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Relationships Between Caregiver Satisfaction with Hospice Nursing Care and Selected Demographic Variables

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RELATIONSHIP BETWEEN CAREGIVER
SATISFACTION WITH HOSPICE NURSING CARE
AND SELECTED DEMOGRAPHIC VARIABLES

By

Kathleen F. Nyeste

A THESIS

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1993

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ABSTRACT

RELATIONSHIP BETWEEN CAREGIVER SATISFACTION WITH HOSPICE NURSING CARE AND SELECTED DEMOGRAPHIC VARIABLES

By

Kathleen F. Nyeste

A descriptive correlational retrospective survey of caregivers of hospice patients was used to determine the degree of caregiver satisfaction with hospice nursing care and to examine the relationship between satisfaction with nursing care and selected caregiver demographic variables. A random sample of 180 caregivers from 12 randomly selected home based hospices in Michigan's lower peninsula was surveyed utilizing the Revised La Monica/Oberst Patient Satisfaction Scale and a Caregiver Demographic Sheet. Response rate was 63% (N = 114) with 56% (N = 100) of forms usable for data analysis.

The mean satisfaction score was 332 (possible range 51 to 357), indicating no significant relationships were found between caregiver satisfaction and the selected demographic variables. Pearson's r for age was .19, $p > .05$. The t -test results for gender and sole caregiver status were .46 and .03 respectively, $p > .05$. One-way analysis of variance for additional caregiver responsibilities was $F(3, 96) = 1.49$, $p > .05$.

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CHAPTER I

INTRODUCTION

The recent development of Hospice programs throughout the United States has brought into focus the needs and care of the dying person. The current trend toward inpatient treatment of only acute or complex disorders means that palliative care of the terminally ill must be provided in a setting other than the hospital. For many this care is provided at home by family members or non-family caregivers with help from the local hospice team. Sometimes this kind of care is the preferred choice of both patient and caregiver. In other situations care at home is just the best of the available options, none of which is preferred; and hospice care is reluctantly accepted as a way to get through this end stage of the illness.

In hospice care, the patient, the caregiver, the nurse, and other members of the interdisciplinary team together establish the plan of care to be implemented in the home setting. The hospice nurse is responsible for directing the care provided by the home caregiver, and must therefore be aware of the needs of the caregiver and of the nurse's own role in meeting these needs (Code of Federal Regulations [CFR], 1991; National Hospice Organization [NHO], 1982).

Over the last decade, literature addressing the caregiving experience has focused on chronic illness and the situations of frail elderly patients rather than on caregiving in the terminal situation (Archbold, 1982; Brody,

Johnsen, Fulcomer, & Lang, 1983; Cantor, 1983; Montgomery, Gonyea, & Hooyman, 1984; Robinson, 1983; Worcester, & Quayhagen, 1983). But the terminal stage of an illness, characterized by life expectancy measured in weeks or months and usually an escalating downhill course, involves care needs and personal adjustments very different from chronic illness.

More recently, the unique situation of family members of the terminally ill has been investigated (Garland, Bass, & Otto, 1984; Grobe, Ahmann, & Ilstrup, 1982; Grobe, Ilstrup, & Ahmann, 1981; Kane, Klein, Bernstein, Rothenberg, & Wales, 1985; Kirschling, 1985 & 1986; Skorupka & Bohnet, 1982; Welch, 1981; Wright & Dyck, 1984). But the findings of these studies cannot be generalized to caregivers of hospice patients at home, since some patients in these studies were hospitalized at the time of the study and family members were not assuming the role of caregiver. In Welch's (1981) study, subjects were not all terminally ill and were hospitalized rather than being cared for at home. In two of the studies, Skorupka and Bohnet (1982) and Welch (1981), family caregivers identified nursing behaviors directed toward care of the patient as most helpful, while nursing actions directed toward support of family members were least helpful. This suggests that caregivers may discount their own needs while focusing on the patient's needs, or that caregiver's needs may not be accurately identified.

Other studies have found that nurses may not be correctly identifying family or caregiver needs, an essential first step in being supportive. Irwin and Meier (1973), Molter (1976) and Norris and Grove (1986), in studies done with families of hospitalized critically ill patients, found that self perceived needs of family members differed from needs of family members as identified by nurses.

Present literature does not address the hospice caregiver's satisfaction with the level of support provided by the hospice nurse. Yet, nursing support of family members or caregivers is an essential part of hospice care. Hospice is an interdisciplinary team approach to providing care and support for the terminally ill person and the family or caregiver. Both patient and caregiver are clearly identified as comprising the unit of care in the hospice philosophy, policies, and structure. As the primary professional representative for the interdisciplinary team, the hospice nurse determines, with the patient and caregiver, the overall plan of care within the home setting. Implementation of this care plan proceeds under the direction of the hospice nurse. The confidence level of the patient and caregiver in the nursing care provided, and the subsequent satisfaction with that care, may determine the degree to which interventions are carried out by the home caregiver, and the extent to which the goals of hospice care are realized. Caregiver satisfaction with hospice care will

ultimately be reflected in the long term success or failure of the hospice movement in the United States, and determine to some extent its place in our healthcare system. Hospice caregiver satisfaction with nursing care is therefore an important issue.

Purpose

The purpose of this study is to determine the degree of caregiver satisfaction with hospice nursing care, and to examine the relationship between caregiver satisfaction with hospice nursing care and selected demographic variables of the caregiver. Improved understanding of caregiver variables and satisfaction with nursing care should enable the hospice nurse to develop an individualized plan to meet both the care needs of the dying patient and the support needs of the caregiver.

CHAPTER II

LITERATURE REVIEW AND CONCEPTUAL FRAMEWORK

Literature Review

Completed studies of patients' family members included in this review range from those conducted in hospital acute care units and hospital based hospice units to studies conducted in community based hospices with care being provided in the home setting. Study topics progress from caregiver needs identification and caregiver evaluation of a hospice program to examination of nursing behaviors directed toward patients and toward caregivers and descriptive information on hospice patients and caregivers.

The psychosocial needs of family members of the terminally ill have been investigated including Hampe's (1975) research with spouses whose mates were terminally ill or had died. Eight needs were identified by ninety-three percent of the spouses. These needs of the spouse included: (a) being able to visit the mate at any time and for any length of time, (b) helping with the physical care of the mate, (c) prompt acknowledgment of and competent attention to the physical and emotional needs of the mate by health professionals, (d) daily update on mate's general medical condition by medical and nursing staff, (e) awareness of the impending death, (f) verbalizing anxieties, (g) comfort and support of family members, and (h) demonstration of friendliness and concern by health professionals. Breu and Dracup (1978) in interviews with spouses of coronary unit

patients found that Hampe's needs were again identified plus the need for relief of initial anxiety. These studies were done with families of hospitalized critically ill patients and the findings may or may not be relevant to the hospice family population.

Grobe and colleagues' studies (1981, 1982) used structured interviews with terminally ill patients and their family members to identify family educational needs regarding care of the patient and services needed. Both studies found disagreement between patient and family about perceived needs. This suggests a lack of communication within the family and supports the belief that nursing care and communication must be focused on the family as well as on the patient. However, neither study addressed the issues of validity and reliability. While many of the sample sizes in these studies were small, thus preventing generalization, an overall picture of areas of concern to family members has emerged.

The extent to which the needs of family members are recognized and met seems a reasonable measure of hospice effectiveness. In a randomized controlled study of hospice care in a Veteran's Administration hospital, Kane, Klein, Bernstein, Rothenberg and Wales (1985) found that patients receiving hospice care exhibited significantly greater satisfaction with interpersonal care and involvement in care decisions than did the control group of patients receiving conventional care. Significant others of the hospice

patients showed some decrease in anxiety and greater satisfaction with care involvement than did the significant others of control patients. These differences were partly attributed to hospice staff better meeting significant others' perceived needs. While this is one of the few experimental studies of hospice patients and families, being able to generalize the findings is an issue because all patients were veterans and more than 97% of both patient groups were men. The significant others were overwhelmingly female (87% of the hospice group and 81% of the control group). This study took place in a single hospital-based hospice, yet home care is the primary model for hospices in the United States. Also the significant others were not necessarily caregivers, and were not responsible for the patients' care during the study.

Satisfaction with care received is an important issue for hospices since the federal government requires evaluation of services according to specific criteria as a condition of participation in the hospice Medicare benefit. The Federal Health Care Financing Administration suggests that critiques by patients' families provide a useful means to measure the effectiveness of a hospice program (CFR, 1991). An evaluation tool was developed by Byrd and Taylor (1989) based on the major tenets of the hospice concept and the National Standards of Care (NHO, 1982). The twenty statement hospice program evaluation tool using a four-point Likert scale was administered to 74 randomly selected

caregivers who had participated in hospice services through a community based hospice. The mean overall program evaluation score was 3.0, indicating that the caregivers perceived the statements to be descriptive of the services they received. Using the Pearson correlation coefficient, the split half reliability coefficient was .87 and the Spearman Brown estimate for the whole tool was .93. Validity was not addressed and this tool was tested in only one hospice.

Based on demographic information of caregiver age, gender and relationship to patient, Byrd and Taylor (1989) also reported that women caregivers typically rated the hospice program higher than men in all categories. It was suggested that, due to a lack of caregiving skills, the men may have had expectations that were unrealistic, indicating a need for special teaching and support. This was the only report of the relationship between demographic variables and rating of the hospice program. However, two other groups of caregivers were identified as possibly having special needs to consider in planning patient care: (a) the elderly caregiver who may be frail with functional limitations and (b) the middle aged daughter caregiver who may have home, family and employment responsibilities in addition to the needs of a dying parent. However, Byrd and Taylor failed to give supporting data for these suggestions. While this tool can identify strengths and weaknesses of the overall hospice

program, it is not specific to particular components of hospice care.

Researchers have frequently observed that the role of the nurse is central to hospice care. This observation is supported by staffing patterns and attitudes of patients and caregivers toward hospice services (Burns & Carney, 1986). In another study with physicians, nurses, and social workers, home nursing care was put at the top of a prioritized list of hospice services (Rainey, Crane, Breslow, & Ganz, 1984). Therefore, hospice nursing care must be evaluated in any attempt to determine the effectiveness of hospice care. An exploratory study by Skorupka and Bohnet (1982) provided baseline data on nursing behaviors perceived to be most helpful to caregivers in a home care hospice setting. Using a Q-sort method, caregivers were asked to rank 75 nursing behaviors from those being most helpful to those being least helpful. The nursing behaviors related to one of three categories: (a) patient's physical needs, (b) patient's psychosocial needs, and (c) psychosocial needs of the caregiver. Caregivers found nursing behaviors directed toward the patient to be more helpful than those behaviors directed toward themselves. Content validity was addressed by using six nurse experts currently practicing in the content area to review and categorize the 75 statements in the Q-sort. A test-retest pilot study was also conducted with 10 families. The small sample size of 20 and the setting of only one home

care hospice limits the generalization of the study.

Caregivers' needs have been identified, and helpful nursing behaviors have been identified. Further research is needed to evaluate the hospice nursing care actually being provided to patients and families.

To plan and deliver effective health care, it is essential to know the demographic characteristics of the recipients. Petrosino (1985) conducted a descriptive survey of 350 hospice patients and caregivers from 41 states to identify the characteristics of hospice patients, their primary caregivers and major nursing problems. The tool was pilot-tested for clarity and content by eight professional nurse educators and revised according to their responses. Primary nurses were asked to complete the forms for the first patients who died within a certain time period. It was presumed that this selection method would eliminate bias in choosing subjects. Patient records served as the source of data. Caregiver data included relationship to the patient. Setting information included the number of days in hospice care and the relationship and ages of others in the immediate household. Caregivers were identified by gender only when they were spouses or daughters; siblings and other caregivers were not identified according to gender. Age of caregivers was not directly addressed in the survey, but spouses who were caregivers were assumed to be of comparable age to the patient. This may not be a valid assumption from

which to draw implications, and therefore may be a weakness of this study.

Petrosino (1985) reported that the intent of this study was to provide a broad-based descriptive foundation for future research. While relationships between caregiver demographics and nursing problems were not studied, Petrosino suggested that nurses be alert to the special needs of caregivers who must assume their responsibility alone or who have additional responsibilities of home, family, or employment. Also the caregiver spouse in an older age group was identified as being of particular concern. This spouse has the typical age related developmental tasks to accomplish, in addition to those adjustments resulting from dealing with another's terminal illness and its attendant physical and psychological stresses. Petrosino points out that basic knowledge and experience with physical care and nurturing activities should not be assumed to exist in the caregiver of any age or gender, especially males who have performed traditional roles and may be inexperienced with daily household tasks.

Caregiver needs have been repeatedly identified, but only a few studies have examined caregiver satisfaction with hospice care or, more particularly, hospice nursing care. More direct data is needed on caregiver demographics of age, gender, lone caregiver status, and additional caregiver responsibilities. When relationships are studied between these demographic variables and caregiver satisfaction with

hospice nursing care, the nursing problems suggested by Petrosino (1985) can be better addressed. Increased knowledge of caregiver demographics and their relationship to satisfaction with nursing care could facilitate the selection of the most appropriate nursing intervention from the intervention options available, thus improving the effectiveness of hospice nursing care. This strategy is particularly applicable to teaching and supporting interventions and to the impact of the interventions on the hospice caregiver.

Conceptual Framework

Since hospice views the dying person and family or caregiver as a single unit of care, a systems approach is used to study the problem. Sister Callista Roy's Adaptation Model of Nursing is the conceptual framework most suitable to this study, as it is based on systems theory and views the person as an adaptive system. Dying persons and their caregivers comprise a system undergoing an enormous crisis, and the nurse's role is to assist the caregiver as well as the patient in adapting to the new situation (Gordon & Rooney, 1984). Each caregiver may be viewed as an adaptive system. Information obtained from this study of caregivers of the terminally ill can be used to facilitate the adaptation of caregivers to their role.

The Roy Adaption Model, as shown in Figure 1, uses a basic format of input, control process, output. Input or stimuli feeds into a person's control processes or adaptive

mechanisms which work through effectors or adaptive modes to express output or behavioral responses. Roy (1983) views the person as an adaptive system with regulator and cognator control processes acting to cope with changing internal and external stimuli to produce adaptive and ineffective responses that are manifested in behavior related to physiological function, self-concept, role-function, and interdependence.

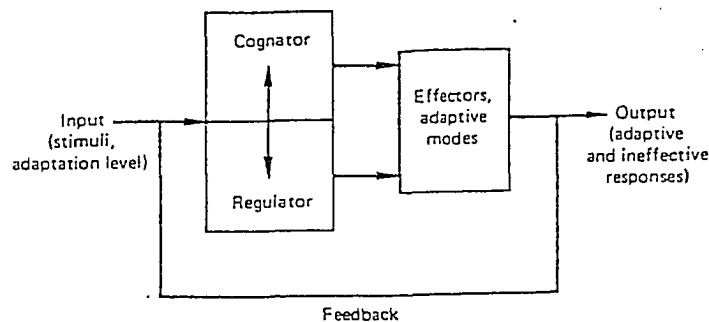


Figure 1. The Person as an Adaptive System (Roy, 1983)

The input portion of the model contains the environmental factors--those internal and external stimuli that affect adaptation and thereby affect health or personal integration of self. Stimuli are classified as focal (stimuli immediately confronting the individual), contextual or background stimuli, and residual stimuli (such as beliefs, attitudes or traits). The combined effect of these three classes of stimuli determine a person's adaptation level, which delineates a zone within which stimulation leads to a positive or adaptive response, and stimulation

outside this zone leads to a negative or ineffective response.

The control processes in the model, the regulator and cognator, are the mechanisms of adapting or coping with a changing environment (Tiedeman, 1983). The regulator processes stimuli from the external environment and from the person's internal state through neural-chemical channels, resulting in autonomic nervous system and endocrine responses to the stimuli.

The cognator receives the same internal and external stimuli affecting the whole system, and processes this stimuli through cognitive-emotive pathways. There are four pathways: perceptual/information processing (selective attention, coding, memory), learning (imitation, reinforcement, insight), judgment (problem solving, decision making), and emotion (defenses against anxiety, affective appraisal, attachment). These pathways generate the person's internal ability to cope or adapt.

The output portion of the model is the effectors or adaptive modes. These modes provide the particular form or manifestation of cognator and regulator activity. The coping mechanisms of the cognator and regulator act in relation to the four modes of adaptation: physiological function, self concept, role function and interdependence (Roy & Roberts, 1981), resulting in behaviors which are adaptive or ineffective. Adaptive responses promote the goals of the human system--survival, growth, reproduction

and mastery. Ineffective responses are the person's behaviors that do not contribute to these goals. A person's behavior, both adaptive and ineffective responses, acts as feedback and becomes further input for the person as an adaptive system (Roy, 1983).

According to Roy, adaptation is a process involving the holistic functioning of a person using one's total potential to affect health positively. A person's adaptation is a function of the stimuli experienced and one's adaptive or coping mechanisms.

Roy defines health as a state and a process of being and becoming an integrated and whole person. It is the goal of nursing to promote adaptation and therefore health by enhancing stimuli and adaptation levels.

Putting this study into the framework of Roy's Adaptation Model, the caregiver will become the adaptive system being studied. Assumption of the caregiver role will be the focal stimuli. Demographic variables of gender, age, and being the sole caregiver in the home will be the contextual and residual stimuli and coping mechanisms or control processes of Roy's model. Hospice nursing care interacting with these stimuli and coping mechanisms enhances the adaptation of the caregiver. Caregiver satisfaction with hospice nursing care will be used as a measure of the effectiveness of that nursing care in facilitating the adaptation process (CFR, 1991). Roy's Adaptation Model will illustrate how the hospice nurse may

need to alter nursing interventions to fit the caregiver's unique characteristics so as to achieve the highest level of adaptation.

Definition of Terms

The major variables in this study include: caregiver, satisfaction, hospice nursing care, and selected demographic variables.

1. Caregiver is defined as the person identified in the hospice record as having responsibility for providing day to day care at home to the terminally ill patient.

2. Satisfaction with hospice nursing care is defined as the degree to which the caregiver perceives the nurse's actions as helpful.

3. Hospice nursing care is defined as the services provided to the patient and/or caregiver by the hospice nurse including physical, psychosocial, emotional, spiritual and instructional.

4. Selected caregiver demographic variables include gender, age, being the sole caregiver, and also having additional responsibilities, such as child care and /or employment.

This descriptive study will use a survey method to determine the degree of caregiver satisfaction with hospice nursing care. In addition, the relationship between caregiver satisfaction with hospice nursing care and the caregiver demographic variables of gender, age, being the sole caregiver, and also having child care and/or employment

responsibilities will be examined. Based on previous studies (Byrd & Taylor, 1989), male caregivers may be less satisfied with hospice nursing care than female caregivers. Also, as suggested by Petrosino (1985), differences in satisfaction levels may be anticipated in older caregivers, sole caregivers, and caregivers with additional responsibilities. These caregivers may have increased or different needs which provide additional challenges.

CHAPTER III

METHOD

This study was done in conjunction with a more extensive doctoral dissertation study by Lucille Grimm, R.N., Ed.D. The investigator participated in data collection applicable to both studies and performed data analysis for this study.

Research Design

The design of this study was a descriptive correlational retrospective survey of caregivers of hospice patients from home based hospices in the lower peninsula of the state of Michigan. The satisfaction survey and caregiver demographic sheet was mailed to the caregivers of patients who had died two to six months prior to sample selection.

Caregiver satisfaction is a phenomenon that can be measured only after the intervention of hospice nursing care has been performed. Because caregivers were expected to differ in terms of a number of characteristics which cannot be controlled (such as gender, age, being the sole caregiver, and having additional responsibilities), a correlational research design was selected as the most efficient and effective means of studying the interrelationship of these variables and caregiver satisfaction. Studying these phenomena as they operated in a natural setting provided information that was strong in realism and applicable to the solution of practical problems (Polit & Hungler, 1987).

The external validity of this retrospective descriptive correlational study was increased by the natural setting in which the study was done. The realism of the findings from this study make them generalizable to other hospice caregivers in community settings, but the findings may not be applicable to other populations in other settings.

Sample and Setting

The caregivers for this study were selected from the accessible population of caregivers in the 71 home based hospices in Michigan's lower peninsula. Caregivers from hospices in Michigan's upper peninsula were eliminated due to the low census of under 5 patients in hospices in that area. Caregivers from hospital based hospices were eliminated because there are so few of these hospices and because the caregiving responsibilities are different from the responsibilities of caregivers in home based hospices. Caregivers from hospices with average daily census (ADC) under 5 were also eliminated. Caregivers from the remaining 34 hospices constituted the accessible population.

To insure a more representative sample, these 34 hospices were grouped by size according to ADC: small = ADC of 5 to 10 (20 hospices), medium = ADC of 11 to 25 (8 hospices), large = ADC greater than 25 (6 hospices). Using a table of random numbers, 4 hospices were randomly selected from each group making a total of 12 hospices selected. From each of these 12 hospices, caregivers of 15 patients (total of 180 caregivers) were randomly selected from a list

of all caregivers meeting sample selection criteria. The criteria for selection of caregivers were that English is their major language and that they had provided care for hospice patients who: (a) had a diagnosis of cancer, (b) were 21 years of age or older, (c) were admitted to hospice at least one week prior to death, and (d) died two to six months prior to the onset of the study.

Instruments

The Revised La Monica/Oberst Patient Satisfaction Scale and a Caregiver Demographic Sheet were used to collect data. Both instruments were self-administered by the subjects in the study. Self-administered questionnaires were selected as the most appropriate data gathering medium. According to Dillman (1978), self-administered questionnaires have the strength of lower response bias compared to telephone and face-to-face interviews, because respondents are able to answer questions in privacy and at their own pace. With decreased time pressures on the respondent, more detailed questioning can be done. Weaknesses of questionnaires are lower response rates and the inability of respondents to clarify items not clearly understood.

Caregiver Demographic Sheet. This instrument was used to collect demographic data about the caregiver (see appendix A). The tool includes questions about gender, age, help received from others in caring for the hospice patient, and additional responsibilities of child care and/or employment.

Revised LOPSS. The La Monica/Oberst Patient Satisfaction Scale (LOPSS) has been used to measure satisfaction with nursing care among hospitalized cancer patients (La Monica, Oberst, Madea, & Wolf, 1986). In this study, caregiver satisfaction with hospice nursing care was measured using the Revised LOPSS (see Appendix B) developed by Grimm (1991) for her research with hospice caregivers. A letter of permission to use the Revised LOPSS for this study was obtained from Lucille Grimm (see Appendix B).

Grimm (1991) revised the LOPSS for use in her study of caregivers of hospice patients. She adapted the LOPSS statements to make them applicable to caregivers rather than patients and added statements specific to hospice care. The Revised LOPSS (Grimm, 1991) contains 51 items that describe nursing behaviors deemed necessary for caregiver satisfaction (original LOPSS 41 items plus 10 items pertaining to hospice care). The individual items are stated either negatively (19 items) or positively (32 items), to decrease the likelihood of acquiescent response set. The instrument is a paper and pencil, self-administered questionnaire with a seven-point Likert scale of response alternatives varying from strongly disagree (1) to strongly agree (7).

Content validity of the Revised LOPSS was established by having a jury of two nursing faculty who were involved in research and three hospice nurses review the changes to the

instrument. Reliability analysis of the Revised LOPSS showed alpha = .89.

Scoring of the Revised LOPSS was done by first reversing the scaling of the scores on the negative items (1 becomes 7 and 7 becomes 1), and then adding all of the item scores to yield an overall satisfaction score. Total score of the Revised LOPSS ranges from 51 to 357. The highest score is indicative of strong agreement with all of the statements describing nursing behaviors.

Procedures

A letter of transmittal, including a "Request For Permission To Conduct The Survey" form (see Appendix C), was sent to each of the twelve randomly selected hospices. The letter and the permission form included: (a) reason for the survey, (b) assurance of confidentiality, (c) purpose of the study, (d) criteria for caregiver selection, (e) statement of association with a professional institution, (f) offer to share the data and the results of the survey, and (g) request for return by a specified date. A self addressed, stamped envelope was enclosed with the letter. An official of the selected hospices was asked to sign and return the permission form giving the investigator permission to conduct the survey at the specific hospice. The signed permission form was kept on file by the investigator. The hospices agreeing to participate in the study were requested to compile a list of caregivers who met the criteria for inclusion in the study. A visit was made to each of the

participating hospices to draw the caregiver sample from the list using a table of random numbers.

Once selection of caregivers was completed, a list of the caregiver addresses was compiled. A letter was sent to each caregiver (see Appendix D) explaining: (a) reason for the survey, (b) assurance of confidentiality, (c) purpose of the study, (d) association with a professional organization, and (e) request for return by a specified date. A Caregiver Demographic Sheet (see Appendix A) and the Revised LOPSS survey form (see Appendix B) was mailed with the cover letter to the 180 randomly selected caregivers. A permission form (see Appendix D) to access the hospice patient record was also included so that the investigator could verify the patient related criteria for inclusion of the caregiver in the study sample. Respondents were asked to complete the survey and demographic form as instructed and return them with the signed permission form within two weeks in the stamped envelope provided. The questionnaire was coded so that the investigator could identify which questionnaires had been returned. Five weeks after the initial mailing to the caregivers, a follow up letter, also including a questionnaire and demographic form, was sent to those caregivers who did not respond within the requested time.

There were no known risks resulting from participation in this survey and confidentiality was maintained as outlined in the cover letter to the caregivers (see Appendix

D). Return of the completed questionnaire constituted acceptance of participation by the caregiver.

Data Analysis

Analysis of the data was computed using the EPISTAT Statistical Package for the IBM Personal Computer software. The degree of caregiver satisfaction with hospice nursing care was determined by summative scoring of the Revised LOPSS. These scores were then analyzed to find the mean, standard deviation, and range of scores.

Relationship between caregiver satisfaction with hospice nursing care and selected caregiver demographic variables was determined by three different methods as appropriate for the level of measurement of the variable (Polit & Hungler, 1987). The Pearson correlation coefficient was used for the variable age, the t-test was used for the variables gender and sole caregiver status, and one-way analysis of variance (ANOVA) was used for the variable additional responsibilities of child care and/or employment. The summative scores from the Likert scale of the Revised LOPPS were, strictly speaking, at ordinal level; but Polit and Hungler (1987) support using Likert scale data as interval because "the distortion introduced by treating them as interval measures is too small to warrant an abandonment of powerful statistical analyses" (p. 344).

CHAPTER IV

RESULTS

LOPSS questionnaires and Caregiver Demographic sheets were mailed to 180 randomly selected hospice caregivers. A total of 114 questionnaires (63%) and 112 demographic sheets (62%) were returned. Fourteen of the returned questionnaires were discarded for the following reasons: criteria for inclusion in study not met (4), refused to answer questionnaire (7), moved with no forwarding address (1), and demographic sheet not returned (2). The remaining 100 questionnaires and demographic sheets comprised the sample group for data analysis.

Sample Characteristics

Demographic characteristics of subjects are presented in Table 1. The majority of caregivers sampled (74%) were female, with 26% being male. Ages of subjects ranged from 25 years to 86 years with a mean of 60 years and standard deviation of 13.8 years. Seven caregivers (7%) were within the 25 to 40 year age range, 38 caregivers (38%) were within the 41 to 60 year age range, 50 caregivers (50%) were within the 61 to 80 year age range, and 5 caregivers (5%) were over 80 years of age.

Twenty-nine subjects (29%) were sole caregivers for the dying patient with intermittent help from the hospice team. The other 71 caregivers (71%) had assistance from one or more adults in addition to the hospice team.

Table 1

Demographic Characteristics of Subjects

Characteristics	n	%
Gender		
Male	26	26
Female	74	74
Sole Caregiver Status		
Sole Caregiver	29	29
Not Sole Caregiver	71	71
Additional Responsibilities		
No Child Care, No employment	60	60
Child Care and Employment	10	10
Child Care, No Employment	10	10
Employment, No Child Care	20	20

While caring for the patient, 60 subjects (60%) had no additional responsibilities of child care or employment. Ten subjects (10%) had additional responsibilities of both child care and employment. Ten subjects (10%) had the additional responsibility of child care but not of employment. Twenty subjects (20%) had the additional responsibility of employment but not of child care.

Research Objective One

The first research objective of this study was to determine the degree of caregiver satisfaction with hospice nursing care. This was done by computing summative scores of the Revised LOPSS and analyzing the data. Satisfaction scores ranged from 246 to 357 (possible range of 51 to 357). The mean score was 332 and the standard deviation was 23.1.

Research Objective Two

The second research objective of this study was to examine the relationship between caregiver satisfaction with hospice nursing care and the selected variables of age, gender, sole caregiver status, and additional responsibilities of child care and/or employment. This was done by computing the mean and standard deviation of caregiver satisfaction with hospice nursing scores based on the selected demographic variables.

Age. The relationship between caregiver satisfaction and caregiver age was computed using Pearson's correlation coefficient with results of $r = .19$, $p > .05$. No significant relationship was found.

Gender. Means and standard deviations of caregiver satisfaction scores for males and females are presented in Table 2 along with the results of the t-test. No significant differences in caregiver satisfaction were found based on gender.

Sole Caregiver Status. Means and standard deviations of caregiver satisfaction scores for subjects who were sole

caregivers and for subjects who were not sole caregivers are presented in Table 2 along with the results of the t-test. No significant differences in caregiver satisfaction were found based on sole caregiver status.

Table 2

Results of the t-Test of Satisfaction Scores Based on
Selected Demographic Variables

Group	M	SD	df	t*
Gender				
Male	330	21.1	98	.46
Female	333	23.8		
Sole Caregiver Status				
Sole Caregiver	331	21.1	98	.03
Not Sole Caregiver	332	24.0		

* None of t-test results were significant at the .05 level.

Additional Responsibilities. Means and standard deviations of caregiver satisfaction scores for subjects based on the presence or absence of additional responsibilities of child care and/or employment are provided in Table 3. Results of the one-way analysis of variance demonstrated no significant difference in caregiver satisfaction scores based on additional responsibilities (see Table 4).

Table 3

Means and Standard Deviations of Satisfaction Scores Based on Additional Responsibilities

Group	n	M	SD
No Child Care, No Employment	60	335	21.6
Child Care and Employment	10	332	16.2
Child Care, No Employment	10	332	22.3
Employment, No Child Care	20	323	29.0

Table 4

Results of the Analysis of Variance of Satisfaction Scores Based on Additional Responsibilities

Source	df	Sum of Squares	MS	F*
Between	3	2344	781.33	1.49
Within	96	50470	525.73	

* F test was not significant at the .05 level.

CHAPTER V

DISCUSSION AND CONCLUSIONS

The purpose of this study was to determine the degree of caregiver satisfaction with hospice nursing care, and to examine the relationship between caregiver satisfaction with hospice nursing care and selected demographic variables of the caregiver. In this chapter, further discussion of the results of the data analysis according to research objectives is presented. In addition, limitations of the study, implications for nursing, and suggestions for further research are addressed.

Discussion

Research Objective One. Satisfaction scores were skewed toward high levels of satisfaction. There were 13 Revised LOPSS scores of 357 (highest possible) representing each of the selected demographic variable groups except the group of caregivers with both the additional responsibilities of child care and employment. This reaffirms the high scores reported by individual hospices on the family evaluation of hospice services form used by many hospices. Since hospice care is a choice made by the patient and the caregiver, the care provided by the hospice nurse is, in effect, helping the caregiver achieve the self-selected goal of caring for the dying patient till death occurs. At the outset of hospice care, the caregiver

may be uncertain about achieving this goal due to lack of prior experience. So it might be inconceivable for the caregiver to be less than satisfied with care which resulted in accomplishment of the caregiver's own goal.

Research Objective Two. Differences in satisfaction scores were anticipated in older caregivers, male caregivers, sole caregivers, and caregivers with additional responsibilities. This study failed to support these expected differences suggested by Byrd and Taylor (1989) and Petrosino (1985). When looking at additional responsibilities, interpretation of the study results is limited by the unequal sample size of the groups which varied from 10 to 60. In spite of this limitation, some explanation can be offered. Given, Collins, and Given (1988) suggest that "employment may provide relief from caregiving" rather than being perceived as an additional burden.

For the sole caregiver, the amount of assistance and perceived support is important to prevent a sense of abandonment according to Given, Stommel, Collins, King, and Given (1990). The involvement of the hospice team may fill this need for the sole caregiver in the absence of family assistance and support. The multiple person team approach of hospice care may offer a more supportive service than nursing care alone could accomplish thereby eliminating the anticipated difference in satisfaction for this group of caregivers. It may not be possible to evaluate the effect

of hospice nursing care separate from the effect of the entire interdisciplinary team. The high satisfaction scores may be reflecting more than satisfaction with nursing care. Grimm (1991) notes "primary caregivers did not differentiate between the disciplines who supplied information and support."

Limitations

Threats to internal validity of this design might have come from history, maturation, instrumentation or selection. History and maturation are dynamic forces impacting the subject directly. History refers to events occurring in the caregiver's life between the time of hospice service and the time of responding to the questionnaire (2-6 months) which might have altered perception of the care or satisfaction with the care. The questionnaire was sent to the caregiver two to six months following the death of the hospice patient. This time frame was selected in order to minimize the influence of initial acute grieving on the responses of the caregiver and yet elicit response while perception of care was still accurately recalled. Maturation refers to changes in memory over time, such as perception and judgment, which could have been affected by either lessening or deepening of grief over the loss of the patient.

Instrumentation and selection are threats to validity external to the subject. Instrumentation refers to clarity of the questionnaire and response set bias of the caregivers responding. Both were potential sources of measurement

error. Efforts to reduce this threat to internal validity were made by including instructions on the questionnaire stating that there were no right or wrong answers and stressing the importance of honest answers. A guarantee of anonymity and confidentiality of responses was stated in the cover letter. Selection as a threat to internal validity was reduced by stratified random sampling of hospices and simple random sampling of all patients from those hospices who met the criteria of this study.

Sample size was limited by three of the selected hospices not allowing the investigator access to the list of family names and addresses as an additional assurance of confidentiality. A second mailing of the questionnaire was not possible to the caregivers from these hospices who failed to respond to the first mailing. The second mailing to the other nine hospices produced an additional 28 questionnaires, so it is likely that 9 more could have been obtained if a second mailing had been done for these three hospices.

Another limitation was the degree of truthfulness of the responses which could be influenced by a sense of gratitude or loyalty to the hospice nurse who provided care. Influence on responses could also come from previous or current experience with other nurses in other situations.

A threat to internal validity was the lack of control over administration of the questionnaire. It was not possible for the investigator to know the conditions under

which the subjects completed the questionnaire. There may have been interruptions or distractions seriously affecting the subject's concentration. This is an inherent limitation of the survey method of data collection. A suggestion about selection of the best setting in which to fill out the questionnaire could be added to the instructions on the instrument.

The ex post facto design is not a strong research design. Causal inferences cannot be made about the relationships under study. Despite this weakness, knowledge about relations can lead to practical applications or lay the groundwork for more rigorous research (Polit & Hungler, (1987).

Implications

While hospice nursing care is generally well received and appreciated by dying patients and their caregivers, it remains important for hospice nurses and hospice agencies not to become satisfied and content with current methods of care delivery and scope of services. Rather, hospice agencies and nurses should participate in further studies and keep aware of research on caregiver needs so as to maintain a high quality of care directed to caregivers as well as patients.

Satisfaction may be too broad a concept on which to base nursing plans for interventions with caregivers. The success that hospices have demonstrated in facilitating the caregiver's involvement in the patient/family plan of care

may indicate that most caregivers are capable of identifying their perceived needs and verbalizing their expectations. Greater involvement of the caregiver at the planning stage may result in more individualized and effective nursing interventions for both patients and caregivers.

Recommendations for Future Research

Grimm (1991) supports further study of Herzberg's two factor theory of dissatisfiers and satisfiers (White & Bednar, 1986) as it might apply to recipients of nursing services. Herzberg believed individuals had two separate and distinct sets of needs which he labeled satisfiers and dissatisfiers. The dissatisfiers when present could prevent dissatisfaction but did not contribute to the employee's sense of satisfaction. If nursing research could identify the satisfiers and dissatisfiers of hospice care, hospice nurses could select the most appropriate interventions to achieve satisfactory results.

This study could be repeated in Michigan's upper peninsula where comprehensive hospice programs are relatively new, or in another state where subject's expectations may be different. A similar study might be done measuring satisfaction of family members with hospice nursing care provided to their loved one in a residential setting such as an adult foster care home. This would provide information on another method of delivering hospice care.

Summary

The purpose of this study was to determine the degree of caregiver satisfaction with hospice nursing care, and to examine the relationship between caregiver satisfaction with hospice nursing care and selected demographic variables of the caregiver. It was found that caregivers express a consistently high level of satisfaction with hospice nursing care. There were no significant differences in satisfaction between groups of caregivers based on any of the demographic variables studied.

There is still much to learn about the widespread acceptance of and satisfaction with hospice care in the United States over the last twenty years. If the key factors or underlying components of satisfaction could be identified and better understood they might be applicable to other areas of health care as well as to hospice care.

APPENDICES

APPENDIX A

Caregiver Demographic Sheet

ID # _____

Now I would like to ask you a few background questions about you and your family so that your answers can be grouped with those of persons with a similar background to help us analyze the results of the study. This information will be kept confidential.

Please circle the appropriate answer or fill in the space.

1. What is your gender?

1 male 2 female

2. How old were you on your last birthday? _____

3. Please circle the highest grade you have completed.

none 00

elementary 01 02 03 04 05 06 07 08

high school 09 10 11 12

college 13 14 15 16

some graduate school 17

graduate or professional degree 18

4a. During the time you were providing care to the patient, were there other adults beside yourself who participated in the care?

1 yes 2 no (skip question 4b)

4b. If yes, did any of these people reside in the household?

1 yes 2 no

5. While caring for the patient, were you also responsible for the care of children in the home?

1 yes 2 no

6a. While caring for the patient, were you employed outside the home?

1 yes 2 no (skip question 6b)

6b. If yes,

1 mostly full time 2 mostly part time

APPENDIX B



Letter of Permission

1 CAMPUS DRIVE • ALLENDALE MICHIGAN 49401-9403 • 616/895-6611

February 17, 1993

Kathleen Nyeste
P.O. Box 95 Main Street
Naubinway, MI 49762

Dear Ms. Nyeste,

Please be advised that you have my permission to use the revised LaMonica/Oberst Patient Satisfaction Scale for your research investigation titled "Relationship Between Caregiver Satisfaction with Hospice Nursing Care and Selected Demographic Variables".

Sincerely,

A black rectangular box redacting the signature of Lucille I. Grimm.

Lucille, I. Grimm Ed.D, R.N.

APPENDIX B

Revised

La Monica/Oberst Patient Satisfaction Scale

Instructions to the primary caregiver:

The following are fifty one statements about hospice registered nurses. In the columns next to the statements are seven possible responses. For each statement, decide how much you agree or disagree with the view expressed and circle the number under the response that comes closest to your opinion. "Strongly Disagree" and "Strongly Agree" are reserved for those opinions on which you have no exceptions. "Neutral" means equally "yes" and "no".

There are no right or wrong answers. Since people differ in their views, your response should be your personal opinion. Form your opinions based upon your general impression of all the hospice registered nurses with whom you were in contact with during the hospice experience. It is extremely important that your responses are honest.

Please now try these two examples:

	Strongly Disagree	Moderately Disagree	Slightly Disagree	Neutral	Slightly Agree	Moderately Agree	Strongly Agree
A. The nurse has a neat appearance.	1	2	3	4	5	6	7
B. The nurse is always too busy to talk with me.	1	2	3	4	5	6	7

The staff at the hospice know that I am asking for your help, and they support this study. However, the information you give me will be strictly confidential and under no circumstances will your responses be shared with the hospice.

Thank you very much for your time and your help. You have had a part in making nursing care more satisfactory for the patient and your needs.

PLEASE TURN THE PAGE AND COMPLETE THE QUESTIONNAIRE

No.	Item	Strongly Disagree	Moderately Disagree	Slightly Disagree	Neutral	Slightly Agree	Moderately Agree	Strongly Agree
1.	The nurse was not as attentive as she should be.	1	2	3	4	5	6	7
2.	The nurse appeared to be skillful in doing her work.	1	2	3	4	5	6	7
3.	The nurse made helpful suggestions.	1	2	3	4	5	6	7
4.	The nurse did not seem to do anything with the information the patient and I gave her.	1	2	3	4	5	6	7
5.	The nurse treated us with respect.	1	2	3	4	5	6	7
6.	The nurse seemed more interested in getting the tasks finished than in listening to our concerns.	1	2	3	4	5	6	7
7.	The nurse did not follow through quickly enough on her care for the patient.	1	2	3	4	5	6	7
8.	When the patient needed physical assistance, the nurse saw to it that the patient received it.	1	2	3	4	5	6	7
9.	The nurse was not as friendly as she should be.	1	2	3	4	5	6	7
10.	The nurse explained things in a manner that was easy to understand.	1	2	3	4	5	6	7
11.	The nurse appeared to enjoy caring for the patient.	1	2	3	4	5	6	7
12.	The nurse gave the impression that the patient care was her top priority while she was with us.	1	2	3	4	5	6	7
13.	The nurse was impatient.	1	2	3	4	5	6	7
14.	I felt free to ask the nurse questions.	1	2	3	4	5	6	7
15.	The nurse gave complete explanations.	1	2	3	4	5	6	7
16.	The patient felt more like a "case" than an individual with the nurse.	1	2	3	4	5	6	7
17.	The nurse talked down to us.	1	2	3	4	5	6	7
18.	If I had another family member with the same problem, I would gladly come back to this hospice.	1	2	3	4	5	6	7
19.	The nurse did not answer my telephone calls promptly enough.	1	2	3	4	5	6	7
20.	The nurse told us all she could about what to expect from the patient's disease.	1	2	3	4	5	6	7
21.	The nurse told us things that conflicted with what the doctor told us.	1	2	3	4	5	6	7

No.	Items	Strongly Disagree	Moderately Disagree	Slightly Disagree	Neutral	Slightly Agree	Moderately Agree	Strongly Agree
22.	The nurse was pleasant to have around.	1	2	3	4	5	6	7
23.	The nurse told us she would return to do something for us and then did not keep her promise.	1	2	3	4	5	6	7
24.	I was confident that the nurse knew what to do in an emergency.	1	2	3	4	5	6	7
25.	The nurse showed me how I could care for the patient.	1	2	3	4	5	6	7
26.	When the patient or I needed to talk with someone, we could share our feelings with the nurse.	1	2	3	4	5	6	7
27.	The nurse did things that made the patient more comfortable.	1	2	3	4	5	6	7
28.	I would have liked the nurse to be more thorough.	1	2	3	4	5	6	7
29.	The nurse seemed disorganized and flustered.	1	2	3	4	5	6	7
30.	The nurse neglected to make sure that the patient and I understood the importance of taking medications as instructed.	1	2	3	4	5	6	7
31.	Just talking to the nurse made the patient and I feel better.	1	2	3	4	5	6	7
32.	The nurse helped the patient and I to understand the illness.	1	2	3	4	5	6	7
33.	The nurse was available when the patient and I needed support.	1	2	3	4	5	6	7
34.	The nurse really seemed to know what she was talking about.	1	2	3	4	5	6	7
35.	The nurse acted like the patient and I couldn't understand the medical explanation of the illness when, in fact, we really could.	1	2	3	4	5	6	7
36.	The nurse failed to consider the patient and my opinions and preferences regarding the plan of care.	1	2	3	4	5	6	7
37.	The nurse was gentle in caring for the patient.	1	2	3	4	5	6	7
38.	The nurse seemed reluctant to give us assistance when we needed it.	1	2	3	4	5	6	7
39.	The nurse gave directions at just the right speed.	1	2	3	4	5	6	7
40.	The nurse understood the patient and I when we shared our problems.	1	2	3	4	5	6	7
41.	I felt secure when the nurse was giving direct care to the patient.	1	2	3	4	5	6	7
42.	The nurse made sure the patient had a spiritual source of comfort.	1	2	3	4	5	6	7

No.	Item	Strongly Disagree	Moderately Disagree	Slightly Disagree	Neutral	Slightly Agree	Moderately Agree	Strongly Agree
43.	The nurse neglected to help me make funeral arrangements.	1	2	3	4	5	6	7
44.	The nurse provided me with emergency measures when needed.	1	2	3	4	5	6	7
45.	The nurse taught me how to keep the patient comfortable.	1	2	3	4	5	6	7
46.	The nurse helped me to locate special equipment (for example, hospital bed) to make the patient more comfortable.	1	2	3	4	5	6	7
47.	The nurse made sure the patient had comfort from pain.	1	2	3	4	5	6	7
48.	The nurse assisted the patient to be able to die at home.	1	2	3	4	5	6	7
49.	The nurse provided guidance in how to talk with the patient about impending death.	1	2	3	4	5	6	7
50.	The nurse provided me with information about bereavement services.	1	2	3	4	5	6	7
51.	The nurse failed to provide me with assistance with respite care.	1	2	3	4	5	6	7

PLEASE RETURN THIS QUESTIONNAIRE IN THE ENVELOPE PROVIDED

La Monica, E., Oberst, M., Madea, A., & Wolf, R. (1986).
 Development of patient satisfaction scale.
Research in Nursing and Health, 9, 43-50.
 Reproduced with permission.

APPENDIX C

Letter of Transmittal to the Hospice

Date

Hospice name and address

Dear

I am a doctoral candidate in the Department of Educational Leadership at Western Michigan University. Also, I am an assistant professor of nursing at Grand Valley State University. The purpose of my dissertation is to determine whether relationships exist between providing nursing care and perceived satisfaction with nursing care by the hospice family. I am writing to ask you to participate in my study by granting me permission to collect data from your agency. Hospice of Western Michigan, Inc has been informed of my research plans and has endorsed my study (see letter of endorsement attached).

If you are willing to participate in this study, I will request to randomly select fifteen patient records from your agency. I will audit those records and send a separate questionnaire to the patient's primary caregiver.

Criteria for patient selection will include the following:

1. Diagnosis of cancer
2. Patient age, a minimum of twenty one years of age
3. Patient admitted to hospice at least one week prior to death, and death occurring two to six months prior to onset of the study.
4. English as the major language of the primary caregiver.

Each institution and family will be assigned a code in order to keep all data collected confidential. The temporary master list of codes and names will be destroyed after the study is completed. Data will be reported as group tendencies only. It will be impossible to identify individual hospices, nurses or families. A summary of this study will be sent to your hospice upon completion of the study.

If your hospice is willing to participate please sign the attached permission form and return it in the stamped envelope provided. Upon receiving your permission, I will

contact you to arrange a meeting to share the two data collection instruments with you and to randomly select the patient sample.

Thank you for your cooperation in this project, I remain,

Very truly yours,

Lucille I. Grimm RN, MSN
2736 Hampshire S.E.
East Grand Rapids, MI 49506

(tear off here)

Permission Form

Lucille I. Grimm has been granted permission to conduct research for her doctoral dissertation at (Hospice name)

Signed: _____

Title: _____

Date: _____

APPENDIX D

Letter of Transmittal to the Primary Caregiver

(Date)

(Hospice family name and address)

Dear -----,

I am a doctoral candidate in the Department of Educational Leadership at Western Michigan University. Also, I am an assistant professor of nursing at Grand Valley State University. This letter is to request your participation in my research for my doctoral dissertation. I have been given permission to do this study by (Hospice name).

The purpose of this study is to determine whether relationships exist between nursing care provided and the hospice family's perceived satisfaction with nursing care. The information obtained is to be studied in terms of making decisions on improving the quality of nursing care provided to hospice patients and their families.

If you decide to participate in this study, you are asked to complete the enclosed questionnaire and return it to me in the stamped envelope provided. The questionnaire will take about thirty minutes to complete. Please do not sign your name to the questionnaire. The form is precoded; the temporary master list of codes and names will be destroyed after the study is completed. Any information collected will remain anonymous and confidential and the results of this study will be reported as group data only. It will be impossible to identify individual patients, families or hospices. By completing and returning the questionnaire you are consenting to participate in the study. While filling out the questionnaire, if you have any questions about the items, please contact me at either phone number or address below. Your participation in this study will be greatly appreciated.

This study will use two data collection sources. The questionnaire I am asking you to complete and my audit of the Patient Record of your family member, at your local hospice office. In order to audit the record I will need your permission to go into the patient record. A consent form to allow me to do this is attached to the next page of this letter.

Please return the completed questionnaire by (date).
Thank you for your participation in this project, I
remain,

Sincerely yours,

Lucille I. Grimm RN, MSN
2736 Hampshire S.E.
East Grand Rapids, MI 49506
(616) 949-1983

Grand Valley State University
Kirkhof School of Nursing
Lake Michigan Hall, Rm. 122
Allendale, MI 49401
(616) 895-3452 or 895-3558

Please sign and return the consent form, below, with your
completed questionnaire.

"Cut on dotted line"

CONSENT FORM

Lucille I. Grimm has permission to go into the patient care
record of (patient name).

Signed: _____

Date: _____

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