



Uncertainty in spouses of hospitalized cancer patients  
by Susan Ellen Molaris

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

© Copyright by Susan Ellen Molaris (1987)

Abstract:

This study measured uncertainty in spouses of hospitalized cancer patients, described the elements of uncertainty identified by the spouses, and tested the relationship of uncertainty to eight demographic variables. Uncertainty was measured using the Spouse's Perception of Uncertainty Scale, a modification of the Parent's Perception of Uncertainty Scale (Mishel, 1983a). The sample included 17 spouses of cancer patients receiving treatment at the Oncology Unit of a hospital in a small city. Mean uncertainty scores for demographic variables were compared. The probability that each demographic variable had significantly different summed ranks of scores was determined using the Mann-Whitney U test. The elements of highest and lowest uncertainty were described. Spouses' uncertainty was compared to uncertainty studied in parents of hospitalized children and cancer patients (Mishel, 1983a, 1983b).

These results suggested that the responses were heterogeneous; however, one of the eight demographic variables contributed significantly to the deviations in scores. Spouses aged 50 years and older had significantly ( $p < .05$ ) higher summed ranks of uncertainty scores than those under 50. Three other variables approached significance: number of years married, educational status, and illness/treatment complications. Spouses in this study had the highest uncertainty regarding the following elements: Ambiguity of the state of the illness and Unpredictability of the course of the illness. Mishel's cancer patients also had the highest uncertainty about Ambiguity of the controllability of the illness. Spouses identified Complexity as an element representing lowest uncertainty, in contrast to Mishel's cancer patients who identified Complexity as an element of highest uncertainty. Spouses had higher mean uncertainty scores than parents of hospitalized children (Mishel, 1983a).

These results suggest that an individual's perceived uncertainty is highly variable. Since age significantly affects uncertainty in spouses, older spouses should be provided with additional information and support to address their uncertainty.

UNCERTAINTY IN SPOUSES OF HOSPITALIZED CANCER PATIENTS

by

Susan Ellen Molaris

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

of

Master of Nursing

MONTANA STATE UNIVERSITY  
Bozeman, Montana

August, 1987

APPROVAL

of a thesis submitted by

Susan Ellen Molaris

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

9-2-87  
Date

Barbara Rogers  
Chairperson, Graduate Committee

Approved for the Major Department

8-27-87  
Date

Kathleen Ann Long  
Head, Major Department

Approved for the College of Graduate Studies

9-24-87  
Date

W. B. Malaris  
Graduate Dean

## STATEMENT OF PERMISSION TO USE

In presenting this thesis in partial fulfillment of the requirements for a master's degree at Montana State University, I agree that the Library shall make it 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.

Permission for extensive quotation from or reproduction of this thesis may be granted by my major professor, or in her absence, by the Director of Libraries when, in the opinion of either, the proposed use of the material is for scholarly purposes. Any copying or use of the material in this thesis for financial gain shall not be allowed without my written permission.

Signature Susan Ellen Malore

Date 8/25/87

## ACKNOWLEDGMENTS

I would like to thank special individuals who contributed their guidance and support to this project. Their boundless encouragement and expertise helped make my thesis a reality:

Dr. Barbara P. Rogers

Teresa Snyder

Dr. Clarann Weinert

Mary Clover

Beth Brennan, Word Weaver

Helena Chambers

Emery Computer

Ann and Basil Molaris

Friends and co-workers

## TABLE OF CONTENTS

	Page
APPROVAL .....	ii
STATEMENT OF PERMISSION TO USE .....	iii
VITA .....	iv
ACKNOWLEDGMENTS .....	v
TABLE OF CONTENTS .....	vi
LIST OF TABLES .....	ix
ABSTRACT .....	x
1. INTRODUCTION .....	1
Background and Rationale for Study .....	1
Statement of the Problem .....	3
Statement of Purpose .....	4
Assumptions .....	5
Significance to Nursing .....	5
2. LITERATURE REVIEW AND CONCEPTUAL FRAMEWORK .....	7
Uncertainty .....	8
Definition and Description .....	8
Uncertainty as a Stress Factor .....	9
Factors of Uncertainty Defined .....	10
Ambiguity .....	11
Complexity .....	11
Deficient Information .....	11
Unpredictability .....	12
Specificity to Treatment Form .....	12
Specificity to Diagnosis .....	15
Specificity to Cancer .....	16
Uncertainty and Psychosocial Adjustment .....	18
Uncertainty in Family Members .....	20
The Family .....	21
The Spouse .....	22

TABLE OF CONTENTS-Continued

	Page
Impact of Hospitalization and Cancer on the Spouse .....	22
Coping .....	25
Definition .....	25
Diagnostic Stage .....	26
Treatment Stage .....	27
Terminal Stage .....	28
Conceptual Framework .....	29
Family Systems .....	29
Coping .....	30
Uncertainty .....	32
Conclusion .....	33
 3. RESEARCH METHODOLOGY .....	 35
Research Design .....	35
Respondents and Sample Setting .....	36
Operational Definitions .....	36
Protection of Human Subjects .....	37
Data Collection .....	38
Description of the Instruments .....	38
PPUS .....	38
Methods .....	40
Data Analysis Methods .....	41
Spouses' Uncertainty .....	41
Difference in Spousal Uncertainty by Illness Phase .....	42
Uncertainty Scores by Demographic Characteristics .....	43
Testing Statistical Significance by Demographic Characteristics .....	45
Elements of Uncertainty .....	47
Reliability .....	48
Content Validity .....	49
External Validity .....	49
 4. RESULTS .....	 51
Sample .....	51
Spouse's Perceived Uncertainty Scale .....	53
Measures of Central Tendency .....	53
Demographic Data .....	53
Differences in Mean Scores .....	53
Statistical Significance of Difference in Scores .....	55
Elements of Uncertainty .....	56

TABLE OF CONTENTS-Continued

	Page
Reliability .....	57
External Validity .....	58
Parents .....	60
Cancer Patients .....	61
5. DISCUSSION AND CONCLUSIONS .....	64
Spouses' Perceived Uncertainty .....	64
Elements of Uncertainty .....	65
Uncertainty and Illness Phase .....	68
Variability of Spouses' Uncertainty .....	69
Treatment Phase .....	69
Uncertainty by Demographic Characteristics .....	71
Age .....	72
Length of Marriage .....	74
Education .....	75
Influence of Other Variables .....	77
Uncertainty Scores .....	77
Elements of Uncertainty .....	78
Comparison with Other Studies .....	79
Parents .....	79
Cancer Patients .....	80
Limitations of the Study .....	81
Recommendations for Future Study .....	83
Implications for Nursing .....	85
REFERENCES CITED .....	87
APPENDICES .....	92
Appendix A - Study Consent .....	93
University Consent .....	94
Hospital Consent .....	95
Spouse's Consent .....	97
Appendix B - Study Questionnaires .....	98
Explanation of the Project .....	99
Spouse's Perceived Uncertainty Scale and Demographic Questionnaire .....	100
Appendix C - Permission for use of Questionnaires .....	108
Dr. Merle Mishel - Spouse's Perceived Uncertainty Scale .....	109
Dr. Clarann Weinert - Demographic Questionnaire .....	110
Appendix D - Tables 6 - 9 .....	111



## LIST OF TABLES

Table	Page
1. Mean uncertainty scores by demographic variables ...	54
2. Items of uncertainty rated high by spouses .....	58
3. Items of uncertainty rated low by spouses .....	59
4. Uncertainty scores of spouses versus parents of hospitalized children .....	60
5. Items of uncertainty rated high by spouses versus Mishels' cancer patients .....	62
6. Demographic characteristics of spouses .....	112
7. Items of uncertainty rated high by older spouses versus younger spouses .....	113
8. Items of uncertainty rated high by more educated spouses versus less educated spouses .....	114
9. Items of uncertainty rated high by spouses of patients with complications versus spouses of patients without complications .....	115

## ABSTRACT

This study measured uncertainty in spouses of hospitalized cancer patients, described the elements of uncertainty identified by the spouses, and tested the relationship of uncertainty to eight demographic variables. Uncertainty was measured using the Spouse's Perception of Uncertainty Scale, a modification of the Parent's Perception of Uncertainty Scale (Mishel, 1983a). The sample included 17 spouses of cancer patients receiving treatment at the Oncology Unit of a hospital in a small city. Mean uncertainty scores for demographic variables were compared. The probability that each demographic variable had significantly different summed ranks of scores was determined using the Mann-Whitney U test. The elements of highest and lowest uncertainty were described. Spouses' uncertainty was compared to uncertainty studied in parents of hospitalized children and cancer patients (Mishel, 1983a, 1983b).

These results suggested that the responses were heterogeneous; however, one of the eight demographic variables contributed significantly to the deviations in scores. Spouses aged 50 years and older had significantly ( $p < .05$ ) higher summed ranks of uncertainty scores than those under 50. Three other variables approached significance: number of years married, educational status, and illness/treatment complications. Spouses in this study had the highest uncertainty regarding the following elements: Ambiguity of the state of the illness and Unpredictability of the course of the illness. Mishel's cancer patients also had the highest uncertainty about Ambiguity of the controllability of the illness. Spouses identified Complexity as an element representing lowest uncertainty, in contrast to Mishel's cancer patients who identified Complexity as an element of highest uncertainty. Spouses had higher mean uncertainty scores than parents of hospitalized children (Mishel, 1983a).

These results suggest that an individual's perceived uncertainty is highly variable. Since age significantly affects uncertainty in spouses, older spouses should be provided with additional information and support to address their uncertainty.

## CHAPTER 1

## INTRODUCTION

Background and Rationale for Study

The hospitalization of an adult with cancer is viewed as an emotionally charged event for patients and their families. Illness and hospitalization threaten family stability (Giacquinta, 1977). As this occurs, the focus of the family's energy is to regain stability by restoring health to the medically identified patient (Freihofer & Felton, 1976; Hampe, 1975; Welch, 1981). In addition, the hospital staff directs most of its efforts towards the patient with little effort devoted to the family as a unit.

Unfortunately, cancer often becomes a chronic illness and family members are expected to become caregivers at home, provide the patient and each other with psychosocial support, and fill role gaps left by the patient for extended periods of time (Griffin, 1980). It is clear that the entire family faces the crisis of a cancer diagnosis and should be the "target of nursing care" (Giacquinta, 1977, p. 1585).

Nursing literature on family needs of hospitalized cancer patients indicates that families want information

and reassurance about the patients' status, treatments, and diagnoses from nurses (Giacquinta, 1977; Rogers & Mengel, 1979; Welch, 1981). Cancer is described as a progressive disease with disabling symptoms. Acute exacerbations often require hospitalization and aggressive interventions. There is no cure and treatment outcomes are unpredictable; however one hopes for long-term remission (Edstrom & Miller, 1981). There are many questions about cancer diagnosis and prognosis which have no definite answers. This translates into a high degree of uncertainty associated with cancer (McIntosh, 1974).

A nurse researcher building on the work of McIntosh has defined uncertainty as a "perceptual variable (that) occurs in situations where the decision-maker is unable to assign definite values to objects and events and/or is unable to accurately predict outcomes" (Mishel, 1983b, p. 356). Perceived uncertainty may result from the nature of the event/situation itself, the characteristics of the perceiver, or from the interaction between the stimuli and the perceiver (Mishel, 1983a). Perceived uncertainty limits the individual's ability to make decisions and react logically to any or all aspects of the illness-treatment situation: symptoms, treatment procedures, technical environment and routines, diagnosis, relationships with caregivers, and prognosis (Mishel, 1984; Moos & Tsu, 1977). Uncertainty inhibits one's ability to cope

effectively and is perceived as a threat (Mishel, 1981).

Based on her research, Mishel (1981, 1983a, 1983b, 1984b; Mishel, Hostetter, King, & Graham, 1984) observed that perceived uncertainty scores were highest among patients and parents of hospitalized children during the diagnostic phase of an illness, and uncertainty was related to problems in psychosocial adjustment among women newly diagnosed with gynecological cancer. The work of Welch (1981) and Abrams (1966) suggested that the need for information and open communication was highest during diagnosis.

It appeared to Mishel (1983b) that the elements of perceived uncertainty differed among diagnostic groups, reflecting the specific concerns of each patient population. This suggested that perceived uncertainty was not generalizable to all patients but was disease- and phase-specific. The two elements of uncertainty found in the cancer populations were labelled Ambiguity concerning the controllability of the illness and Complexity regarding the information provided by caregivers (Mishel, 1983b).

#### Statement of the Problem

While Mishel's research has focused on the patient's uncertainty regarding symptomology, treatment, diagnosis, prognosis, and relationship with caregivers, it is postulated that the spouse experiences similar uncertainty

when the cancer victim is hospitalized. There is a large body of literature available describing the importance of the spouse/family to the patient's recovery, the effect of hospitalization on spouse/family roles and coping strategies, and the need for family-focused research and interventions (Giacquinta, 1977; Leavitt, 1984; Lewis, 1983; Moos & Tsu, 1977). A systematic study of the uncertainty measured in spouses of hospitalized cancer patients has not been reported. Therefore, this study is designed to answer the following questions:

1. What is the degree of perceived uncertainty in spouses of hospitalized cancer patients?
2. What are the elements of perceived uncertainty specific to this group?
3. Do the spouses' uncertainty scores differ based on the phase of the illness: diagnostic, treatment, or terminal?
4. Is there a difference in the uncertainty scores based on the spouses' demographic characteristics?

#### Statement of Purpose

Perceived uncertainty affects the individual's ability to cope with the destabilizing effects of illness and hospitalization. Spouses of cancer patients are expected to support their mates psychosocially and fill role gaps during hospitalization, as well as adjust to the event

themselves. The author has personal experience with spouses who have tremendous difficulty accomplishing these tasks.

The primary purpose of this study is to determine the degree of perceived uncertainty found in spouses of hospitalized cancer patients and describe the elements of uncertainty associated with this population. Another purpose is to describe uncertainty by the patient's phase of the illness and the spouse's demographic characteristics. A third purpose is to add to the knowledge base regarding uncertainty and meet the demand for family-centered investigations.

#### Assumptions

This research is based on the following assumptions:

1. Perceived uncertainty can be measured in spouses of patients diagnosed with cancer.
2. Findings from family-centered literature apply to spouses given that spouses comprise approximately 50% of the subjects studied in family research.
3. The spouse is the family member most affected by the patient's illness and hospitalization.

#### Significance to Nursing

Patients belong to a family system and their health partially depends upon the family's ability to cope with

illness/hospitalization. Although spouses may be physically excluded from patients in the hospital, they must be included in the plan of care. Logistically, nurses are in the best position to provide therapeutic interventions for the spouse and patient.

Nurses themselves may be uncomfortable working with patients and spouses who experience high uncertainty. Recognizing this allows the nurse to identify her own defense mechanisms and develop more therapeutic behaviors. Nurses who understand the concept of uncertainty can help spouses identify areas of uncertainty, assess the resulting degree of stress, and help them cope effectively with it.

Nursing autonomy and recognition as a profession will occur provided nurses can identify "a distinct body of knowledge about the individuals, groups, situations, and events of interest to nursing" (Fawcett, 1980, p. 36). Nursing practice must be founded on the clinical applications of professional knowledge and scientific research. This project is important to nursing because there is no systematic study of perceived uncertainty in spouses of cancer patients. The results will add to the knowledge base necessary for the development of a nursing theory of uncertainty in illness. Developing the theoretical framework provides the basis for "effective, well-timed nursing interventions" (Thomas, 1978, p. 54).



## CHAPTER 2

## LITERATURE REVIEW AND CONCEPTUAL FRAMEWORK

Uncertainty in illness has appeared in the literature in the form of anecdotal notes describing the ambiguity, unpredictability, vagueness, and inadequacy of information that accompanies any hospital experience. Only recently has there been a systematic study of uncertainty in illness as a perceptual variable that influences the patient's ability to cope with illness-related events. Based on clinical experience with hospitalized patients, nurse researcher Dr. Merle Mishel has developed a theoretical model and a reliable tool to measure perceived uncertainty in illness.

The literature reviewed in this chapter includes uncertainty as a perceptual variable, its relationship to coping and stress, and the specificity of uncertainty to treatment forms and diagnoses. Also discussed are the importance of the spouse to the patient's recovery, including role theory and systems theory; the needs of spouses of cancer patients; and the specificity of those needs to the stage of cancer. Finally, a conceptual framework that suggests a relationship between perceived uncertainty in spouses, family systems theory, and coping

theory as the disease progresses from diagnostic through treatment to terminal stages is presented.

### Uncertainty

#### Definition and Description

Uncertainty has been defined as a "perceptual variable which occurs in situations where the decision-maker is unable to assign definite values to objects and events and/or is unable to accurately predict outcomes" (Mishel, 1983b, p. 356). Based on her research and a review of the literature, Mishel (1981) developed a conceptual framework of uncertainty. She described uncertainty as a cognitive state created by characteristics within the person, the nature of the stimuli, and/or the interaction between the two (Mishel, 1984a). When the stimuli is perceived as uncertain, it is difficult to recognize or classify the stimuli among existing frames of reference, which impedes the formation of a cognitive structure of the stimulus (Mishel, 1984a). Inability to form a cognitive structure prevents a person from adequately appraising the situation and selecting appropriate actions (Mishel, 1984b).

For example, uncertainty regarding symptoms occurs when a patient experiences nausea several days after receiving chemotherapy. The nausea is unrelated to oral intake so the stimulus generates uncertainty due to its unexpected or unpredictable pattern of occurrence. In

addition, the patient has deficient understanding of the complex nature of cancer treatments, which increases the uncertainty.

The formation of a cognitive structure of the event requires that the event be evaluated as dangerous, benign, or an opportunity. Those events considered to be dangerous imply harm and promote the use of coping strategies to reduce the uncertainty involved (Mishel, 1984a). One coping method has been to seek and classify information regarding the present state and future prospects (Mishel, 1983a). To continue with the above example, the patient determines that nausea for an unknown reason is harmful. He or she reports this episode to the nurse and asks why it occurred and if it will recur. The patient may or may not be satisfied with the nurse's explanation that the nausea was a side effect of chemotherapy.

Finally, effective coping has been influenced by how well a person deals with the uncertainty involved (Mishel, 1983a). In other words, limited coping promotes uncertainty, while uncertainty limits coping. Furthermore, unsuccessful coping promotes stress. It has been suggested that uncertainty is a stress factor in illness.

#### Uncertainty as a Stress Factor

Mishel (1984b) studied the relationship of perceived uncertainty and stress in 100 medical patients by having

them complete the Mishel Uncertainty in Illness Scale (MUIS) and Volicer's Hospital Stress Rating Scale (HSRS). The results followed the predictions that the degree of perceived uncertainty about symptoms, treatments, and results (outcomes) was positively correlated ( $r = .35$ ,  $p < .001$ ) to the degree of stress in hospitalized medical patients. Patients with high uncertainty scores also had high lack of information subscores ( $r = .50$ ,  $p < .001$ ). Lack of information was a factor of both uncertainty and hospital stress.

#### Factors of Uncertainty Defined

Mishel's clinical research revealed four factors of uncertainty as: (a) Ambiguity concerning the state of the illness, (b) Complexity regarding treatment and the system of care, (c) Deficient Information about the diagnosis and seriousness of the illness, and (d) Unpredictability of the course of the disease and prognosis (Mishel, 1984a). In Mishel's early work Multi-attributed Ambiguity and Lack of Information only were identified as factors. As her research and conceptual classifications progressed, four factors consistently appeared in the analyses. The change in titles and definitions has created difficulties in comparing material in early works. The four factors as currently titled with refined definitions follow.

Ambiguity. Ambiguity refers to the patient's judgement of the illness status as vague or unclear (Mishel, 1983b). The details seem to blur and overlap. Shalit (1977) suggested that the presence of ambiguity threatens stability and impairs coping ability because it is difficult for the patient to identify a harmful agent. In an analysis of Mishel's material, it has been observed that Ambiguity consistently accounted for the largest degree of variance among all uncertainty factors.

Complexity. Complexity (formerly Lack of Clarity) refers "to the multiple and varied cues the patient perceives about treatment and the system of care" (Mishel, 1983b, p. 358). Complexity places limits on an understanding of the situation. Mishel (1983b) asserted that Complexity results from inadequate explanations and lack of comprehension of the information provided. Furthermore, anxiety, fatigue, and stress decreases understanding and impairs clear perception of the information given, thus increasing the amount of uncertainty perceived by the individual.

Deficient Information. Deficient Information is defined as the lack of factual knowledge surrounding the diagnosis, treatment, prognosis, relationship with caregivers, and symptomology of an illness because the information is not shared or is unknown (Mishel, 1983b).

Mishel (1981, 1983a, 1983b) reported that the Deficient Information scores were highest among patients in the diagnostic phase of an illness, or when the patient presented with symptoms not yet attributable to a known cause. Information-seeking has been a basic coping mechanism for the fear and anxiety generated by illness and hospitalization (Moos, 1977). Notably, some patients and families believed that health care providers, especially physicians, controlled the flow of information for their own reasons and that nurses promoted information control by referring difficult questions to physicians. Patients and families who perceived a tight control of information seemed to exhibit greater uncertainty and anxiety (Wright & Dyck, 1984).

Unpredictability. Unpredictability refers to the perception of an unstable course of illness and the lack of predictable outcomes (Mishel, 1983b). The individual does not easily determine the cause and effect of actions and outcomes if they are judged as unpredictable. This detracts from an ability to plan for the future.

#### Specificity to Treatment Form

Mishel (1983a) reported that uncertainty scores were specific to the type of treatment the patient received: diagnostic workup, medical, or surgical. She administered

a modified MUIS to parents of 272 children hospitalized for different treatments. The results indicated that the uncertainty scores for parents of children receiving medical treatment were significantly higher than scores of parents of children having surgery. These scores were significantly higher for the total scale and for all factors except Lack of Clarity (Complexity). The uncertainty scores of parents in the diagnostic group were significantly higher than scores of parents in the surgical group for the entire uncertainty scale and all four subscales except Lack of Clarity (Complexity). The higher scores obtained from parents in the diagnostic group were highly significant ( $p < .001$ ) for the Lack of (Deficient) Information and Unpredictability subscales. Finally, the difference between medical and diagnostic parent scores were insignificant except that parents in the diagnostic group had higher Lack of (Deficient) Information scores (Mishel, 1983a).

Mishel's (1983a) study supported the idea that both the degree of perceived uncertainty and the factors of uncertainty were influenced by the type of treatment prescribed. Perceived uncertainty was highest among parents of children receiving diagnostic workups, medical treatments, and surgical treatments, in that order. Mishel (1983a) suggested that the uncertainty scores of parents of surgical patients were lowest because much was known about

surgical procedures and parents' questions could be answered concretely.

Persons without a diagnosis had high uncertainty scores in another study by Mishel (1983b). She administered the MUIS to 268 patients with varying diagnoses, including 35 with "symptoms of unknown origin". These 35 subjects had the highest total uncertainty scores, and they identified items from the MUIS which belonged to each of the four clusters as determined by cluster analysis: Ambiguity, Unpredictability, Complexity, and Deficient Information. The only other subgroup which identified items pertaining to all four clusters was cancer patients. This finding demonstrated that a broad-based and high degree of uncertainty was specific to patients undergoing a diagnostic workup (Mishel, 1983b).

Findings from a third study suggested a difference between surgical and medical patients regarding psychosocial stress due to hospitalization. Volicer, Isenberg, and Burns (1977) developed and administered the Hospital Stress Rating Scale (HSRS) to 283 medical and 252 surgical patients. They observed that surgical patients had significantly higher mean scores than medical patients, as well as different scores for each stress factor. Greater stress in surgical patients was related to the unfamiliarity of surroundings, loss of independence, and the threat of severe illness,



while psychosocial stress in medical patients was associated with financial problems and lack of information. An analysis of these three studies suggests that stress and uncertainty associated with illness and hospitalization are specific to the type of treatment the patient receives.

#### Specificity to Diagnosis

Mishel believed that her early work with perceived uncertainty provided results too general for clinical application. The distinct differences in patient populations allowed for too much error to make sound clinical predictions; therefore, she investigated the possibility of developing more precise scales to measure uncertainty among patients with different diagnoses (Mishel, 1983b).

Mishel (1983b) administered the MUIS to 268 subjects with six separate diagnoses: cardiovascular disease, gastrointestinal conditions, cancer, systemic lupus erythematosus, symptoms receiving primary treatment and cardiac catheterization. From a cluster analysis of all diagnostic subgroups, Mishel reported that all populations clustered well except for the gastrointestinal group. Mishel noted that the patients in the gastrointestinal group included acutely and chronically ill patients receiving varied treatments, thus providing too many variables to form a neat cluster by diagnosis.

The four clusters found were similar to the four factors of uncertainty seen in earlier studies: Ambiguity, Complexity, Deficient Information, and Unpredictability.

Mishel presented evidence that, despite a certain degree of overlap, each diagnostic group had a unique pattern of uncertainty. Each diagnostic group identified a different number of clusters or factors as representing their uncertainty. In addition, the items composing the clusters were different for every group. In some cases, identical items were placed in different clusters by different groups. According to Mishel (1983b), the findings indicated that the concerns of each patient population were specific to the diagnosis. Furthermore, the measure of uncertainty as a perceptual variable seemed to be disease-specific.

#### Specificity to Cancer

The cancer patients from the study described above identified two clusters of uncertainty labelled Ambiguity concerning the controllability of the illness and Complexity regarding information provided by caregivers (Mishel, 1983b). Mishel believed that the uncertainty over the ability to control the illness seemed to distinguish the cancer group from all others studied. For example, they selected the following item from the MUIS: "Because of the unpredictability of my illness, I cannot plan for the

future" (Mishel, 1983b, p. 364).

Mishel cited Lewis (1982) to defend the interpretation of controllability as being a "central issue in cancer". Lewis (1982) studied the relationship between personal control experienced in life and health and the quality of life in 57 advanced-stage cancer patients. Quality of life was determined by scales measuring self-esteem, anxiety, and sense of purpose in life. Control was measured by the Health Locus of Control Scale and a solitary item that stated, "My life is in my hands and I am in control of it," or the negatively scored item, "My life is out of my hands and controlled by external factors" (Lewis, 1982, p. 114). Lewis reported that subjects who expressed higher degrees of self-control in life also had higher self-esteem and purpose in life scores, and lower anxiety scores. In addition, lower health control scores were associated with less perceived purpose in life. The results supported Lewis' hypothesis that the longer patients had a disease, the less they felt in control of their health and the more anxiety they reported. Lewis' findings partially supported Mishel's assertion that cancer patients, especially those in the advanced stages, were most concerned with controllability of the illness.

Mishel (1983b) found a second cluster of six items identified by cancer patients as representing perceived uncertainty. An example of an item selected by the cancer

patients follows: "The explanations they give me about my treatment seem hazy to me" (Mishel, 1983b, p. 356). This cluster was interpreted as Complexity regarding information provided by caregivers. Mishel cited the findings of Lauer, Murphy, and Powers (1982) to support her interpretation of this cluster. The study by Lauer et al. (1982) was a comparison of the learning needs of cancer patients as perceived by the patients ( $n = 27$ ) and their nurses ( $n = 33$ ). Cancer patients in the Lauer study identified areas of concern which were similar to some of the items identified by cancer patients in Mishel's study. Beyond that point, the two studies bore little resemblance to each other.

#### Uncertainty and Psychosocial Adjustment

Mishel, Hostetter, King, and Graham (1984) studied the impact of uncertainty, optimism, seriousness of illness, and loss of control over physical function on the psychosocial adjustment of 54 patients with a new diagnosis of gynecological cancer. They found that control over physical function was strongly associated with uncertainty in general and the Complexity factor in particular. Respondents with high scores on the uncertainty scale and the Ambiguity and Complexity subscales also had low control over their physical functions. Additionally, less control over physical functions was related to an increase in

psychosocial adjustment problems, especially with family relationships and recreational activities. The investigators interpreted this as increased uncertainty and as problems with adjustment among patients with poor control over physical functions.

Other findings from the study of patients with gynecological cancer led Mishel et al. (1984) to report that uncertainty had a significant inverse association with optimism, and that uncertainty contributed more than 25% of the variance to optimism. The characteristics of optimism studied by Mishel included the degree of happiness/sadness regarding the future, positive predictions of the future, and increased motivation to push for desired outcomes. Ambiguity about the state of the illness and Complexity concerning treatment were significantly associated with pessimism toward self-motivated change and negative future expectations. Deficient Information was negatively correlated with motivation, indicating that ignorance of the diagnosis inhibited the person's desire to change the situation. Unpredictability related strongly to pessimism. Based on these findings, Mishel et al. (1984) believed that the degree of uncertainty influenced the cancer victim's hopes for the future.

Along with a decrease in optimism, women with higher scores of perceived uncertainty reported more adjustment problems with the health care system, the family

environment, extended family relationships, and recreation. Interestingly, these women reported pre-existing family strain. In addition, the research team observed that problems with psychosocial adjustment could be predicted by the degree of uncertainty, the level of control over physical function, and the pessimism measured in the subjects (Mishel et al., 1984).

To summarize the findings of the study of women with gynecological cancer as related to uncertainty, increased uncertainty was associated with pessimism, lack of control over physical function, lack of motivation, and problems with psychosocial adjustment to the health care system and family relationships. One questions whether uncertainty in family members might be a contributing factor to the patient's pessimism, motivation and uncertainty.

#### Uncertainty in Family Members

Uncertainty was measured successfully in subjects other than the medically identified patient. Mishel (1983a) examined the uncertainty levels of parents of hospitalized children because of the documented effect of parents' coping abilities on their children's recovery (Wolfer & Visitainer, 1975). Researchers have agreed that the entire family's ability to adjust to the illness influences the patient's rehabilitation (Griffin, 1980; Klein, Dean, & Bogdonoff, 1966; Litman, 1974). According to Foxall, Ekberg, and

Griffith (1985, p. 444) "the spouse has frequently been cited as the most important 'significant other' in the ill person's success or failure in his or her personal adjustment." It is anticipated that perceived uncertainty could be measured in all family members, especially in the spouses of hospitalized patients.

### The Family

According to family studies, the family is measurably affected by the hospitalization of one of its members and might require nursing intervention. The need for care of the family was supported by Griffin (1980), who stated that the family affects the patient's outcome while the patient's illness and treatment outcomes affect the family. Experts have agreed that the family as a whole is affected by a cancer diagnosis (Lewis, 1983) and must adapt and cope with the patient's illness and hospitalization in much the same way as the sick person (Foxall et al., 1985; Moos, 1977).

The existence of family stress was documented by Cooper (1984), who found that spouses showed more signs of stress than the 15 hospitalized patients, in the form of self-reported nervousness, sleeplessness, loss of appetite, inability to concentrate, and irritability. Welch (1981) noted that 27% of the 41 family members of adult cancer victims had an increase in psychosomatic symptoms after the onset of the patient's illness.

### The Spouse

It has been well-accepted that the spouse is the person most affected by a family member's illness (Litman, 1974). Rees (1972) noted that the probability of illness during bereavement was much higher in widowed people than in other close relatives. Spouses exhibited an increase in physical ailments and emotional problems (Klein et al., 1966; Oberst & James, 1985; Welch, 1981), and an increase in mortality and morbidity if recently widowed (Maddison & Raphael, 1972; Rees, 1972).

In Dyk and Sutherland's (1956) study of colostomy patients, both men and women stated they preferred that their spouses help with personal care rather than other kin, were such care needed. They particularly did not want personal care or financial aid from their children. They felt that psychological support was very important from their spouses but were glad to accept this support from other family members.

### Impact of Hospitalization and Cancer on the Spouse

The effects of cancer and hospitalization on the patient's spouse were reported in many research studies (Cooper, 1984; Foxall et al., 1985; Hampe, 1975; Oberst et al., 1985). Litman (1974) found that two-thirds of the 210 families studied reported that hospitalization of a family member created problems as simple as missing the patient,



inconvenience, restricted mobility, and disruption of home activities, to more complex difficulties due to role alteration or role reversal. Thorne (1985) interviewed eight oncology patients and their families at home. Findings from the interviews suggested that even patients and family members who initially described life as normal agreed that the illness had affected their emotional status, performance of roles, patterns of communication, and social interaction.

Oberst et al. (1985) conducted a longitudinal study of 40 patient-spouse pairs following surgery for bowel or genitourinary cancer. The information gathered from the loosely structured interviews was placed into 11 categories of problems associated with adjustment to chronic illness. A minimum of 40% of the spouses reported problems associated with (a) lifestyle disruptions during hospitalization; (b) providing physical care 10 days post-discharge; (c) distress over their own physical symptoms, which were most prevalent during hospitalization and 30 to 180 days post-discharge; (d) perceived uncertainty over the efficacy of treatment throughout the study period; and (e) emotional distress, especially anxiety and depression, which was consistently worse than the distress described by the patient during the same period.

Wright et al. (1984) conducted a descriptive study which examined the needs and concerns of the 45 next-of-kin

of adult cancer victims, and determined whether these needs changed during the diagnostic, recurrent, and terminal stages of the illness. They reported that the respondents were most concerned with (a) "problems created by the symptoms of the disease...", (b) "fear of the future," (c) "waiting," and (d) "difficulty with obtaining information" (Wright et al., 1984, p. 372). The researchers noted that concern over symptomology increased as the disease progressed to the terminal stage. Fear of the future and waiting were most important at diagnosis and decreased as the illness continued.

Responses to a needs scale developed by the researchers indicated that the two needs most important to the next-of-kin were the need to be kept informed about the patient's condition, and the need to be assured that the patient was comfortable (Wright et al., 1984). The need to express one's own emotions was considered only slightly important. The relative insignificance of this need was observed by other nurse investigators (Freihofer & Felton, 1976; Hampe, 1975). However, the next-of-kin considered important the need for acceptance, support, and comfort from both the nursing staff and other family members (Wright et al., 1984).

Coping

Researchers believe that the modern family is at a disadvantage in coping with the illness of a family member (Craven & Sharp, 1972). Hospital stays are shorter so patients recover at home. More families are comprised of small nuclear groups rather than the larger extended networks seen in the past (Craven et al., 1972; MacVicar & Archibold, 1974). Family members are more dependent on each other with fewer external support systems. Therefore, there is greater potential for ineffective coping with extreme stressors such as illness and hospitalization of a family member (Leavitt, 1984).

Definition

Coping has been described as "problem-solving efforts made by individuals when the demands they face are highly relevant to their welfare (that is, a situation of considerable jeopardy or promise), and when these demands tax their adaptive resources" (Lazarus, Averill, & Opton, 1974, pp. 250-251). This definition includes adaptation to situations with uncertain outcomes that strain the limits of the individual's adaptive skills. The hospitalization of a spouse with cancer is one such situation.

Coping tasks are specific to the illness and treatment prescribed (Kaplan, Smith, Grobstein, & Fischman,

1977). Two nurse researchers independently developed similar models of coping based on the stages of cancer (Giacquinta, 1977; Thomas, 1978). Thomas (1978) developed a model of psychosocial adjustment to breast cancer that spans ten events or periods of the illness from prodromal to terminal. The ten periods were condensed into the three stages being studied here: diagnostic, treatment, and terminal. Giacquinta (1977) described four stages that include the three mentioned above, plus a post-terminal period called "Re-establishment."

#### Diagnostic Stage

Thomas (1978) and Giacquinta (1977) described the family as initially responding to the cancer diagnosis with shock, disbelief, uncertainty, and fear. The family attempts to be supportive and encourages the patient to obtain information. However, family members feel excluded from the relationship between the patient and caregivers and report a sense of powerlessness to influence decisions (Thomas, 1978). In addition to experiencing isolation and despair, the family suffers a functional disruption, in which family stability decreases and roles are inadequately filled. Attempting to solve daily problems could encourage the family to overcome their sense of helplessness and engage in the intense emotions triggered by the cancer diagnosis (Giacquinta, 1977).

### Treatment Stage

The treatment phase could be the most stressful for the patient and family (Abrams, 1966; Thomas, 1978). The goal of treatment is long-term remission if complete eradication cannot be achieved. This phase has been characterized as a chronic illness, in which patients have ceased to fulfill their family roles and have received some level of care at home for extended periods (Giacquinta, 1977; Griffin, 1980).

During treatment, the family and patient experience a guarded sense of hopefulness. The family becomes frustrated and impatient with the inconvenience of treatments, and experiences ambivalent feelings towards the caregivers (Thomas, 1977). Family members feel inadequate about their abilities to actively support the patient and guilty about their inability to effectively deal with the physical and emotional symptoms affecting the patient (Thomas, 1978). Families cope with the resulting confusion and uncertainty by maintaining normalcy within the family system. Family members work toward reorganizing family life and adjusting to new roles and responsibilities. They become less supportive of the sick person as they try to forget about the illness and reestablish a normal life independent of health care providers (Giacquinta, 1978; Thomas, 1978; Thorne, 1985).

### Terminal Stage

The terminal phase occurs once the disease is deemed irreversible and treatment is provided for care, not cure (Abrams, 1966). The major concern of the family is "not the fact of the dying but the quality of the dying" (Thomas, 1977, p. 60). Independent studies by nurse researchers have confirmed that the family wants information regarding the patient's condition and reassurance that symptoms are controlled, the patient is comfortable and is receiving excellent nursing care (Freihofer et al., 1976; Hampe, 1975; Welch, 1981; Wright et al., 1984). It has been assumed that the spouse's perceived uncertainty during the terminal stage is related to concerns over the quality of death.

The family, attempting to cope with the inevitable loss, exhibits signs of increased anxiety, such as confusion, insomnia, anorexia, and feelings of hopelessness, bitterness, and depression (Thomas, 1978). To combat their sense of isolation and self-absorption, family members establish intimacy and derive support from each other. Families grieve the inevitable and actual death in the mourning phase. They deal with their guilt by expressing their grief and thereby attain relief from the intense emotions (Giacquinta, 1977).

In summary, coping with cancer is influenced by the patient's illness phase: diagnostic, treatment, or terminal. Coping is a dynamic process and is only

represented in clear-cut stages to facilitate description. No two spouses have identical experiences or methods of coping with illness and hospitalization. However, healthy coping is the goal for all patients and spouses. Possibly, spousal uncertainty is a dynamic process influenced by and described in terms of stages of the illness. It is expected that each spouse could have a unique measure of uncertainty. The conceptual framework for the proposed clinical investigation of spouses' perceived uncertainty links the concept of perceived uncertainty as a barrier to coping with family systems and coping theories.

### Conceptual Framework

#### Family Systems

Spouses are greatly affected by their partner's illness and hospitalization, according to family systems theory and clinical research. The spouse is the most significant other in the marital dyad and has a unique relationship with the patient. Several studies (Cooper, 1984; Dyk et al., 1956; Foxall et al., 1985; Freihofer et al., 1976; Hampe, 1975; Molter, 1979; Oberst et al., 1985; Stember, 1976; Thomas, 1978; Welch, 1981; Wright et al., 1984) enumerated spouse-identified needs and concerns such as information, reassurance, hope, dignity, and support. According to some findings, the needs changed with the patient's illness phase. Bereavement was linked with

increased mortality and morbidity in spouses, while an increase in somatic and emotional problems occurred during all phases of the illness.

Hospitalization of a family member impairs that person's ability to fulfill assigned roles, which causes system disequilibrium. First, the family restructures itself so as to obtain treatment and services for the patient. It also attempts to reestablish family routines and meet family goals. Roles might be redefined and/or reassigned to accomplish these tasks (Lewis, 1983). The family's ability to cope with illness depends on its ability to change roles, perform family tasks, and modify personal expectations and goals (MacVicar et al., 1974).

### Coping

According to experts, spouses must cope with the destabilizing effects of their partners' illness and hospitalization. Coping has been defined as an attempt to solve problems which are highly relevant to one's well-being and stress one's adaptive abilities (Lazarus et al., 1974). This definition includes adaptation to situations with uncertain outcomes. Healthy coping has been described as the resumption of a balanced state in the system or the individual in such a way that personal growth and life satisfaction are encouraged (Moos & Tsu, 1977).



Coping abilities are dependent on personal and situational factors. In this study, personal factors included the spouses' demographic characteristics and their uncertainty scores. As reported by Mishel et al. (1984), the educational status of a woman recently diagnosed with cancer significantly affected her uncertainty and adjustment scores. Age and length of marriage were reported as significant variables in the adjustment of spouses who cared for chronically ill partners (Foxall et al., 1985). It was proposed that uncertainty scores could be different according to the spouses' demographic characteristics, and that the differences in uncertainty could influence the spouses' ability to cope.

The situational factors influencing coping in this study are uncertainty inherent in the situation, the characteristics of the illness, and the patient's phase of the illness. Illness phase is associated with different needs and coping tasks for the spouse. During the diagnostic phase, spouses try to overcome their sense of isolation and despair and to regain stability in their family systems. The treatment phase, similar to a chronic illness, requires that spouses adjust to new roles and responsibilities and yet maintain normal lives. Finally, in the terminal phase, spouses must grieve the impending or actual loss of their partners, establish intimacy with other family members and accept support in overcoming their guilt.

Another situational factor related to coping is the characteristics of the illness. Cancer has been described as a progressive disease with disabling symptoms. Acute exacerbations require aggressive interventions and hospitalization. There is no cure and treatment outcomes are unpredictable, yet a long-term remission is hoped for (Edstrom & Miller, 1981). Concrete answers may not be obtained to questions regarding symptom control and disease prognosis. It appears that the uncertainties inherent in cancer create obstacles to the performance of coping tasks.

### Uncertainty

Uncertainty, the third situational factor related to coping, has been described as a perceptual variable which limits one's ability to cope. When an event or situation is perceived as uncertain, it cannot be classified among existing frames of reference. Inability to classify the event into a familiar pattern acts as a deterrent to adequate appraisal of the situation and selection of appropriate actions (Mishel, 1984b). Appraisal of the situation includes evaluating it to be dangerous, benign, or an opportunity. Those events considered to be dangerous imply harm and promote the use of coping strategies to reduce the uncertainty involved. Effective coping is influenced by how well a person deals with the uncertainty (Mishel, 1983a).

Perceived uncertainty has been measured in parents of hospitalized children and in patients with various diagnoses. Mishel (1983b) found that cancer patients had a unique pattern of uncertainty when compared to subjects with other diagnoses. The uncertainty in cancer patients was related to Ambiguity over the controllability of the illness and Complexity regarding the information provided by caregivers. It appears that the uncertainty noted in cancer patients influences their ability to cope with their disease.

### Conclusion

The conceptual framework is a synthesis of family systems theory, coping with illness theory, and findings from uncertainty research. When a person is hospitalized, the spouse notes the disequilibrium in the family system, experiences uncertainty regarding the illness-treatment situation, and initiates coping strategies to decrease the uncertainty and restore system stability. A study of uncertainty in spouses of cancer patients is necessary to enhance the theoretical relationships between family systems, coping with illness, and perceived uncertainty. Therefore, it is proposed that uncertainty be measured in spouses by the SPUS, and that uncertainty scores may be different according to the spouses' demographic characteristics.

























































































































































































