As is characteristic of grounded theory, data were simultaneously gathered and analyzed. Recordings of the focus group interviews were transcribed. Data were analyzed after each of the two focus groups.

The systematic process of coding led to the development of categories and their properties. Memos were written to describe how the codes, categories and possible
relationships would be integrated. Relationships between categories continued to be
developed until a pattern among relationships was conceptualized. Categories were
determined to be "saturated" (Chenitz & Swanson, 1986), when it became evident no
new information was being obtained.
CHAPTER 4

FINDINGS OF THE STUDY

Findings from the study are contained in this chapter. First, demographic characteristics of the sample will be presented to enable the reader to more fully understand the context in which the study was conducted. The emergent perspectives of rural Montanans regarding end-of-life decisions are then discussed.

Demographics

Superlatively, Montana is a land of broad physical margins. It is a state of few people, 187,000 of them, distributed over 145,000 square miles or 93 million acres of rugged mountains, deep valleys and wide open plains. Montana is the fourth largest state in land area (U.S. Census Bureau, 1995). Montana is a largely agricultural state, a slow-growth state, a quality of life state, whose residents have their own independent, and unique perspectives on life and death.

Michael Malone wrote in his book, Montana Century: 100 Years In Pictures and Words:

Socially and demographically the state defies easy or simple analysis. Larger communities such as Butte and Anaconda and smaller cites like Glendive and Cut Bank have been hard hit and the general trend of rural depopulation and urban growth still continue (1999, p. 36).
And yet, even considering the seeming lack of economic potential, Montana is deemed by Montanans to be the last, best place. Because my nursing career has been spent predominantly working with people in the rural Montana setting, the population of interest in regard to end-of-life decisions was rural Montanans.

The focus group members resided on either a farm, ranch or in a rural area. The 19 study subjects ranged from 40 to 82 years of age with a mean age of 52.8 years. Of the 19 subjects in the sample, 11 were female and 8 were male. Age and gender categories for the combined two focus groups are shown in Table 1.

<table>
<thead>
<tr>
<th>Age categories*</th>
<th>Male</th>
<th>Female</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>40 to 49</td>
<td>4</td>
<td>6</td>
<td>10</td>
</tr>
<tr>
<td>50 to 59</td>
<td>3</td>
<td>3</td>
<td>6</td>
</tr>
<tr>
<td>70 to 79</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>80 to 89</td>
<td>1</td>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>

*Mean age of 52.8 years

Education completed ranged from a Graduate Equivalency Diploma (G.E.D) to 16 years with the mean number of years of education as 14.5. Comparatively, the group had a higher educational attainment than that of Montanans state wide with 37% (7) of the members having obtained a Bachelor’s degree compared to 14% of the general Montana population (U.S. Census Bureau, 1992). Table 2 on the following page shows years of education.
Sixteen of the study subjects were married, one was divorced, and two were single. Support systems included friends, family, spouse and parents. In response to religious affiliation, twelve of the respondents were Protestant, one was Catholic, one indicated other, and five indicated none. Study participants were asked to specify the length of time they lived in Montana. Responses of the sample ranged from 25 years to 82 years with the mean length of time in Montana as 49 years.

Accessibility to emergency care was analyzed by means of travel time and miles one way. Weinert and Boik (1998) identified that emergency assistance in a rural state is provided in a variety of ways such as in the Emergency Room of a small hospital or a community’s primary care clinic. Distance to emergency care is preferred as a measure of rurality over distance to other health care services, because in an emergency the nearest source of assistance is sought.

Distance traveled for emergency medical care ranged from 7 miles to 38 miles with travel time for emergency care spanning 14 minutes to 45 minutes, one way. Rural road conditions, weather and geography are some of the variables influencing travel time to emergency medical care in Montana. The number of miles and the approximate travel time for emergency care for the sample is shown in Table 3 on the following page.
Table 3. Number of Miles & Travel Time One Way for Emergency Care of Rural Sample (N = 19)

<table>
<thead>
<tr>
<th>Number of miles travel for emergency medical care (one way)</th>
<th>Approximate travel time in minutes (one way)</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>30 - 39 miles</td>
<td>30 - 45 minutes</td>
<td>6</td>
</tr>
<tr>
<td>20 - 29 miles</td>
<td>15 - 40 minutes</td>
<td>7</td>
</tr>
<tr>
<td>10 - 19 miles</td>
<td>10 - 25 minutes</td>
<td>5</td>
</tr>
<tr>
<td>Less than 9 miles</td>
<td>14 minutes</td>
<td>1</td>
</tr>
</tbody>
</table>

Sources of emergency care listed by the subjects included both sites (clinic, hospital, critical access hospital) and personnel (physician, nurse practitioner, and emergency medical technicians).

A composite of the study subject would be an individual who is Caucasian, most likely Protestant and married, with some years of college education, living on a Montana farm or ranch for over 25 years, and traveling a distance of 30 miles one way for emergency care.

Planning for the Last Roundup: Values and Perspectives

An understanding of the qualities rural Montanans considered worthwhile as they discussed health care at the end of life provided useful insights into how Montanans made decisions and came to conclusions about end-of-life care. One senior gentleman responded to the question of what he would say if someone asked what he had discussed the evening of the focus group: “I would tell them I was planning for the last roundup. You’ve got to get a few points across before you cash in.”

Vital elements emerged as the groups talked about their hopes and fears at the end of life. The diagram which follows on the next page represents a conceptual model
of the common themes which arose during end-of-life discussions with the rural sample studied. At the hub of the model is the Natural World View. Properties of the “Natural World View” theme include: unpretentiousness, a natural life-death cycle, and an ideal place and way to die. Extending out from the hub are the elements of: Free Choice, Family Advocacy and Responsibility, Trust in Local Provider, Mistrust of Health Care System and Barriers to End-of-Life Care. Properties of “Barriers to End-of-Life Care” include: lack of resources, distance coupled with feelings of isolation, lack of knowledge, and coping abilities.

Figure 1. End-of-Life Decisions: Rural Values and Perspectives

Free Choice

Family Advocacy & Responsibility

Trust in Local Provider

Natural World View

Barriers to End-of-Life Care

Mistrust of Health Care System
Natural World View

At the hub of the sample’s perspectives is a natural world view. The word *nature* conjures up images of forces that produce and control all the phenomena of the world of living things and the outdoors. It is a world free from affectation or artificiality, a spontaneous place unaltered or disguised. For some of the participants in the study, the natural world view held a naturalistic spiritual quality; for others a Christian religious view was expressed. The natural world is one of the expected and accepted. This unpretentious world is such portrayed by the rural Montanans interviewed in this study. One subject talked about lifestyle: “I think our lifestyles too, make a difference. I think we’re raising animals and death is just a natural part of the cycle. I think even in dealing with our own deaths and our family’s deaths we look at death as a natural part of life.”

A man from the second focus group stated:

> Being ranchers, as we are, we deal with death, not necessarily with humans, but with livestock quite a bit. It gives us, at least in my case a little different twist on death, because you dealt with it. We just really love our livestock and we hate to have anything happen to them, they are kinda like family when you don’t have a family I guess.

A man in the first group said:

> It seems to me they just don’t let anybody die anymore. And I mean I don’t know where you draw the line, I mean I don’t, it’s a tough question but we’ve all lived in the country and we see things die all the time. Death is a part of life and like my grandparents, they didn’t have the options that my mother had to keep living because they didn’t have all that technology but you know my mother had no quality of life for the last four years.

Focus group members presented a need for connection with nature which also interfaced with a sense of independence. One person said, “I love my life, I like to be outdoors and
I like to be able to choose what I want to do everyday.”

When focus group members were asked where the ideal place would be to die, again a need for contact with the natural world was pervasive as indicated by the response, “I’d rather be out on a hilltop.” Similarly, one woman said, “I’d rather fall dead off my horse, well in a few years.” The need for relationship to the land and a need to return to the land was well stated by one participant:

What I enjoy about my life is living where we live, we are talking about rural roots and we enjoy the quiet and the space and having some freedom to be your own boss. Sometimes there are those things I don’t enjoy too, being your own boss and having to get all your work done. This is well timed. My best friend, my cousin who grew up with me as a brother to me died at 52 just this winter. His last request was to be buried on the ranch because he spent so many summers working there and growing up there so we did just go through a death event that was very close to me and was hard but also interesting and poignant at the same time.

There seemed to be a moral certainty, a lack of pretension in the perspectives shared by the group, as one gentleman shared about his surrounding community:

As to the good things in life that I have enjoyed, living in a tightly knit community where everyone’s your friend unless he wants to be your enemy. We all take a person at face value, and the social interplay between your friends has been very important. The fact that I was the sexton of the (name of small town) cemetery for years brought me in contact with a lot of people at a very discouraging time in their lives.

Another man in the same group added:

I think there is a lot to that. In town people never go to funerals....The older families are usually scattered somewhere across the country. We don’t deal with that here. You are hanging around your peer group until you are very old. We have a better perspective of it, we see the cycle.

One woman told a story she had heard from a sheriff from the northwest part of Montana who told of being called to a rural farm house:
There had been a death and it was in the morning and he was invited into the farm kitchen and the lady that was there was an elderly lady and she invited him in for coffee and so they sat in at the kitchen table and visited. He finally said, ‘Was I called for a death?’ and she said, ‘Yes, it’s my husband, he’s dead in the other room.’ And he said, ‘Well, when did he die?’ and her response was, ‘Well, he died last night, I didn’t want to disturb you. I didn’t want you to come out at night, there was nothing that could be done.’ It was part of a natural thing you know.

Discussions of end-of-life decisions with rural Montanans were often emotional, but at the same time reasonable. A natural death was preferred by the study participants in familiar surroundings with loved ones. More conventional Christian beliefs entered into some of the participants’ conversations particular to attempting to understand the loss of loved ones. The following comments were made by various informants:

“When there is room in heaven then they will take you.”

I think He is also fussy because when my dad was sick I didn’t know why He didn’t take this old sheepherder in town instead of my dad. But even the dirty sheepherder, he had some good points, maybe I just had to look for them a little harder, but he was alright.

“I always think the Lord could take me. He has taken all my best friends, every one of them.”

“It’s a higher power that’s regulating this.”

Family Advocacy & Responsibility

Family advocacy came forth in the analysis as implying an ability to care, to feel what others feel and to act accordingly. Giving comfort, looking out for the good of the patient (loved one) was associated with empathetic emotions of love and sympathy. The participants viewed the patient as needing an advocate to assure that his/her best interests were protected.
One woman spoke of the medical care of her seriously ill mother:

There were a lot of situations when my mom was sick that many of the establishment, the medical establishment, had written her off. So how do you, you know, shake and say.... HELLO! THERE’S SOMEBODY HERE WHO NEEDS SOME HELP!

Another member of the group offered further insight:

The other thing we realized, maybe anytime in the medical treatment, certainly end of life treatment, is the family ends up becoming the advocate. You are the sustaining force that takes it from one wing of the hospital to the other and they are moved all the time and of course the people who are giving the care don’t know what the hell is going on.

Yet another member offered this view:

“Yes, I think you’re in really deep doo doo if you have to go in the hospital and you don’t have a family member there or somebody asking the questions, and making sure that things get done and try to see the doctor.”

Such perspectives may come as a surprise to those of us in the health care field who see ourselves as patient advocates and not as “people who are giving the care” who “don’t know what the hell is going on.” As one man put it, “You can get lost in the hospital shuffle.”

Assuming responsibility as a member of the family unit was a strongly identified value of the participants in the study. One responsibility was that the dying person would show concern for the welfare of his/her family when making end-of-life decisions. One woman was very concerned about how difficult a serious illness in her family would be, especially for her husband. Dying at home was not a consideration for this woman who saw no dignity in death, no matter the setting, and reported she would be the most comfortable dying in the hospital when the time came so as to not burden her loved ones.
Group members voiced a sense of thoughtfulness and commitment for protecting the family who would be left behind. Death was seen as a potential burden to families due to financial, mental and emotional costs. Because of this perspective, the majority of focus group members did not think it right to subjugate loved ones to such burdens. Nor did they want their deaths unnecessarily prolonged, creating the possibility of family stress or disagreement over treatment decisions. This sense of responsibility for family welfare formed support for advance directives in many cases. As one woman who had completed a living will stated:

“Because of our kids, we didn’t want our kids saddled with years of expense, years of indecision. We wanted to say what we wanted and that takes it out. They don’t have to fulfill what they think we would have wanted.”

Another member added:

It’s a heartstring thing, there’s quality of life and each one of us in this room knows what that is. And once you’re beyond that, you know kids, they’re hung up on someone they love, and even wouldn’t have quality of life anymore, they’ve got to let go. And so if we make that transition a little easier, that makes sense to me.

Said a man contemplating advance directives:

In my mind I think a living will is good especially if you have no quality of life, if you are in a coma or something. There is just nothing then, I mean, why pay, saddle your kids or family or anybody else with all that caring for you when it isn’t doing anything but spending money.

One man spoke of the difficulties his family faced by his mother not having a written living will in place:

My mother never had a living will but she made it clear that she did not want to linger on, suffer and all that. She didn’t want that and everybody in the family knew that but when it came right down to it, there was nobody to say to the doctor. You know my Dad couldn’t do it, he could not do it, and I sat in there and
it was one of the hardest things I had to do in my life. I sat in there with one of my brothers and my Dad and my mother was, you know, I mean she was ready to go, and if they had taken her off the feeding tubes and that, she would have passed away. And I said, 'That's what she wanted', and my Dad says, 'I just can't,' and my brother says well, he says, 'We can't do it because Dad says no.' And I said, 'That's NOT right, we're not thinking about my mom!' And so consequently, you know, I didn't get my way. My mother, she had to suffer through some more. She finally fooled everybody, she finally refused to eat, she starved herself to death. She was mad and I knew she was mad.

A "natural world view" response to the above story was given by a listening member:

"She starved herself, I think that's an animal instinct though too."

Instead of putting family members in positions of having to make such decisions, many participants believed that a living will would relieve family members of such an obligation, decreasing guilt and anguish. One woman summed it up well:

It's a real fine line that you cross from being able to make these decisions, know what you are doing and then not. Like my mother just kind of lost the ability to make the decisions about what she wanted, you know she's not the same person. So you've got to get it done before you start getting closer.

Living wills, therefore, were seen as a means of possibly reducing negative emotions associated with end-of-life decisions even though only 2 of the 19 participants (10%) had completed such a document.

For the most part, focus group members affirmed that each person should take responsibility for end-of-life planning. Some participants had acted on this sense of responsibility and had talked to family members about their wishes. Other focus group members indicated they experienced emotions of discomfort or anxiety when thinking about their own death or the death of a loved one, so they avoided such topics. Some of the "avoiders" brought a different perspective to the groups. One man stated in response
to a question about family discussions surrounding end-of-life issues: "I've never thought about it. Don't like to think about it. Just never have. I don't want to die. Never talked to our kids about it." When another group member asked the man if he was planning on not dying, his response was "Hope not."

Free Choice

Free choice emerged in this study as a value implying freedom or lack of constraint on individual decisions and actions. Choice is the right, power, or liberty to choose without limitation. Independence is also a strong component of free choice and suggests self reliance, autonomy, and the ability to get the job done without outside resources. Individual rights and responsibilities for decision-making were traits verbalized by the focus group members. Participants indicated they wanted the opportunity to choose among treatment options and to decide for themselves if those treatments would be beneficial. The value of free choice was stated by this woman:

Our ability to participate, or be like an actor, when it comes to that point in our lives or significant others in our lives about how much control we ourselves have, and the decisions that we can make for ourselves, on those kinds of end-of-life decisions, like, can we do it our way?

Many participants noted that quality of life would greatly affect their decisions regarding life prolonging medical treatments. Whether or not a treatment was futile would not be as important to some participants as whether it could improve quality of life, even temporarily. The freedom to make this decision on an individual basis was very important to all focus group participants. Lack of control and being dependent on others for their needs invoked images of indignity and humiliation for some participants.
One man expressed his emotion as he recounted coping with his mother’s incapacity:

She hated it, she hated the condition she was in and everybody knew it but I said if I had known how severe her stroke was when she had it, she never would have went on the helicopter to Billings. I would have, if it would have been my choice, let her stay in the hospital here and she would have just passed away. And she would have been happier and I mean that’s what she really wanted but we didn’t know how bad it was.

Some group members believed an individual had control over deciding when to die. It was thought that the dying person may wait to die until he/she sensed the ability of loved ones to come to terms with the impending loss and “let go” of the dying person. In this way self-determination was a component of free choice. One woman related the concept to her mother:

“That’s what I think with my mom, we are so lucky, she was in control, right up to the very end and as soon as my dad was ready to let her go, she went. She hung in there and I think she would have continued until he was ready.”

Another member added his thoughts to the dialogue:

It seems there is a kind of will to die too. You know in a bunch of terminally ill cases where somebody seemed to be just hanging on, hanging on... they needed to be released by their closest loved ones saying almost ‘Go ahead, die,’ or ‘they’re not going to die.’

When the focus groups were asked if the wishes of people to control end-of-life issues should always be followed, varied responses were noted:

“If you were in your right mind when you made your decision.”

“Within the limits of the law.”

The topic of assisted suicide came up in both focus groups and was considered a means of self-determination. One man eloquently stated his case:
I feel too that if you are in your right mind and you feel that life is a drudgery to you that you should be allowed to end it. I think you should be able to have someone help you. I mean if life is a drudgery to you and you are suffering, and there is no hope in your own mind that you can recover, end it. But it’s got to be completely with your free will. If I told my friend, ‘I have nothing to live for and the end is in sight anyway before too long and I am suffering and I would like to end it, will you help me?’ Of course, then it may be considered that is he is a murderer but if he provided me with the tools to do it or the medicine or whatever and I administered them then I think it would let him off the hook.

Another man shared his view about people’s right to choose the end of life, stating:

And then that brings up the other thing, what the fine line is between the living will and Dr. Kevorkian, who obviously is in prison now. You know some of those people he euthanized, whatever you would say, were pretty tough. They were at an end-of-life decision and although I think that’s a bit of a creepy deal, I think the issues are exactly these issues right here. He’s kind of making a stand and so somebody has to make a stand, whoever is making a stand against him, society I guess.

One member gave his own personal declaration regarding free choice in the area of end-of-life care, stating: “I think if you have a living will, whoever’s dealing with it, ought to abide by it. It was your, the way you left things. It’s your life, your death.”

No one in the focus groups spoke out with strong feelings against assisted suicide. Some saw it as the ultimate individual right and choice. The belief that individuals have the right to make end-of-life decisions for themselves was a fundamental principle that permeated the discussions in both focus groups.

Trust in Local Provider

Trust emerged as a value representing confidence in the integrity of the local physician. Trust, based on familiarity with local health care, caused group members to be in agreement regarding their preferences to remain in the local community for end-of-life
care. In general, most members of the focus groups preferred local providers raise issues of end-of-life care with their patients. One woman said:

“I think talking about it with your doctor too would be really important, a primary care giver, a doctor you go to for care consistently. And if you do, those directives are on your medical records so they should go with you.

Another group member added this view:

“I think that what is important in the end is that the provider has to lead you through this thing and even with a living will it isn’t that cut and dried.”

Not all members agreed with the idea of the physician raising the issue of advance directives: “That might possibly scare the hell out of somebody”. Another said:

“I’d say most of the time no, because you are just going to scare us to death.” The importance of a trusting patient/physician relationship cannot be emphasized enough as the following comment substantiates:

“We are real lucky in the rural setting that we have doctors that most of us go to that know our names, know our hobbies, know what we like to do. Their kids play baseball with our kids. That counts for a lot.”

Most members believed it necessary to have a familiar and reciprocal relationship with their physician in order to make end-of-life treatment decisions: “They are person to person, not just person to disease”; “They take care of sick people more.”

Familiarity, informal relationships, and intimacy are all adjectives describing relationships involving persons favorably disposed of one another. In the focus groups studied, familiarity was a strong component of the physician/patient relationship and was a strong basis for trust. McNeely and Shreffler (1998) found that familiarity was a characteristic of rural communities influencing provision of health care services. One
man said in regard to the familiar relationship that exists between rural physician and patient: "With them it's hard. It's got to be harder for those rural doctors no doubt because their patients are a name instead of a number."

Mistrust of Health Care System

Trust requires a relationship that develops over time. Those participants in the study who had experiences where relationships with physicians or provision of health care were inconsistent often felt mistrust of care. One woman shared her misgivings in regard to her ailing parent:

"It's just the way it's set up. You start out in (name of small town), which is where you would rather be. They don't have the facilities to handle it. So you go someplace else and that's where we felt mother was written off."

Relocation of the patient out of the familiarity of the local health care setting led to development of mistrust of the regional health care system. Another woman said:

My mom, when we went through the hip surgery there was the same thing, she had three different doctors and none of them knew what the other one was doing. They kind of run into each other, bump into each other in the hall and say, 'Well, you know she has an embolism, don't make her get up and walk.'

Mistrust of the health care system influenced this gentleman's view of organ procurement at the end of life:

I'm approaching the age now and you have the little inkling of thought, now supposing that I could make it and the doctor says well, he's a goner, and we'll get the organs. You don't know exactly how eager they are to get the organs or if they thought you'd be better off dead....If you are at death's door and one of these miracles happen and you could get another six months of good enjoyable life, you wonder, now is the doctor going to need those organs. Is he going to keep me alive? I have no, I haven't made any gift of organs yet.

A man whose brother was a hospital administrator shared a perspective regarding
terminal care of their mother at a regional medical center where familiarity with the system was advantageous:

My brother happens to be a hospital administrator in a large facility. Very easy... I mean I didn’t do anything. I just, we left everything to him. He knew exactly what was going on. When he would ask questions of the doctors, he was asking the proper questions. He knew the system.

Mistrust also emerged in discussion about the language associated with end-of-life planning. Uncertainty and confusion about the meanings of the specialized language of advance directives did not foster trust in the health care system in general. Time was spent by the researcher during focus group conversations educating members about the terms used in advance directives. Some of the participants assumed that they would need a lawyer to complete the documents. A concern one woman voiced was the fear once a document was filled out, it became permanent and preferences for care could not be changed.

Barriers to End-of-Life Care

Barriers to management of the death and dying experience emerged as a theme throughout the two focus groups. Properties of barriers to end-of-life care included: lack of resources, distance and isolation, lack of knowledge, and coping abilities.

Lack of Resources. None of the participants believed the current health care system supported their ideal concept of death and dying primarily in the area of access to health care at the end of life. This issue predominated in discussions as one where end-of-life resources were seen as very limited to rural areas. A participant from the first focus group said:
In a rural setting, we deal with, we don’t have a lot of amenities that they do when you live like in (name of small town), or a larger town. So how, how can you make the people who are in that process, how can you make it what they want....How can you plug the system into their process?

One informant added this perspective:

And in a lot of ways in this end-of-life stuff, the toughest part is the mental part which, it’s tough talking about because of experiences. A lot of the care, there is so much involved with the family and taking care of the people around the person who is dying that is the issue, and in a rural area we just don’t have the resources. It’s harder to find them, it makes the whole thing more complicated.

Another man stated:

What I thought about is that I think rural home health would be a wonderful thing. It seems to me that even financially, that in a nursing home, if you are going to pay three to five thousand dollars a month, it seems like there would be an opportunity to, the ideal thing is to die in your own home with dignity and it seems like there might possibly be a job market in the future for someone that can deal with death....I know that in towns there’s getting to be more home health care but I’m not sure what is happening in rural areas.

One woman was grateful to have access to any health care facilities as she stated:

“We are fortunate to have the facilities nearby that, in our two county area, fairly nearby that we have. Let’s hope we always have at least that.”

Another participant articulated her view regarding the lack of rural end-of-life resources:

We have more problems out here because we aren’t close to a hospital, we aren’t close to immediate medical facilities and a lot of people in the cities can stay in their homes much easier than we can because there is someone right there that doesn’t necessarily have to live with you. It is very difficult. I have talked to some friends even in (name of small town) in the last couple months who needed care for their mother. And it was almost next to impossible to find and I don’t think there is that much of a problem in the cities as there is way out here in the sticks.

Distance and Isolation. Distance entered into one woman’s view of barriers to end-of-life resources as she stated: “I think distance, you feel more alone than when the
doctor is a block away.” In response to this statement, another woman replied: “You are and you just don’t shed a tear.” Isolation was also an aspect of lack of access to healthcare at the end of life as one woman who had cared for her ailing mother reported:

I think the emotional part is the most difficult. With my mother, that made things a lot harder and my children kind of disappeared and so I was alone with mom all the time. If I had lived in town, I think people would stop in for a minute....For me it was the loneliness, I was so completely stuck with mom and of course we didn’t have a phone then, we didn’t have a T.V.

Another informant added: “To bring my husband home after heart surgery and to be out here in the country by myself, to have the responsibility of it.”

Lack of Knowledge. Living wills and other advance directives are a means of protecting and asserting the right of individuals and families to specify the conditions under which technology should be used to prolong their lives. Such end-of-life choices involve the idea of an informed choice and families and individuals must have access to information. However, they must take responsibility for acquiring information allowing them to make the best decisions possible. In this sense knowledge becomes power.

Members of the first focus group were more familiar with the specialized vocabulary of advance directives. This was possibly related to the fact that two of the participants in that group had recently experienced a death of a close family member who died at home after a chronic illness and multiple hospitalizations. Additionally, one of the members was a retired health care professional and had some basic understanding of the jargon associated with advance care planning. The second group sought information regularly throughout the focus group in regard to gaining understanding of the association between
different terms and would periodically apply terms as the group progressed as if assimilating the information during the course of conversation.

Although all participants acknowledged the importance of at least some advanced planning for end-of-life decisions and care, they were uncomfortable or unknowledgeable about the topic. Only 2 of the 19 participants in the study had completed advance directives prior to the focus groups and those directives had been completed 13 years prior and had not been updated. However, it is possible that as a consequence of participating in this study, other informants may decide to complete end-of-life planning documents.

**Coping Abilities.** The Montanans studied wanted to control what happened to them at the end of their lives. Yet, they were reluctant to take the steps necessary to do so. The avoidance and denial of death, coupled with the belief that loved ones would know what they want, kept many from being pro-active in planning for death and dying. Numerous reasons were provided for not talking about death: “Well, I don’t know that anything prevents it, it just seems irrelevant, at the moment.” “I’m young and healthy.” “Don’t like to think about it. Just never have. I don’t want to die. Never talked to our kids about it.” “It’s sad, depressing, uncomfortable.” “Talking about death is bad luck.” “Dying is always in the future.”

One elderly man stated: “Well of course you know, we’re not ready to go yet so we have lots of time. That’s the kind of attitude I take.”

Another woman in the group reported difficulty communicating with her parents:
"I would like, I wish my folks would talk to me about what they want because it is like there is a wall there, they won't talk. And it would make me feel better if I knew that I could, I have to know their wishes to be able to do them."

Death was also a difficult topic to discuss because losing a loved one was beyond comprehension, as one member reported: "If I had to decide for my loved one, I can't even imagine knowing how I would feel, it's almost beyond anything I can think about."

Many in the groups took comfort in their belief their loved ones would make the "right decisions" for them at the end of life. They hadn't spoken to family or friends about what they would want. The vaguest of references, they thought, provided enough adequate guidance to those who would have to make the decisions for them at the end of life. One woman summarized the general consensus of both groups in the following comment: "Well, I think they mainly know us well enough, they know from our general actions....don't need to nag about it..."

Individuals drew on their own life experiences and often identified their ways of coping as having been based on patterns learned from parents or grandparents when dealing with serious illness or death. A woman in the second focus group illustrated such a point of view:

I grew up with death. My dad had a stroke when I was probably three years old, and that relationship changed overnight. And my mother, just whatever happened, happened. You just took it. You didn't fuss about it. You didn't talk about it. But I do think how you handle life depends on how your parents have.
Summary

The conceptual model *End-of-Life Decisions: Rural Values and Perspectives* emerged from the qualitative study of this sample of rural Montanans. The major elements of the conceptual model are *natural world view*, *family advocacy and responsibility*, *free choice*, *trust in local provider*, *mistrust of health care system*, and *barriers to end-of-life care*.

The natural world view embodies love of the land and an understanding of the natural cycle of life and death. Characteristics of this view included spontaneity, lack of pretense, and a moral certainty about one's decisions. A naturalistic spirituality mixed with more conventional religious beliefs to form a basis for mutual acceptance and respect for each other's view points. A sense of community and common bonds extended from the hub of the natural world view into the other elements of the conceptual model.

Family advocacy and responsibility were elements which demonstrated the value rural Montanans placed in looking out for the good of their loved ones. Family advocacy was associated with empathetic emotions of love and sympathy. Participants viewed the role of patient advocate to be important in protecting the best interests of loved ones. The need for patient advocacy increased proportionately to the degree of mistrust felt toward the health care system where a loved one was receiving care. Subjects believed that the dying person would demonstrate responsibility to his/her family and show concern for the welfare of family members by making end-of-life decisions. Focus group
members affirmed that each person should take responsibility for end-of-life planning although only two of the nineteen participants had completed an advance directive.

Free choice emerged as a value implying freedom or lack of constraint on individual decisions and actions. Independence was a strong component of free choice and suggested self reliance, autonomy, the ability to get the job done without outside resources. Individual rights and responsibilities for decision making were also aspects of this element. Self-determination and control over one’s life and death were important components of free choice. Lack of control and being dependent on others invoked images of indignity for many of the subjects studied.

Trust in the local provider represented confidence in the integrity of the local physician. Trust based on familiarity with local health care, caused participants to be in agreement regarding preferences to remain in the local community for end-of-life care.

Mistrust of the health care system developed from inconsistent relationships with specialty physicians and unfamiliarity with regional health care systems. Uncertainty and confusion about the meanings of the specialized language used in advance directives did not foster trust in the health care system either.

Barriers to end-of-life care included lack of knowledge, lack of resources, distance and isolation, and coping abilities. Completion of advance directives suggests making an informed choice. Participants were unknowledgeable about the terms used in advance directives and sought information throughout the focus groups to improve their level of knowledge in this area. Lack of resources for end-of-life care added to the barrier of distance and feelings of isolation by those who had attempted to care for loved
ones at home in the rural setting. Ways of coping with end-of-life decisions included avoidance, denial of death and the inability to comprehend the potential loss of a loved one. Many in the groups took comfort in their belief that their loved ones would make the “right decisions” for them at the end of life although few participants had discussed the issue with their families.

As care at the end of life has evolved, possible solutions to the discordance between patient wishes and the care they actually receive is evolving. Exploration of patient values, perspectives and surrounding issues could provide a more meaningful guide to managing end-of-life care. In the final chapter of this thesis, discussion and implications of the study Montana’s Rural Voices on End-of-Life Decisions is presented.
CHAPTER 5

CONCLUSIONS

Introduction

This thesis was a descriptive exploratory study to discover the values and perceptions of a sample of rural Montanans regarding end-of-life decisions. This chapter contains a summary, discussion and conclusions drawn from the study findings. Additionally, this chapter reflects on the study findings and compares them with the national study *The Quest to Die with Dignity* (Tyler et al., 1997). Study limitations and implications for nursing are also discussed.

Summary of Findings

The major outcome of the study was the development of a conceptual model entitled “End-of-Life Decisions: Rural Values and Perspectives.” This conceptual framework was grounded in and emerged from data collected through semi-structured focus group interviews and observations of a sample of rural informants residing in Montana. The diagram on page 28 represents the common themes which arose during end-of-life discussions with the rural sample studied.

The elements of the model were: a natural world view, family advocacy and responsibility, free choice, trust in local providers, mistrust of the health care system, and
barriers to end-of-life health care. These were themes for consideration and contemplation rural Montanans used in making end-of-life decisions.

The natural world view was the core variable of the study and contained the properties of unpretentiousness, a natural life-death cycle, and an ideal place and way to die. This natural world was valued by the participants as one of the expected and accepted. It was a world without pretense, enabling the subjects to accept others at face value. A strong sense of “rural community” was conveyed by group members, irrespective of the number of miles between family or friends. A naturalistic spirituality, based on love of the land and animals, and an understanding of the natural order of life and death, were commonly held beliefs of the groups. For some study subjects, Judeo-Christian religious beliefs were expressed.

Free choice emerged as a value implying freedom or lack of constraint. Independence was also an aspect of free choice and suggested self reliance, a trait all group members held preciously. Individuals believed in the right to self determination and noted quality of life would greatly affect decisions regarding medical treatments to prolong life. Another value important to the sample was family advocacy. Advocacy, or “looking out” for the good of the patient (loved one), was viewed as an important value by members to assure the best interests of the patient were protected, especially in the unfamiliar setting of regional health care facilities.

Responsibility as a member of a family in completion of advance directives was also a strongly identified value. Participants believed the dying person would demonstrate concern for his/her family by making end-of-life decisions. Concomitant
with protecting family left behind after death was the concern that prolonging death would add to family stress and disagreement over decisions. Living wills were seen as a means of possibly reducing negative emotions associated with end-of-life decisions. However, of the 19 participants, only two (10%) had completed an advanced directive. These findings are congruent with the literature in regard to failure to complete advance directives.

Trust based on familiarity with the physician and the care provided on the local level supported focus group member’s preferences to remain in the local community for end-of-life care. Most participants preferred local providers raise issues of end-of-life care with their patients. While trust existed locally, mistrust of regional care by the sample was evident. Inconsistencies in relationships with providers and unfamiliarity with health care facilities at the regional level led to mistrust of the health care system in general. Relocation of the patient outside of the local health care setting also lent to development of mistrust of regional health care. Uncertainty and confusion about the meanings of the specialized language of advance directives propagated mistrust of the health care system.

Barriers perceived by the sample in care for the dying included lack of resources, distance and isolation, lack of knowledge, and coping abilities. Lack of resources prevailed in conversations about the rural dilemma of how to care for the dying at home. Rural resources for end-of-life care were very limited. Distance, with its accompanying geographic and psychosocial isolation from supportive end-of-life care services was challenging for participants.
Lack of knowledge was a barrier because end-of-life choices involve an informed choice. Access to and utilization of information is vital to completion of advance directives. Many group members sought information throughout the focus groups to gain understanding of the terms used in advance directives. The participants would then periodically apply the terms as the groups progressed, as if assimilating the information during the course of discussion. All participants acknowledged the importance of some advanced planning for end-of-life decisions, yet they were uncomfortable and uninformed about the topic.

Another dimension of barriers faced when making end-of-life decisions was the coping abilities of the study subjects. Avoidance, denial of death, reluctance to discuss, as well as the belief loved ones would know what was wanted, kept most of the members from being pro-active in planning for death and dying. Group members hadn’t spoken to family or friends about what they would want for end-of-life care.

Discussion of Findings
Montana’s Rural Voices on End-of-Life Decisions and The Quest to Die with Dignity

The findings of this replication study will be compared with the national study, *The Quest to Die with Dignity* (Tyler, et al. 1997), for similarities and differences particular to the rural Montanan sample.

Similarities

One similarity between the two studies was that Montanans and other Americans alike revealed overall anxieties about the health care system. Participants of the rural
study and of the national study were concerned about the future of health care. Emphasis on managed care and capitated fee structures altered many patient’s relationships with their physicians in the national study. Those in that study who still maintained long term relationships with their physicians remained happy with their care. Although rural informants did not address managed care per se, they did acknowledge mistrust and unfamiliarity with regional health care provision. Similarly, rural participants acknowledged positive feelings and associations with their primary care providers with whom it can be assumed a long term relationship has existed.

The need for family advocacy was an important trait identified in both studies. Whether in the rural or urban setting, Montanans and other Americans recognized the need for an advocate for their loved ones thereby looking out for them when they are unable to speak for themselves. Another area of similarity between the two groups was the avoidance of discussions about death. Participants in the national study said that death was the “ultimate” unpleasant subject to talk about, let alone plan for. The Montanans studied would agree with this statement. One man illustrated the consensus of the second group in the “Rural Voices” sample when he responded to the question of what he thought of when he was called and asked to participate in a study of end-of-life care, stating: “Why did I answer the phone?” Resistance to discussion of death was found in both studies to be a major obstacle in planning for end-of-life care. Having to face their own mortality provoked anxiety for rural Montanan and other American subjects alike.
Some Americans in the national study, as well as in the rural study, were ambivalent about tools which exist to plan for end-of-life decisions. Both studies identified the absence of a common vocabulary to express wishes for end-of-life care. Many worried that written documents, such as a living will, might be too final and inflexible.

Spirituality was a common value held by members in both studies and referred to either concepts of religious faith or individual beliefs. Participants in the studies identified death as a part of a natural process. Additionally, death was perceived as a part of life itself. The values of family responsibility, and freedom (free choice) were similar in the national and rural studies.

Differences

Differences also became evident between the national study and the “Rural Voices” study in some areas. First, participants in the rural study articulated a unique natural world view. Such a view may be attributable to the setting, geography and lifestyle of the focus group participants. Second, the national study identified societal responsibility as a value referring to notions of financial accountability that individuals and the health care system share in regard to management of end-of-life care. From the rural Montanan perspective, participants struggled to identify basic end-of-life resources within their communities. Yet, no mention was made by the rural informants regarding the responsibility of society or the government to assure such care be provided rurally. This difference in perspective may be due to the independent and self-reliant nature of
The third value which emerged from the national study that significantly differed from the study of rural Montanans pertained to the topic of assisted suicide. No one in the two Montana focus groups spoke out strongly against assisted suicide and many spoke for the right of self-determination at the end of life. There were many in the national study who would not support assisted suicide under any circumstances. The difference in perspective between the two studies may be attributable to the natural world view of the rural dweller who has had experience, on a day to day basis, with the cycle of life and death. Another possible reason for the difference may be due to the sample size of the national study versus that of the rural study. As the number of people studied increases, so does the probability of varying views.

Lastly, the problem of lack of resources in the area of health care is not new to the population of rural Montana. Distance to travel for care and the accompanying feelings of isolation from others when attempting to care for a loved one at home were areas of deficiency readily acknowledged by the rural sample studied. These issues were not identified in the national study.

Planning End-of-Life Care

It has been recognized that individuals must play a role in planning and advocating for their own care at the end of life. Utilization of the Health Belief Model (Becker, Drachman & Kirsch, 1974) may be another way for health care providers to gain understanding of the complex decision-making processes involved in planning for
end-of-life care and then taking action to implement such plans. The Model was originally developed to conceptualize a theory of preventative health behavior. It was used as a systematic method to explain and predict health behavior. It focused on the relationship of health behaviors, practices and utilization of health services. The theory dealt with the behavior of individuals who were not currently suffering disabling disease and was oriented to the avoidance of disease.

The Health Belief Model attempts to predict health-related behavior in terms of certain belief patterns and can be applied to study all types of human behavior. A person’s motivation to undertake a health behavior can be divided into three main categories: individual perceptions, modifying behaviors, and the likelihood of action. The combination of these factors causes a response that often manifests into action (Becker et al., 1974).

Application of the characteristics of the Model to end-of-life decision-making are that in order for an individual to take action, she/he would need to believe that (1) they are susceptible to their own mortality, (2) that the occurrence of the disease or threat of death would have at least moderate severity on some component of their life, and (3) that taking a particular action, such as completion of an advance directive would in fact be beneficial by reducing susceptibility to having no control in end-of-life decision-making at the time of impending death.

Review of the model assists in identification of the many possible factors affecting the “decision-making” process of individuals and are important aspects to be mindful of when assisting patients in completion of advance directives. Figure 2 is a
modified version of the Health Belief Model, substituting the word Death for Disease and adapted to end-of-life decision-making.

Figure 2. Adapted “Health Belief Model” as predictor of end-of-life decision making (after Becker et al.)

INDIVIDUAL PERCEPTIONS

MODIFYING FACTORS

LIKELIHOOD OF ACTION

Perceived Threat of Death

Demographic variables (age, sex, race, ethnicity, etc.)
Sociopsychological variables (personality, social class, peer and reference group pressure, etc.)
Structural variables (knowledge of end-of-life care and prior use of Advance Directives)

Perceived benefits of action minus Perceived barriers to action

Likelihood of Taking Action to make End-of-Life Decisions

Cues to Action for End-of-Life Decisions
Media campaigns, newspaper, magazine article
Advice from others, discussion with family
Discussion with health care provider
Illness or Death of family member or friend

Study Limitations

As with most qualitative studies, this study had a small sample size. There may be a regional bias affecting data that were collected. It was not the focus or intent of this study to define or describe the entire value systems of the sample regarding end-of-life
decisions. No general conclusions or inferences can be made regarding values of the sample as a whole. The findings of this study cannot be generalized to other settings or populations but, implications of the study may be applicable in similar circumstances.

**Implications**

The first and most important implication of this study was the value of the rural provider/patient relationship as a trusting partnership from which end-of-life decisions can be made. The research clearly showed that communication regarding end-of-life matters with a trusted health care provider known to the individual was preferable to an outsider. The rural participants in this study were very private. The study results underscore the need for privacy and familiarity between provider and patient when discussing end-of-life care.

The second implication of this study relates to the need to incorporate advance care planning into family practice. Open communication by providers with their patients regarding end-of-life issues is necessary to improve the ability of patients to articulate advance directives with guidance and support from the health care professional. Additionally, patients need their providers to apprize them honestly concerning their conditions and their alternatives for treatment.

The third implication of this study is the importance of recognizing individual values and perceptions when planning for end-of-life care. Reflection, communication and discussion with patients regarding their values, perspectives and spiritual beliefs in regard to end-of-life issues and decisions will allow clinicians to understand patients
more fully and thus, plan end-of-life care more comprehensively.

The fourth implication of this study relates to the need for further research regarding how to provide resources for end-of-life care in the rural setting. Further research is needed to explore health care delivery models which could provide end-of-life resources to rural areas in a realistic and cost effective manner. The vast majority of participants in this study wanted to die at home in familiar surroundings, among family and friends. Concern regarding the assistance families would need to assume end-of-life care was paramount for participants. With home health agencies closing throughout Montana due to funding constraints, rural outreach services are even more limited. Lack of such resources decreases or completely removes options for the rural dweller to die at home with supportive end-of-life services available.

We, as health care providers, need to collaborate with our patients and their families in understanding the informally documented wishes of patients. At the end of life, individuals want control over themselves and the course of their care. They want to manage their dying in a trusting relationship with their health care provider. How to create a health care system in the rural setting that responds to, and supports the values expressed by these rural dwellers in the area of end-of-life care is our greatest challenge.

Conclusion

In regard to advance directives, frequently the focus has been on the technical aspects of medical care such as intubation and defibrillation which sidesteps the larger issue of the patient's diagnosis and prognosis in the context of treatment options,
spiritual values, and quality of life. Exploration and documentation of patient values and surrounding issues could provide a more meaningful guide to managing the patient’s end-of-life care. Such a process may help the patient better understand his or her disease, help the health care provider better understand the patient’s wishes and desires, and lead to greater concordance between patient wishes and the care received.
REFERENCES
REFERENCES CITED


APPENDIX A

INITIAL PHONE CONSENT
Potential Study Participant:

This is Diane Jones and I am a student in the graduate nursing program of Montana State University. As part of the requirements of my program, I am conducting a research study of the opinions of Montanans about death and dying. You have been identified as an articulate rural Montanan by me, the researcher, and your views on these topics are desired for the purposes of the study.

The study involves a meeting called a focus group where 6 to 8 people will be interviewed together and discussion will center around end-of-life care and decisions such as advance directives. I will be the only person conducting the interviews. All information shared in the group will be held in confidence. Participation in the study is entirely voluntary and you may choose not to participate at any time. The focus group interviews are anticipated to take 2 to 2 ½ hours to complete and the interviews will be tape recorded. Your interview answers will not be marked in any way to identify you.

The data will be transcribed from the tapes without names and only the researcher and members of her thesis committee will have access to the tapes or transcription. After the tapes are transcribed, they will be erased and the transcription will be kept in a locked cabinet for 2 years at the College of Nursing. Results of the study will be reported as grouped data. There will be no financial costs to you and you will not be paid for your participation. Participation in the study may not be of immediate benefit to you, although information obtained may benefit other persons in the future by increasing the knowledge base of those who work with individuals and families making end-of-life
decisions. The only risks may be some emotional upset associated with discussing your opinions about end-of-life care.

A meeting time and place will be arranged in the near future that is convenient for all participants. A written consent will be sent to you for your review and signature and should be returned to the researcher in the enclosed stamped envelope after completion.

Thank you,

Diane Jones, B.S.N., R.N.

Family Nurse Practitioner Graduate Student
APPENDIX B

CONSENT FORM
Rural Montanan’s Values, Opinions and Attitudes

About End-of-Life Issues and Decisions

The purpose of this study is to discuss health care at the end of life including end-of-life issues and decisions. The intent is to gain insight into your opinions, values and attitudes about these subjects. Participation in the study may not be of immediate benefit to you, although the information obtained may benefit other persons in the future by increasing the knowledge base of those who work with individuals and families making end-of-life decisions. The only risks may be some emotional upset associated with discussing your opinions, values and attitudes about end-of-life care.

If you choose to participate in this study, you will be interviewed in a group of 6 to 8 individuals called a focus group. The focus group interviews are anticipated to take 2 to 2 ½ hours to complete. The interviews will be tape recorded. Your interview answers will not be marked in any way to identify you. The data will be transcribed from the tapes without names and only the researcher and members of her thesis committee will have access to the tapes and transcription. After the tapes are transcribed, they will be erased and the transcription will be kept in a locked cabinet for a period of 2 years at the College of Nursing. Results of the study will be reported as grouped data.

There are no financial costs to you and you will not be paid for your participation.

_________________________________________    __________
Signature of researcher                          Date
Participant’s Statement

The study described above has been explained to me, and I voluntarily consent to participate. I have had an opportunity to ask questions about the activity and understand that future questions will be answered by the researcher or the faculty chair of the thesis committee. The researcher (Diane Jones, B.S.N., R.N.) may be reached at (406) 632-4734 or (406) 256-0475. Dr. Janice Buehler, Chairperson of the Thesis Committee is available at (406) 657-1774 to answer any further questions.

__________________________  _______________________
Consent of subject Date
APPENDIX C

INTERVIEW INSTRUMENT FOR FOCUS GROUPS
I. Introduction (10 minutes)

Introduce self

Explain purpose of focus group

Explain how/why individuals were contacted

Explain what focus groups are

Participant introductions

II. Starting Points (10 minutes)

When you were called and asked to come to a meeting to discuss health care at the end of life, what did you think you would be talking about today?

Why did that particular topic come to mind?

Please raise your hands if you are familiar with any of the following terms:

- Advance care planning or advance directives
- Living wills
- Durable power of attorney for health care or agent for health care
- Do Not Resuscitate (DNR) or Cardiopulmonary Resuscitation (CPR)
- Persistent Vegetative State
- Medically futile treatment
- Life sustaining treatment

Could anyone explain (ask 2 or 3 terms that seem to be least known) to the rest of the group?
(Facilitator- provide definition of terms most unfamiliar to everyone)

What does it mean to you when you are told a person is terminal?

III. Taking Control- Planning for Your Own End-of-Life Care (30 minutes)

For the next part of our discussion, please think about what kind of health care you would want for yourself should you ever be in one of the following conditions:

A permanent coma and receiving nourishment through a feeding tube—generally, this condition results from an accident, drowning or drug overdose.

Breathing with the help of a breathing machine (a respirator) following severe congestive heart failure or some similar condition

Suffering from an illness such as cancer, AIDS, etc. which is leading to your death while possibly experiencing a good deal of pain.

Would it be important for you to control what would happen and what treatments you would receive in these types of conditions? Why or why not?

Should your wishes about your end-of-life care always be followed? What if your family doesn’t agree? What if your doctor doesn’t agree?

What would you do to take control over what treatments you might receive?

Discuss with family?

Complete a living will?

Name an agent for health care?
Discuss with doctor?

Other?

How do you feel about someone taking this type of responsibility for you?

Have any of you spoken to your loved ones about these issues?

If yes:

What was the motivation for you to have this conversation? Who initiated the discussion? Who participated?

Was it a difficult conversation to have? Was anyone in your family resistant to talking about this? Were you able to overcome this resistance? How?

What kinds of things did you talk about?

Do you think your loved one is prepared to make decisions for you based on this conversation?

Could you make decisions for your loved one based on the conversations you have had? How do you feel about having to make these decisions?

If no:

Do you think you need to talk to your loved ones about these issues?

What prevents you from discussing these issues with your family?

Who would be the most likely person in your family to initiate this conversation?

Who would be the most resistant to having this conversation? Why?
Not having discussed these issues, do you think you know what your loved ones would want? Do they know what you would want?

How would you feel if you had to make an unexpected decision for your loved one? How would they feel about making a decision for you?

Has anyone completed a written document of any kind that outlines your wishes about the type of health care you would want in these kinds of situations?

To those who have, what type of document? Living Will? Durable power of attorney?

To those who have, what made you decide to take this action?

Do you think your loved ones will follow your Living Will?

Do you have concerns about these documents?

Is there something that keeps you from completing such documents?

Do you think you need the help of a professional (lawyer or physician) to complete a living will?

If you have not expressed your own wishes about end-of-life care in writing, who do you think would make decisions for you should you be in one of these situations?

What do you think about legally appointing someone to make sure your wishes are followed should you not be able to talk for yourself?

Do you think that is too much to ask of someone?

Who would you appoint and why?
How would you feel if you were appointed by a loved one to be their legal agent to make decisions? What would you do?

Do you trust your health care provider?

Have any of you discussed your wished for end-of-life care with your health care provider?

If you have a Living Will, have you given a copy to your health care provider?

Do you think your health care provider will follow your Living Will?

How would you feel about having this kind of conversation with your health care provider?

Do you think providers should raise this issue with their patients?

When do you think providers should raise this issue with patients?

The four ways we have discussed to control your health care at the end of life: taking to your family, making a living will, appointing an agent for health care, talking to your health care provider; which do you think would be the most effective in making sure your wishes are followed? Why that one?

IV. Understanding the Decisions to be Made (15 minutes)

I'm going to describe a real life situation that could require you to make some difficult decisions about pursuing medical treatment for a loved one. Here's the situation:

Your loved one (spouse, parent, etc.) has had chronic emphysema over a period of
several years which causes shortness of breath and limits their physical activity. One
day, they develop a cold which gradually gets worse. They are experiencing heavy
coughing and a high fever. You come home and find them confused and somewhat
delirious.

What do you think you would do? (Answer- probably call emergency services,
911, take to emergency room, etc.)

You get to the emergency room and are met there by your family doctor. A chest x-ray
indicates your loved one has pneumonia with an extremely low blood oxygen level. The
doctor says your loved one’s conditions is very grave and the only chance of survival is to
be put on a ventilator and start antibiotics. They will certainly die without the ventilator,
but the outcome of putting them on the ventilator is uncertain.

Do you know what decision your loved one would want you to make in this
situation? Does your loved one know what decision you would want them to
make for you?

Let’s say you made the decision to try the ventilator for a while. The doctor then comes
to you and asks if you would want your loved one to receive CPR should they go into
cardiac arrest while on the ventilator.

Do you know what decision your loved one would want you to make? Does your
loved one know what decision you would want them to make for you?

Over a period of a few days your loved one improves and is able to come off of the
ventilator. They are transferred out of the ICU and spend a couple of more days
recuperating in the hospital, but one afternoon the nurse goes into the room and finds
your loved one unconscious. A CAT scan shows a stroke from an embolism. The doctor
tells you that your loved one is currently paralyzed and cannot speak but that the
permanent effects of a stroke are never predictable in the first 48 hours. For the moment,
your loved one can be treated with blood thinners and would need to be put back on the
ventilator since their breathing is once again much worse.

Would you know what decision your loved one would want you to make? Does
your loved one know what decision you would want them to make for you?
What if your loved one had made general comments to you in the past that they
would not ever want to be on a ventilator, would you make a different decision?

V. Making End of Life Decisions (20 minutes)

If you were going to decide whether or not to pursue a treatment for a disease
such as cancer, what criteria would you use in making your decision?

For instance, would you consider:

- Reduction of elimination of pain
- Probability of successful outcome
- Cost of treatment
- Quality of life following treatment
- Age of patient
- Distance to travel for treatment

How would you rank these criteria in order of importance to you in making these
decisions?

Using a flip chart present the following viewpoints as a scale from 1 to 4.

Ask each participant to identify their position from 1 to 4 and indicate why.

One being: I would fight off death as long as possible by any means possible.

Four being: I want to die a natural death without the support of modern technology (such as breathing machines and feeding tubes).

VII. Understanding Montanan’s Language (20 minutes)

If you were to go to work tomorrow and tell someone you work with what you did today/tonight, what would you say to them?

Do you think you would have to define some terms and concepts for them?

Which ones? How would you define these terms?

If a workshop on how to complete a living will were available at your hospital or church, do you think you would attend?

VII. Paperwork

Pass out and collect participant demographic profile (Appendix D)

Thank group for their interest and participation.
APPENDIX D

DEMOGRAPHIC PROFILE
Age: _____

Gender: Male _____ Female _____

Ethnicity: White ____ Native American ____ Black ____ Hispanic ____
Asian ____ Other ____

Religious Affiliation: Protestant ____ Catholic ____ Jewish ____ Other ____
None ____

Years of Education Completed: ________________________________

Marital Status: Married ____ Divorced ____ Widowed ____ Single ____

Support System (ex.: friends, family, spouse, parents, etc.):
__________________________________________________________

Residence: Town ____ Farm ____ Ranch ____ Other ____

Approximate population size of nearest community to participant: _________

Length lived in Montana: ________

1. How far must you travel for emergency medical care? In answering this question think about a potential emergency such as a serious cut from broken glass. How far (ONE WAY) must you travel to get assistance such as stitches? Please try to be as accurate as possible when recording the distance, e.g. 8 city blocks or 3 3/4 miles, etc.

_______ NUMBER OF MILES (one way)

_______ APPROXIMATE TRAVEL TIME
Please describe your source of emergency care (For example: Nurse Practitioner, Hospital, Physician's office, etc.)

I would describe myself as living: (Please CIRCLE only ONE response)

1. ON A FARM/RANCH
2. IN A RURAL AREA (NOT A FARM/RANCH)
3. IN A SMALL RURAL TOWN
4. IN A SMALL TOWN
5. IN A MEDIUM SIZE CITY
6. IN A LARGE CITY
7. IN A SUBURBAN AREA
8. IN A MAJOR METROPOLITAN AREA