Technical communication, hospice documents, and the ethic of care: an analysis of the technical communicator's role in dealing with issues related to terminal illness

Erin Marie Duncan
Iowa State University

Follow this and additional works at: https://lib.dr.iastate.edu/rtd

Part of the English Language and Literature Commons, and the Rhetoric and Composition Commons

Recommended Citation

This Thesis is brought to you for free and open access by the Iowa State University Capstones, Theses and Dissertations at Iowa State University Digital Repository. It has been accepted for inclusion in Retrospective Theses and Dissertations by an authorized administrator of Iowa State University Digital Repository. For more information, please contact digirep@iastate.edu.
Technical communication, hospice documents, and the ethic of care:
An analysis of the technical communicator's role
in dealing with issues related to terminal illness

by

Erin Marie Duncan

A thesis submitted to the graduate faculty
in partial fulfillment of the requirements for the degree of
MASTER OF ARTS

Major: English (Rhetoric, Composition and Professional Communication)

Major Professor: Helen Rothschild Ewald

Iowa State University
Ames, Iowa

1998

©Erin Marie Duncan, 1998. All rights reserved.
Graduate College
Iowa State University

This is to certify that the Master's thesis of
Erin Marie Duncan

has met the thesis requirements of Iowa State University

Signatures have been redacted for privacy
With all my heart, I dedicate this thesis to the memory of my beloved grandmother, Twyla McConnell Wessels, whose courageous and dignified battle with amyotrophic lateral sclerosis inspired this work.
# TABLE OF CONTENTS

<table>
<thead>
<tr>
<th>Chapter</th>
<th>Title</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>INTRODUCTION: IDEAS ABOUT CARE</td>
<td>1</td>
</tr>
<tr>
<td>2</td>
<td>LITERATURE REVIEW: DEFINING THE ETHIC OF CARE</td>
<td>6</td>
</tr>
<tr>
<td>3</td>
<td>METHODOLOGY: STUDYING THE ETHIC OF CARE</td>
<td>19</td>
</tr>
<tr>
<td>4</td>
<td>SURVEY AND INTERVIEW RESULTS: INTERPRETING THE ETHIC OF CARE</td>
<td>27</td>
</tr>
<tr>
<td>5</td>
<td>IMPLICATIONS AND CONCLUSIONS: INCORPORATING THE ETHIC OF CARE</td>
<td>67</td>
</tr>
<tr>
<td>A</td>
<td>SURVEY AND COVER LETTER</td>
<td>80</td>
</tr>
<tr>
<td>B</td>
<td>LIST OF DOCUMENTS BY GENRE COLLECTED FROM HOSPICES INTERVIEWED AND SURVEYED</td>
<td>82</td>
</tr>
<tr>
<td>C</td>
<td>EXAMPLES OF HOSPICE DOCUMENTS ANALYZED</td>
<td>84</td>
</tr>
<tr>
<td></td>
<td>WORKS CITED</td>
<td>88</td>
</tr>
</tbody>
</table>
I would like to thank Dr. Helen Rothschild Ewald for her patience and her help with this project. I would also like to acknowledge the many hospice workers who participated in my research and interviews. Finally, I am grateful for the encouragement of my friends and family as I worked on my thesis.
In this study, the relationship between the ethic of care and hospice documents is explored. This project includes an in-depth discussion of the nature of documents designed for the hospice situation. Specifically, it focuses on hospice documents as a way to study the effectiveness of feminist ethics to connect with a specific audience. Feminist ethics are significant to study within hospice documents because, as the act of hospice is rooted within the ethic of care, hospice documents provide an excellent forum for implementing feminist ethics into technical writing. This project studies how “caring for” people is expressed in technical writing and how documents and subsequent training can be vehicles for feminist ethics. Using surveys and interview methods, this thesis identifies major themes present in hospice documents and among hospice workers. These themes are then outlined and discussed in light of Mary Raugust's theory of the ethic of care: a distinct and particular other, interdependence, and a non-linear, accepting approach to processes. Finally, conclusions are drawn about the way in which hospice documents function and ways in which improving documents could, in turn, improve technical communication, technical communication pedagogy, and, most importantly, the hospice experience for patients and families.
CHAPTER 1. INTRODUCTION:
IDEAS ABOUT CARE

This thesis is about caring and documents and the way in which documents can communicate important messages about care. In this paper, I argue that documents used in one specific health care situation, hospice, do not, for the most part, support the ethic of care which is established and exhibited in the actual interpersonal processes of hospice, which is a form of holistic medical care designed to meet the unique needs of the dying and their families.

Most of us don't like to think about dying. We prefer to think about health in terms of wellness— eating fruits and vegetables, undergoing cancer screening, and exercising. However, dying is as much a part of life as being born. Years ago, before lifesaving technology and medical treatments, the lines between life and death were much less distinct. With the advent of improved technology, however, death has become less of a fact of life and more of a failure of medicine. Because we can cure many diseases, when we can't cure some of them, we view it as a failure of doctors, body, or spirit, and feel defeated, rather than accepting terminal diseases as part of life.

Accepting terminal disease as a part of life is where my project begins. Hospice care, since its inception in the late 1960's, has been working to make the dying process as productive and as comfortable as possible for both patients and families. Using a holistic model of care, incorporating mental, psychological, social, spiritual, as well as physical aspects of care, hospice offers a type of caring to the dying and their families that had been downplayed by Western medicine more intent on curing disease than helping terminal
patients and their families benefit from a death with dignity.

Unlike most medical fields where the focus is on a cure, hospice work focuses on the concept of the ethic of care, which in modern philosophy and theology has been identified as a distinctly feminist ethic. Hospice is important to study for a number of reasons. First, health communication has been studied in the past, but direct links between the communication and the ethics represented in that communication are not typically drawn (Addington and Wegescheide-Harris 269). Moreover, understanding hospice is important in terms of our changing population and its changing needs. Andolsen notes that the American population is getting considerably older. As the baby-boom generation ages, senior citizens are quickly becoming one of the largest portions of the American population. Moreover, chronic illness is a growing cause of death, as opposed to severe short illnesses. Andolsen adds, "Many people live longer and experience one or more protracted periods of bodily, and perhaps mental, impairment" (128). In addition, chronic diseases are more likely to be treated on a prolonged basis, which is exactly the type of care supplied by hospice. For these reasons, hospice offers an excellent opportunity to analyze the the ethic of care, which has been defined by Mary Raugust in terms of its focus on a distinct and particular other, non-linear approach to processes, and interdependence, and the way that the ethic of care is shown in written health care communication (128-129).
My Argument With Technical Communication

Until I began this project, I had been growing frustrated with my study of technical communication because of the chasm I saw between technical communication and the people it serves. Although technical writers write for an audience, often a very specific audience, this can be an unrewarding and unfulfilling experience because we may never meet nor be able to verify that we are meeting the needs of our audiences. In many cases the only time we hear from an audience occurs when a problem with our writing causes dissatisfaction or legal recourse. In health care communication, technical writing is taken to a different level. Not only do these documents relate technical terminology and governmental regulations, but they also attempt to explain death and dying to patients and families, a difficult juxtaposition. The difference between this kind of writing and other types of technical communication lies in the fact that health care communication requires an ethic of interaction, what I and others call an ethic of care. Hospice documents are intended to be used as tools for education which will help patients and families deal with terminal illness and death. These issues create within hospice a unique situation in which actions are not designed to progress toward a particular goal. Rather, the hospice care situation is intensely personal and tailored to meet the needs of each patient and his or her family.

My Personal Involvement

This project began as I worked through my own grief following the death of my grandmother, Twyla McConnell Wessels, in January 1997. After my grandmother was diagnosed in November 1995, with amyotrophic lateral sclerosis (ALS), also known as Lou Gerhig's disease, my grandmother and my
family prepared to face her and our uncertain future. ALS is a debilitating neurological disorder that, in the case of my grandmother, affected first her speech and her throat processes and then progressed throughout her body, destroying her muscles and their functions. It is a cruel, painful disease that tore apart my grandmother's life and forever changed the lives of all of us who interacted with her.

Although watching my grandmother's disease progress was incredibly difficult, the care she received from the medical community made a significant impact on the way she chose to die. At the end of her fight with ALS, my grandmother and our family benefited from the care of two different hospice organizations, both of which are profiled in this thesis. After her death, I began to think of the way in which those two hospices had made her passing more bearable for both my grandmother and our family. After some initial research, I realized that technical writing was a strong force in the hospice care we received. As part of hospice, numerous documents are used by hospice professionals—social workers, chaplains, nurses, and administrators—who work with patients and families throughout their stay in hospice. These documents orient, inform, and train patients and families about hospice care, terminal illness, caregiving, and the dying process. In short, hospice documents, together with interpersonal hospice care, train both patients and families about death with dignity.

In this thesis I analyze the messages of hospice by first outlining the rhetorical and ethical impact of recent research in the ethic of care, describing my research that I did in order to study the ethic of care in hospice documents, and finally identifying and drawing conclusions about the future
of hospice and the role hospice documents assume.
CHAPTER 2. LITERATURE REVIEW: DEFINING THE ETHIC OF CARE

In this chapter I argue that understanding hospice care in terms of the ethic of care is an effective way of thinking about hospice documents. In order to understand the ethic of care as a framework for understanding hospice care, this chapter focuses on current and past research in the ethic of care. Because hospice care falls under the umbrella of general nursing care, it may be obvious to link it to theoretical discussions of the nature of care. However, although many feminists have done work into the nature of moral theory and, in particular, the "women's" ethic of care, there are no specific discussions about how the ethic of care fits into documents used in health care situations.

Foundations of the Ethic of Care

Understanding how hospice documents express and incorporate the ethic of care provides a foundation from which to address the development and implementation of the ethic of care in technical writing. Technical writing serves an important function within the structure of hospice, and the ethic of care offers a way of coordinating the actions of hospice within the messages offered by hospice documents.

Many scholars characterize the ethic of care as being based on the concept that caring for others is the most important action human beings can make toward one another (Andolsen 1993; Dillon 1992; Nunner-Winkler 1993; Raugust 1992; Tronto 1993a and 1993b). Gertrud Nunner-Winkler explains, "the most eminent goals of the ethic of care are the wish to care for
and help others, to meet obligations and responsibilities, a concern for others and feelings of compassion, a responsibility to discern and alleviate trouble in the world" (144).

Previously, ethics in technical communication have been based not upon the ethic of care but upon the ethic of justice, which emphasizes detached morality and decision-making based upon impartiality (e.g. justice is blind). For example, an often-cited model for the role of the ethic of justice in business contexts, developed by Gerald Cavanagh, Dennis Moberg, and Manuel Velasquez, focuses the ethic of justice around three questions:

1. Does the act optimize the utility or satisfactions of all constituencies?
2. Does the act represent the rights of the individuals involved?
3. Is the act consistent with the norms of justice? (400)

While the principle of equality is important, the move from the ethic of justice toward the ethic of care, however, offers us an added advantage of treating each situation individually and according to the requirements of unique situations in which results do not necessarily have to be based in justice. This principle is applicable to hospice documents because people are not equally stricken with terminal diseases, and the dying, in most cases, cannot and do not want to be treated like everyone else. Therefore, the principle of equality as emphasized within the ethic of justice, has less importance in the context of hospice.

Many early feminist works discuss in detail the origins of the ethic of care. And, although many contextualize it as a gendered (feminine) ethic, its applications are far-reaching and not necessarily gender specific. An early
characterization of the ethic of care came from Carol Gilligan who wrote in her landmark book *In A Different Voice*, "an ethic of justice proceeds from the premise of equality — that everyone should be treated the same — an ethic of care rests on the premise of nonviolence — that no one should be hurt" (174).

Because the ethic of care is grounded in the principle of non-violence, it follows that the ethic of care practitioners will most likely empathize and identify with those for whom they care. In other words, positioning oneself within the ethic of care must include personal action. Although the basic concept of nonviolence within the ethic of care is common throughout feminist literature, describing how this ethic works is a somewhat more complicated process. For one, rather than possessing a linear (masculine) quality like the ethic of justice which emphasizes results (note the importance of the verdict when using the ethic of justice), the ethic of care is generally characterized as circular and process-oriented (see Gilligan 1982; Cavanagh, Moberg, and Velasquez 1995; Tronto 1993a and 1993b; and Belenky et al. 1986).

Jean Tronto explains that there are four qualities of care:

First, care implies a reaching out to something other than the self: it is neither self-referring nor self-absorbing. Second, care implicitly suggests that it will lead to some type of action... care derives from an association with the notion of burden; to care implies more than simply a passing interest or fancy but instead the acceptance of some form of burden. Third, we insist that the activity of caring is largely defined culturally, and will vary among different cultures. Fourth, we see caring as ongoing. Care
can characterize a single activity, or it can describe a process. In this regard, caring is not simply a cerebral concern, or a character trait, but the concern of living, active humans engaged in the processes of everyday living. Care is both a practice and a disposition. (Moral Boundaries 102-104)

In addition to Tronto’s provisions, Raugust further outlines general tenets for the ethic of care. She explains that the ethic of care requires relationship with other beings . . . the giving and receiving of care, appropriate to specific persons and their situations . . . interdependence over individualism, and a mutuality of giving and receiving . . . focus on a distinct and particular other. (128-129)

Raugust’s definition of the ethic of care emphasizes interdependence and communication with a concrete other. Moreover, because connection and personal involvement are crucial aspects of the ethic of care, a person involved in a caring act must interact on a personal level with the person he or she is caring for. Nel Noddings's work is especially instrumental in developing this component of the ethic of care. Noddings describes the ethic of care as an ongoing process rather than a completed event:

Taking relation as ontologically basic simply means that we recognize human encounter and affective response as a basic fact of human existence. As we examine what it means to care and to be cared for, we shall see that both parties contribute to the relation; my caring must be somehow completed in the other if the relation is to be described as caring. (4)
This idea of caring as an event is important to recognize as we work to apply ethic of care to more static situations, i.e., technical documents. However, just as the ethic of justice characterizes a traditional approach to logic and thought that is embodied in both action and text, I argue so too can the ethic of care transcend process and be represented in text.

The Ethic of Care in Hospice

Hospice is primarily a nursing activity that incorporates elements of social work, spiritual care, and psychological counseling. By virtue of hospice's caring functions, it is primarily administered through health care agencies, specifically, nursing agencies. For this reason, the ethical implications of nursing are important to consider in a discussion of hospice and the ethic of care. According to Peta Bowden in her book *Caring: Gender-sensitive Ethics*, nursing has a problematic relationship to the ethic of care. While nurses do, in fact, care directly for others every day, utilizing the ethic outlined by Tronto, Raugust, Noddings and others, they must do so from a professional distance in order to protect themselves, the privacy of their patients, and, Bowden argues, the "professionalization" of their industry. Moreover, the nursing industry juxtaposes qualities of the ethic of care such as interdependence and dynamic processes with the linear qualities required by the heavily regulated and systemized health care industry. Bowden explains that nursing "provides the opportunity for exploring some of the ways in which terms of public organization and accountability directly influence the nature of caring and for understanding the ethic possibilities of impersonally administered relations of person-to-person care" (102). In their
exploration of communication techniques used in dialysis decisions, Stephen Hines, Alvin Moss, and John McKenzie explain that communication differences may also have to do with the way in which a specific institution (such as hospice or nursing) is socialized. They explain, "Differences in institutional context may entail different socially constructed definitions of the doctor-patient relationship, quality of life, old age, and death" (375).

Just as Bowden notes that nursing has a unique role in interpreting the ethic of care and Hines, Moss, and McKenzie stress the importance of understanding the institutional socialization of an organization, Thomas Addington and Jeanne Wegescheide-Harris explain that health care communication and ethics are inextricably linked, especially in cases of terminal illness. They explain that during terminal illness, the ethic of care exhibited by health care professionals becomes powerful on the most subtle levels. Addington and Wegescheide-Harris have found that "there is a disjunction between what is an acknowledged ethical value and what is actually evidenced at the level of physical action and communication" (279). Addington and Wegescheide-Harris explain, "Changes in verbal and nonverbal communication with the patient as terminal disease progresses to its end stages carry heavy ethical significance. When a patient observes behavior characterized by avoidance and asks: 'Does the doctor care about me less because I am going to die?' he or she questions communicative action that cuts to the center of ethical orientations concerning the value of life" (268).

Models of caring and coping are also found in studies of sociology and psychology. Studies on the role of communication and health have made the
connection between self-efficacy, controlling one's situation, and mental and physical health. For example, Viktor Gecas identifies the way in which social structure affects self-efficacy (302). Moreover, Philip Brickman, V.C. Rabinowitz, and J. Karuza define four models of approaching the study of helping and coping. These four models describe the ways in which helping and coping are most frequently addressed within social structures:

- Moral model: People are responsible for problems and solutions
- Compensatory model: People are not responsible for problems but are responsible for solutions
- Medical model: People are not responsible for problems or solutions
- Enlightenment model: People are not responsible for solutions but are responsible for problems (370-373)

Brickman, Rabinowitz, and Karuza discuss each of these models in terms of their effectiveness and strategic differences. They also explain how each model facilitates different types of communication and social support. For example, they hypothesize that the medical model fosters a stable "unequal status relationship . . . likely to foster deference from the recipient" (Brickman et al. 377). Understanding the various models of helping and coping is significant to identify within the context of the ethic of care because it allows greater understanding of the traditional perceptions of medical workers and potential emotional or socialized obstacles within the hospice audience. Because care for the terminally ill in health care situations of both hospice and non-hospice can lack a caring emphasis or patients may misinterpret
moves toward caring, understanding and identifying the ethics portrayed in hospice care and documents is crucial as it offers a way of evaluating whether or not hospice does indeed fully support the ethics upon which it is founded.

Communication as Care

In order to identify hospice and hospice documents as caring acts, we must recognize that communication, as exhibited in health care situations, can constitute messages of care. Addington and Wegescheide-Harris stress that communication is an important indicator of involvement on the part of the patient and caregiver during the final stages of a terminal illness. They report that "Health care relationships serve as channels for sharing and processing information, formulating health care decisions, and providing patients with tools for contending, physically and emotionally, with disease" (269).

Several theories exist about the effect that communication has on patients suffering from terminal or very serious diseases. In a study analyzing how communication about disease contributed to the well-adjustment or maladjustment of cancer patients, J. Micheal Gotcher identified communication about disease as a significant factor in the survival rate and quality of life of cancer patients. Gotcher surveyed 102 patients being treated for breast and prostate cancer and found that the level of honesty with which the patients could talk about their disease with their families directly affected their adjustment or maladjustment to coping with the disease. Perhaps most interesting for the purposes of hospice studies, Gotcher's study found that both well-adjusted and maladjusted patients wished that they could discuss
more thoroughly "aversive topics of fear, cancer recurrence, and death" (29).

As I have discussed, one of the roles of hospice caring is the sharing of information, including information about difficult topics such as pain and death. In order to quantify and describe the ethical nature of communication in health care situations, Addington and Wegescheide-Harris developed a model of communication to describe communicative decision-making in health-care situations. This model includes four points:

1. Ethical theories: Abstract precepts of moral duty and obligation
2. Principles: Guides that permit or prohibit action in certain circumstances. Can include self-determination, quality of life, confidentiality, truth-telling.
3. Judgment: Guides that permit or prohibit action in particular cases. Issues that determine guides can include: patient's medical history, prognosis, treatment options and potential effects, legal constraints, religious or cultural considerations.
4. Action: A thing done. Communication: Verbal and non-verbal interaction, including speaking with patient and other principals, eye-contact, tone of voice, touch, frequency or length of interaction. Physical: Any non-communicative initiative including surgery, medical prescription, beginning or ending life support, admitting or discharging from the hospital. (271)

Moreover, this model is set up so that it moves "between the abstract
philosophical dimension to practical medical communication" (Addington and Wegescheide-Harris 272). As the model moves from ethical theories to action, it becomes more prescriptive. Addington and Wegescheide-Harris explain, "stated ethical theory mandates appropriate communication and physical action" (272). Movement from action to ethical theories is characterized as descriptive, "observable communication action illustrates some ethical presupposition" (272). Thus, Addington and Wegescheide-Harris offer yet another way of describing the communication that takes place in health care situations and the way in which ethics impact this genre of communication.

The Ethic of Care in Technical Communication

How is it that we can integrate the ideas of the ethic of care into technical communication? With the realization that different audiences have specific needs that cannot always, in the case of hospice, be met using the methods of the ethic of justice, the ethic of care is an important addition to technical communication. Consequently, technical writers, especially those working on documents that will be used in sensitive situations, such as hospice, have an ethical responsibility to the document and to the readers of those documents (Dombrowski 174). Michael Bayles adds, "professionals offer important services to society so they have an obligation to behave ethically in relation to those they serve" (qtd. in Beck 537).

At a basic level, I interpret writing technical documents from the perspective of the ethic of care as audience-focused writing to the extreme degree. Feminist ethics offers technical writers the opportunity to interact
with their readers on a more personal level and to explore different contexts and styles within technical communication, a field that has been characterized in feminist theories as overly systematized and exclusive. According to feminist theorists, the ethic of care requires that technical writers closely examine the situations for which they are writing and craft a dialogue in which they invoke their audience in a respectful, inclusive, and sensitive manner. Margaret Thorell Murray explains, "technical writing does not have to be confined and formulaic. If we approach technical writing from a rhetorical stance, the idea of audience becomes paramount. Serious consideration of audience leads to serious consideration of the political, social, and ethical contexts for technical prose" (152). However, despite Murray's strong support, caring is not ordinarily part of the paradigm for technical writing, largely in part, according to Kathryn Graham, because of caring's unscientific nature. Graham explains, "In terms of composition... Theories and models derived from a science, like cognitive psychology or linguistics, argue their superiority over what have come to be known as "touchy-feely" approaches to composition such as Elbow's and Murray's, which are rooted in the ideas of trust and community, caring and connecting" (2). While some may argue with Murray's and Graham's assertions about the nature of technical communication, their interpretations are consistent with feminist critiques and offer insight into established perceptions of technical communication.
Issues With the Ethic of Care

Despite the resounding support that care receives from feminist philosophers, composition scholars, and others, the ethic of care is rightly scrutinized and critiqued. Gender, power, and authority are three issues that are most frequently discussed. Many feminists, for example, question whether the ethic of care can simply be categorized as an ethic related to gender, marginalized as primarily a "women's ethic," and abused by both feminists and more traditional ethicists to reinforce outdated stereotypes about the role of women in the caregiving process. For example, Tronto explains, "If feminists think of the ethic of care as categorized by gender difference, they are likely to become trapped trying to defend women's morality rather than looking critically at the philosophical promises and problems of the ethic of care" ("Beyond Gender Difference to a Theory of Care" 241).

As Tronto warns, because of the ethic of care's relationship to women's experiences and the potential for subsequent marginalization that often accompanies that association, authority can be problematic in documents written from the perspective of the ethic of care. At issue here is the idea that the ethic of care is an exclusive, different type of morality somehow apart from conventional needs of professional writing. Technical writers wishing to use the ethic of care in documents must acknowledge that the ethic of care cannot be understood as an exclusive or limiting theoretical perspective. However, this issue can be resolved if theoretical discussions within technical writing are expanded to incorporate an awareness of the origins of the ethic of care in earlier theoretical frameworks that have been accepted as part of traditional notions of "authority" (Mortensen and Kirsch 565). Tronto
explains, "only if we understand care as a political idea will we be able to change its status and the status of those who do caring work in our culture" (Moral Boundaries 157).

Care is also problematized by moves to universalize the ethic of care and disregard the need for individuality in caring situations. Andolsen explains that the ethic of care is susceptible to being generically universalized which, in effect, demeans the notion of caring. She explains, "Caring labor takes on a different texture in specific communities" (Andolsen 136). While we may work to develop frameworks from which to understand caring behavior, these frameworks cannot underrepresent or ignore the impact that social context and community have on a caring activity and the communication that characterizes a caring activity.

Conclusion

In this section, I have outlined various methods of characterizing the ethic of care according to theories developed by a number of philosophers, rhetoricians, and health care providers. From this brief discussion, we can glean much about the development and concerns that the ethic of care have raised and more deeply appreciate the challenge that caring presents philosophers, medical professionals, as well as technical writers.
CHAPTER 3. METHODOLOGY: STUDYING THE ETHIC OF CARE

As I have explained, hospice offers care to thousands of people who are in the final stages of terminal illnesses. Hospices are found in hospitals and home health care agencies around the world. While hospice programs were originally founded to help those suffering from terminal cancer take their pain treatments at home, the scope of hospice care now includes caring for patients with other terminal diseases. Hospice includes a variety of physical, emotional, intellectual, and spiritual services (Zimmerman and Applegate 240). In addition to caring for their patients' medical needs, hospice workers are responsible for helping patients and families learn to accept and deal with the reality of death, to encourage them to make peace with their circumstances, and to counsel families and patients as they make heart-wrenching decisions regarding medical care at the end of life. These types of caring activities take on a number of forms. Hospice caregivers work within patients' homes to offer medical care and assistance, in addition to providing printed materials and other resources for both patients and families. Caring is a crucial aspect of hospice and documents are often used to reinforce the message of hospice; however, the influence of the ethic of care in the production of hospice documents is an area that has not been addressed. This study analyzes the way that hospice documents reflect or do not reflect the nature of hospice. This section details the methods, as approved by Iowa State University, that I used to conduct my research both at the survey and interview levels as well as the steps I took to interpret that data.
Collecting and Interpreting Survey Data

In order to assess the various influences affecting hospice care, I sent out surveys to all of the hospice organizations in the state of Nebraska, 27 total, and to 30 randomly selected hospice organizations in Iowa (roughly one-third of hospices in the state). All of my contact information for these hospices came from *The 1997-98 Guide to the Nation’s Hospices*, published by the National Hospice Organization, which is a comprehensive list of hospice organizations across the country. Each survey was marked with a number and letter code. A copy of my survey can be found in Appendix A. Each survey was sent with a cover letter and self-addressed, stamped envelope for each hospice’s response. I received 19 out of 57 surveys back, a return rate of 33%.

The survey served two functions. First, it served as a means to gather basic information from a number of hospice organizations about documents and their relationship to the ethical concerns of hospice. Second, the survey gave hospice directors the opportunity to identify themselves as persons who would be willing to be interviewed about hospice and hospice documents (more on this a little later). The questions I asked are shown in Table 1.

I developed these questions in order to capture an idea about the type of work that takes place on a daily basis within hospice organizations and to gain a broader understanding of the role that hospice documents play in the caring process. Keeping within the focus of the ethic of care, I was especially interested in the perceived audience for the documents, factors that went into choosing and creating documents for various hospice organizations, and the perceived audiences’ reception of the documents.
Table 1. Survey Questions and Rationale

<table>
<thead>
<tr>
<th>Question</th>
<th>Rationale for Question</th>
</tr>
</thead>
<tbody>
<tr>
<td>How do you use hospice documents in your work?</td>
<td>For the first question, I focused on the way that hospice organizations used hospice documents in their work. I was interested in finding out how different organizations chose to incorporate written materials into their caring activities and processes because this would enable me to understand how important the documents were to their activities and gain a better understanding of the way that caring and the documents were linked.</td>
</tr>
<tr>
<td>What kind of hospice documents do you distribute? Pamphlets? Booklets? Guides?</td>
<td>In this question I was interested in the types of documents in use in hospice organizations. For example, does a hospice use a variety of documents, or are longer materials (e.g. booklets) more widely used?</td>
</tr>
<tr>
<td>Who designs and writes the hospice documents that you distribute? Are they written within and for your specific hospice organization? If you design hospice documents, what issues come to mind when you create them?</td>
<td>Writing technical documents requires consideration of form, audience, and message. In this question, I wanted to determine whether hospice directors were responsible for balancing these concerns in documents or whether they relied upon commercially prepared documents to distribute to their clients. Because an element of the ethic of care relies upon specificity and individuality, this question allowed me to identify how much individual organizations created their own documents.</td>
</tr>
<tr>
<td>What impact, if any, does the religious (or ethical) orientation of your parent hospital/organization have on the types of documents that you have produced?</td>
<td>Because of my interest in the implementation of ethics into hospice documents and the focus of my study being the infusion of the ethic of care into technical writing, I included this question to glean an understanding of what hospice directors saw as the role of ethics in the documents that they provide their clients.</td>
</tr>
<tr>
<td>Are the documents you use purchased from a publishing company? (If you purchase documents from a publishing company, what are the titles of the documents that you use?)</td>
<td>This question offered information so that I could draw conclusions about the use of commercially prepared documents and perhaps see trends about which documents were used the most frequently and which publishing companies supplied the majority of documents.</td>
</tr>
<tr>
<td>For whom are the hospice documents designed (Patients? Families? Hospice workers?)</td>
<td>Since technical writing focuses on the both the material produced and the needs of the audience for whom the material is prepared, this question provided much necessary information about the perceptions under which hospice administrators operate when they choose documentation for their organization.</td>
</tr>
<tr>
<td>In your experience, how have hospice documents been received by patients and families?</td>
<td>I was interested in understanding how hospice directors perceived their documents in use and the way in which their audiences responded to the documents that they used.</td>
</tr>
</tbody>
</table>
To arrive at my results, I created a database for each question on the survey in which I recorded the response supplied from the surveys. By removing each response from the context of the individual survey, I was able to compare the general responses supplied for each question and draw conclusions about each question based on my survey. In order to choose the representative results, I looked at the degree to which an individual response elaborated on the question. For example, I looked at whether the survey respondent had answered the question completely or provided particularly descriptive examples in his or her answers.

**Collecting and Interpreting Interview Data**

In each survey, as I described in my survey methodology, I left an optional space for survey respondents to identify themselves in order to indicate whether or not they would be interested in being interviewed for the second part of my research. Twelve indicated that they would be interested in being interviewed. Of those 12, I chose five Nebraska hospice organizations
with which to conduct interviews. These organizations offer a cross-section of the types of hospice care and hospice administration in the state of Nebraska. I chose these particular hospices because (1) I could visit each site, (2) these hospices represented a cross-section of the various types of hospices in the state of Nebraska (i.e., Catholic hospitals, public hospitals, regional health centers, rural health centers, larger urban markets), (3) each hospice was located within the state of Nebraska and belonged to the same state hospice organization. All of the interviews took place between December 30, 1997, and January 6, 1998, at hospice organizations across the state of Nebraska. I interviewed the hospice directors at five hospices:

- **Good Samaritan Hospice.** Good Samaritan Hospice, headquartered in Kearney, Nebraska, is part of a large, regional Catholic-based hospital, Good Samaritan Health Systems. There are six satellite offices of the hospice located in ten counties in south-central Nebraska. Director of the hospice is Barbara Hedrick.

- **Providence Hospice.** Providence Hospice, located in Wayne, Nebraska, is part of a local, Catholic-based hospital, Providence Medical Center. It serves a 30-mile radius surrounding Wayne, Nebraska, a town of approximately 4,000 in northeastern Nebraska on the edge of the Winnebago Indian Reservation. Hospice director is Jean Kinney.

- **Heartland Home Health and Hospice.** Heartland Hospice is the home health and hospice branch of St. Elizabeth Health Center, a large, urban, Catholic-based hospital in Lincoln,
Nebraska, a city of 150,000 and the second largest city in the state. It serves the area of the Lincoln metropolitan and approximately twenty miles outside of the city. Hospice director is LaDonna Van Engen.

- **Beatrice Community Hospital Hospice.** Beatrice Community Hospital Hospice is part of the Beatrice Community Hospital, a public hospital located in Beatrice, Nebraska, a small city (population 3,000) in southeast Nebraska. It serves an area of six counties in southeast Nebraska as well as a small part of northeastern Kansas. Hospice director is Kay Wiens.

- **Mary Lanning Hospice.** Mary Lanning Hospice is part of a regional, public hospital serving Adams, Webster, Kearney, Nuckolls, Clay, and Hall counties in south-central Nebraska. Hospice director is Marcia Donley.

During each of my interviews with the hospice directors, I toured facilities (usually just a main office), collected documents, reviewed hospice philosophies, and discussed how documents were used in the hospice process. I audiotaped each interview.

Each interview lasted between 45 minutes and 75 minutes and took place in the administration offices of each of the respective hospices. I asked each hospice director a series of questions designed to elaborate on her survey responses and discuss in more detail the process of hospice, document usage, and document design. My interview questions are shown in Table 2.
Table 2. Interview questions and rationale

<table>
<thead>
<tr>
<th>Question</th>
<th>Rationale for Question</th>
</tr>
</thead>
<tbody>
<tr>
<td>How do the documents that you use define hospice?</td>
<td>With this question, I wanted to determine how documents used in the hospice process actually described the hospice experience. I was especially interested in the role that the documents played in hospice interactions.</td>
</tr>
<tr>
<td>Could you please explain your definition of the hospice process?</td>
<td>In this question I wanted to get a clearer idea of the way that each person I interviewed understood hospice and identify any idiosyncrasies.</td>
</tr>
<tr>
<td>How does the hospice process work here (name of organization)?</td>
<td>This question was designed to help me identify and understand how each individual hospice I interviewed facilitated hospice care.</td>
</tr>
<tr>
<td>How does training affect hospice documents?</td>
<td>In this question, I wanted to understand how each hospice director's individual training as a nurse or administrator may or may not have prepared them for writing and choosing hospice documents.</td>
</tr>
<tr>
<td>Are your documents related to the way training takes place in this hospice, for nurses, volunteers, families, patients? Do they impact the hospice interaction?</td>
<td>This question was designed to identify how documents are used and affect different hospice constituencies.</td>
</tr>
<tr>
<td>Are the materials you distribute through hospice similar to those that you received in your hospice training?</td>
<td>In this question, I was interested in whether or not there were any overlaps or connections between hospice nurse and administrator training and the documents that are used in hospice work itself.</td>
</tr>
<tr>
<td>What types of documents do you use?</td>
<td>This question was, again, to underline and emphasize the types of documents used by hospice administrators in their individual hospice programs.</td>
</tr>
<tr>
<td>If you create documents, what criteria do you use to produce documents? If you purchase documents, what criteria do you use to choose a document?</td>
<td>In these two questions, I was interested in the various decisions and criteria that go into writing and choosing hospice documents.</td>
</tr>
<tr>
<td>Do you have samples of documents that you use?</td>
<td>I wanted to collect representative documents used by the five hospices I interviewed in order to have concrete examples of the documents they were discussing in the interviews.</td>
</tr>
<tr>
<td>What area does this hospice service?</td>
<td>This question helped me gain a better idea of the constituency that each hospice served and the number of patients that it serviced.</td>
</tr>
<tr>
<td>What are some issues that concern this hospice?</td>
<td>I used this question as an opportunity to gain information about other problems that might affect care at this hospice.</td>
</tr>
<tr>
<td>What is the biggest challenge facing this hospice?</td>
<td>This was my final question and I was interested in the responses to see what each hospice director might identify as the most pressing issue for the individual hospice.</td>
</tr>
</tbody>
</table>
After each interview, I transcribed the audiotapes in order to compare the interviews to one another, draw conclusions, and make generalizations about hospice care according to their responses. To evaluate responses to specific questions, I looked at the extent to which each person I interviewed explained their response and gave examples to support their responses which made their information clearer.

Conclusion

In this chapter, I have outlined the methodology that I used to collect data from hospices across Iowa and Nebraska in order to assess the impact that ethics, documents, and care have in their hospice organization. I used a number of basic techniques and an organic evaluation process in order to develop, assess, and interpret my survey and interview results.
CHAPTER 4: SURVEY AND INTERVIEW RESULTS: INTERPRETING THE ETHIC OF CARE

In this section I outline and evaluate the data that I collected from my survey and interviews as described in my methodology. I also begin to draw some conclusions and evaluations based on that data.

Survey Results

To study how hospice works in an actual hospice situation, I collected data from hospice organizations in Nebraska and Iowa. I randomly contacted 30 hospice organizations in the state of Iowa (approximately one-third of the total number of hospices in Iowa), and contacted 27 hospice organizations in the state of Nebraska (the total number of hospice organizations in the state).

For each question that I included on the survey, I did a careful analysis of the responses that I received from each organization participating in the survey. Although these responses were intentionally removed from the original context of their survey, they do allow an opportunity to observe trends in hospice work from across an area and provide a glimpse into the concerns and challenges of hospice work. Later, I interpret the results of the survey in terms of Raugust's outline of the ethic of care.

How do you use hospice documents in your work? For the first question, I focused on the way that hospice organizations used hospice documents in their work. I was interested in finding out how different organizations chose to incorporate written materials into their caring activities and process because this would enable me to understand how important the documents were to their activities and gain a better
understanding of the way that caring and the documents were linked. Most of the respondents replied that they used the materials to supplement their care, and nearly all of those surveyed reported that they used documents for the education and orientation of patients and families when enrolling in hospice care. A number of those surveyed said that documents were important as a supplement to the care provided by health professionals in hospice work. For example, one wrote, "Documents provide written material to read as questions arise." In addition, four hospice directors reported that documents served a marketing and public relations purpose for their organizations. Documents were also used for a variety of clerical duties, to keep patient records, and to inform patients of rules and regulations required by the U.S. government or Medicare.

What kind of hospice documents do you distribute? Pamphlets? Booklets? Guides? In this question I was interested in the types of documents in use in hospice organizations. For example, does a hospice use a variety of documents, or are longer materials (e.g., booklets) more widely used? Depending on the answers, this question offered information about perceived audience for the hospice documents. For example, a hospice using primarily booklets and longer pamphlets perceives a more involved readership than those relying on brief brochures and handouts. The majority of my respondents said that they used pamphlets and booklets. Some also replied that they used single-sheet handouts as well. While many of my survey respondents explained that they used pamphlets and booklets in their hospice organizations, some also said that they considered the forms they used for clinical records as crucial hospice documents. National Hospice Organization
guidelines were important to the hospices responding as were documentation provided by Medicare about Medicare benefits and facts. Many of the organizations that I contacted reported that they use the same documents as other hospice organizations across the country, to explain, for example, Medicare benefits.

Who designs and writes the hospice documents that you distribute? Are they written within and for your specific hospice organization? If you design hospice documents, what issues come to mind when you create them? Writing technical documents requires consideration of form, audience, and message. In this question, I wanted to ascertain whether hospice directors were responsible for balancing these concerns in documents or whether they relied upon commercially prepared documents to distribute to their clients. Because an element of the ethic of care relies upon specificity and individuality, this question allowed me to identify how frequently individual organizations created their own documents.

Fourteen of my 19 respondents used documents created by their own hospice organization for distribution to patients and families. Some responses did not clearly identify exactly who was responsible for writing the documents. Explained one, "Our staff writes and designs—Following NCFA and Medicare regulations." Another explained that the documents produced for their hospice were written by their hospital's marketing department "for us specifically." Others explained that while they did create certain documents that were specific to their organization and that, "When designing we think of specificness and who will use," some explained that they also used documents provided free of charge by drug companies in their hospice care. A
number of respondents also explained that commercially prepared documents (not counting those provided free-of-charge by drug companies) were used in the care process.

What impact, if any, does the religious (or ethical) orientation of your parent hospital/organization have on the types of documents that you have produced? Because of my interest in the implementation of ethics into hospice documents and the focus of my study being the infusion of the ethic of care into technical writing, I included this question to develop an understanding of what hospice directors saw as the role of ethics in the documents that they provide their clients. The overwhelming majority of responders reported that the religious/ethical orientation of their parent organization did not have any impact on the documents that they use. A few, Catholic-oriented and owned organizations reported that the religious orientation of their parent organization was important. For example, one hospice organization included the prayer of St. Francis of Assisi on its documents as well as language about serving Christ. Several other organizations reported that while specific religious overtones were not found in their documents, ideas about ethics and spirituality were still included. For example, one respondent wrote that religion and spirituality had "no impact other than providing care to the best of our abilities, and honoring advanced directives when within the law." Another reported, "[The] Parent hospital does have impact. We deal with many ethical issues and use the hospital ethics board." One organization that had a Catholic name and Jewish owners explained that the extent of ethics represented in their documents included language about autonomy and dignified death. Another Catholic
organization reported that they did use religious brochures in their caring process "because of our Catholic orientation."

Are the documents you use purchased from a publishing company? (If you purchase documents from a publishing company, what are the titles of the documents that you use?) With this question, I was wanted to see whether or not certain commercially produced documents were widely used by various hospice organizations. Thirteen survey respondents provided a list of the names of documents that they purchased. The Channing L. Bete Co., and the Abbey Press were two frequently named publishing houses providing documents to the hospice organizations responding. Non-profit groups creating brochures used by a number of respondents included the U.S. Consumer Product Safety Commission, Nebraska Department of Health Bureau of Health Facilities Standards, American Cancer Society, National Institute of Health, National Hospice Organization, Center for Disease Control, and the Iowa Pain Initiative. One respondent reported that most of their documents came from drug companies.

Documents purchased from publishing companies included a high percentage of death and bereavement process materials. More than one hospice reported using documents with titles such as Gone from My Sight, Journey’s End, Care Notes, A Time to Live, and A Time to Heal.

For whom are the hospice documents designed (Patients? Families? Hospice workers?) Since technical writing focuses on the both the material produced and the needs of the audience for whom the material is prepared, this question provided necessary information about the perceptions under which hospice administrators operate when they choose documentation for
their organization. The majority of respondents reported that their documents were designed for patients and families. A smaller number of those responding reported that documents were used by community members, volunteers, and health care professionals, such as hospital discharge planners or social workers.

In your experience, how have hospice documents been received by patients and families? Sixteen of 19 respondents reported that the documents used in hospice care were received "very well" by the majority of people with whom they work. One wrote, "it gives them something to refer to after the initial visit. Also they facilitate questions and a comfort level with written information in hand." How patients and families use the documents provided to them by hospice workers varied, however. "Some read [them] cover to cover, some not at all," one wrote. Another added, "how much is absorbed [from the documents] is an interesting question. More information seems to be realized by families as time goes on, but [the information available is] overwhelming at hospice admission time." Another aspect of document reception reported by hospice administrators is the level to which patients and families use and reuse the documents. According to one, "sometimes they even share them with other friends and family and ask for more."

What do you see as the role of hospice documents in the caring process? With this question, I hoped to identify what the hospice administrators intended to accomplish with the documents that they used in the hospice interactions and develop a better understanding of the level of involvement that hospice administrators had with the documents they used.
The responses I received for this answer were quite varied. Some of those responding explained that the documents were used for "important information transmission." In other words, they saw hospice documents as primarily a tool for relaying information, perhaps Medicare regulations or other "requirements." Still others mentioned the documents' primary role was to "teach patients and families" and "record patient information correctly." However, in addition to the important role of relaying crucial legal and medical information to patients and families, these documents often also have the complicated role of conveying messages of support and reassurance. One respondent reported that the documents "promote nurturing, gentleness, yet explain the dying process of the whole person, physical, emotional and spiritual." Several added that documents allowed families to conquer information about hospice at their own pace. One wrote that documents are, "something the family can refer to often and on admission everything is overwhelming and documents allow the family to take in information at their own time and comfort."

Can you explain in two or three sentences a summary of your philosophy of hospice work? In this question, I was interested in drawing connections between the hospice administrator's personal philosophy of hospice and what I had studied as integral parts of the ethic of care. Nearly every respondent mentioned holistic care, supporting families, and quality of life in their responses. Several mentioned that hospice "neither hastens death or prolongs life." Moreover, almost all of the respondents also mentioned the role of the family and caregiver in the hospice process. "You are on the most special journey with a patient and family they will ever make," wrote one.
Another added, "Hospice allows us to be human."

**How long have you been at your current organization?** As with any profession, I wanted to see if those who had been working in hospice longer had a different understanding of hospice work or varied experiences with working with documents. Every respondent had been at their current organization for at least one year. The longest was 16 years, the shortest was one and a half years. The average length of time working in hospice was five and a half years. I was unable to draw any significant links between length of time working in hospice to awareness of documents and document style.

**What are your primary job responsibilities?** Most persons responding were hospice administrators, but the way that they described their primary job responsibilities varied. For example, many described themselves as coordinators of patient care, volunteer services, nurses, and bereavement services. The size of the hospice organization seemed to impact the number of responsibilities that each hospice director had. Several listed their primary job responsibilities; these included: management, budget, contracts, initial hospice evaluation and admission of patients, fundraising, marketing, education, and insurance verification. Again, depending upon the size of the hospice organization, direct patient interaction was also handled by the survey respondents or hospicenurses under their management. In most cases, hospice administrators met with each patient and family at least upon hospice admission and used a variety of materials to explain hospice and Medicare regulations to them.

**How did you get involved in hospice work?** There is no doubt that hospice work is a challenging occupation. Since it directly deals with death
and dying on a daily basis (and as a result, one would assume, is a stressful occupation), I was interested in the circumstances that brought each of my survey participants to the field. Answers varied. Some reported that they had simply answered ads or job opening notices. Others explained that they had personal experiences that led them to feel comfortable dealing with issues of death and dying. For example, one wrote, "[I] got interested in death and dying and the challenges of providing a dignified death for patients that had totally lost control over their lives. This all occurred while working in an acute care setting." Another explained, "I began 14 years ago as a Clerk/Typist, advanced to Executive Secretary, and then became the director of a volunteer program for 8 1/2 years. Relocated and now have current position. I truly believe in Hospice and what a difference it can make for people." The majority of those responding had led professional careers prior to joining hospice programs that put them into contact with the terminally ill. Oncology nursing and acute care were two of the most common past occupations.

**Interpreting the Survey Results**

Although very few respondents directly discussed the ethical implications of their work, nearly all of their responses fit with the definition of the three areas of the ethic of care as identified by Raugust:

- a distinct and particular other
- a non-linear, accepting approach to processes
- a focus toward interdependence
A distinct and particular other

The survey results revealed that the majority of the respondents viewed their clients as individuals with individual needs. For example, words like autonomy, dignified death, and specificity toward patients and families were used frequently in the responses. When asked about the role of religious orientation of the parent hospital or organization on the documents used, one person wrote, "Each patient and family will have a different interpretation of spiritual language and rituals will be different—must apply to all." When asked about individual philosophies of hospice another wrote, "To care for the patient and caregiver with dignity, respect and compassion with the dying process."

The hospice administrators surveyed also described the documents that they chose based upon whether they would meet the needs of their audience of patients, families, and volunteers. One explained, "[Documents are] very important—it is something the family can refer to often and on admission everything is overwhelming... documents allow the family to take in information at their own time and comfort." Clearly, the audience that the hospice administrators are targeting is very specific, but even more importantly, the individual families that they are dealing with are treated as unique. The surveys revealed a great deal of care between the hospices and their clients.
A non-linear, accepting approach to processes

From the survey responses, it was clear that both the documents and the process of hospice at these various agencies emphasize individuality when it comes to patterns and strategies of care. For example, the very fact that the documents are used implies an accepting, non-linear approach to hospice processes since it emphasizes that hospice care occurs not only when a nurse visits a patient, but afterwards as well. As one respondent explained, "It gives them something to refer to after the initial visit. Also they facilitate questions—and a comfort level with written information in hand."

A focus toward interdependence

A focus toward interdependence between the various elements of hospice care as well as interdependence between professionals and patients was definitely present in the documents, as related by the surveys. Many of those responding explained that the documents were used in conjunction with or in addition to visits and explanations by hospice nurses and other hospice workers. Hospice workers used the documents interdependently, and the documents also fostered interdependence between the hospice and patients and their families because the documents can be used as talking points for patients, families, and hospice to discuss difficult and sensitive subjects. For example, one person explained, "The documents assist with continuity of information, care, symptom control, education, and for legal purposes. The documents provide easy access to the past care provided and for the future goals."

I chose these particular hospices because (1) it was geographically feasible to
actually visit each site, (2) these hospices represented a cross-section of the various types of hospices in the state of Nebraska (i.e. Catholic hospitals, public hospitals, regional health centers, rural health centers, larger urban markets), (3) each hospice was located within the state of Nebraska and belonged to the same state hospice organization.

**Interview Results**

As I explained in my methodology, the survey results provided the information necessary to proceed with in-depth interviews of self-selected hospice organizations that I then chose based upon location and representation of the industry in a particular area. Overwhelmingly, the results of my interviews revealed that these hospice directors implemented the ethic of care into their work in their hospices although they might not formally recognize it as such. It seemed that although none of the hospice directors came out and said it, and several of them had mentioned in their surveys that ethics did not necessarily apply to the work that they did or to the documents that they distributed, that a strong ethic of care was at work toward their patients as well as toward their staff.

**How do the documents that you use define hospice?** From my interviews, it was clear that hospice workers used documents even at the very earliest stages of hospice care. All of my interview subjects explained how they used documents to explain hospice during the admission period as well as during talks or other informational meetings that they or members of their staff held for community groups or nursing homes. Hedrick of Good Samaritan Hospice explained that documents describing Medicare regulations
(a crucial factor in hospice care as so many of their patients are elderly or have medical conditions that require government assistance to afford treatment) are used very frequently during the hospice process. Hedrick explains:

We have found out that with a lot of brochures and a lot of the information that we've given out with hospice it's a matter of explaining it and then leaving information there for them to read later because when you first explain hospice it is overwhelming to the point that they're no longer listening...We don't try to explain all of the Medicare rules and regulations. . .I don't think we'd understand it all! (30 Dec. 1997)

Nearly all of my interview subjects also explained that they used documents to relate what their hospice would allow as far as end-of-life decisions and other aspects of hospice care. Kay Wiens of Beatrice Hospice explains, "I can think of advanced directives being an example, that I look through some literature and searched some information that I thought would be appropriate for us to use for teaching tools and that would be very easily understood" (5 Jan. 1998). Using hospice documents as teaching tools was important for Van Engen of the Heartland Hospice as she explained a situation that had happened the weekend before our interview.

Van Engen: Well, you know we do a lot of educational about the process of dying.

Duncan: And this is with the family?

Van Engen: Right.

Duncan: The patients?
Van Engen: Both. It depends. But today, I left a little brochure; it's called "Gone from my Sight," and I can give you a copy of that. And it goes through what to expect as far as death.

Duncan: And you left that with the patient?

Van Engen: The patient herself. She can't read, because of her vision, but I left it in a pile for her family. And I thought and I said that there's information here and we can share that with you, read it aloud to you, whatever. Today she's not ready for that, she's not ready, but her family, they had to make a decision about no code this weekend. And so they need to see that, yes, she is having some of the signs and symptoms and, yes, we're looking at one-to-three months here.

The booklet kind of goes through three-to-six months, one-to-three months, a couple weeks, and a few days, that kind of thing before. And so you do a lot of education about the reason your face is drooping is because your brain tumor's increasing and causing some pressure, and that's why this is happening. We really try to let the patient have as much control over their life as possible in every way that we can. (5 Jan. 1998)

Could you please explain your definition of the hospice process? In my five interviews, each person defined hospice using similar words and phrases. "Holistic care" and "meeting the needs of both patients and families" were phrases that were used often. Several I interviewed explained their hospice work in terms of what it is not. Another key idea supported by those I interviewed was the idea that hospice is about caring for and not curing a patient. For example, Hedrick explained, "Our goal for the patient and family is for the patient. We have to refocus our goals: It's not for them to get better;
it's not to have their disease cured. It's for them to live and get done what they want to get done and then die at home peacefully. And so our goals have to change, which is hard for people... whose goal is to get this patient better, independent, back on their feet again" (30 Dec. 1997).

**How does the hospice process work here (name of organization)?** All of the five hospice directors I interviewed described basically the same process of being enrolled in hospice. Ordinarily, patients are given a limited life diagnosis by their physician, a diagnosis that comes around the six months life-expectancy mark or after. Physicians then usually refer their patients to hospice. Kinney of Providence Hospice explained that she occasionally had referrals from family members or neighbors. Kinney explained, "A lot of times what happens with our patient is that the home health nurse at some point and then maybe the patient decides that they're no longer going to have chemotherapy or radiation therapy and then at that point hospice is appropriate" (2 Jan. 1998).

All of my interview subjects also added that enrolling patients as early as possible allows them to actually go through the entire hospice process with patients, but early admissions don't usually occur. Of my interview subjects, many reported having hospice stays a short as 24 hours, meaning that a patient died within 24 hours of admission to the hospice. The longest average hospice stay was 51 days (Beatrice Community Hospice). The general length of stay in hospice was around 20 days. Considering that the average length of stay in the hospices I interviewed is well under the length of time for which hospice is designed, length of stay is a major issue affecting the effectiveness of hospice care at these agencies.
Are the materials you distribute through hospice similar to those that you received in your hospice training? Surprisingly, training had little impact on the way that these documents were distributed or the way that they were developed. Only two of those that I interviewed could talk about documents that they had actually designed and the type of issues they discussed as a part of the document's design. One, Donley of Mary Lanning Hospice, explained that her nursing program had emphasized patient communication. The others explained that they learned to be hospice nurses either through experiences in cancer care or through life experience and other volunteer hospice experience. The training that each hospice director had received usually included some sort of nursing training, although the specific needs of the hospice they were serving seemed to translate into their particular skills as well. Kinney of Providence Hospice, for example, has an MBA and teaches accounting at the local university. She was hired, she explained, because the hospice at the time was badly in need of someone to help manage money.

Experience seemed especially important when it came to raising the issue of spiritual concerns of hospice patients. Van Engen noted, "Sometimes it's 'I don't want any of that God talk.' You know, and that's OK" (5 Jan. 1998). Hedrick said, "to explain hospice, I think sometimes you just have to experience it. And it's the stories and the fact that you've been there that really add credibility... it's death is always a scary experience, and I think that people add more credibility to you knowing what you're talking about if you've actually been there and done that kind of thing" (30 Dec. 1997). Through their experience, those I interviewed learned how to adapt and
change their approach to patients and families on an individual basis, thus strengthening the personal nature of hospice care.

Are your documents related to the way training takes place in this hospice, for nurses, volunteers, families, patients? Do they impact the hospice interaction? Every person interviewed explained that the documents that they used definitely had an impact on the type of interaction they had with patients and families. Wiens of the Beatrice Community Hospice explained how she used documents and materials in her interactions with families:

I guess I wanted it [documents] to be real user friendly. . . I don't know when a person defines that you're an expert and I don't mean to be an expert, but you need to have some experience in the field, and the material I need to use needs to be, like I said, user friendly, something that's very applicable, very simple because people who are going through difficult times don't need a real high technical stuff. . . Sometimes they're nervous, caregivers have never ever taken care of anyone or helped them into a bed . . . just simple things. . . I just really feel like home is totally different than hospital setting and so you know you need to work with them and individualize it. (5 Jan. 1998)

Many administrators referred to the educational process that takes place during hospice, how documents can help prepare a family for death, and how documents can help them understand the changes their loved one will be going through. Donley of Mary Lanning Hospice explains, "We have a lot of patient information brochures. . .And these stay with the family and the patient. . .so many times we have families who absolutely cannot talk about
the issues directly. . .and so these are some things that way people can pick them up when they are ready. It doesn't have to be at two o'clock in the afternoon when we are making a visit" (6 Jan. 1998).

**What types of documents do you use?** All of the hospices I interviewed explained that they used documents that covered a variety of issues including Medicare, the dying process, advanced directives, bereavement, pain control, and general safety issues. The Heartland Hospice also showed me a series they purchased called *CareNotes*, which deals with specific spiritual concerns that might affect a dying person.

Documents used were not limited to pamphlets and brochures, either. Donley at Mary Lanning Hospice, for example, showed me a variety of documents that were packaged together in a folder and given to the patient's family at the time of the hospice admission. This folder with the Mary Lanning logo on it contained much of the basic information that a hospice family would need at various stages of the hospice process. Donley has also developed documents that speak directly to caregivers and their responsibilities in the hospice process. One deals with the plan for a caregiver. Donley explained, "We tell them, for instance, this isn't a legal document this doesn't bind you to do this [care for hospice patient], but it just gives us a chance to say that we've talked about it and we've established this and answered questions. It's more of a vehicle to insure that communication is done" (6 Jan. 1998).

**If you create documents, what criteria do you use to produce documents?** Three of the hospice directors I interviewed had created documents on their own for their respective hospices. One, the Family
Notebook, currently being compiled by Good Samaritan Hospice, is a collaborative effort among Hedrick, the hospice director, the hospice social worker, and hospice nurses. Hedrick explained that the choice to develop a Family Notebook for the hospice patients and their families arose when she saw the need to include documents for family members to better explain the hospice process. Hedrick explains, "We're finding that patients. . . weren't picking up the roles. They knew what the nurses did, but they had a hard time understanding why they needed the social worker, why they needed spiritual, why they needed a volunteer. . . So we had to do that on our own, we didn't really find anything that explained that well" (30 Dec. 1997).

Aside from the issues of need, hospice directors also used a variety of audience analysis techniques when designing their documents. Donley created a brochure to market and explain hospice to families and community groups. She said that she worked with the public relations department, but that she learned the majority of her techniques from trial and error. She explained, "Flat out, things need to be at a readable level. . . And we do run into some things here. It's hard to explain things; you get too simplistic and you insult a lot of people. . . You know, it needs to be readable and yet at the same time if somebody's just scanning it I wanted to make sure that they saw. . . the essential parts of it" (6 Jan. 1998).

Wiens of the Beatrice Hospice also relied on her experience when designing documents. "I'm just very personal about what things that I do. And the same way with this type of thing. You know these are just flyers that I try to put together out of information that I have and my vast amount that I've collected" (5 Jan. 1998).
If you purchase documents, what criteria do you use to choose a document? Most of those I interviewed explained that they looked for clarity and appropriateness in the documents that they ordered for their organizations. Several said that they chose the same documents as the last place where they had worked in hospice because they knew that those documents had worked well for the situation. Hedrick explained that her hospice tended to switch documents quite frequently, but that when they did switch to a new brochure or pamphlet the hospice team member who would use that document was generally the one who suggested the change. "I've been here just over a year and a half, and you know we keep on looking for new documents, we keep on looking for new ideas so we don't stick with just one thing," Hedrick explained (30 Dec. 1997).

What are some issues that concern this hospice? Major issues that concerned the hospices I interviewed were financial stability and competition. Surprisingly, all of the hospices except for Good Samaritan Hospice and Mary Lanning Hospice, both of which are the largest in their geographic area, were very concerned about the impact that competition had on their work. Van Engen, whose Heartland Hospice is located in the city of Lincoln, explained that competition made her want to provide even better care for her patients. This concern spilled over into her hospice's marketing concerns. Van Engen explained, "We try to put in what's different about us, what's different about us probably is that we give more home health aide coverage than most people" (5 Jan. 1998).

Financial stability, marketing, and competition are also concerns for some of the smaller organizations I interviewed. Competition from larger
hospice organizations threatens individuality of smaller hospice programs. Kinney at the Providence Hospice in Wayne, Nebraska, explained, "Competitiveness is the issue and probably the biggest challenge is to be able to remain... financially solvent without needing to become involved with a larger hospice and giving up local control" (2 Jan. 1998).

Another concern that was brought up by nearly every hospice administrator I interviewed was the damage that Jack Kevorkian and his assisted-suicide campaign has done to the hospice industry. Every hospice administrator I talked to gave anecdotes of explaining their work to others and having members of the community believe that hospice was part of the work that Jack Kevorkian does. The National Hospice Organization does not have anything to do with Kevorkian's work and does not support his methods at hastening death. In fact, Kevorkian's work goes against the fundamental values of hospice care. Hedrick emphasized that Kevorkian's newsmaking actions have damaged the effectiveness of hospice, "Sometimes the doctors explain hospice [to patients and families], I mean they just do a general overview of hospice and people pretty much I mean... hospice has been a lot of times in the news lately, especially with Jack Kevorkian, you know because hospice is really, the national hospice organization has really tried to downplay Kevorkian... no, no, no, no. Hospice does not believe in physician-assisted suicide" (30 Dec. 1997). Van Engen adds, "if you've ever been in hospice and you've been with a good death, you would never never want what he offers" (5 Jan. 1998).

What is the biggest challenge facing this hospice? Although these hospices represented a cross-section of the hospices in Nebraska, they did
have very similar issues of challenge and concern for their hospices. Two aspects of hospice that concerned them were marketing and competing for patients with other hospice organizations. Another major concern to all five hospices was the length of time that hospice patients were enrolled in hospice. Because the process of hospice involves a great deal of training and education on the part of the hospice nurses toward the patient and the family members, when patients aren't enrolled until there is a crisis situation, it makes it exceptionally difficult for a hospice to do its job.

Finally, another challenge that was mentioned by several of the hospices was the gap that exists between hospice and other medical fields, most notably oncology and primary care physicians. Nearly every hospice director I interviewed said that offering hospice as an option to patients is a difficult task for these physicians. It was almost as though the communication gap existed because physicians didn't want to be seen as "giving up" on a patient by suggesting that the patient enroll in hospice. Donley explains, "That's hard because treatments and cures are what the physicians have been taught... I think that they don't want the patient to feel like they've given up on them" (6 Jan. 1998). Donley adds that she feels that rather than "giving up" on a patient, hospice care really adds an intensity to care that cannot be met by "cure" focused medicine.

Interpreting Interview Results

Analyzing my interview results provided opportunities to classify the responses according to the framework of Raugust's ethic of care. This framework allowed opportunities to study my interviews in a structured way.
A distinct and particular other

The hospice administrators whom I interviewed provided evidence of viewing families and patients and distinct and particular others throughout the hospice process. Many explained how they reinterpreted the hospice process for each of the families according to their needs. For example, Hedrick of the Good Samaritan Hospice in Kearney, Nebraska, explained, "We're all such an individual that you know, somebody who does not have the education... someone who did not make it through... high school compared to someone who has a Ph.D. or has a medical background, you have to tailor it [hospice]" (30 Dec. 1997).

A non-linear, accepting approach to processes

Another major factor mentioned by all of the hospice administrators was the ability of the hospice and the hospice nurses to be as flexible as possible with the care needed by patients and families. However, at times this causes frustration because of the necessary Medicare rules and regulations that govern hospice care. Kinney of Providence Hospice explains, "I guess one thing that's always bothered me is the way the regulations are set up with Medicare, and we're supposed to follow those regulations and contact other home health care agencies and try to find out what it is that they did that made them follow those regulations... It's just like it creates jobs for bureaucrats. I find that real frustrating. You know, like these forms could all be standardized and then all hospices could have that information" (2 Jan. 1998).
A focus toward interdependence

There were two different ways that interdependence was discussed by the hospice administrators I interviewed. First, interdependence was referenced in terms of the relationship between the hospice and the patients and families. For instance, Van Engen explains, "Each person's very individual as you go in. I really remember in my heart and in my head that I'm here for them and their family. So sometimes it's not the patient that I'm so much caring for; it's the family. Or I always remember them as a unit, because if the patient wants to die, that's fine, but if the family doesn't want to let them, that's not. So, I have to make sure that the whole family is ready for this before I start hospice" (5 Jan. 1998).

In addition to the interdependent nature between families and patients and hospice workers, interdependence is also a factor for the hospice as a team. Because hospice care involves many elements of care—physical, social, psychological, and spiritual—there are many people working toward the care of each individual patient and family. Wiens explains, "Hospice is a team approach and on that team is a social worker, a clergy, and a nurse and myself as a coordinator and then anyone else that's involved in the care of that particular patient and so those services are not only available but they should be utilized for that patient" (5 Jan. 1998).

A part of the hospice team approach is hospice care and hospice documents. Documents and caregivers work in conjunction to deliver educational materials, legal information, and support to patients and families throughout the hospice process. Hedrick explained,
I think that the documents are used as a training. . . we're going to put this in the notebook that the family can then refer back to time and time and time again. So that's how they do their own and that's how they learn through that. So it is a partnership. There's something that by reading one sentence ten people could get ten different things out of one sentence. So it does come down towards a partnership where the family develops a trust with that nurse and is able to ask those questions and then the nurse is able to take it from there and either go back to one of the documents in the family notebook and explain what was meant by this or point out where it is in the family notebook. Cause our goal is to empower the family to do the care for the patient. So, yeah, it's a partnership . . . (30 Dec. 1997)

The notion of partnership between the actions of hospice care and documents used to communicate hospice care was strongly exhibited in most of my interviews. A deeper understanding of the role that documents play is necessary in order to understand how the descriptive nature of communication indicates the ethical viewpoint from which they are written and used.

Documents and the Ethic of Care

In the hospice surveys I distributed and at each hospice I visited, I was interested in learning more about the documents used in hospice care interactions. As I learned, hospices rely upon basically two different types of documents: those that are prepared for the individual hospice, often public
relations or admissions materials, and those that are commercially prepared or distributed through government agencies, such as brochures designed to explain Medicare regulations (for a complete list of the documents surveyed, see Appendix B).

Of course, this study is admittedly limited in its scope and, consequently, in its generalizability. However, by studying actual hospices we gain at least a marginal understanding of the documents they use. In addition, since many of these documents are commercially designed, developed, and printed by organizations other than the supplying hospice, it is likely that other hospice organizations across the country use these documents as well or documents similar to these. More important, examining these documents offers one example of the way in which technical writers can potentially incorporate the ethic of care into their work.

**Locally produced documents**

In order to more closely relate documents with the ethic of care exhibited in the interviews, I focused the first part of my analysis on the documents that I knew were produced by hospice employees and that I had discussed with them in our interviews. In every situation except with the Providence Hospice in Wayne, Nebraska, I received introductory brochures that were used in a variety of situations to explaining hospice. In most cases, the same document was used to explain hospice to patients and families upon hospice admission, as well as market the hospice to the community. I looked at the type of language and the topics discussed in the brochures. In each case the individual hospice's main concerns were apparent through the style and
format of the document that each brochure addressed issues that had been raised in our interviews.

My analysis of these locally produced documents was limited by the level of writing in these examples. The majority of the documents I studied had fundamental rhetorical problems with audience and context that prevented a more theoretical analysis relating the documents to the ethic of care. My observation is consistent with the research of Addington and Wegescheide-Harris who have noted that health care communication can be formed on many levels from the ethical foundation upon which it is based (272). The introductory brochures that I studied suggest that because the writers of these documents began at the action level on the Addington Wegescheide-Harris model, the ethical foundation is more difficult to determine. I discovered that fundamental issues of writing were more primary concerns in these documents. For this reason, I cannot use criteria of the ethic of care as part of the evaluation methodology for locally produced documents and must focus on more basic rhetorical elements. Given their limitations, I analyzed locally produced documents in terms of their approach to audience and descriptions of hospice.

Audience

Throughout my examination of documents that most patients and families receive in the hospice admission process, I discovered that while elements of the ethic of care were often present, a muddled sense of audience prevented the documents from being as effective as they potentially could. Although hospice administrators described in detail extensive evidence of the
ethic of care in their hospice work in each of the interviews I conducted at Good Samaritan Hospice, Heartland Hospice, and Beatrice Community Hospice, that evidence is not strongly supported in their introductory materials.

For example, the wording of the brochure Hospice: A Special Kind of Caring distributed by Good Samaritan Hospice never specifically addresses either the family or the terminally ill patient (e.g., using phrases like "you", "your family", or "as a caregiver"). The first page of the brochure explains,

Most people do not want to die alone in a sterile, impersonal surrounding, hooked up by tubes to machines and cut off from their family, friends and everything that's familiar. Nor do they want to die in pain. They would prefer, if possible, to spend their last days at home . . . alert and free of pain . . . among the people and things they love. (Good Samaritan Health Systems 1)

This type of language makes it seem as though the audience reading the brochure would be a disinterested third party, not someone closely involved in making a decision to enroll in this particular hospice program. Of course, one audience for the brochure could potentially be a disinterested third party, for example, a community member attending a grief workshop or extension club meeting. However, for the crucial audience of families and patients involved in hospice care, the document does use descriptive language that involves them in the process of hospice.
Descriptions of Hospice Care

In addition to the different audiences of patients, families, and community, the context in which hospice care is offered also affects the rhetorical strategies used in a document. For instance, in contrast with the Good Samaritan Hospice document, the Heartland Hospice document has obviously been designed to meet the demands of a competitive hospice care market. The document is printed on slick, cardstock style paper and the cover contains a large photograph of an attractive young woman, apparently a nurse, smiling confidently. The words "comfort," "caring," "support," and "compassion" are superimposed over a black background (see Figure C1 in Appendix C). Getting past the surface design of the document, the text offers a similar marketing-package impression of Heartland Hospice:

Heartland Hospice is a unique care program designed to provide medical, emotional and spiritual support to terminally ill patients in the privacy of their own homes. Heartland Hospice is available to patients when curative treatment is not possible. The Hospice team works in cooperation with the attending physician to provide the highest level of comfort and quality of life possible. Their focus is on pain management and symptom control, assisting the patient to maintain the dignity and respect they deserve. (St. Elizabeth Heartland Home Health and Hospice 11)

To describe their hospice environment, Heartland Hospice has made the decision to evoke the feeling of hospice rather than explicitly describing the services that the hospice may provide. For example, rather than detailing the
hospice service, they use the phrase "highest level of comfort and quality of life possible" to describe their services, which to some may make hospice seem more like a Caribbean resort than a medical service.

Although the Beatrice Hospice does not operate in a competitive environment like the Heartland Hospice does, its introductory brochure also tries to target a number of audiences. However, unlike Good Samaritan and Heartland Hospices, the Beatrice Hospice brochure does not feature a flow or narrative to the text included in the document. Because it tries to speak to too many audiences, the Beatrice Hospice document seems to compromise its ability to address any one audience coherently or to describe its services effectively. For instance, in three panels the brochure covers the philosophy of hospice, explains the program's Medicare certification, and uses bulleted lists to outline criteria for admission, services provided, bereavement services, and volunteer services without linking one section to the other and switching writing styles between the sections (for instance, the philosophy of hospice section is written in prose, but the other four sections are non-parallel bulleted lists) (see Figure C2). On one of the back panels at the end of the document, a detachable form indicates the different audiences for whom the brochure is intended:

- I am interested in learning more about receiving Hospice Care.
- I am interested in becoming a volunteer.
- I would like to know how to give a memorial gift to the Hospice.
• I am enclosing a tax-deductible contribution. (Beatrice Community Hospice 6)

These four options indicate that the brochure is intended to reach a variety of audiences, including patients and their families. However, the language used within the brochure does nothing to indicate a concrete audience of any kind. Even the quotation included in the brochure by Rabindranath Tagore, "The butterfly counts not months, but moments and has time enough" seems to miss the mark at relating to hospice patients (Beatrice Community Hospice 6). After all, it seems to equate their final months of life with a beautiful, yet insignificant, insect? This is hardly the image that the hospice is probably trying to relate about the indepth, high-quality medical, emotional, and spiritual care described by Beatrice Community Hospice director Wiens in our interview.

In each of these three examples, the audience of patients and families is not invoked as a concrete, particular other (Raugust 129). In other words, the language used to refer to the terminally ill and their families, especially the use of the words "the patient" and "families" in general without making reference to the realistic potential that readers might be "the patient" or "families," does not foster interdependence but creates distance between the readers' situations and the hospice. Since a large audience for these documents would most likely be people who are in need of hospice service, it seems curious that writers creating these documents do not use strategies to create a closer relationship between the hospice and these readers. Moreover, since the general purpose of hospice is to care for the dying and their families, it seems obvious that the first contact patients and families have
with hospice should work to connect this type of value with hospice care. More than anything, the basic writing problems in these documents indicate that those writing the documents do not perhaps have the time or skills necessary to write complicated documents of this type.

Balancing Audience and Descriptions of Hospice

Contrasting with the materials of the Good Samaritan, Heartland, and Beatrice hospices is the introductory brochure used by Mary Lanning Hospice. In this brochure, the writers have achieved a sense of balance between the various audiences through the use of a variety of rhetorically savvy techniques including language, design, and color.

The front panel of the brochure includes the name of the hospice and of the hospital, the hospice logo, a separate hospital logo, and a quotation from the founder of the modern hospice movement, Dame Cicely Saunders, "You matter to the last moment of your life, and we will do all we can, not only to help you die peacefully, but to live until you die" (Mary Lanning Hospice 1). Immediately, the reader is addressed directly and informed about the main issues in hospice, from the founder of the hospice movement herself. This quotation not only lends a sense that patients are regarded as "distinct" and "particular," but also sets the tone of the brochure: caring, serious, and involved.

In our interview, the writer of this brochure, Donley, the hospice administrator, explained that she had many goals for the brochure. First, it had to be readable for a wide range of people including patients and families from a range of educational backgrounds as well as members of the
community. Donley explained that she struggled to keep the information in the brochure specific, yet basic. Evidence of Donley's desire to serve two audiences is evident in the brochure's text, yet design elements like highlighting help to address the specific needs of various groups (a hurried, stressed family member, for example). In fact, the highlighted material in the text of the Mary Lanning brochure tells its own story to an audience of patients and families. Consistent themes of caring and involvement are carried throughout the highlighted material with phrases such as "quality of life," "special way of caring," "this program encourages patients and their families to be actively involved in the patient’s care," "this approach encourages efficient care of the ‘total person,’” and "time is measured in months or weeks, rather than years" (Mary Lanning Hospice 2-4).

In addition to the story told by highlighted material, Donley directly addresses the concerns of hospice patients by including a poem in the brochure.

When my life is finally measured in months... weeks... days
... hours,
I want to live free of pain, free of fears, free of loneliness.
Give me shelter.
Give me your hand.
Give me your care.
Give me your understanding.
Give me your love.
Then let me go peacefully.
And help my family to understand. (Mary Lanning Hospice 5)
With its first-person language, this poem reinforces the presence of the hospice patient in the brochure and closely identifies itself (and, by extension, the hospice) with understanding the unique situation of persons needing hospice care.

The Mary Lanning Hospice logo, which figures prominently on the front and back of the brochure and is explained on the back of the brochure is another design element that identifies the presence and needs of hospice patients. The logo involves three symbols: a dove, clouds, and sunrise and sunset (see Figure C3). The brochure explains the significance of each.

Dove: Signifies peace at the sunset of life, and hope for the sunrise of a new life. Clouds: Represents the trials and adversity of life—disease, illness, sadness and hardship. Sunrise & Sunset: Signifies the natural circle of life. As each day ends, another day begins. (Mary Lanning Hospice 6)

Although these definitions do not specifically refer to the hospice patients and their families, the references to hope, trials and adversity of life, and the natural cycle of life represent the different emotional and spiritual aspects with which hospice patients are faced. A paragraph below the logo and its explanation explains,

Together, these embrace the hospice concept. While clouds may gather, Mary Lanning Hospice is available to provide assistance and care, sharing and offering support to patients and their families through the sunset, to the dawning of a new day. (Mary Lanning Hospice 6)

On both the language and design levels, the Mary Lanning hospice brochure
offers evidence that elements of the ethic of care can be incorporated into multi-audience documents created by individual hospices to serve their marketing and informational needs.

**Commercially Prepared Documents**

In addition to creating their own documents, most of the hospices that I studied relied upon commercially available materials for their work. For the most part, the commercially prepared documents I analyzed are available for any hospice program across the country and were often used by more than one hospice that I surveyed or interviewed. Because these documents were designed and written by professional writers effectively using principles of rhetoric, I relied upon Raugust's outline of the ethic of care in order to analyze the general effectiveness of writing in these documents.

**A distinct and particular other**

Because the ethic of care emphasizes an identification with a concrete "other," I first examined these documents to see if they identified and invoked a specific audience. I discovered that the majority of the documents addressing caregivers, particularly those related to the theme of grief do, in fact, address a concrete and particular other. For example, one booklet by James E. Miller, *How Will I Get Through The Holidays*, specifically addresses the concerns of a person who has experienced a loss in his or her family. Miller uses language and invokes specific occasions in which his audience may have sad, mournful feelings. Miller writes, "Familiar songs, once so comforting, may catch in your throat or bring tears to your eyes" (5). Miller's
document appears to be designed to be read by family members and caregivers after or during the dying process of the hospice patient. Other documents, however, are not as explicit about their audience or in their identification with the experiences and emotions their audience may be experiencing.

The Medicare: Hospice Benefits brochure created by the United States Department of Health and Human Services fails to identify a distinct and particular other in its text. Instead, the document gives general statements on the state of hospice Medicare benefits, services that Medicare will and will not cover, eligibility, and payment options. Of course, these differences could be the result of this document being a government produced and distributed document. However, I argue that all hospice documents can and should contain elements of the ethic of care. Further, the United States government might actually benefit if all of its documents used more qualities of the ethic of care.

A focus toward interdependence

Interdependence was evident in these documents in several ways. First, and most obviously, the presence of the quality of interdependence could be suggested by the word and phrasing choices made by the writers of these documents. Second, the layout of a document could also suggest interdependence and the interdependent nature of hospice care.

Interdependence through language was evident in many of these documents. For example, in the first paragraph of the booklet Hard Choices for Loving People, author Hank Dunn writes,

Treatment decisions are arrived at through an agreement among
the physician, the competent patient and the family. A medical facility staff needs to know what the wishes of the patient are in regard to treatment decisions. There are several things you can do to arrive at a treatment plan and to see that the plan is implemented. [emphasis his] (25)

Dunn then continues this section by identifying the guidelines that dying patients and their families may choose to follow in order to make these end-of-life decisions in sections entitled "What to Do," "Questions to Help Make a Decision," and "Getting Help with End-of-Life Decisions" (25-30). By using language that stresses the interrelatedness of the factors involved in making these decisions, and stressing the role of the hospice in making these decisions, Dunn establishes the interdependent nature of such decisions and utilizes this aspect of the ethic of care in his document.

In addition to examples of interdependence in Dunn's booklet, Pat Herrington and Jim Ewens use a form of interdependence in their booklet *Hospice: A Special Kind of Caring Handbook for Families Facing a Terminal Illness*. In this document, Herrington and Ewens include stories of other families who have made end-of-life decisions. By using testimonials to help their readers feel less alone in the process of making medical decisions, Herrington and Ewens foster a sense of interdependence between their readers and the anecdotal families they use as examples. These testimonials show readers that others have made the same difficult decisions with which they are faced.

Interdependence can also be expressed by the physical layout of a document. For example, two booklets written by Miller are formatted in a
mirror-image way, each with a different audience. *When You're Ill or Incapacitated* addresses the patient, but by turning the booklet over and upside down, the booklet becomes *When You're the Caregiver* (see Figure C4). This booklet and Miller's other booklet for a grieving person *What Will Help Me?* and its flipside *How Can I Help?* physically emphasize the interdependent nature of being terminally ill and caring for the terminally ill and suffering loss and understanding those who have suffered loss. This layout implies that caregivers and patients are working together and possibly sharing the same document, but with different objectives for its use.

**Non-linear, accepting approach to processes**

Even more significant in their identification with the other through non-linear, accepting approaches are those documents made to assist caregivers coping with the dying process. For example, the booklet *Living the Dying Process: A Guide for Caregivers* by Jody Gyulay is indicative of this quality. In each section of the booklet, Gyulay lists "Gentlers" that affirm the feelings of both the patient and the caregiver. In her chapter on the death event, Gyulay affirms nearly every act or feeling that a caregiver or family member may experience:

- share all you needed or wanted to say
- you may light his way
- share the communion of his life
- hold, lie with or cuddle him
- bless yourself for the care you have given to your precious one
• share his life with trusted others
• share your loss with trusted others
• take in the support of trusted others
• take in the love of others
• please do not make the journey of your grief alone
• gentle and tender your broken, empty heart. (50)

Although Gyulay's language is gender-biased and can be interpreted as too "touchy-feely" for some readers, and despite her confusing writing style, by listing so many possible actions that a caregiver may take at the death of a loved one, she clearly understands and wants to project the idea that all experiences involved with grief are valid and that people approach the end of the hospice process, death, in many different ways.

As a point of contrast, several of the grief-themed documents that were written from a more mainline religious perspective were much more prescriptive in their interpretations of the "correct" way to grieve. For example, in the brochure, How to Live with a Death in the Family, author Father David Hitch instructs readers to "Turn to the Scriptures to find examples and models for grieving" (7). Later in the document, Hitch writes that in order to grieve "four features of the grief process . . . anger, guilt, sadness, and relief . . . should be emphasized because they can impede or postpone a person's reaction to death" (16). While I do not doubt Father Hitch's sincerity in writing this manual about how to handle grief, his language choices (e.g., "should be emphasized") seem to limit the extent of the ethic of care and emphasize instead the "correct" Christian way to grieve, which, while it may be appropriate for some readers (some Christians, for
instance), it might also reinforce feelings of confusion and guilt for other readers worried they are not grieving "appropriately" or alienate an audience that does not hold Christian views. The case of Father Hitch offers evidence that the definitions of the ethic of care can vary and, at least according to Raugust's definition of the ethic of care, the components of the ethic of care are not always evident in Christian-themed documents.

Conclusion

In this section, I have identified and described the results from my survey and interview work. I also interpreted those results in terms of Raugust's model of the ethic of care which includes a distinct and particular other, interdependence, and an organic approach to processes. Further, I have provided an analysis of the documents used by hospice on both a local and commercial level in order to investigate their role in describing and participating in the ethic operating in the hospice situation.

My analysis suggests that one of the biggest problems associated with hospice documents arises when the document is required to address more than one audience. In some cases, the documents fall miserably short and instead become catalog copy about the hospice rather than invoking readers of any kind. However, the example of the Mary Lanning brochure suggests that the ethic of care can be included in materials with more than one audience if writers are creative and make use of a variety of textual and design elements that address many different types of readers and their respective concerns.
A number of implications about the present and future of technical writing as it relates to hospice care can be drawn from my interviews and surveys. This section outlines how hospice documents can be improved to integrate a more effective use of the ethic of care, why understanding the ethic of care is important for hospices working to develop and choose effective documents for their organizations, and how a deeper appreciation and understanding of the ethic of care can impact technical writing and technical writing pedagogy.

### Implications for Hospice Organizations

Over the course of my study I became familiar with the general organization of hospice programs. All of the hospices I visited used a holistic approach to hospice care that included nurses, social workers, chaplains, volunteers, and physicians. In every case, hospice documents had an important role in the process of hospice care. Both the surveys and interviews I conducted described how individuals involved in hospice care had to individualize their care to each patient and family. Ultimately, this means that hospice relies upon the integrity of individuals to insure that a crucial connection is made between the documents and the elements of care. More than one hospice administrator I interviewed explained that documents and the actual caregivers work in partnership to communicate information about hospice care. Moreover, many of the hospice workers I interviewed described
how the documents were pieces of the caring process that were used by many families and patients during the times when hospice workers were not present in the home. If this is indeed the case, the shift from interpersonal communication to communication about hospice relying upon documents requires/implies that the documents need to be more attuned to the needs of their particular audiences and be able to communicate the message of hospice without a hospice worker there to back up the ethic implied in the document.

What I found in my analysis of the hospice documents was that the documents that were created by specific organizations for their individual use were often designed for too many audiences and, as a result, the rhetorical strategies used in the documents were so general that the documents could not be effective at all. In addition, the serious concerns of competition and financial stability that most hospices are dealing with leads to further questions about whether or not these documents are designed with the patient and families in mind at all, or whether their main role is to sell the hospice's services. With all of this concern about financial stability and competition, what will happen in the future as medical spending changes in the government, Medicare is further scrutinized, and the aging population forces changes in the insurance industry? Because hospice is based on the idea of intensive, high-quality care for those who need it, there is a danger that the changing American health care system will change that focus to be increasingly oriented toward economics. If this becomes the case, it is likely that documents will play an even more important role in hospice care, as documents are less expensive than nurse or social worker time with a patient and his or her family. Thus, it is vital that documents convey the ethic of care
that is often currently supplemented to the documents by hospice workers. Hospice director at Heartland Hospice Van Engen explained,

> From a business standpoint, competition is big here. . . I guess I don't have to be the biggest or best in town, but I think we should lead because I think we do it right. We do more than anyone else does for somebody and if we can make money doing it, we don't need to make a billion dollars and so I guess the competition, marketing is something I need to continue to get better on. . . And then of course the financial thing. It's getting very very tough. Everything's going up and up, costs are going up, payments are going down. . . I think that will be a challenge for the future to continue to get the same kind of care for the patients for the money because costs are kind of going out of sight.

To an extent, there is already evidence of the shifting focus of hospice care as concerns about financial stability have influenced the type of hiring that takes place at some levels of hospice. For example, Providence Hospice in Wayne, Nebraska, hired their director, Kinney, based on her accounting and business background.

Although competition and financial concerns are important in many industries, when they become primary concerns for a caring industry, it raises concern about the quality of care that these organizations can provide. While caring and financial stability seem like opposing forces, Jeanne Liedtka explains that it is possible for organizations to use caring as a primary value if it is supported through "goals, systems, strategies, and values" (187).
Furthermore, in an industry like hospice, caregivers are charged with an almost sacred duty to help patients and families through one of the most vulnerable times in their lives. The concern that this care may be compromised by concerns about finances or competition causes is an issue well-worth acknowledging.

**Implications for Hospice Documents**

Issues of training are important in terms of hospice administration and for those who write hospice documents. Although I am no expert in the administration of hospice programs, the issue of hospice training was discussed in several interviews and surveys. In the majority of my interviews and surveys, few hospice directors had received training to do the work that hospice required. Although most of them were very well-trained as oncology nurses or nurse managers, few had received formal hospice certification. In addition, according to Wiens of the Beatrice Community Hospice, hospice certification requires thousands of hours of experience which seems to defeat the idea of actually training for hospice. For this reason, hospice as an industry seems to lack the kind of training program necessary to insure that future hospice workers have the same personal commitment to hospice care as the five hospice directors I interviewed did. Although experience is an important part of hospice work, an integrated training program early in the hospice worker's career may provide an added understanding of hospice work, analyzing the needs of families and patients, and writing and integrating hospice documents into existing programs.

An additional issue related to training and hospice documents is the
way that fiscal concerns affect hospice documents. In many cases, financial concerns required hospice administrators I interviewed to spend little time involved in direct patient care, let alone thinking about the messages portrayed in documents used at all levels of hospice care (e.g. introductory brochures, bereavement materials, family materials). Concerns about insurance coverage, government certification demoralize and distract hospice providers to the point where their work becomes increasingly difficult. In their research on communication and the terminally ill, Addington and Wegescheide-Harris describe health care funding as, "not oriented toward humanity for either the patient or the health care provider (279).

Finances also affect all stages of document design, purchase, and production. Often, documents were chosen only for financial reasons. For example, although many of the hospice administrators discussed how they integrate documents into the caring process and the prominent place that documents held for patients and families, many distributed documents that were provided to them free by drug companies as promotions for their products. Although finances are definitely a legitimate concern, this trend is unfortunate given the important role that hospice documents play. For this reason, there needs to be more emphasis within nursing programs and certainly within hospice programs to understand the importance of the ethic of care within documents and within their work. Giving nurses and volunteers a deeper understanding of the ethic of care would provide them a context from which to request additional funds for hospice documents or time in their busy schedules to learn to write the documents necessary to illustrate the ethic of care to their patients.
Implications for Technical Communication and Technical Communication Pedagogy

Because of the nature of hospice and the needs of the audience that read these materials, hospice documents provide valuable insight into the way that technical writing and the ethic of care can change the everyday lives of thousands of people and make, for patients, the acceptance of one's mortality and, for families, the painful process of losing a loved one, easier to brave. The goal of the technical writer drafting hospice documents must be to communicate information to and create a sense of self-efficacy in an audience that feels little if no control over their situations when they receive these documents and, in fact, have nothing to wait for but the outcome of a terminal illness. Using the ethic of care can help create a rhetorical situation in which readers feel valued and cared for. Including strategies of the ethic of care at every level of documents produced for hospices, from the introductory brochures to the materials explaining the grieving process, must be a priority for technical writers as they interact with patients and families during an intensely personal and difficult time.

Once a terminally ill patient develops a need for hospice care, most families have spent months, if not years, fighting a debilitating disease, searching for second opinions, or preparing for the inevitable. Materials provided to patients and families during this time do not reveal a truth that these people are not aware of at least on some level. Death is not an option for persons facing hospice care. Death is a certainty. However, the way in which issues about dying are presented can make a difference for these
families and patients and help make the dying process less painful, if only a little.

Smoothing the way should be the goal of technical writing documents created for the hospice situation. As a result, implementing strategies of the ethic of care in hospice documents can help create within readers a sense of empowerment, control, and peace during a time in which they may feel powerless and victimized (Kirkwood and Brown 57). However, when using the ethic of care, technical writers would do well to analyze and understand how they implement metaphors for death and dying as well. Within the caring framework, euphemistic language and symbols are often used to replace "offensive" or "difficult" language. While some of these metaphors may be intended to soften the harsh realities, these attempts might actually muddle caring communication. Judith Bowker explains that metaphors are often used to classify experiences (93). Susan Sontag adds, "For the time being, much in the way of individual experience and social policy depends on the struggle for rhetorical ownership of the illness: how it is possessed, assimilated in argument and in cliché" (93-94)

Working with the frameworks of the ethic of care can also change the composing experience and force a greater awareness of audience. Wanda Martin and Scott Sanders explain that composing through the ethic of care offers writers an opportunity for an expanded perceptions of their readers:

Ethical character is created in the composing process. When writers play the reader's role well they are changed by the experience—whether they accept or reject, modify or shape, or even attempt to ignore the reader's perspective—the return to
the writer's intentionality and the subsequent production of text reflects a changed character. (157)

The ethic of care does have a place in technical communication, particularly when the documents address personal issues, such as terminal illness and death. In the case of hospice, caring is the primary motivation upon which the entire industry is based. Therefore, it should not be surprising that these documents do employ at least some of the qualities of the ethic of care. It is important to remember, however, that the ethic of care has many other uses and that feminist ethics can enrich the frameworks of technical writers working in other genres. From hospice documents, as Mary Lay explains, "we must go on to ask how we can make accessible to both women and men a wide range of communication strategies—free from the limitations of gender role—to meet the communication demands of the next century" (83). For example, understanding how the ethic of care works can influence the way that technical writers consider audience in a variety of situations ranging from world wide web design to instructional manuals. Technical writers have the obligation to change some of their approach to writing hospice documents in order to begin to enhance both the discipline of technical writing as well as to meet the growing and changing needs of the public. In order to make this possible, then, technical writing pedagogy must undergo change as well.

The way we communicate has a direct relationship on the way in which we live our daily lives and also reflects on what we value. However, communicating in health care situations and utilizing the ethic of care within technical writing has not been a closely studied area. There are several
arguments explaining this lack of focus. First, as I have shown, the ethic of
care characterizes a traditionally feminine way of communicating the world.
According to Lesley DiMare, the public nature of rhetoric and the traditionally
private realm of women's lives "has acted as a tool of the dominant cultural
position to promote the notion that women are capable of only one function
— a biological one. Such a conception of women has led society to believe
that women cannot operate effectively in the public realm" (47). However, as
I have shown with my analysis of hospice documents and hospice care, the
use of the ethic of care in documents is a very productive way of using
technical communication in specific situations. With this in mind, the ethic
of care offers feminist studies yet another way of becoming part of the
mainstream culture of technical writing and, as a result, influence the
language we use to illustrate and describe our experiences. Feminist ethics
offer an alternative form of discourse that answers the need to represent
alternative voices and ways of reasoning, especially in technical writing
pedagogy.

Incorporating feminist ethics into technical writing pedagogy requires a
multi-faceted approach. As Rae Rosenthal notes, "we tend to teach what is
male, and we tend to value what we teach" (122). Thus, we must strive to
include discussions of feminist ethics into technical writing pedagogy so that
it too will become valued. According to Graham, "At the "core" of feminist
pedagogy... is shaped by (1) Interaction, Cooperation and Trust; (2)
Connected, holistic thought; (3) Intuition and Insight; (4) Joining Feeling and
Thinking; and (5) Social Responsibility" (303-305). Foremost in this study
would be increasing audience awareness. Technical writers must more deeply
consider their audience when they write. This means that they have to take a careful look at who they are writing to and begin to develop empathy for that audience. Perhaps there will come a time when technical writers will perform service-learning projects in hospitals, day care centers, or nursing homes in order to come to terms with what it truly means to care for others. Perhaps then communicating care will become not a matter of chance, but a highly held standard.

As technical communicators, we must also be aware of the multifaceted nature of documents and learn when specific documents are necessary for specific audiences. One of the biggest problems associated with the documents I looked at was that some documents tried to deal with too many audiences at once. The ethic of care requires specificity; certainly in some rhetorical situations the ethic is more necessary than in others, for example in hospice documents. As teachers and practitioners in technical communication, we need to address the fact that in some aspects of technical writing, certain rhetorical situations require different approaches at a more fundamental level than the usual work we do to analyze audience, context, and purpose of a document. Technical writers need to be prepared with a foundation of knowledge to recognize and understand the fundamental differences between these situations.

Areas for Future Study

Feminist ethics offer technical writers the opportunity to interact with their readers on a more personal level and to explore different contexts and styles within technical communication. The ethic of care requires that
technical writers closely examine the situations for which they are writing and craft a dialogue in which they invoke their audience in a respectful, inclusive, and sensitive manner. As Murray explains, "Serious consideration of audience leads to serious consideration of the political, social, and ethical contexts for technical prose" (152). Feminist ethics do have a place in technical writing, particularly, but certainly not exclusively, when the documents address personal issues, such as terminal illness and death.

Understanding the ethic of care within hospice documents offers a new area of investigation for both the hospice industry and for technical writing. Future studies of hospice documents could include a closer analysis of the role that the philosophical orientation of the parent hospital has on the hospice organization and its documents, the role that metaphor plays in the documents themselves, and the difference that perceived audience plays in a document. Moreover, an investigation of the role of region, religion, and other cultural factors associated with death and dying and how these affect the production of a document, or how the gender of the document's writer affects the ethic portrayed in the document are other areas that would be worthy of analysis and discussion.

Because of the nature of hospice and the needs of the audience that read these materials, hospice documents provide valuable insight into the way that technical writing and feminist ethics can change the everyday lives of thousands of people and make, for patients, the acceptance of one's mortality and, for families, the painful process of losing a loved one, easier to brave. The goal of the technical writer drafting hospice documents must be to communicate information to and create a sense of self-efficacy in an audience
that, when they receive these documents, feel little if no control over their situations and, in fact, have nothing to wait for but the outcome of a terminal illness. Using the ethic of care can help create a rhetorical situation in which readers feel valued and cared for. Including strategies of the ethic of care at every level of documents produced for hospices—from the introductory brochures to the materials explaining the grieving process—must be a priority for technical writers as they interact with patients and families during an intensely personal and difficult time. The ethic of care's applications in other areas of technical writing is an area that must continue to be explored and critiqued.

Concluding Thoughts

From the beginning, this study was about many things for me. On a personal level, it was a way for me to begin to work through the many issues that I had after losing someone very close to me to a terminal illness requiring hospice care. It helped me to understand better the dying process and make sense of the myriad of feelings I have experienced over the last year. Professionally, this project helped me to identify ways in which human interactions and genuine caring for others can operate in a profession with which, frankly, I had grown disillusioned. Integrating the ethic of care into both the teaching and the practice of technical writing opens new avenues for expression for technical writers, but, more importantly, it offers our audiences, sometimes those in a great deal of physical and emotional pain, another, perhaps better, way of understanding their illnesses, coping strategies, and messages of hope during the darkest moments.
Being skilled as a writer is a great responsibility. As technical communicators we are called upon to explain a variety of situations to others, from instructional manuals about compact disc players to operating machine guns. Similarly, in documents used in hospice care we instruct others about the dying process. This is an awesome responsibility, one which should not be taken lightly by either hospices or technical writers preparing the materials. The ethic of care allows us to expand our repertoire of theories and ways of approaching our subject material. For these reasons, taking a closer look at the ethic of care allows both technical writers and our respective audiences a broader range of possibilities when it comes to writing documents that thoroughly, accurately, and sensitively portray what can be confusing and complicated situations for patients and families—hospice and the dying process.
APPENDIX A. SURVEY AND COVER LETTER

November 15, 1997

My name is Erin Duncan and I'm working on my master's thesis in rhetoric and professional communication at Iowa State University. As part of my thesis, I am examining the nature and function of hospice documents within hospice organizations. In particular, I am interested in identifying and understanding how hospice documents are used and interpreted. Eventually, I hope to identify ways in which a deeper understanding of hospice and hospice documents can enhance training for hospice workers and volunteers.

Would you mind taking a few minutes to answer the following survey? Your answers will be completely confidential and you will only be identified by a number code in the upper right hand corner. However, for the second part of my research, I am interested in interviewing selected members of hospice organizations. If you would like to be considered for the interview process, would you please fill out the attached personal information form?

Thank you so much for your time. I really appreciate your cooperation. If you have any questions about this survey or my project in general, please feel free to contact me.

Cordially,

Erin Duncan
3117 Lincolnway
Ames, IA 50014
(515) 296-4832 (home)
(515) 294-8350
eduncan@iastate.edu
1. How do you use hospice documents in your work?


3. Who designs and writes the hospice documents that you distribute? Are they written within and for your specific hospice organization? If you design hospice documents, what issues come to mind when you create them?
   
   What impact, if any, does the religious (or ethical) orientation of your parent hospital/organization have on the types of documents that you have produced?
   
   Are the documents you use purchased from a publishing company? (If you purchase documents from a publishing company, what are the titles of the documents that you use?)

   For whom are the hospice documents designed? (Patients? Families? Hospice workers?)

4. In your experience, how have hospice documents been received by patients and families?

5. What do you see as the role of hospice documents in the caring process?

6. Can you explain in two or three sentences a summary of your philosophy of hospice work?

7. How long have you been at your current organization?

8. What are your primary job responsibilities?

9. How did you get involved in hospice work?

Personal Information (Optional)

Name: 
Organization: 
Address: 
E-mail: 

Title: 
Degrees earned/Educational background: 
Phone: 
Fax:
APPENDIX B. LIST OF DOCUMENTS BY GENRE COLLECTED FROM HOSPICES INTERVIEWED AND SURVEYED

<table>
<thead>
<tr>
<th>Document Type</th>
<th>Document Title, Author/Publishing Company</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bereavement</td>
<td>• Healing Grief; Amy Hillyard Jensen</td>
</tr>
<tr>
<td></td>
<td>• When Someone You Love Dies; Channing L. Bete (CLB)</td>
</tr>
<tr>
<td></td>
<td>• Water Bugs and Dragonflies; Doris Stickney</td>
</tr>
<tr>
<td></td>
<td>• Letting Tears Bring Healing and Renewal; Mildred Tengbom</td>
</tr>
<tr>
<td></td>
<td>• Grieving When You Lose Someone Close; St. Meinrad Archabbey</td>
</tr>
<tr>
<td></td>
<td>• About Funeral Planning; CLB</td>
</tr>
<tr>
<td></td>
<td>• Living the Dying Process: A Guide for Caregivers; Jody Gyulay</td>
</tr>
<tr>
<td></td>
<td>• How Will I Get Through the Holidays; James E. Miller</td>
</tr>
<tr>
<td></td>
<td>• What Will Help Me?; James E. Miller</td>
</tr>
<tr>
<td></td>
<td>• How Can I Help?; James E. Miller</td>
</tr>
<tr>
<td>Caregiver</td>
<td>• “Suggestions for Communicating Effectively with The Dying Person”; Beatrice Community Hospital (BCH)</td>
</tr>
<tr>
<td></td>
<td>• “Signs of Approaching Death”; BCH</td>
</tr>
<tr>
<td></td>
<td>• Coping When Someone You Love is Dying; Kathlyn S. Baldwin</td>
</tr>
<tr>
<td></td>
<td>• Home Care of the Hospice Patient; The Purdue Frederick Company</td>
</tr>
<tr>
<td></td>
<td>• About Infection Control in the Home; CLB</td>
</tr>
<tr>
<td></td>
<td>• About Patient Safety in the Home; CLB</td>
</tr>
<tr>
<td></td>
<td>• Patient and Caregiver Guide; Mary Lanning Hospice</td>
</tr>
<tr>
<td></td>
<td>• When You’re the Caregiver; James E. Miller</td>
</tr>
<tr>
<td></td>
<td>• “Love and Chicken Soup”; Synthia L. Cathcart</td>
</tr>
<tr>
<td></td>
<td>• “How fluid deprivation affects the terminally ill”; Legally Speaking</td>
</tr>
<tr>
<td>Legal Issues</td>
<td>• About DNR Orders; Channing L. Bete</td>
</tr>
<tr>
<td></td>
<td>• Hospice Under Medicare; National Hospice Organization</td>
</tr>
<tr>
<td></td>
<td>• Medicare: Hospice Benefits; Dept. of Health and Human Services</td>
</tr>
<tr>
<td></td>
<td>• Your Right to Decide; Good Samaritan Health Systems</td>
</tr>
</tbody>
</table>
| Introductory                                      | • Hospice Care of Nebraska; Hospice Care of Nebraska  
|                                                 | • Your Rights and Responsibilities; Heartland Home Health/Hospice  
|                                                 | • St. Elizabeth Heartland Home Health and Hospice; St. Elizabeth Community Health Center  
|                                                 | • About Hospice; National Hospice Organization  
|                                                 | • Patient Bill of Rights and Responsibilities; Good Samaritan Hospital Hospice Services  
|                                                 | • Hospice: A Special Kind of Caring; Beatrice Community Hospital and Health Center  
|                                                 | • Mary Lanning Hospice; Mary Lanning Hospice  
|                                                 | • Hospice: A Special Kind of Caring; Good Samaritan Hospital  
|                                                 | • St. Elizabeth Heartland Home Health and Hospice; St. Elizabeth Hospice  
| Terminal Illness                                 | • A Time to Live; Barbara Karnes  
|                                                 | • Daily Survival Kit for Serious Illness; Thomas L. McDermitt  
|                                                 | • Advanced Cancer: Living Each Day; National Institutes of Health  
|                                                 | • Managing Cancer Pain; US Department of Health and Human Services  
|                                                 | • When You're Ill or Incapacitated; James E. Miller  
|                                                 | • Some Effects of the Terminal Disease  
|                                                 | • Process on the Terminal Disease; Good Samaritan Hospice  
|                                                 | • Process on the Individual; Good Samaritan Hospice |
APPENDIX C. EXAMPLES OF HOSPICE DOCUMENTS ANALYZED

Figure C1. Front covers of Good Samaritan Hospice and Heartland Hospice brochures
Figure C2. Inside panels of Beatrice Community Hospice brochure
Figure C3. Back panel of the Mary Lanning Hospice brochure featuring the hospice logo
Figure C4. James Miller's booklet illustrates physical interdependence in hospice documents
WORKS CITED


Donley, Marcia. Personal interview. 6 Jan. 1998.


--- When You're Ill or Incapacitated: 12 Things to Remember in Times of Sickness, Injury, or Disability. Fort Wayne, IN: Willowgreen, 1995.

--- When You’re the Caregiver: 12 Things to Do If Someone You Care For Is Ill or Incapacitated. Fort Wayne, IN: Willowgreen, 1995.


Van Engen, LaDonna. Personal interview. 5 Jan. 1998.

Wiens, Kay. Personal interview. 5 Jan. 1998.