INFORMATION TO USERS

This reproduction was made from a copy of a document sent to us for microfilming. While the most advanced technology has been used to photograph and reproduce this document, the quality of the reproduction is heavily dependent upon the quality of the material submitted.

The following explanation of techniques is provided to help clarify markings or notations which may appear on this reproduction.

1. The sign or "target" for pages apparently lacking from the document photographed is "Missing Page(s)". If it was possible to obtain the missing page(s) or section, they are spliced into the film along with adjacent pages. This may have necessitated cutting through an image and duplicating adjacent pages to assure complete continuity.

2. When an image on the film is obliterated with a round black mark, it is an indication of either blurred copy because of movement during exposure, duplicate copy, or copyrighted materials that should not have been filmed. For blurred pages, a good image of the page can be found in the adjacent frame. If copyrighted materials were deleted, a target note will appear listing the pages in the adjacent frame.

3. When a map, drawing or chart, etc., is part of the material being photographed, a definite method of "sectioning" the material has been followed. It is customary to begin filming at the upper left hand corner of a large sheet and to continue from left to right in equal sections with small overlaps. If necessary, sectioning is continued again—beginning below the first row and continuing on until complete.

4. For illustrations that cannot be satisfactorily reproduced by xerographic means, photographic prints can be purchased at additional cost and inserted into your xerographic copy. These prints are available upon request from the Dissertations Customer Services Department.

5. Some pages in any document may have indistinct print. In all cases the best available copy has been filmed.
STEMPEL, JOAN EGNEW

CAREGIVERS' PERCEPTIONS OF FACTORS INFLUENCING THE INSTUTIONALIZATION OF TERMINALLY ILL PATIENTS DESIRING TO DIE AT HOME

THE UNIVERSITY OF ARIZONA M.S. 1983

University Microfilms International 300 N. Zeeb Road, Ann Arbor, MI 48106
CAREGIVERS' PERCEPTIONS OF FACTORS INFLUENCING
THE INSTITUTIONALIZATION OF TERMINALLY ILL
PATIENTS DESIRING TO DIE AT HOME

by

Joan Egnew Stempel

A Thesis Submitted to the Faculty of the
COLLEGE OF NURSING
In Partial Fulfillment of the Requirements
For the Degree of
MASTER OF SCIENCE
In the Graduate College
THE UNIVERSITY OF ARIZONA

1983
STATEMENT BY AUTHOR

This thesis has been submitted in partial fulfillment of requirements for an advanced degree at The University of Arizona and is deposited in the University Library to be made available to borrowers under rules of the Library.

Brief quotations from this thesis are allowable without special permission, provided that accurate acknowledgment of source is made. Requests for permission for extended quotation from or reproduction of this manuscript in whole or in part may be granted by the head of the major department or the Dean of the Graduate College when in his judgment the proposed use of the material is in the interests of scholarship. In all other instances, however, permission must be obtained from the author.

SIGNED: 

APPROVAL BY THESIS DIRECTOR

This thesis has been approved on the date shown below:

Carolyn Murdaugh
Assistant Professor

Date
This study is dedicated to my husband, my daughters, and my parents for their encouragement and loving support.
ACKNOWLEDGMENTS

The author wishes to express her deep gratitude to Dr. Carolyn Murdaugh for chairing the thesis committee and for her support, suggestions and encouragement. Special appreciation is also given to Dr. Merle Mishel for sharing her expertise in grounded theory methodology. Appreciation is also extended to Dr. Alice Longman for her helpful assistance and guidance.

Finally a very special thank you to the caregivers who participated in this study. Their willingness to discuss their experiences made this study possible.
# TABLE OF CONTENTS

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>LIST OF TABLES</td>
<td>vii</td>
</tr>
<tr>
<td>LIST OF ILLUSTRATIONS</td>
<td>viii</td>
</tr>
<tr>
<td>ABSTRACT</td>
<td>ix</td>
</tr>
<tr>
<td><strong>CHAPTER</strong></td>
<td></td>
</tr>
<tr>
<td>1. INTRODUCTION</td>
<td>1</td>
</tr>
<tr>
<td>Historical Perspective</td>
<td>1</td>
</tr>
<tr>
<td>Overview of the Problem</td>
<td>6</td>
</tr>
<tr>
<td>Significance</td>
<td>7</td>
</tr>
<tr>
<td>Statement of the Problem</td>
<td>9</td>
</tr>
<tr>
<td>Purpose</td>
<td>9</td>
</tr>
<tr>
<td>Summary</td>
<td>10</td>
</tr>
<tr>
<td>2. CONCEPTUAL ORIENTATION</td>
<td>11</td>
</tr>
<tr>
<td>Needs of the Patient and Family During a Terminal Illness</td>
<td>11</td>
</tr>
<tr>
<td>Emotional Needs</td>
<td>11</td>
</tr>
<tr>
<td>Spiritual Needs</td>
<td>14</td>
</tr>
<tr>
<td>Financial Needs</td>
<td>16</td>
</tr>
<tr>
<td>Physical Needs</td>
<td>17</td>
</tr>
<tr>
<td>Social Support</td>
<td>18</td>
</tr>
<tr>
<td>Research Question</td>
<td>20</td>
</tr>
<tr>
<td>Conceptual Definitions</td>
<td>20</td>
</tr>
<tr>
<td>Assumptions Underlying Study</td>
<td>22</td>
</tr>
<tr>
<td>Summary</td>
<td>22</td>
</tr>
<tr>
<td>3. METHODOLOGY</td>
<td>23</td>
</tr>
<tr>
<td>Design</td>
<td>23</td>
</tr>
<tr>
<td>The Setting</td>
<td>24</td>
</tr>
<tr>
<td>The Sample</td>
<td>24</td>
</tr>
<tr>
<td>Protection of Human Rights</td>
<td>25</td>
</tr>
<tr>
<td>Data Collection Protocol</td>
<td>26</td>
</tr>
<tr>
<td>Data Analysis Plan</td>
<td>27</td>
</tr>
<tr>
<td>Summary</td>
<td>28</td>
</tr>
</tbody>
</table>
## TABLE OF CONTENTS—Continued

<table>
<thead>
<tr>
<th>CHAPTER</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>4. RESULTS OF DATA ANALYSIS</td>
<td>29</td>
</tr>
<tr>
<td>Characteristics of the Sample</td>
<td>29</td>
</tr>
<tr>
<td>Results of the Initial Interviews</td>
<td>30</td>
</tr>
<tr>
<td>Prophecy Model</td>
<td>32</td>
</tr>
<tr>
<td>Negative Prophecies</td>
<td>32</td>
</tr>
<tr>
<td>Painful Death</td>
<td>32</td>
</tr>
<tr>
<td>Prolonged Death</td>
<td>32</td>
</tr>
<tr>
<td>Unmanageable Coma</td>
<td>32</td>
</tr>
<tr>
<td>Positive Prophecies</td>
<td>36</td>
</tr>
<tr>
<td>Sudden Death</td>
<td>36</td>
</tr>
<tr>
<td>Manageable Coma</td>
<td>36</td>
</tr>
<tr>
<td>Input</td>
<td>37</td>
</tr>
<tr>
<td>Personal Experience</td>
<td>38</td>
</tr>
<tr>
<td>Discussions with Friends or Family Members</td>
<td>39</td>
</tr>
<tr>
<td>Information Received from the Physician</td>
<td>41</td>
</tr>
<tr>
<td>Written Material</td>
<td>41</td>
</tr>
<tr>
<td>Triggers</td>
<td>42</td>
</tr>
<tr>
<td>Triggers of Congruence</td>
<td>43</td>
</tr>
<tr>
<td>Triggers of Incongruence</td>
<td>46</td>
</tr>
<tr>
<td>Behaviors</td>
<td>47</td>
</tr>
<tr>
<td>Anxiety Distraction Behaviors</td>
<td>47</td>
</tr>
<tr>
<td>Summary</td>
<td>49</td>
</tr>
</tbody>
</table>

| 5. CONCLUSIONS AND IMPLICATIONS | 50 |
| Limitations | 55 |
| Recommendations | 56 |
| Implications for Nursing Practice and Research | 57 |
| Summary | 58 |

APPENDIX A  HUMAN SUBJECTS FORM | 59 |
APPENDIX B  DISCLAIMER | 61 |
APPENDIX C  CHART DATA FORM | 63 |
APPENDIX D  "GRAND TOUR" QUESTIONS | 65 |
REFERENCES | 67 |
LIST OF TABLES

Table 1  Demographic Data, The sample .......................... 31
| Figure 1 | Prophecy: A Key Variable in Explaining Decision to Institutionalize | 54 |
ABSTRACT

The purpose of this study was to identify factors which influenced the decision to institutionalize a terminally ill patient during the final stage of illness who was enrolled in a home care hospice program and desired a home death. Eight caregivers of terminally ill patients who had been institutionalized shortly before death occurred were interviewed. The interviews were analyzed using grounded theory methodology to identify factors influencing the institutionalization of the patient.

The major factor influencing the institutionalization of patients in this study was the type of prophecy made by the caregiver. This prophecy predicted the manner in which the caregiver anticipated the patient's death would occur.
CHAPTER 1

INTRODUCTION

This study sought to identify those factors which led terminally ill patients and their families enrolled in a home care hospice program to institutionalize the patients in the final stage of illness, although the patient and the family had initially expressed a desire for the death to occur at home. By identifying unmet needs of dying patients and their families, it is hoped that mechanisms to meet those needs can be developed by home care hospice programs, allowing more patients wishing to experience a home death to remain in the home setting.

Historical Perspective

The word "hospice" has its roots in the Latin word hospitium meaning hospitality, entertainment, a lodging, or inn. Hospice is derived from a medieval French term for places of rest or refuge, constructed to house wandering pilgrims and soldiers journeying to the Middle East and the Crusades (Krant, 1981).

Mary Aikenhead is considered to be the founder of hospice as it is known today. She founded a religious order, the Irish Sisters of Charity, whose mission was to care for the dying in Dublin, Ireland in the middle of the nineteenth century. She organized and opened nursing homes which she called hospices, an anglicized form of the medieval
French term, to carry out the work of caring for the terminally ill, thus introducing the word Hospice into modern medical terminology (Stoddard, 1978).

The modern concept of hospice did not emerge until Dr. Cicely Saunders became the first full-time medical officer at St. Joseph's Hospice in London. However, a number of hospices appeared in Great Britain shortly after the turn of the century operated by an English branch of the Sisters of Charity order (McCabe, 1982). Dr. Saunders became aware of the complex needs of dying patients and their families, while working on methods to control the severe pain experienced by many terminally ill patients. Dr. Saunders developed a system of care, based on her experience, which she thought would begin to meet the needs of the terminally ill and their family members (Saunders, 1978).

Dr. Saunders decided a new concept of medical treatment needed to be developed to provide the care required by terminally ill patients. The new concept was based on a palliative care model rather than the curative plan of treatment found in acute care hospitals. She opened St. Christopher's Hospice in Sydenham, England in 1967 to develop this palliative model of medical treatment (Krant, 1981). Since 1967, St. Christopher's Hospice has made significant alterations in the care techniques utilized with terminally ill patients. The approach is based on vigorous symptom control as well as emotional and spiritual support to terminally ill patients and their families. St. Christopher's Hospice rapidly became the modern prototype for terminal care on which most later hospices were based (McCabe, 1982).
The staff of St. Christopher's Hospice foresaw the need for service to patients at home as early as 1965, when plans for a 54 bed in-patient unit were nearing completion. However, home care services actually began in 1969 with six patients discharged from the in-patient hospice unit who desired to die at home. The staff recognized a family member would have to be willing to assume the role of caregiver for the terminally ill patient to receive the type of nursing care he required at home. Family members were observed to be unsure of their abilities to provide the required care or unable to cope in an emergency situation, although they were willing to care for their sick member.

A support system was developed by the St. Christopher's staff to meet the needs of patients and their caregivers in the home setting. The system consisted of an interdisciplinary team: a physician, nurse, chaplain, and a medical social worker. This team became responsible for instructing family members in techniques to provide the physical care needed by the patient, providing 24 hour availability in case of an emergency, offering the spiritual and emotional counseling and support needed by the patient and family, and providing bereavement follow-up for the survivors. During the first 52 weeks of outpatient services, a total of 1,123 home visits were made to 232 patients. One hundred and eighty six of these patients were new referrals and 46 of the patients had been discharged from the in-patient unit (McNulty, 1971).

American visitors to St. Christopher's often returned home critical of the United States health care system's failure to meet the needs of terminally ill patients and their families. Most terminally ill patients were dying in acute care hospitals where the emphasis was
on curative treatment. Also, in acute care hospitals staff performance was measured in terms of physical care tasks rather than in terms of responsiveness to the equally important social and psychological needs of the dying patient (Strauss, Glaser and Quint, 1964).

Several other events increased public interest in developing a system in America which offered patients an opportunity to die a "death with dignity." Kubler-Ross's work (1970) with terminally ill patients made a great impact on the consciousness of the American public. She acquainted American people with the sense of isolation and emotional pain experienced by many dying patients in acute care hospitals. In 1975, the case of Karen Anne Quinlan, a young woman kept alive on life support systems with no hope of recovery, received wide publicity. The case raised public concern that medical decisions were being based solely on prolonging the length of survival without regard for the quality of the life. Concern as to whether or not an individual's or family's right to refuse medical treatment was being respected was expressed by many persons both inside and outside the medical profession (Kron, 1976; McCabe, 1982). Hospices, with their emphasis on palliative care, appeared one way in which the right to refuse life prolonging measures could be guaranteed.

On October 27, 1971 a "Hospice Day" was held at Yale University. This event was sponsored by Hospice Incorporated, an independent corporation composed of chaplains, physicians, nurses, and social workers who had studied at St. Christopher's. The corporation sponsored "Hospice Day" in an attempt to interest people in the New Haven area in raising money to build a hospice. The purpose of the proposed hospice would be
to provide palliative care for the terminally ill based on the methods
developed by Dr. Saunders at St. Christopher's in England. In March
1974, Hospice Incorporated opened the first Hospice in the United States.
The hospice started with a home care program which served 150 patients
during the first year of operation. The home care program was closely
modeled after St. Christopher's approach using an interdisciplinary team
to provide the care needed by patients and their families. The medical
director of the home care program was Dr. Sylvia Lack who had previously
served as Medical Officer at St. Joseph's and St. Christopher's Hospices
in London. A 44 bed in-patient unit was later added (Lack and
Buckingham, 1978; McCabe, 1982).

In the later 1970's, the hospice movement in the United States
experienced a period of extremely rapid growth. Only three teams in the
United States were carrying out hospice care for patients in 1976:
Hospice Incorporated of Hew Haven, Connecticut; Hospice of Marin,
California, and an interdisciplinary group operating on a very limited
basis within St. Luke's Hospital, New York (Stoddard, 1978). On
April 17, 1977, the first free standing hospice was opened in Tucson,
Arizona (Hackley, 1977). A 1981 survey of hospices by Falknow and
Kugler showed only five years later, 440 hospice programs were operating
in the United States, and 51 percent of these programs had become
operational in 1980 and 1981 (Bohnet, 1982).

In summary, the hospice movement has attempted to develop a
system of palliative care for terminally ill patients and a system of
spiritual and emotional support for dying patients and their families.
The first hospice using a palliative treatment concept was begun in 1967 by Dr. Cecily Saunders at St. Christopher's in London. The hospice concept spread rapidly and by 1981 440 hospices were operating in the United States.

Overview of the Problem

The home care component of the hospice movement involves several basic principles rooted in health care concepts which differ widely from concepts commonly used in the American Health Care system today. These concepts include bereavement services, the view of the family as the unit of care, and the family as the main provider of care to the patient. The health practitioner assumes the role of consultant and educator in the home care hospice model (McCabe, 1982).

Most home care hospice programs in this country have not been developed to meet identified needs of terminally ill patients and their families. Because of the rapid growth of the hospice movement in the United States, studies documenting the perceived needs of patients and families who attempt to care for the patient with a terminal illness in the home setting have not been performed (Parks, 1980). Articles in the literature which discuss the needs of terminally ill patients and their families and the support system necessary to meet those needs are based on opinions of health practitioners experienced in the hospice field and anecdotal reports of supportive behaviors believed to be helpful. No actual research data have been gathered from patients and families themselves (Lack and Buckingham, 1978; Estrom and Miller, 1981).
Most home care hospice programs in this country are based on a model of supportive services developed nearly 20 years ago at St. Christophers in Great Britain, rather than on identified needs of terminally ill patients and their families in the United States.

One study attempted to identify patient needs by interviewing 100 patients who were aware of their imminent death. The investigation found that although 80 percent of the patients expressed a deep desire to die in their own home, 68 percent of these patients actually died in an institutional setting (Skelton, 1982). Reasons found for the discrepancy were lack of such simple services as respite at night for the caregiver, or lack of adequate laundry facilities which made it impossible for the family to continue to care for the patient at home. Thus, the terminally ill family member had to be institutionalized.

More studies are needed to identify areas where the home care hospice support system is failing to meet the needs of terminally ill patients and their families. Families will not receive the support necessary for maintaining the patient at home until their needs are identified. Needless institutionalization of the terminally ill patient may be avoided if these identified needs can be met.

**Significance**

Many terminally ill patients wishing to die at home may be denied the right because of the failure of hospice home care programs to adequately meet the needs present in terminally ill patients and the families providing their care. Institutionalizing terminally ill patients not only denies them the opportunity to die in familiar surroundings,
but the cost of care is greatly increased, thus increasing the financial burden of the family.

Much more important, perhaps, than financial considerations and fulfilling the patient's wish to die at home, is the impact that institutionalizing the patient at the time of his death has on the bereavement of the survivors. Hospice clinicians working with terminally ill patients and their families have often observed that achieving a home death for the patient lessens the emotional trauma of the bereavement period for the family, especially the main caregivers. A sense of deep satisfaction at having fulfilled the patient's last request to die at home is observed together with the grief experienced by these caregivers. This sense of satisfaction is particularly strong if the main caregiver was the spouse (Mulkern, 1983).

When the caregiver has had to institutionalize the patient, a sense of guilt and a feeling of having let the patient down are often verbalized by the caregiver. This sense of guilt occurs even if the period of time the patient was cared for at home was extensive. The caregivers tend to blame themselves for failing to provide adequate care to maintain the patient at home. This guilt and self blame may interfere with the resolution of the survivor's grief and bereavement process (Rusch, 1983; Meston, 1983).

The fact that place of death has a significant influence on the bereavement of survivors was observed in a study done in Great Britain which looked at mortality rates during bereavement (Rees and Lutkin, 1967). Prior to this study, bereavement had been associated with an
increased mortality rate for survivors during the first year after the
death of a patient (Parkes; 1970; Glick, Weiss and Parkes, 1974). Rees
and Lutkin's results indicated the risk of a close relative dying during
the first year of bereavement doubled when the primary death causing
bereavement occurred in a hospital as compared with a home death.

**Statement of the Problem**

Those areas in which the home care hospice support system is
failing to meet the needs of terminally ill patients and their families
to prevent unnecessary institutionalization of the patient at the time
of death need to be identified. After these needs are identified, the
nurse may be able to help families maintain their terminally ill member
at home more effectively. The patient can die in familiar surroundings,
the cost of care is decreased considerably and the hazards of bereave­
ment of the survivors may be substantially reduced when families are able
to achieve their goal of a home death for the dying patient.

**Purpose**

The purpose of this study was to identify reasons patients who
were enrolled in a home care hospice program were institutionalized in
the final stage of illness. The caregivers of terminally ill patients
enrolled in a home care hospice program were interviewed to ascertain
those factors which led to the decision by the patient and/or the family
to institutionalize the patient during the final stage of the patient's
illness. Both the patient and family had initially expressed a desire
for the patient to die at home.
Little research has been done to identify types of support terminally ill patients and family members in the United States perceive they need from a home care hospice team because of the rapid growth in the hospice movement in the United States. A study done on 100 terminally patients showed that although 80 percent of the patients expressed a desire to die at home, only 32 percent actually experienced a home death (Skelton, 1982). The study indicates that many needs of terminally ill patients and their families are not being met by the hospice team. Research needs to be done to identify those unmet needs.

The purpose of this study was to identify those factors which influenced the decision to institutionalize a terminally ill patient in the final stage of illness who was enrolled in a home care hospice program and who had expressed the desire to die at home. If needs of terminally ill patients and their families which were not being successfully met under the present home care hospice model could be identified, the hospice system might be modified to meet those needs. Modification of the hospice system, based upon the identification of needs of terminally ill patients and their families which are not presently met may allow a larger percentage of patients wishing to die at home to achieve a home death.

Summary

Little research has been done to identify types of support terminally ill patients and family members in the United States perceive they need from a home care hospice team because of the rapid growth in the hospice movement in the United States. A study done on 100 terminally patients showed that although 80 percent of the patients expressed a desire to die at home, only 32 percent actually experienced a home death (Skelton, 1982). The study indicates that many needs of terminally ill patients and their families are not being met by the hospice team. Research needs to be done to identify those unmet needs.

The purpose of this study was to identify those factors which influenced the decision to institutionalize a terminally ill patient in the final stage of illness who was enrolled in a home care hospice program and who had expressed the desire to die at home. If needs of terminally ill patients and their families which were not being successfully met under the present home care hospice model could be identified, the hospice system might be modified to meet those needs. Modification of the hospice system, based upon the identification of needs of terminally ill patients and their families which are not presently met may allow a larger percentage of patients wishing to die at home to achieve a home death.
CHAPTER 2

CONCEPTUAL ORIENTATION

The emotional, spiritual, financial, and physical needs and the role of social support for terminally ill patients and their families will be discussed as major concepts in the conceptual orientation for the present study. When the support system is successful in identifying and meeting the needs of the dying patient and his family, the patient is more apt to remain at home throughout his illness and death. When the support system either fails to identify a major problem, or lacks the resources needed to help the family meet the need, the family may become overwhelmed by the demands of care for the patient and institutionalization often occurs.

Needs of the Patient and Family During a Terminal Illness

Emotional Needs

The dying and death of a family member is one of the most stressful events a family can encounter (Craven and Sharp, 1972). Adaptive tasks required are numerous. The family tries to function as a social unit and provide structure for growth and development of its members while adjusting to role changes, assuming the care of the dying person, and being immersed in grieving (Barton, 1977). Resources used in response to crisis vary from family to family. Some sources of emotional
support include the existing relationships between family members, the presence of extended family or close friends, the presence of a confident, community affiliations such as church membership, and coping strategies developed by the family in a prior crisis experience (Estrom and Miller, 1982; Meter and White, 1982).

Hospice team members make their knowledge, special expertise, experience, and understanding available to the distressed family member as the family member struggles to come to terms with the crisis (Garfield, 1978). The team members help the patient and family verbalize feelings, develop coping techniques, solve problems, and accomplish the tasks of adjustment and reorganization of the family structure (DuBois, 1980).

The emotional needs of terminally ill patients and their caregivers are often very different. Five psychosocial needs have consistently been identified in terminally ill patients: the need for hope, honesty, information, emotional expression, and a discussion of issues related to death and dying (Young-Brockopp, 1982). Emotional needs of the caregiver include the work of anticipatory grieving and the emotional issues involved with the assumption of the caregivers role.

Assuming the role of caregiver is often difficult for a family member to achieve. Most family caregivers lack the expertise required to provide the nursing care needed by the patient and the request is made at a time when the family equilibrium has been shattered by the impact of the terminal illness. Thus, the family member who assumes the caregiver role finds himself trying to learn new skills and handle new responsibilities at a time when he may be overwhelmed by emotional anxiety and stress (McCabe, 1982; Poss, 1981).
Role restriction also may become a problem. The individual who assumes the role of caregiver may find virtually all his activities are centered around a single role and all of his interpersonal transactions are primarily with one other person, the patient. If the situation continues over a period of time, the patient becomes increasingly dependent on the caregiver. The caregiver becomes as housebound as the patient, leading to "role fatigue" on the part of the caregiver (Goldstein, Regnery, and Wellin, 1981; Weisman, 1981). Caretaking will adversely affect the physical and emotional health of the caregiver if the situation is allowed to continue without provision for respite (Klein, Dean and Bogdonoff, 1967).

How well the emotional issues involved with the dying and death of the patient are resolved by family members often influences whether the family can provide the care needed to maintain the patient at home. When these issues are effectively resolved by the patient and family members, the final stages of terminal illness becomes a period of growth and preparation for "letting go" of the dying member. A sense of marriage completion and closure are experienced by family members as they communicate their mutual suffering and grief to one another. Family bonds are strengthened and cooperative participation increases between family members to maintain the patient at home. Without a united effort among family members, the necessary care is not provided resulting in institutionalization of the terminally ill member (Zimmerman, 1981).
Spiritual Needs

Spiritual needs of the family differ from those of the patient. The spiritual needs of family members are centered around finding an answer to the question, "Why is this illness and death happening to us?" This question must be answered by each family member in a manner which allows the questioner to maintain his belief in a just world and a logical and orderly universe (Ross, 1981). Each family member's answer will be personal and specific to the questioner and will be influenced by his own belief system (McCubbin et al., 1980).

The failure to find a meaningful answer to the question, "Why is this happening to us?" leads to a belief that the world is unjust and people are stricken with a terminal illness randomly or by chance. The belief in an illogical or unjust world results in a high level of anxiety among family members. This anxiety immobilizes the caregivers, making them incapable of developing coping strategies to meet the physical and emotional needs of the patient. The presence or absence of explanations that help the family make sense of what is happening determines the degree of dysfunction experienced by the family in crisis (McCubbin et al., 1980). A high degree of dysfunction among family members results in the inability of the family to provide the care needed to maintain the patient at home, resulting in the institutionalization of the patient.

The spiritual needs of the patient change as he progresses towards death. As the patient's life is reduced to a matter of weeks or months, the patient concentrates on his "unfinished business." He
attempts to resolve relationships where conflict is present or closure needs to be achieved (McIntier, 1980). If the patient is religious, he often finds his relationship with God is threatened by his anger and despair (Kubler-Ross, 1970). Some patients express a fear of dying because they believe retribution or punishment for "sins" they have committed awaits them (Meter and White, 1982).

Failure of the patient to resolve these spiritual difficulties may provoke denial, fear, resistance to surrendering independence, and withdrawing from life in preparation for dying (Ross, 1981). When spiritual issues remain unresolved, the patient develops fears of abandonment (Meter and White, 1982). He may become agitated and demand constant attention from his caregivers. Fearful, demanding behavior places enormous physical and emotional burdens on family members leading to exhaustion of the caregiver and institutionalization of the patient (Platt, 1977).

In his final weeks or days of life, the patient begins to focus his energies on relinquishing life and facing his imminent death. The patient becomes withdrawn and introspective during this period, often refusing to communicate with family members who have been caring for him. These caregivers experience a sense of rejection and hurt in response to the patient's withdrawal behaviors. Because of this sense of rejection and hurt, the caregiver may become angry and neglect the patient at the time when his physical and emotional needs are the greatest. The caregiver therefore needs help in accepting the patient's
emotional withdrawal as a normal part of the dying process and not a rejection of the caregiver.

The hospice team works to meet the spiritual needs of dying patients and their families in several ways. These include: facilitating closure of relationships and the resolution of interpersonal conflicts between the patient and family members; helping the patient verbalize and resolve fears centered around dying; explaining the spiritual tasks of the dying patient to family members and helping them to accept the patient's need for withdrawal; and helping family members find a meaningful answer to the question, "Why is this illness and death happening to us?" Unless the patient's and family's spiritual needs are met and resolved, the family may not be successful in maintaining the patient in the home environment and institutionalization of the patient may occur.

Financial Needs

Medical expenses such as hospitalization, drugs, private nursing care, outpatient tests and treatments, and home care are obvious costs incurred by a cancer patient. In many instances these costs are not covered or only partially covered by medicare or the patient's insurance (Feifel, 1977). Psychosocial expenses of cancer also exist. These include "hidden expenses" such as loss of income of the patient or caregiver if either has been employed, cost of transportation, food, and housing during outpatient treatment programs, cost of maintaining additional family members who move into the household to assist with patient care, and child care expenses. The American Cancer Society estimates
the average cancer patient's medical bill is $20,000 with the indirect costs of cancer to each patient amounting to a similar figure (American Cancer Society, 1983).

Frequently the family is unable to afford the additional help needed to maintain the patient at home. When the family can not afford services such as respite care of the patient or assistance with household chores, role fatigue and exhaustion of the caregivers occur. Hospice programs provide needed respite and household assistance free of charge to families by using volunteers trained by the hospice organization. Thus, additional help is provided without cost to the family, allowing the patient to remain at home.

Social workers also offer financial counseling to terminally ill patients and their families. Financial counseling insures patients receive the full extent of their insurance coverage. Often through the intervention of social workers, the cost of uncovered medical expenses such as outpatient radiation treatments can be reduced by negotiating with the facility providing the treatment. Thus, families save thousands of dollars in medical expenses. The family is often referred to community resources as well (Daniel, 1973; McNulty, 1971). In spite of the assistance of the social workers, many families are unable to obtain the help needed or avoid severe financial stresses when coping with a terminally ill member (Rose, 1976).

Physical Needs

The physical care of the terminally ill patient is provided by training the primary care person in nursing methods needed to maintain
the patient at home (Edstrom and Miller, 1981). A recent study documented patient and family perception of skills needed by family members of terminally ill cancer patients to provide patient care management. These skills included: (1) ambulation, (2) bowel management, (3) comfort care, (4) dietary control, (5) symptom management, and (6) wound and skin care (Grobe, Ahmann, and Ilstrup, 1982). Assistance was also needed in obtaining special equipment such as a hospital bed or commode (Rose, 1978). More skilled nursing procedures such as intramuscular injections or tracheal suctioning may be required as the patient's physical status deteriorates (Zimmerman, 1981). These skills are taught to the family by hospice nurses.

Symptom control is a great concern to families and a major focus of hospice care. Unless symptoms of nausea, vomiting, and pain can be adequately controlled at home, the family may decide they are unable to provide the care needed by the patient and institutionalization occurs.

A major concern of families is their ability to handle an emergency situation or an unexpected change in the physical status of the patient (Skorpuka and Bohnet, 1982; Putnam et al., 1980). Hospices provide assurance that emergency help can be obtained by making hospice nurses available 24 hours a day, 7 days a week (Dubois, 1980). If the patient requires treatment by a physician, he is often hospitalized because many physicians refuse to make home visits (Rose, 1978).

**Social Support**

The ability of most families to provide the care needed to maintain a terminally ill member at home without seeking help from outside
the immediate family circle has been greatly impaired because of the small size of today's nuclear family (Craven and Sharp, 1972). The family utilizes several support systems to obtain the necessary help. The most frequently utilized systems are the relatives and close friends of the terminally ill patient and his family. Most of the patient's physical needs such as feeding, bathing, household tasks, and shopping are done by family members as they assume the role of caregiver (Rose, 1978).

The second support system available to patients and families enrolled in a home care hospice program is the hospice team itself. Professionals on the team often become a main source of emotional support to terminally ill patients and their families (Googe and Varricchio, 1981). Team members act as a resource to help identify problems and assist the family in planning and carrying out interventions. Home health aides help meet the physical care needs of the patient. When relatives and close friends are unavailable or their support is inadequate to meet the needs of the patient and family, hospice volunteers provide additional assistance to help meet the patient's physical and emotional needs.

Community organizations constitute the third support system utilized by terminally ill patients and their families. This system includes church groups and community volunteer agencies which provide supplementary help with patient care and household tasks.

Few families use professional caregivers to provide patient care. A study looking at 26 caregivers of terminally ill patients found only
one caregiver employed someone to assist with nursing care or household tasks, even though obtaining adequate rest at night and child care were identified as major problems by many of the caregivers in the study (Rose, 1978).

Patients and families with inadequate support and high need must be identified to successfully maintain a patient at home during a terminal illness. Supplementary social support by the hospice team, relatives, close friends, or community organizations must be provided to prevent the family from becoming overwhelmed and exhausted by the patient's care (Murawski, Penman, and Schmitt, 1978). When the need for adequate social support is not identified or the support is unavailable, institutionalization of the patient is more likely to occur.

Research Question

The research question addressed was: what factors influence the decision to institutionalize a terminally ill patient who is enrolled in a home care hospice program during the final stage of illness when the patient and family have expressed the desire for a home death?

Conceptual Definitions

A. Terminally ill patient: A patient experiencing an illness for which therapeutic strategies directed toward cure, outside the context of symptom control are no longer appropriate (NHO Standards, 1981).

B. Main caregiver: The person, usually a family member, who assumes the responsibility for seeing that the necessary physical care is provided for the terminally ill patient (McCabe, 1982).
C. Home care hospice program: A program which provides palliative and supportive care in the home setting to terminally ill patients and their families through an interdisciplinary team (Cohn, 1979).

D. Institutionalization: The removal of the terminally ill patient from a home environment and the placement of the patient into an in-patient hospice unit, an acute care hospital setting, a nursing home, or any other non-home setting which provides the patient with the physical care he needs during his terminal illness.

E. Final stage of illness: The final two weeks of life before the death of the patient occurs.

F. Emotional need: The desire to successfully resolve the emotional tasks of the dying and/or "letting go" including giving up hope of recovery and accepting the eventual separation and loss (Daniel, 1973).

G. Spiritual need: The desire to resolve relationships, to turn, to return, or to grow closer to God, and to assign meaning to the experience of the death of the family member (McIntier, 1980; Poss, 1981; and McCubbin et al., 1980).

H. Financial need: The desire to meet the direct, indirect, and psychosocial costs which are incurred because a family member is terminally ill (McNaul, 1981).

I. Physical need: The desire to provide the nursing care necessary to achieve symptom control and to maintain the terminally ill patient at home.

J. Social support: Those persons or institutions the terminally ill patient or his family believes constitutes his interpersonal support
system and upon whom he can draw in a time of crisis (Murawski et al., 1978).

Assumptions Underlying Study

The following assumptions were made by the investigator and are based on a review of the literature and clinical experience.

1. Terminally ill patients and their families who have expressed a desire to die at home have set death of the patient at home as a goal to achieve.

2. Factors which influence a patient and/or his family to discard the goal of a home death for the patient and agree to institutionalization of the patient can be obtained by self-report.

Summary

Terminally ill patients and their families who desire the patient to die at home have emotional, spiritual, financial, and physical needs. These patients and their families who are enrolled in a home care hospice program utilize three types of support to meet these needs: (1) relatives and close friends, (2) members of the hospice team, and (3) community organizations. Few families use paid caregivers even though child care and night respite have been listed as major problems. How well families needs are identified and the availability of support to meet those needs often determines whether or not a family is able to maintain the patient at home.
CHAPTER 3

METHODOLOGY

The design and methodology of this exploratory study is discussed in Chapter Three. A description of the sample studied, the setting, methods of data collection and analysis, human subjects considerations, and the limitations of the study are reviewed.

Design

An exploratory design was chosen to generate insight into caregivers' of terminally ill patients' perceptions of factors influencing the institutionalization of the patient during the final stage of illness. Exploratory designs aid in discovering and identifying important variables in nursing studies where little research has been carried out and the literature has a scarcity of information on the topic (Simms, 1980).

The emphasis of the study was on the discovery and development of categories and their properties rather than the development of a theory. These categories were developed from data gathered during open-ended taped interviews. The use of open-ended questions rather than a more structured means of data collection allowed the investigator freedom to explore directions and motives arising from the data which were unknown and unanticipated (Selltiz, Wrightsman, and Cook, 1976).

23
The Setting

Caregivers were given the opportunity to choose the place where the interviewing would occur. All subjects participating in the study chose to be interviewed in their own homes.

The Sample

The charts of deceased patients enrolled in the home care hospice program of a local hospice were audited to identify patients and their families who initially expressed a desire for the patient to die at home but the death had actually occurred in an institution. The main caregivers of these patients formed the population from which the subjects were selected. The criteria established for participation included:

1. The subject must have been the main caregiver of a terminally ill patient enrolled in a home care hospice program whose death had occurred within six months of the time the interviews were conducted.

2. The patient and the caregiver selected must have expressed the desire for the patient to experience a home death, and the decision was recorded on the patient's chart.

3. The patient for whom the subject acted as caregiver must have been institutionalized in the final stages of his illness, and death must have occurred in the institution rather than the home.

4. The subjects must have been experiencing a normal bereavement process and participation in the study would not
represent a hazard to their bereavement in the view of the home care hospice bereavement counselor.

5. The subjects must have spoken English.

6. The subjects had to live in the Tucson area.

A sample size of five participants was selected initially. Four of the five initial participants were reinterviewed until a saturation of information was achieved and no new data emerged. Three new participants were then added to the study. The total sample size was eight participants.

**Protection of Human Rights**

The study was approved by the Human Subjects Committee of the University of Arizona College of Nursing (Appendix A). Permission to interview caregivers whose family members had been enrolled in the home care program of a local hospice was obtained from the hospice administration and the hospice bereavement counselor.

A form explaining the purpose of the study was given to each participant (Appendix B). The purpose also was explained verbally and in writing. Each participant was given the opportunity to ask questions. Subjects were assured they had the right to withdraw from the study at any time. Anonymity of each subject was maintained. The investigator verified that participation in the study would not threaten the bereavement process by consultation with a bereavement counselor before the subject was asked to participate.
Data Collection Protocol

Data collection began with a chart audit to identify the population (Appendix C). Data were then gathered through semi-structured interviews. Each subject was asked to complete a Personal Data Form. The form gathered the following information:

1. The age of the caregiver and the age of the terminally ill patient.
2. The length of time the patient was in the outpatient home care hospice program.
3. The length of time between the death of the patient and the interviewing of the caregiver.
4. The primary diagnosis of the patient.
5. The relationship of the caregiver to the patient.
6. The sex of the caregiver and the sex of the patient.

Each interview began with a broad open-ended question, "What led to the decision to admit (name of patient) into the (In-Patient Hospice Unit, Acute Care Hospital, or Nursing Home)?" The list of grand tour questions used during the initial interview of the first five participants appears in Appendix D. These questions were intended to elicit the caregivers' perceptions of factors which influenced the caregiver's and/or patient's decision to institutionalize the patient.

If the perceived cause of institutionalization was a medical complication which was unmanageable outside an institutionalized setting, the institution to which the patient was admitted and the reason for the admission were noted. No further questions were asked if a family member fit this category and the subject was eliminated from the study.
The interview was continued if the response to the opening question indicated the caregiver thought he or she was unable to continue maintaining the patient in the home setting in the absence of a medical complication. Semi-structured open-ended questioning was conducted to elicit the caregiver's perception of those factors which led to the decision to institutionalize the patient. These questions explored the physical, emotional, financial, and spiritual needs of the terminally ill patient and family, the social support system available, and how adequately the caregiver perceived these needs were met by the available support system.

A focused interview technique was used. In a focused interview, a list of topics or aspects of a given experience upon which the interviewer wishes to focus is available. However, the manner in which questions are asked and their timing are left to the interviewer's discretion (Selltiz et al., 1976). This format gave the interviewer the freedom to explore further into directions which were unanticipated. The interviews were tape recorded. Each interview lasted approximately one hour. Following data collection, each interview was analyzed to identify factors thought to influence institutionalization of the patient. Subjects were reinterviewed when necessary until no new information emerged.

**Data Analysis Plan**

Descriptive statistics were used to describe the demographic information collected on the subjects. Factors such as age of the patient and caregiver, diagnosis of the patient, length of time in the home care hospice program before the death of the patient occurred,
the relationship between the caregiver and the patient, and the sex of each were obtained to describe the sample.

The tape recorded interviews were analyzed to ascertain those factors perceived by the caregiver as influencing the decision to institutionalize the terminally ill patient in the final stage of his illness. These factors were categorized and a taxonomy was developed.

**Summary**

Caregivers of terminally ill patients enrolled in a home care hospice program were interviewed using semi-structured open-ended questions. The purpose of the interviews was to elicit the caregivers' perceptions of factors which led to the decision to institutionalize the terminally ill patient rather than to continue to maintain the patient at home. The tape recorded interviews were analyzed to identify factors which influenced the decision to institutionalize the patient.
CHAPTER 4

RESULTS OF DATA ANALYSIS

The characteristics of the sample will first be described in this chapter. Factors identified as influencing the institutionalization of terminally ill patients wishing to die at home will then be presented and discussed.

Characteristics of the Sample

Eight caregivers who met the criteria agreed to participate in the study when contacted by phone. All eight had been married to the patients. Six of the caregivers were women and two were men. The caregivers' ages ranged from 62 to 78 with the average age being 69.8 years and the standard deviation was 5.7 years.

The length of time between the initial interview by the investigator and the death of the patient varied. The shortest time interval between the interview of the caregiver and the death of the patient was 20 days. The longest interval was 154 days. The average interval was 97.5 days or approximately three months, with a standard deviation of 44.1 days.

The length of time the patient and caregiver had been enrolled in the hospice home care program varied considerably. The shortest length of enrollment from the date of initial visit by the home care hospice nurse until the death of the patient was 10 days. The longest
length of enrollment in the program was 156 days with the average number of days enrolled being 65.6 days or approximately two months. The standard deviation was 53.6 days.

Two patients of caregivers who participated in the study died in acute care hospitals. The remaining six died on an inpatient hospice unit. All the patients cared for by the caregivers were terminally ill with various kinds of cancer. Demographic data describing the patients and caregivers appear in Table 1.

Results of the Initial Interviews

Five caregivers were initially interviewed for the study. Using the grand tour questions as a guideline, the interviews gathered data about the perceived problems these caregivers encountered while caring for the patient. The types of support available to each was also discussed.

From the review of the literature, it was anticipated that unmet physical, emotional, spiritual and/or financial needs would emerge as major factors influencing the decision to institutionalize the patient. However, all caregivers stated adequate support systems had provided the assistance they needed while caring for the terminally ill patient. When asked "What kind of help would you have liked to have had?", none of these caregivers could identify an unmet need.

The data were then re-examined focusing on statements made by caregivers which had not been categorized. The comment of one caregiver offered a possible clue to why the institutionalization of these patients had occurred. She stated:
<table>
<thead>
<tr>
<th>Caregiver</th>
<th>Age of Patient</th>
<th>Age of Caregiver</th>
<th>Diagnosis of Patient</th>
<th>Number of Days in Program</th>
<th>Number of Days in Institution</th>
<th>Time Between Death &amp; Interview</th>
<th>Relationship to Patient</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>66</td>
<td>69</td>
<td>Ca lungs mets to brain</td>
<td>156</td>
<td>3</td>
<td>20</td>
<td>Wife</td>
</tr>
<tr>
<td>2</td>
<td>80</td>
<td>73</td>
<td>Ca prostate mets to lungs</td>
<td>12</td>
<td>1</td>
<td>75</td>
<td>Wife</td>
</tr>
<tr>
<td>3</td>
<td>75</td>
<td>78</td>
<td>Ca colon mets to lungs</td>
<td>27</td>
<td>1</td>
<td>116</td>
<td>Wife</td>
</tr>
<tr>
<td>4</td>
<td>66</td>
<td>67</td>
<td>Dissiminated Ca of lungs</td>
<td>10</td>
<td>1</td>
<td>76</td>
<td>Husband</td>
</tr>
<tr>
<td>5</td>
<td>67</td>
<td>77</td>
<td>Ca of the esophagus</td>
<td>76</td>
<td>5</td>
<td>79</td>
<td>Husband</td>
</tr>
<tr>
<td>6</td>
<td>61</td>
<td>65</td>
<td>Ca esophagus mets to stomach</td>
<td>76</td>
<td>3</td>
<td>112</td>
<td>Wife</td>
</tr>
<tr>
<td>7</td>
<td>70</td>
<td>68</td>
<td>Ca spine, brain, lung</td>
<td>126</td>
<td>9</td>
<td>154</td>
<td>Wife</td>
</tr>
<tr>
<td>8</td>
<td>68</td>
<td>62</td>
<td>Ca lung widespread mets</td>
<td>41</td>
<td>7</td>
<td>148</td>
<td>Wife</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Mean</th>
<th>69.1</th>
<th>69.9</th>
<th>65.5</th>
<th>3.8</th>
<th>97.5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Standard Deviation</td>
<td>5.9</td>
<td>5.7</td>
<td>53.6</td>
<td>3.0</td>
<td>44.1</td>
</tr>
</tbody>
</table>
"As soon as I heard he (her husband) had cancer, I knew how he would die... in a lot of pain. People always talk about the last days being so traumatic... the horrible pain cancer patients have."

This statement seemed to indicate the caregiver had anticipated her husband would experience tremendous pain at the time of his death. The expectancy appeared to have begun when she was told her husband had cancer two years before his death.

The comments of this caregiver raised several questions. Did the caregiver have a mental image of how she anticipated the death would occur? Did other caregivers share a similar type of expectation regarding how the patient's death would happen?

The caregivers were reinterviewed in an attempt to answer the above questions. Several new grand tour questions were devised to elicit the caregivers' expectations of how the patient's death would occur, the source of these expectations and their influence on the decision to institutionalize the patient.

**Prohecy Model**

Data indicated that caregivers did have a mental expectation of how the anticipated death of the patient would occur. The expectation primarily influenced the decision to institutionalize the terminally ill patient in the final stage of illness. These expectancies were categorized as either negative or positive prophecies.

**Negative Prophecies**

Negative prophecy was defined as the anticipation on the part of the caregiver that the patient's condition would worsen to such an extent
he would require medical treatment unavailable at home. Four caregivers held negative expectancies. These expectancies were very specific and were divided into three separate subcategories. The subcategories were painful death, prolonged death, and unmanageable coma.

Painful Death

Three of the caregivers expressed an expectation that severe pain would occur just before death; thus, the patient would die in agony. Examples of this type negative prophecy were found in caregivers' comments:

"Well, they all said it was pretty horrible what went on at the very last. The pain so terrible and having to watch them go through that...I just felt that he was going to be in a lot of pain and probably have a horrible death."

Another caregiver expressed her negative prophecy of a painful death in these words:

"People talked about the last days as being so traumatic...All the people who have had cancer patients have always talked about the pain. I was aware of the fact that with cancer of the prostate there is a lot of pain at the end. Dr. C. told me that."

A third caregiver stated:

"I just couldn't believe that he would sleep away or that he could be fortunate enough to just not have a lot of pain at the end."

None of the three caregivers who anticipated an agonizing death were present when their spouses died. Each had visited the patient during his hospitalization, but all expressed feelings of relief that they had not "witnessed the death". This relief was reflected in the following comments:
"I don't think I'd like to have been there when he died. I would have been afraid of what he might have gone through although apparently he didn't have any problem...it was very peaceful the nurse told me."

Another caregiver was asked if she wished she had been with her husband when he died. She replied:

"I keep thinking about that...yes and no. Yes because I think I should have been there at the time so he wouldn't have been alone. I'd probably have had a heart attack if I'd been there, seeing him struggling for air."

One caregiver refused to even discuss what his image of his wife's death was like. He stated:

"No, I don't want to tell you what I thought it would be like, no way, it's too painful...let's just say I don't think it was pleasant."

In summary, the comments of these caregivers described their anticipation of increased pain and suffering at the time of death. All were similar in meaning and formed the subcategory, painful death.

Prolonged Death

Two of the three caregivers who expressed anticipation of a painful death also anticipated that the final stage of dying would be quite prolonged, lasting several weeks or even months. They described their surprise at how quickly the death occurred:

"I didn't think about him going that quickly. I just thought he'd get some help there at the hospital that they could take care of him and really I wasn't expecting him to die that quickly."

Another caregiver stated she had expected the final stage to be more prolonged:

"I really didn't think he'd go so fast as he did...that's the thing that has puzzled me how quickly he went. I thought it would be long and painful and of course one hears this all the time about people who die of cancer."
Not all caregivers who anticipated a painful death expected the death to be prolonged. Therefore, a separate category was developed and labelled prolonged death.

Unmanageable Coma

Three caregivers expected the patient to become comatose before death occurred. For two of the caregivers the idea of a comatose patient triggered a number of negative expectancies. One caregiver expressed her expectancies in these words:

"I thought he could go into a coma and I didn't know whether I could handle it or not, give that kind of care... there (in the in-patient unit) I knew he was being taken care of, there were people there who knew exactly what was going on where I wouldn't have known what he might need, I wouldn't have known how to care for him if he was like that."

Another caregiver had a much more specific negative prophecy of what it would be like if her husband became comatose. She described it in the following words:

"I was afraid he would get comatose so he wasn't awake and he would get constipated and not be able to move his bowels because he did that so easy. This would happen and the pressure would be awful and he would be in such pain and I wouldn't be able to do anything about it."

The comments of these caregivers indicated they anticipated if the patient became comatose, a change in the type of care required by the patient would occur. The patient would be unmanageable at home because of the increased care requirements. Thus, comments assigned to the subcategory were labelled unmanageable coma.
Positive Prophecies

Not all caregivers interviewed had negative prophecies about the anticipated death of the spouse. Three caregivers held positive prophecies regarding how they anticipated the patient's death would occur. Positive prophecies were defined as the caregiver's expectation that the patient's death would occur without the development of unmanageable symptoms. These expectancies were divided into two subcategories labeled sudden death and manageable coma.

Sudden Death

Two spouses expected the patient to die suddenly. One caregiver stated:

"I thought it would be more sudden you know, not a drawn out affair of a coma...I thought when G. died it would be just bingo, she'd be gone."

The second caregiver stated that his wife's death had occurred suddenly as he had anticipated. Hospitalization of the patient occurred when the caregiver's physician decided the caregiver's health was failing and he could no longer provide the nursing care required by the patient.

The comments of these caregivers indicated similarities in that the patient's death would occur suddenly. These comments formed the subcategory sudden death.

Manageable Coma

One wife anticipated her husband would slip into a coma shortly before death. She described this expectancy stating:

"When I pictured J. dying, I always pictured that he would just slip into a coma and we would sit around and watch
him draw his last breath...the whole family would be there...it would be very peaceful."

Unlike the caregivers discussed earlier, this wife stated she thought she could manage the care of a comatose patient at home. The term manageable coma was used to describe the subcategory formed by this caregiver's statements. The term manageable coma was selected to distinguish this subcategory from the subcategory unmanageable coma, where caregivers stated they would be unable to manage the comatose patient at home. Therefore, manageable coma became a key link to the concept positive prophecy while unmanageable coma formed a link to the concept of negative prophecy.

One caregiver denied having an image of how the death would occur. She stated her husband had demanded to be hospitalized because he anticipated he would have uncontrollable pain as he approached death and his care would be too much for his wife to manage in the home setting.

In summary, most of the caregivers in this study appeared to have mental images or prophecies regarding how they expected the patient's death to occur. Caregivers who anticipated painful death, prolonged death or unmanageable coma were categorized as having negative prophecies regarding how the patient's death would occur. Caregivers who had anticipated a sudden death or a manageable coma were classified as having positive prophecies about how the death would happen.

Input

Input refers to the information upon which the caregiver based his prophecy of how the patient's death would take place. Four major sources of input contributing to the development of the prophecies were
identified. These sources were personal experience of the death of another, discussion with friends or family members, information received from the patient's physician, and written material. Each of these sources could become the basis for either a negative or positive prophecy, depending on the type of impact the experience had on the caregiver.

Personal Experience

Personal experience is defined as being present at the death of another person. Two participants had been with someone when death occurred prior to the illness of their spouse. The experience affected each of them very differently.

The first caregiver had seen her mother slip into a coma lasting several days. She describes her reaction to the experience in these words:

"My mother had breathing problems right before she died. She went into a coma which lasted for three or four days... and when I thought J. could go into a coma I didn't know whether I could handle it or not. Maybe we could have handled it but I think it was better for him and for us to be there where people know how to take care of him, they knew exactly what to do at the hospice unit where I wouldn't."

From the experience of her mother's death this subject appeared to formulate a negative prophecy regarding how her husband's death would occur. She anticipated that he would become comatose and require expert nursing care found only in a hospital setting.

Being with someone at the time death occurred had a very different impact on the second participant. This participant had been in the Air Force in World War Two. He had seen many young injured airmen die
before they could be flown to a hospital. His father had also died sud-
denly as a result of a heart attack. He describes these experiences:

"The war was terrible. I flew on a lot of missions
during the war. I would see other young guys wounded and
injured and we would be miles from any kind of medical help.
They would fight so hard to live...they'd try so hard to hang
on so that we could get them back to a hospital. You just
can't get help you know, when you are hours and miles away.
You just can't. It's terrible."

"My dad's death was easy. We were coming back from my
brother's and my dad said he'd like to use a restroom. There
was a gas station close by. So I parked and took Dad around
to the restroom and when we came back out he says I've got to
sit down, and I said, Can you make it the 10 feet to the car?
And ah, oh sure that's what he did. We made it to the car
and he sat down and died right then."

When discussion how he expected his wife's death to occur, this
caregiver stated:

"I just sort of expected if she went to sleep she would
die right then. Like the guys in the war - bingo."

This participant formed the positive prophecy that his wife
would die suddenly instead of being a prolonged process. The basis for
his prophecy appeared to be his previous experience involving dying
persons.

Discussions with Friends or Family Members
The greatest input of caregivers came from discussions with
friends or other family members about deaths they had witnessed. Four
participants reported such discussions were the major origins of their
expectations about how their spouses' death would occur. The type
prophecy formulated by each caregiver as the result of the discussions
about death with family or friends varied according to the information
the caregiver received. When the death discussed was described to the caregiver as difficult, painful, or unpleasant, the caregiver formed negative prophecies about the manner in which the death of his or her own spouse would occur. When the death was described to the caregiver as easy or peaceful, positive prophecies were formulated by the caregiver.

For example, two participants stated friends had described the death of their spouses. One participant described what she was told in these words:

"My friend's husband had cancer of the prostate and he suffered so much pain, it took such a long time for him to die it just went on and on. I saw my friend in April and she still can't talk about it hardly. It's been four years since her husband died...it was awfully hard on her."

Thus, the caregiver anticipated her husband would also die a prolonged and painful death. She expressed surprise that his death had "been so easy" and so quick.

Another caregiver described the input she received from a friend in these words:

"E. would tell me about how much her husband was suffering. He had a lot of pain they couldn't control. He kept going from the hospice back to the nursing home and back to the hospice then to the nursing home. That's one reason I thought I knew what was going to occur."

This caregiver also predicted her husband's death would be long and painful. Although she stated his pain had become severe towards the end, she expressed puzzlement regarding the fact he had died so quickly.

Two caregivers had heard family members discuss the death of their spouses. One participant described what she had heard from her sister-in-law about the death of her brother in these words:
"I thought he might go into a coma because my sister-in-law said that's what my brother did. His pain got so bad and he required so much medication, my sister-in-law said it wasn't safe for her to give him his pain medication at home, so they insisted she put my brother into the hospital."

This same caregiver prophecised her husband would go into a coma, become impacted and develop agonizing pain which she would be unable to control at home.

The second caregiver received input from a family member. The input formed the basis for the positive prophecy she made: her husband would "die quietly with all of us gathered around watching him take his last breath". She described the input she received in this manner:

"I never heard a blow by blow account of my brother's death. He had cancer and died three years ago. They called me and said there's no need to come because he was dying and he was in a coma. He had the same thing J. had and he died just like that, in a coma with his family around. They said it was very peaceful."

Information Received from the Physician

Information received from the physician formed the basis for one caregiver's prophecy. The caregiver expected her husband to experience agonizing pain at the time death occurred. The caregiver describes the information she received which led her to formulate this type prophecy:

"Dr. C. had told me years ago when T. was first diagnosed that men with prostate cancer had terrible backaches and he couldn't understand why at that time T. wasn't experiencing more pain, so when T. began complaining of backaches I expected that they would get pretty bad."

Written Material

Two caregivers mentioned reading articles that discussed the uncontrollable pain patients experience as the result of the cancer.
When asked what she expected her husband's death to be like, one caregiver responded:

"Painful, I'd read a lot about it..."

Another caregiver answered the question with these words:

"I can't tell you exactly, I just thought he might be, you know have an awful lot of pain. That's all you hear or read about cancer, the awful pain they suffer."

Neither caregiver could identify the source of the written information. Both thought they had read articles in magazines which had led them to expect cancer patients would experience an increase of pain as they approached death.

The caregivers mentioned four sources of input upon which the prophecies they formulated were based. These sources were personal experience of the death of another, discussions with friends and family members, statements from physicians, and written material. The type of prophecy formulated by the caregiver from the input they received depended on the impact the input had on the caregiver. Personal experience of death, for example, led one caregiver to formulate a positive prophecy and another caregiver to formulate a negative prophecy. Discussions of death with friends or family members also led the caregivers to formulate both negative and positive prophecies. Written material and information received from the physician also formed the basis for negative expectations.

**Triggers**

Two types of events were mentioned which acted as triggers. These triggers produced behavioral and emotional changes among the
caregivers resulting in the institutionalization of the patient. The triggers were classified as either congruent or incongruent. The type trigger experienced was influenced by the type expectation held by each caregiver.

Triggers of Congruence

Triggers of congruence describe the category of events which acted as signals to caregivers who had made negative prophecies of their spouses' death. These triggers indicated that negative prophecies of the caregivers were beginning to be fulfilled. Triggers of congruence centered around two symptoms the caregivers expected the patients to develop. These symptoms were agonizing pain and becoming comatose shortly before death occurred.

Triggers Indicating Painful Death. A variety of signals acted as triggers to convince the caregivers their prediction of a painful death was beginning to become an actuality. One caregiver easily described these triggers when she was asked what had made her think this painful death was beginning to occur. She stated:

"I think it was when we went to see Dr. F. about two or three weeks before he died and Dr. F. said, I think T. needs morphine. I think that's when I really realized that this was really going to be the end and the pain was getting worse."

When this caregiver was asked what had been happening the day she decided to hospitalize her husband, she replied:

"That day he had been given a suppository by the hospice nurse because he was constipated. He started going and he just didn't stop. I felt he was in agony, no not in agony, but very uncomfortable, he was going all the time"
...and then I realized the pain was going to get worse and that I wasn't going to be able to care for him properly at home."

Another caregiver who had anticipated her husband would die in agonizing pain was asked what had led her to believe the pain was beginning to occur. She stated:

"W. was a cold blooded person...he was cold all his life...until the last few days, then he didn't even want that gown on so to me that was just a dead give away that something radical was going on and he would start having pain next."

When asked what made her decide to institutionalize her husband, the caregiver responded:

"I felt I just couldn't stand it another minute, the waiting for the pain to start, the anticipation. He really hadn't been in any pain...you know I just had that feeling that it was going to happen any time and the doctors weren't giving me anything to alleviate any kind of suffering he might have. When he started suddenly being warm all the time, I figured he would start having pain next and that's when I asked that he be put in the in-patient hospice."

Thus, statements made by these caregivers indicated continuous stool, a change in pain medication, a sudden change from being cold to not wanting any clothes, acted as triggers. Because each of these events indicated that the patient was about to begin experiencing intensive pain, these statements were assigned to the subcategory triggers indicating painful death.

**Triggers of Unmanageable Coma.** Two caregivers stated they experienced events which they believed indicated that the patient would soon become comatose. One caregiver's mother had experienced difficulty breathing shortly before the mother became comatose. This caregiver stated she thought her husband was becoming comatose when he exhibited
similar symptoms. She commented:

"J. didn't complain about his breathing, but he complained about coughing all the last week because he had this phlegm he couldn't get rid of...he was wishing he had oxygen...I figured he was having trouble breathing when he said that. Although he didn't complain about his breathing...I knew then he was going to get critical...go into a coma...he probably would have been okay here but I don't know whether I could handle it or not - give that kind of care."

The second caregiver also stated she thought she could not manage her husband at home should he become unconscious. She feared he would become impacted and have severe pain. She described the triggers she interpreted to indicate he was becoming comatose with these statements:

"I was never sure if I thought he was sleeping or if he could hear me if I spoke to him...I didn't think he was completely comatose, but I thought he might be getting that way...There were times when I could talk to him and he would be aware enough that he could watch the TV. He was a great sports fan...but when he got to the point where he would go to sleep during a ball game, I knew that things were going rapidly and I started worrying that he'd slip into a coma."

The two caregivers who had prophesised their spouses would fall into unmanageable comas had different triggers which told them the coma was about to happen. One caregiver's signal appeared to be her husband's desire for oxygen which was interpreted as meaning difficult breathing. For the second caregiver, the fear that her husband was about to become comatose was triggered when he began falling asleep watching ball games on television. Thus, such statements formed the subcategory triggers of unmanageable coma because the events were perceived by the caregiver as a signal the patient would become comatose.
Triggers of Incongruence

Triggers of incongruence were signals to two caregivers who had made positive prophecies that the death of the patient was not going to occur as they anticipated. Triggers of incongruency, therefore, are directly opposite triggers of congruence. Two types of triggers of incongruence were experienced by these caregivers. The two types of triggers of incongruence formed subcategories of this concept.

Triggers of Incongruence - Coma. One caregiver had expected his wife's death to occur suddenly. When he found her in a coma, he was unprepared for the incongruency between his prophecy of a sudden death and the events that occurred. He described his incongruency and how it affected him in these words:

"I thought it would be more sudden ah, you, not a drawn out affair of a coma...I thought death was as I knew it...You see I don't think I realized she was in a coma. I thought she was just sleeping and I couldn't awaken her...I knew that I couldn't get any medicine down her...I didn't think that there was a period of just life ebbing out...I was unprepared...I thought when G. died it would be just bingo...I thought My God, what do I do now? If I get her to a hospital, can something be done? I didn't know."

Triggers of Incongruence - Sudden Death. The second caregiver who experienced incongruency between her prophecy of how her husband's death would occur and the actual events of his death described an opposite situation. She had held the expectation that her husband would slip into a coma and "die quietly with all of us gathered around watching him take his last breath." When her husband began to suddenly experience difficulty breathing and loss of consciousness, she describes her reaction in these words:
"He just couldn't get his breath and he was glass eyed and I'd talk to him...and he'd look at me almost as though he didn't know who I was, it was very spookey...I was certainly terrified...this wasn't what I'd had in mind when I'd thought of him dying. I wanted him to get some help to alleviate the breathing problem. I guess I panicked. It's hard to predict how you'll act you know...I'd sit and think if this happens, I'll do thus and so, trying to prepare myself, but I never expected he would have problems breathing...when I pictured J. dying, I always pictured that he would just slip into a coma."

In summary, caregivers experienced two types of triggers. Caregivers who had made negative predictions of how the patient's death would occur experienced triggers of congruency. These triggers of congruency acted as signals indicating to the caregiver the events they dreaded were about to occur. Caregivers who had made positive predictions of how the patient's death would occur experienced triggers of incongruence. These triggers of incongruence acted as signals to indicate the patient's death would not occur as the caregiver had anticipated.

**Behaviors**

Anxiety was experienced by caregivers who had made a negative prophecy about their spouses' death. These caregivers exhibited two types of reactions or behaviors in their attempt to reduce the anxiety. These behaviors were categorized as being either anxiety distraction behaviors or energizing arousal responses. Most caregivers who made negative prophecies exhibited both types of responses.

Anxiety Distraction Behaviors

Anxiety distraction behavior was thought to occur when the caregiver became so pre-occupied with his concern about the manner in which
the death would occur, he neglected to develop coping strategies to deal with the symptoms he was anticipating or to take measures to avoid their occurrence. For example, one caregiver who had anticipated her husband would experience agonizing pain during his final stage of illness stated:

"I called M. (the hospice nurse) but she couldn't be here for 45 minutes and I couldn't wait. So I called the doctor. He wasn't in but the office had him call me. He said, 'I'm close by and I'll be right over.' When the doctor came he said J. was really bad and he would take him to the hospital in his car. Then I knew this was really bad and I was terrified. This wasn't what I had in mind, it wasn't the way I wanted it to happen. Perhaps if M. had gotten there sooner it would have been different. She could have shown me what to do."

In summary, caregivers who had made negative prophecies displayed two types of behaviors which have been categorized as anxiety reduction behaviors and energy arousal behaviors. Anxiety reduction behaviors were utilized first in an effort to reduce the tension occurring as the caregivers awaited the unfolding of their negative prophecies. Once the anxiety level reached a threshold the caregivers displayed energizing arousal behaviors. The caregiver channelled his energies into facilitating the institutionalization of the patient rather than developing strategies to maintain the patient at home.

Caregivers who held positive prophecies regarding how the death would occur did not appear to display anxiety reduction behaviors. Once the triggers of incongruency occurred, however, these caregivers displayed the same type of energy arousal behaviors which were seen in caregivers who had made negative prophecies.
Summary

Caregivers made prophecies based on the input they had experienced as to the type of death the patient would undergo. When a negative prophecy had been made, the caregiver perceived triggers of congruence which convinced him the patient's death was going to occur as the caregiver had predicted. As he became convinced the event he dreaded was about to happen, the caregiver experienced increasing amount of anxiety. Anxiety reduction behaviors were utilized, in an attempt to reduce the stress experienced. When the anxiety level reached a certain threshold, the caregivers demonstrated energy arousal behaviors whose purpose was to facilitate the institutionalization of the patient.

Caregivers making positive predictions of how the patient's death would occur also experienced anxiety. This anxiety occurred when triggers of incongruency led these caregivers to the conclusion that the patient's death was not occurring as they had predicted. The anxiety created by the incongruence between how they had predicted the patient's death would occur and how it was happening resulted in energy arousal behaviors by the caregivers aimed at the institutionalization of the patient.
CHAPTER 5

CONCLUSIONS AND IMPLICATIONS

The conclusions drawn from the study are discussed in Chapter 5. The limitations are described together with recommendations for further research. Implications for nursing practice are also presented.

The major factor influencing the institutionalization of terminally ill patients was the type prophecy made by the patient's caregiver regarding how the patient's death would occur. These conclusions can best be described in terms of "self-fulfilling prophecy" or expectancy theory.

According to the self-fulfilling prophecy theory, persons develop prophecies about the outcome of events based on their previous experience with the event or on information the subjects have received about the difficulty of the event (Feather, 1966). Caregivers in this study based their prophecies of how the patient's death would occur on input they received. This input came from four sources: personal experience of a previous death of a friend or family member, discussions with friends or family members, the physician, and reading material. This input resulted in the formation of either negative or positive prophecies of how the patient's death would occur depending on the impact the input had on the caregiver.

Negative prophecies were made by four caregivers. A negative prophecy was defined as the anticipation, on the part of the caregiver,
of the development of symptoms which would make it impossible for the patient to be maintained at home. These anticipated symptoms were labelled agonizing pain, unmanageable coma and prolonged death and formed the subcategories of the concept negative prophecy.

According to prophecy theory, if a negative outcome is predicted a state of "anxious anticipation" or dissonance is created within the prophet. The prophet then utilizes several different behaviors to decrease the anxiety or dissonance created by the anticipation of the frightening or unpleasant event (Archibald, 1974). Caregivers who voiced negative prophecies experienced high levels of anxiety as they awaited cues indicating the onset of the negative event they had predicted. Two types of triggers of congruence convinced the caregivers the event they dreaded was about to occur. These triggers of congruence were agonizing pain and unmanageable coma.

Behaviors labelled anxiety distraction behaviors were utilized by the caregivers in an attempt to decrease the anxiety created by the anticipation of the negative event. Once the caregiver's anxiety threshold was reached, energy arousal behaviors were displayed whose purpose was to facilitate the institutionalization of the patient.

Three caregivers made positive prophecies as to how the patient's death would occur. Positive prophecy was defined as the anticipation by the caregiver that the patient's death would occur without the development of symptoms which could not be managed at home. Two caregivers institutionalized the patient when triggers of incongruence occurred.
Triggers of incongruence were cues which indicated to the caregiver that a discrepancy existed between the caregiver's prediction of the patient's death and the actual way the death was occurring. Two types of triggers of incongruence were identified. These were triggers of incongruence - coma, and triggers of incongruence - sudden death.

As a result of incongruence between how the caregiver anticipated the death would occur and the actual event, these caregivers experienced high levels of anxiety and decided the patient could no longer be maintained at home. Energizing arousal behaviors were then utilized which resulted in the institutionalization of the patient.

The effects of a discrepancy between the predicted outcome and what was occurring was investigated by Aronson and Carlsmith (1962). In the study subjects were given a series of tests. After the completion of each test, half of the subjects were given feedback about their performance which did not match the subjects own predictions of how successfully they would complete the tests. Subjects were observed to change their performance to match the feedback they received rather than change their expectation of how well they would perform on the test (Aronson and Carlsmith, 1962). The findings closely parallel the behavior of caregivers who made positive prophecies about how the patient's death would occur. When incongruency occurred and the patient's death was not occurring as the caregiver had predicted, the caregiver preferred to change his behavior rather than his prediction. Change in caregiver's behavior resulted in the institutionalization of the patient.

Institutionalization of the patient was not influenced by the prophecy of the caregiver for two patients in the study. One caregiver
stated he had predicted his wife would die suddenly. Institutionalization of the patient occurred when the physician decided the caregiver's health status was being jeopardized by the demands of caring for the patient.

The second caregiver denied prophecising how her husband's death would occur. Her husband was hospitalized at his request because the patient thought his care would become too difficult for his wife to manage at home.

The diagram in Figure 1 depicts how negative and positive prophecy leads to the institutionalization of the patient. Input suggesting how the death will occur is received by the caregiver. This input causes the caregiver to make either a negative or positive prophecy. If a negative prophecy results, triggers of congruence occur which convince the caregiver his prediction is being fulfilled. The caregiver then displays anxiety distraction behaviors in an attempt to lower the anxiety he is experiencing. When the anxiety reaches an intolerable level, the anxiety threshold, the caregiver then displays energizing arousal behaviors which result in the institutionalization of the patient.

If the caregiver has made a positive prophecy from the input he has received, triggers of incongruence can occur which indicate that the death is not occurring as the caregiver predicted. The anxiety created by the discrepancy between how the death was predicted to occur and how it actually is happening creates anxiety within the caregiver. As the result of the anxiety experienced, the caregiver displays energizing arousal behaviors resulting in the institutionalization of the patient.
Figure 1 Prophecy: A Key Variable in Explaining Decision to Institutionalize
Limitations

The following limitations are recognized by the investigator:

1. The results of the study are not generalizable to other home care hospice patients and their caregivers because of the small sample size and the fact that all participants were enrolled in the same home care hospice program. Factors influencing the institutionalization of terminally ill patients may reflect areas of non-support unique to that particular agency, rather than home care hospice programs in general.

2. In all cases, the caregivers answered the questions in the interviews retrospectively and may not have accurately remembered factors which influenced the decision to institutionalize the terminally ill patient.

3. The commitment of the terminally ill patient and the caregiver being interviewed to the goal of a home death for the patient was not measured. Some patients and families who stated they desired a home death may have stated what they thought hospice workers wanted to hear, rather than expressing the desire for the patient to die at home as a goal they actually wished to achieve.

4. Caregivers who had a difficult time emotionally resolving the death of the patient were excluded because questioning these caregivers might have endangered their bereavement process. By excluding caregivers who had severe emotional problems resolving the loss of the patient, valuable data may have been lost.
Recommendations

Almost no studies have been performed which look at reasons terminally ill patients enrolled in a home care hospice program who wish to die at home either achieve that goal successfully or are institutionalized at the time of death. Many more exploratory studies need to be instituted if nurses are going to discover the information needed to counsel these patients and their families. For example, a study interviewing caregivers of terminally ill patients enrolled in a home care hospice program who wish to die at home and successfully achieved that goal needs to be performed. The purpose of such a study would be to investigate types of prophecies made by caregivers of patients achieving a home death. The study would identify the input the caregivers received, the sources of the input, and the events which surrounded the patient's death. Types of anxiety experienced by these caregivers and the coping strategies utilized also deserves investigation.

One subject stated that she had not made any prophecies about how her husband's death would occur. She wanted to keep her husband at home but the patient wanted to be institutionalized because he predicted he would have uncontrollable pain and be too much for his wife to manage at home. The caregiver's statement suggests that patients as well as caregivers may prophesise how their deaths will occur. The patient's prophecies may also exert an influence on the patient's institutionalization during the final stage of illness. Therefore, prophecies made by patients concerning the type death they will experience also needs further investigation.
Implications for Nursing Practice and Research

The information obtained in the present study is currently being applied clinically in a local home care hospice agency. Hospice clinicians who work with caregivers of terminally ill patients elicit the types of prophecies these caregivers have made concerning the patient's death. The information is then recorded in the patient's chart. The caregiver is then counseled about the likelihood of the death occurring in the manner prophecised. For example, a caregiver is prepared to cope with possible increase of pain in the patient if agonizing pain has been prophecised. The purpose of the counseling is to reduce the anxiety experienced by caregivers by teaching them how to manage the anticipated event.

Caregivers who make very positive predictions are also counseled. Events which may occur that are not included in the predictions are discussed. Coping strategies for these events are devised. The purpose of the counseling is to reduce the amount of discrepancy the caregiver may experience if events surrounding the death do not coincide with the positive prophecy.

By becoming aware of the prophecies made by caregivers, hospice clinicians can design interventions to reduce the anxiety caused by negative prophecies and decrease the agitation which results when discrepancy occurs. Reducing the anxiety experienced by these caregivers may result in enabling more patients to experience a home death as desired.
Further study is also needed to identify other types of prophecies made by patients and caregivers. For instance: (1) Do patients experiencing surgery or child birth prophesise about how these events will happen? (2) What kinds of prophecies does a patient recovering from a myocardial infarction make and how do these prophecies influence his recovery? or (3) What kinds of prophecies does a newly diagnosed cancer patient make about his prognosis? Nurses can help patients and caregivers develop realistic expectations about the events that are happening by helping identify prophecies and discussing the likelihood of their occurring.

Summary

In summary, the type of prophecy made by the caregiver was the major factor influencing the institutionalization of patients in this study. Further studies need to be performed to identify types of prophecies made by terminally ill patients and by caregivers of patients who successfully achieve a home death.

Hospice clinicians need to help terminally ill patients and caregivers develop realistic expectations about events that may occur at the time of the patient's death. Coping strategies can then be devised which will enable the caregiver to maintain the patient at home. These strategies will allow more terminally ill patients and their caregivers who desire a home death for the patient to achieve that goal.
APPENDIX A

HUMAN SUBJECTS FORM
THE UNIVERSITY OF ARIZONA COLLEGE OF NURSING

MEMORANDUM

TO:  Joan E. Stempel
     4110 N. Camino del Celador
     Tucson, Arizona 85718

FROM: Ada Sue Hinshaw, R.N., Ph.D. / Jan R. Atwood, R.N., Ph.D.
      Director of Research / Chairman, Research Committee

DATE: April 11, 1983

RE: Human Subjects Review: Caregivers' Perceptions of Factors Influencing the Institutionalization of Terminally Ill Patients Desiring to Die at Home

Your project has been reviewed and approved as exempt from University review by the College of Nursing Ethical Review Sub-committee of the Research Committee, and the Director of Research. A consent form with subject signature is not required for projects exempt from full University review. Please use only a disclaimer format for subjects to read before giving their oral consent to the research. The Human Subjects Project Approval Form is filed in the office of the Director of Research, if you need access to it.

We wish you a valuable and stimulating experience with your research.

ASH:des
8/82
Title: Caregivers' Perceptions of Factors Influencing the Institutionalization of Terminally Ill Patients Desiring to Die at Home

The purpose of this study is to identify factors which influence a terminally ill patient and his family enrolled in a home care hospice program who desire to die at home to institutionalize the patient in the final stages of his illness.

Participation in this study requires taking part in an interview lasting approximately one hour at a place of your choice and a time which you find convenient. If additional information is needed, one or two more interviews lasting not more than one hour each may be required.

All interviews will be taped. All information will be kept confidential. Transcriptions of the tapes will be used for education, research, and publication. At the end of the study all tapes will be destroyed. Throughout the study your identity and that of the patient will be kept anonymous.

There are no known risks from participation in this study. You are free to ask questions at any point in the interview. You may withdraw from this study at any time without ill will.

___________________________  _______________________
Investigator                     Subject.
APPENDIX C

CHART DATA FORM
CHART DATA FORM

1. What is your name ________________________________?
2. What is your age ________________________________?
3. Name of the patient ________________________________?
4. What was the patient's age ________________________________?
5. What was the patient's diagnosis ________________________________?
6. What was your relationship to the patient ________________________________?
7. When did you receive your first visit from hospice ________________________________?
8. Where did the patient die ________________________________?
9. When did the patient die ________________________________?
10. How long was he/she in the hospital ________________________________?
APPENDIX D

"GRAND TOUR" QUESTIONS
"GRAND TOUR" QUESTIONS

1. What did you expect (name of patient)’s death to be like? Why?

2. What other terminally ill people have you known? Were you with them during their illness? What was it like?

3. Have any of your friends or family members lost someone close to them? Who discussed the death with you? What did they tell you about the death?

4. What did the doctor tell you about how (name of patient) would die? What did the nurse tell you?

5. Out of all the things that happened, what was the worse? Did you expect this to happen? Why? How did you know this was happening? What did you do about it?

6. How did you feel about your ability to provide the care (name of patient) needed? What was difficult? What made it easier?

7. What kind of help did you have during (name of patient)’s illness? What kind of help would you like to have had?

8. Who made the decision to put (name of patient) into the in-patient hospice unit/hospital? Why? What was happening?

9. What did you feel could be done there that you weren’t doing at home? What was done differently in the hospital/in-patient hospice?

10. Were you with (name of patient) when he/she died? Did you want to be? What was the death like? Did the death occur the way you had expected it to?
REFERENCES


