PERCEIVED UNCERTAINTY AND COPING IN THE SPOUSES OF INTENSIVE CARE PATIENTS

By

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Chapter I

Introduction

The literature documents that families experience stress when one of their members is hospitalized with a serious illness (Bedsworth & Molen, 1982; Friedman, 1981; Kaplan & Grobstein, 1976; Williams, 1974). Frequently, hospitalization for a critical illness requires admission to an intensive care unit (ICU). The ICU experience for the family may be perceived as a threat (McCrae, 1984; Williams, 1974) that could overtax coping ability and result in a crisis (Lust,1984; Olsen, 1970; Williams, 1974).

Suls and Mullen (1981) proposed that the psychological state of uncertainty potentiates the stressful nature of an undesirable event. King and Mishel (1986) reported that uncertainty may be perceived by an individual as either a positive state (which one would desire to perpetuate) or a negative state (which one would desire to eliminate) depending on the individual's appraisal of the situation. Mishel (1981) has identified from the literature several areas of uncertainty that affect a patient and might also impact the patient's family: ambiguous and unpredictable symptoms, probable results of treatment, fluctuating course of symptoms, remissions and exacerbations, incomplete

diagnosis, unclear expectations, lack of information, and unclear feedback concerning progress toward health.

Significance To Nursing

The patient's course of illness impacts and is impacted by the family's reaction to that illness experience (Bedsworth & Molen, 1982; Gaglione, 1984; Olsen, 1970). Family members' perceptions of and reactions to a loved one's illness is affected by the uncertainties experienced in the situation. Therefore, in an attempt to intervene more effectively with the patient and the family members, some of nurses' attention should be directed toward family members' perceived areas of uncertainty, how they appraise those uncertainties (as a threat or as an opportunity), and how they are coping with those uncertainties.

Total patient care and holistic patient care are terms frequently seen in the nursing literature and heard on clinical units. This terminology reflects the nurse's responsibility for assessing and intervening not only with the patient, but with the patient's primary support system, the family (Bedsworth & Molen, 1982; Gaglione, 1984; Lust, 1984). A number of articles acknowledge how little time the ICU nurse has to meet family needs because of the time required to meet the immediate critical needs of the

patient (Bedsworth & Molen, 1982; Lust, 1984; Molter, 1979). With a beforehand awareness of what uncertainties the family might be experiencing, the nurse's assessment of a spouse's needs when a husband or wife is in an ICU can be expedited. Armed with a knowledge of what coping strategies have been used by other spouses in these situations, interventions can be selected more quickly to support adaptive strategies and to suggest alternate strategies when necessary. This same information will be of value to mental health clinical specialists and nursing supervisors who may be called upon to intervene with distressed family members when the ICU nurse lacks the time to provide this support.

Additionally, information from this study will offer nurses a perspective on what uncertainties spouses of ICU patients report they are experiencing. This understanding of the situation from the spouses' viewpoint can increase the nurse's empathetic approach when working with these families. In order to be supportive effectively, intervention strategies may need to vary depending on whether the spouse appraises uncertainty as a benefit or as a threat (Mishel, 1986b). Because nurses need to provide support to family members in an efficient and effective manner, it is of the utmost importance that she/he have an

understanding of the particular stressors impacting a family, including uncertainty.

Problem Statement And Purpose

The literature reveals a paucity of studies that identify the areas of uncertainty experienced by the families of ICU patients. Because of this deficit, nurses may lack knowledge concerning the varying categories of uncertainty perceived by these families, how they may appraise those uncertainties, and what common coping strategies they may be utilizing in order to facilitate adaptation.

Therefore, the purpose of this study is to describe the perceived uncertainties experienced by spouses of patients in ICUs, to assess their appraisal of those uncertainties (as a danger or an opportunity), and to describe the coping strategies used by these spouses in an attempt to manage these identified areas of uncertainty.

Chapter II

Reveiw Of The Literature

The review of the literature has been divided into five sections: stress, coping, uncertainty, coping with uncertainty, and families of intensive care patients.

Stress

Although studied earlier, the concept of stress came to the popular and research forefront with the first publication of The Stress of Life by Hans Selye in 1956 (Mason, 1975). Selye (1976) proposed a biologic model of stress he called the "General Adaptation Syndrome" (G.A.S.). He found that a similar pattern of biologic responses occurred in rats exposed to various physiologic "noxious stimuli." The patterns observed were designated into sequenced response states and referred to as: a) the alarm reaction, b) the stage of resistance, and c) the stage of exhaustion.

Many psychosomatic researchers question the validity of Selye's G.A.S. theory. The generalization of his biological research findings to include psychological stressors as initiating the G.A.S. is seen by many as an oversimplification given the range of psychological and physiological reactions to psychosocial stressors (Mason, 1975).

Numerous studies since then have focused on the stress variable, but there is widespread disagreement as to the definition of this concept (Mason, 1975). According to Lazarus and Folkman (1984) stress has been conceptualized in the literature in three ways: as a stimulus, as a response, and as a transactional process. Stress as stimuli or stressor can range in intensity from daily hassles to major catastrophe and change. Stressors also vary in duration. Stress as response refers to a reactive state of stress experienced biologically and psychologically.

Lazarus and Folkman (1984) contend that both dimensions of stress, as stimulus and response, need to be considered simultaneously in order to conceptualize the process of stress. This transactional process considers both the characteristics of the person and the characteristics of the environmental event. According to Lazarus and Folkman (1984), psychological stress occurs when a person cognitively appraises a situation as straining one's coping ability or as beyond one's coping ability and as threatening one's well-being.

In a theoretical paper; Robinson, Bridgewater, Molla, and Wathen (1982) relate that stress is experienced both physiologically and psychologically by the individual in

response to a situation (stressor) necessitating change. In high stress situations an individual may be physiologically and/or psychologically unable to adapt. The authors classify stressors as either biophysiological, psychosocial, or sociotechnical. Stressors are further classified as developemental or situational. An intensive care experience for the patient and the patient's spouse is a situational stressor and any uncertainty surrounding the experience is an additional stressor. The potential for physioloigcal and psychological maladaptiation exists for both patient and spouse. According to several research studies reviewed by Zegans (1983), the stressful nature of this compounded situation can be impacted by the following potential mediators: the characteristics of the person, both psychological and physiological; the social support network and cultural beliefs; and the person's fund of available coping skills.

Coping

Coping is the focus of a large amount of health-related research. As with the concept of stress, definitions of coping are varied. Coping has been defined in terms of defense mechanisms, traits, cognitive responses and behavioral responses (Billings & Moos, 1981). Although the definitions vary, the purpose of coping seems generally

accepted as an individual's attempt to ameliorate a stressful situation. Coping occurs in both adaptive and maladaptive forms. Folkman and Lazarus (1984) suggest three ways in which coping can have deleterious effects on an individual's health: a) Coping can influence neurochemical stress reactions. b) Coping which involves the use of harmful substances or dangerous activities can increase the risk of illness, injury, and death. c) Certain emotionally defensive strategies (e.g., denial) may inhibit adaptive health/illness behaviors.

Lazarus and Folkman (1984) define coping from a process-oriented perspective. Coping is attempting to adapt to stress by utilizing cognitive and behavioral strategies which constantly vary. Ziemer (1982) identified from the literature five variables that impact the coping process: an individual's personal coping style, social support networks, the individual's psychological state, an individual's perception of ability to control a situation, and the degree of uncertainty involved in the situation. Panzarine (1985) adds that the characteristics of the stressor itself impact the coping process.

In a classic study of 100 men and women in a normal community situation, Folkman and Lazarus (1980) investigated how these subjects coped with situations

encountered in everyday living over a 12 month period. Each month subjects were interviewed and completed questionnaires in order to report stressful situations they had experienced that month. Coping strategies utilized in the stressful situations were elicited by using the Ways of Coping checklist. On the checklist, 68 items are classified as either problem-focused or emotion-focused coping strategies. According to Folkman and Lazarus (1984), the problem-focused strategies are cognitive and behavioral efforts used to change or control the source of the problem, while the emotion-focused strategies are cognitive and behavioral efforts utilized to reduce or control emotional distress. The authors report that both types of coping strategies were used extensively by the subjects. Analysis of individual coping patterns showed that most people used a variety of coping strategies depending on the person-environment circumstances versus the use of a consisent pattern of coping. While stressors in the work situation more frequently elicited problem-focused coping, health-related stressors more frequently elicited emotion-focused coping. The authors found that men's and women's use of emotion-focused strategies is alike in similar contexts of living, but the environments in which the stressful situations occur are likely to differ.

Billings and Moos (1981) surveyed 194 randomly selected married couples in a community setting. They were investigating relationships between the following variables: negative life change events, coping responses, social resources, depression, anxiety, and stress-related physical symptoms. Coping strategies, 19 were provided for subjects to choose from, were classified by method (active-cognitive, active-behavioral, and avoidance) and by focus (problem-focused and emotion-focused). Findings indicated that an illness event in the family elicited the most frequent use of the active-behavioral and problem-focused coping strategies while a death event elicited these strategies the least. Coping and social support were found to mediate between the impact of negative life change events on individual functioning. The quality of both the coping strategies and the social support network are important for adaptation to negative life change events.

Uncertainty

According to Mishel (1983a), uncertainty is a perceived cognitive state that occurs in situations when the decision-maker lacks criteria to judge a person, a situation, or an environment and/or the person is unable to predict outcomes with any assurance of accuracy.

Uncertainty is a type of potential stressor which may be individually appraised in negative terms as a danger (Mishel, 1986) or as a threat (Lazarus & Folkman, 1984) or in positive terms as an opportunity (King & Mishel, 1986; Mishel, 1986b). A state of uncertainty may be perceived because of the nature of the situation or because of inadequacies inherent in the individual's perceptual abilities (Lazarus & Folkman, 1984; Norton, 1975; Shalit, 1977).

As part of a study of ambiguity intolerance, Norton (1975) reviewed the literature referenced in Psychological Abstracts pertaining to the concept of ambiguity. Content analysis revealed 125 uses of the word ambiguous, which Norton (1975) reduced to eight categories: multiple meanings; vagueness, incompleteness, fragmented; as a probability; unstructured; lack of information; uncertainty; inconsistencies, contradictions, contraries; and unclear.

Mishel (1986a) stated that she reconceptualized Norton's categories believing uncertainty, rather than ambiguity, to be the overriding psychological state and ambiguity, rather than uncertainty, to be one of the eight categories. Mishel (1981) listed the following categories of uncertainty based on Norton's (1975) original list:

1) vagueness, 2) lack of clarity, 3) ambiguity, 4) unpredictability, 5) inconsistency, 6) probability, 7) multiple meanings, 8) lack of information.

Mishel (1981) studied uncertainty as a variable in the patient's illness experience. It was speculated that uncertainty would be appraised as a threatening stressor. For this investigation, a measurement tool was developed (Mishel Uncertainty in Illness Scale - MUIS) based on a qualitative study of hospitalized patients. For the scale, the eight categories of uncertainty were collapsed into four factors: ambiguity, lack of information, unpredictability and lack of clarity. Pretesting reduced the scale to two factors, ambiguity and unpredictability. [Mishel (1984) notes that the revised MUIS is again a four-factor scale containing 34 items.] Three studies reported by Mishel (1981) supported the investigator's hypotheses and the validity of the MUIS: a) Adult patients hospitalized for diagnostic work-up perceived significantly higher levels of uncertainty than either diagnosed medical or surgical patients. Also, diagnosed medical patients had significantly higher levels of uncertainty than the diagnosed surgical patients. b) Perceived uncertainty was strongly correlated with the hospitalized patient's rating of stress as measured by the Hospital Stress Events Scale.

c) There was an inverse correlation between cancer patients' uncertainty and comprehension, as measured by an adapted Comprehension Interview.

In her doctoral dissertation, Mishel (cited in Mishel, 1984) found that a patient's age, educational level, and recency of prior hospitalization were inversely related to percieved uncertainty. Mishel (1984) conducted a correlational study of 100 V.A. hospital medical patients to ascertain whether there was a correlation between perceived uncertainty and the perceived stress of hospitalization. Uncertainty was measured by the MUIS. Stress was measured with the Hospital Stress Rating Scale and the seriousness of the patient's illness was measured by ranking the primary diagnosis via the Seriousness of Illness Rating Scale. A strong positive correlation (n=.35) was found between a patient's perceived uncertainty and his/her level of stress while in the hospital. Contrary to her dissertation findings, a patient's age, education, and recency of prior hospitalization showed no significant relationship to uncertainty.

A curvilinear relationship was noted between one factor on the stress scale (the threat of serious illness) and uncertainty. Mishel (1984) suggested that one possible explanation for this may be that in illness situations with

moderate to high perceptions of uncertainty the threat potential may be mediated because the patient is allowed the hope that the illness may not be as severe as feared.

Seriousness of the patient's illness correlated positively and significantly with the level of perceived uncertainty. Uncertainty appears to be an intermediate variable and a necessary link in order for the seriousness of an illness to impact the perceived stress of hospitalization (Mishel, 1984).

Mishel (1983b) revised her measurement tool to investigate the perceived uncertainty of parents of hospitalized ill children. One parent or guardian of 272 hospitalized children particiapted in the study (218 were the mothers). The main purpose of the investigation was to establish reliability and validity of the new tool (Parent Perception of Uncertainty Scale - PUIS).

It was hypothesized that parents of surgical, medical, and diagnostic workup patients would differ in their levels of uncertainty with surgical situations being least uncertain and diagnostic workup situations the most uncertain. While parents whose children were hospitalized for medical treatment or diagnostic workup reported significantly higher levels of uncertainty than parents whose children were having surgery, no significant

difference was found between the medical and diagnostic workup levels of uncertainty. The author stated that her hypothesis which was supported in a sample of ill adults was not supported in this parental study perhaps due to a conceptualization error. Mishel (1983b) respeculated that the medical treatment of children can generate as high a level of uncertainty as a diagnostic workup. High uncertainty is generated in parents because of at least two circumstances involved in the medical treatment of children: a) medical treatment is frequently initiated for symptom control in circumstances where the cause of the symptom is uncertain and b) the survival outlook for children receiving medical treatment for a chronic illness is frequently uncertain.

Parental rating of the seriousness of the child's illness correlated significantly with the level of uncertainty, but Mishel (1983b) believes this not to be of clinical significance because of the low levels of correlation between three of the four factors. Only the ambiguity factor seems to correlate at a clinically significant level. A low correlation existed between the predictability factor and a low parental rating of the seriousness of the illness. The lack of information factor had a weak negative relationship to the rated seriousness

of illness. Mishel (1983b) proposed that these findings indicate that in some situations uncertainty may be perceived as a positive state that allows for hope. According to the investigator, further testing of the tool is necessary because of some low reliability coefficients and questions concerning construct validity.

In a retrospective study, Suls and Mullen (1981) gathered data from 126 male and female college students concerning their illness over the last month and their life events for three months prior to that. Subjects also gave perceptions as to the life event's desirability and causation. As hypothesized, the investigators found that the occurence of multiple life events perceived as negative and out of the student's control was associated with subsequent illness. Further, and also as hypothesized, when events were perceived as negative and the controllability element was uncertain, a stronger relationship to subsequent illness was found. This study is limited by its retrospective design and by the lack of data provided concerning the reliability and validity of the measurement tool.

Coping With Uncertainty

Monat, Averill, and Lazarus (1972) studied anticipatory (three minutes) stress in conditions of event uncertainty

(knowing when an event might occur, but not whether it will occur) and temporal uncertainty (knowing an event will occur, but not knowing when) and its relationship to cognitive coping responses. The experimental design utilized male college student subjects. The threat manipulated in the laboratory situation was an electric shock. The findings indicated that while temporal uncertainty situations were at first appraised as more threatening than event uncertainty situations, the use of avoidant-like thoughts (distraction) may lead to a lowering of anticipatory stress. In situations of event uncertainty, regardless of the percentage of the probability of the shock, more vigilant-like thoughts (thinking about the situation at hand) were utilized with an increase in anticipatory stress.

Two replication studies that looked only at temporal uncertainty as a condition of anticipatory stress and coping responses were contradictory in their findings. While Monat (1976) was in agreement with the Monat et al. (1972) findings, Houston and Holmes (1974), using an experimental design, found avoidant thinking to be an ineffective means of reducing the stress associated with temporal uncertainty. The latter study selected the avoidant behavior the subjects used, while the subjects

determined the use of avoidant thinking in the other two studies. Hence, Houston and Holmes (1974) postulated that avoidant thinking generated by the individual may be effective in managing the stress of temporal uncertainty, while experimentally generated avoidant thinking may be ineffective in the same situation. Generalizability of the three aforementioned studies to the clinical situation is questionable because only laboratory settings were utilized, college students were the subjects, electrical shock was the threat, and only brief intervals of anticipatory stress were studied (three to twelve minutes).

Shalit (1977) investigated 75 randomly selected literature reports relating to coping and structural ambiguity. Multidimensional Scalogram Analysis was used to investigate the effectiveness of coping responses in relation to circumstances of psychological, social, or physical demands. These various demand situations had varying degrees of ambiguity potential. His findings indicate that uncertainty has high threat potential and may affect one's ability to adequately appraise a situation and, therefore, may affect one's ability to adequately cope with the situation.

Data from questionnaires completed by 418 cancer patients were studied by Molleman, Krabbendam, Annyas,

Koops, Sleijfer, and Vermey (1984) to ascertain the degree of uncertainty and anxiety experienced by cancer patients, how they coped with these variables, and the effectiveness of the utilized strategies. Seventy-two percent of the subjects reported moderate to high levels of uncertainty. Subjects rated 18 coping strategies for frequency of use. These strategies were reduced for analysis into four factors: social means, self-instruction means, ego-defensive means, and direct action means. Self-instruction strategies were most frequently used to cope with uncertainty. Next frequent were social means, followed by ego-defensive means, and direct action means, respectively. Analysis of variance was used by Molleman et al. (1984) to determine the effectiveness of the utilized strategies to reduce uncertainty. Communicating with professionals (e.g., physicians and nurses) was found to be the most effective way of reducing a patient's uncertainty. A cancer patient's uncertainty can be reduced by the doctor or nurse communicating directly with the patient or indirectly via communication with the patient's support systems who in turn communicate with the patient (Molleman et al., 1984). The ego-defensive strategies were ineffective in reducing uncertainty. No conclusions about the other two strategies could be supported by the data.

King and Mishel (1986) used quantitative (correlational descriptive) and qualitative (content analysis of interviews) methodology to study uncertainty and coping in a sample of patients diagnosed with Systemic Lupus Erythematosus (SLE), a chronic illness. Findings were reported in relation to three research questions. In regard to the first question, subjects who had been diagnosed for at least five years appeared to be familiar with the disease and the effects of treatment (event familiarity). These subjects experienced less uncertainty related to lack of information and unpredictability than did those diagnosed for four years or less. To gain familiarity with the SLE disease state appears to take about five years (King & Mishel, 1986). Also, those subjects able to avoid symptom exacerbation by following a certain regime (event congruence) were found to have lower levels of uncertainty than those persons with SLE who experienced symptomology inspite of following a certain regime.

Question two sought to determine if there was a relationship between two of the three antecedents of uncertainty (event familiarity and event congruity) and the appraisal of uncertainty as either a danger or an opportunity. Findings suggested that subjects who are

familiar with their disease and who can remain exacerbation-free for long periods of time frequently appraised their uncertainty experiences as a positive state with beneficial aspects.

To address question three, qualitative data were analyzed to identify the coping strategies most frequently used to handle the uncertainty of SLE. Delineated categories, in order of frequency were: a) self advocacy, b) change in life style, c) focus on the positive, d) submit and accept, e) seeking/using social support, f) search for understanding, g) participate in health care, 8) pay it no attention, h) live as normal as possible, i) keep to yourself. The uncertainty theory proposed by Mishel (1986b) describes two types of coping strategies utilized when uncertainty is perceived as a danger: mobilizing and immobilizing. Mobilizing methods of coping are action-oriented. When a barrier (intrapersonal or interpersonal) precludes the use of direct-action strategies, immobilizing strategies, to manage the emotional response, will be utilized to combat the threat of uncertainty. Mishel (1986b) described buffering as a coping strategy used when uncertainty is appraised as an opportunity. The purpose of buffering strategies is to maintain the state of uncertainty, which is appraised as

positive when compared with negative certainty. In the study of SLE patient's by King and Mishel (1986), coping strategies from the mobilizing conceptualization and the buffering conceptualization were used by patients in attempts to handle the uncertainty. Therefore, it was concluded that uncertainty was appraised as either a danger or an opportunity by these subjects.

Families of Intensive Care Patients

An exploratory descriptive design was utilized by Molter (1979) to study the needs of 40 relatives of ICU patients. A structured interview was used to obtain data about the rated importance of 45 need statements. The following needs were identified as the ten most important: a) to feel there is hope, b) to feel that hospital personnel care about the patient, c) to have the waiting room near the patient, d) to be called at home about changes in the condition of the patient, e) to know the prognosis, f) to have questions answered honestly, g) to know specific facts concerning the patient's progress, h) to receive information about the patient once a day, i) to have explanations given in terms that are understandable, and j) to see the patient frequently. It was found that most of the family needs were met by nurses and that most needs, and all of the ten most important needs, listed above were met the majority of time.

In a replication study utilizing a different needs categorization strategy, Daily (1984) interviewed 40 adult family members of patients in their first ICU experience. The structured interview schedule consisted of 46 need statements which were divided into six need categories: a) the need for relief of anxiety, b) the need for information, c) the need to be with the patient, d) the need to be helpful to the patient, e) the need for support and ventilation, and f) personal needs. Subjects rated each of the 46 need statements from one (not important) to four (very important). While each of the six need categories had at least two items with means above 3, the category with the most important needs was the need for relief of anxiety. The second most important category was the need for information. The category containing the least important needs was personal needs.

The five most important individual need items (all with means of 3.9 or above), in rank order, were: to know what is wrong with my family member, to have my questions answered honestly, to be reassured that my family member is doing alright, and to be called at home if the family member's condition changes. These relatives perceived that physicians would most frequently meet their ten most important needs and that nurses would most frequently meet almost all other listed needs.

While uncertainty was not an identified variable in either the Molter or the Daily study, many of the family needs related to the uncertainty of the situation. Both studies focused on which health care professionals met the family member's needs. Neither study sought to identify family members' thoughts and feelings associated with the experience, two other important aspects of the coping process.

Using a qualitative research design, Bedsworth and Molen (1982) described the perceived stressors affecting the wives of myocardial infarction patients in the time period immediately after the spouse's admission to the coronary care unit. Qualitative data were also collected concerning how these wives coped with the stress. Twenty subjects were interviewed; interviews lasted from seven to 23 minutes. Lazarus's (1966) stress-coping model provided the framework for the study. Using a semi-structured interview, data were gathered and then coded into one of three categories: threat, coping strategies, or affects. Each subject reported one to four threats; the most frequently reported were loss of mate, loss of healthy mate, and recurrence of myocardial infarction. One to three coping strategies were employed for each perceived threat. Reported strategies were categorized according to

Lazarus' (1966) conceptualization. Bedsworth and Molen (1982) reported these four direct coping strategies to be: a) action aimed at strengthening the individual's resources against harm, b) attack, c) avoidance, or d) inaction. One half of the strategies reported were directed at strengthening the individual's resources against harm. The most frequently reported affects were anxiety and anger. While this study addressed the coping process utilized with perceived threat, the brief interviews did not seem to provide in-depth qualitative data, nor did the study specifically address uncertainty or include the male perspective.

Inferences from the Existing Literature

Having a spouse hospitalized in the ICU is a situational stressor that can be potentiated by the stress of perceived uncertainty. These stressors have the potential to cause untoward biological and psycological responses. Given the high stress nature of this compounded stressful experience for these spouses, some individuals may be psychologically and/or physiologically unable to adapt effectively. Others, because of the nature of the environmental event (Lazarus & Folkman, 1984), the presence of a supportive social network, and/or the available coping skills of the individual (Zegans, 1983), will manage the situation adaptively.

In community based studies of coping (Folkman & Lazarus, 1980; Billings & Moos, 1981), findings indicated that people used a variety of coping strategies versus a set coping pattern to manage stressors. The variation was dependent on the person-environment circumstances. While Folkman and Lazarus (1980) reported that health related stressors more frequently elicited emotion-focused coping strategies, Billings and Moos (1981) reported that an illness event most frequently elicited problem-focused and active-behavioral coping strategies. Further study is required to determine if either of these findings hold true for the families of ICU patients.

Reviewed laboratory studies that focused on event and temporal uncertainty report that avoidant-like thoughts and vigilant-like thoughts were used to cope in these situations (Houston & Holmes, 1974; Monat, 1976; Monat et al., 1972). However, as indicated previously, the generalizability of these studies to the clinical setting is limited. Shalit (1977) studied numerous research literature that reported findings concerning the effectiveness of coping response in relation to circumstances of psychological, social, or physical demands. While this study provides useful general information concerning the conceptualization of uncertainty

(ambiguity) and coping, it is unknown what specific types of situations and uncertainty the subjects in the studied literature were attempting to manage.

Mishel (1981, 1983a,1984, 1986b) has done extensive study of the psychological state of uncertainty with the ill individual, but the generalizability of these studies to the spouses of ICU patients may be limited. One study conducted by Mishel (1983b) focused on the ill individual's family; subjects were the parents of hospitalized children. Parents experienced more uncertainty if their child was hospitalized for a diagnostic work-up or a medical condition than if the child was admitted for a surgical procedure. Some of the children were in intensive care situations. Although the uncertainty measurement instrument used in the parental study (PUIS) has the potential for adaptation to the spouse-spouse dyad, initial reports of some low reliability coefficients and difficulties with construct validity suggest that additional descriptive data may enhance this adaptation.

A paucity of clinical research studies that investigated how individuals coped with uncertainty were identified in the literature. Of those located, none focused on the families of ICU patients. Cancer patients and SLE patients were the subjects in the two studies (King

& Mishel, 1986; Molleman et al., 1984). Cancer patients reported using self-instruction coping strategies (e.g., actively seeking solutions, self-talk, mental framing of the situation, withdrawing) most frequently in situations of uncertainty. However, the most effective way of reducing uncertainty for these patients was through communication with professionals. While Molleman et al.'s study provided valuable information regarding potential strategies that might be used in coping with uncertainty (though not necessarily generalizable to families of patients), only 18 coping options were listed for the subjects to choose from. This seems too limited; qualitative investigation allows for more varied input in regard to coping strategies utilized.

The theory tested in King and Mishel's (1986) study, Mishel's (1986b) theory of uncertainty in illness, was developed to explain perceived uncertainty in relation to an individual's illness experience. Further study is needed to uncover whether this theory (or parts of it) have applicability to the families of ill individuals. Mishel (1983b) recommends that research needs to be done regarding the perceived uncertainties of the spouse when a husband or wife is hospitalized.

While uncertainty was not an identified variable in the

study of the needs of the families of ICU patients (Daily, 1984; Molter, 1979), several of the identified needs related directly to uncertainty (i.e., the family's need for information). Both of these studies reported the importance of the role of the nurse in meeting the needs of the families of ICU patients. Neither investigation looked at what strategies the families utilized to get their needs met, or how they coped when their needs were not or could not be met.

Bedsworth and Molen (1982) studied the wives of patients with myocardial infarction. Investigated variables were threat, coping strategies, and affects. While some of the threats identified by these wives may relate to the uncertainties involved in the situation, the concept of uncertainty was not specifically addressed. The interview question eliciting the information about perceived threats was not designed to bring out information concerning the uncertainty involved in the illness experience. ["In dealing with this situation, what have you been most anxious about?" (p.452-453)] The authors reported that 50% of the coping stategies used by these women were classified as actions aimed at strengthening the individuals resources against harm. Three examples of strategies utilized in this classification were listed in

the report, but for the other three classifications of coping strategies (attack, avoidance, inaction), also used by these wives, no examples of strategies were listed. The sharing of these specific strategies would have increased the clinical relevance of this report.

Summary of the Review of the Literature

Numerous health-related research studies have dealt with the variables of stress and/or coping. Hans Selye's work with the concept of stress brought this concept widespread attention. Lazarus and Folkman (1980, 1984) are in the forefront of investigations that conceptualize stress and coping as a transactional process.

In the nursing literature, Mishel has worked with and reshaped the conceptualization of uncertainty since 1981. She has developed an instrument to measure uncertainty in illness (MUIS) which has enhanced the study of this concept. Adaptations of this instrument have sparked studies with individuals with particualr disease states (King & Mishel, 1986) and with the families of ill children (Mishel, 1983b). Mishel (1986b) has developed the Theory of Uncertainty in Illness that is continually being refined.

While laboratory studies of ambiguity and coping abound, their generalizability to the clinical situation is

limited. Two studies that provide useful clinical data concerning both uncertainty and coping are Molleman et al.'s (1984) study of cancer patients and King and Mishel's (1986) study of individuals with SLE.

The uncertainty variable has not been specifically studied in relationship to the families of intensive care patients. Studies by Molter (1979) and Daily (1984) focused on the needs of families with a member hospitalized in an ICU. A third investigation, which studied wives of patients hospitalized in a coronary care unit, addressed the variables of threat, coping strategies, and affects.

Conceptual Framework

The conceptual framework for this study relies on components of Lazarus and Folkman's (1984) transactional model of stress and coping, Mishel's (1984) conceptualization of the categories of uncertainty, and Mishel's (1986b) theory of uncertainty in illness.

Both primary and secondary appraisal affect the degree of stress experienced in a situation (Lazarus and Folkman, 1984). Primary appraisal refers to a person's judgment of a situation as either irrelevant, benign-positive, or stressful. Situations appraised as irrelevant hold no personal consequence for the individual. In benign-positive appraisals, the situational consequence is

perceived as positive. In situations appraised as stressful, the consequences of the situation affect the individual and the situation is perceived as either a threat, a harm or a challenge. Threat appraisals may arise in instances of uncertainty as an accurate perception of the environment or as an individual's misperception of the situation (Lazarus & Folkman, 1984). During secondary appraisal, an individual assesses what coping strategies could be used in a situation, which of these coping strategies will accomplish the goal, and which coping strategies the individual might be capable of using effectively (Lazarus & Folkman, 1984). Lazarus and Folkman (1984) suggest that in order to evaluate adequately an individual's coping process, reports of the individual's thoughts, feelings, and actions during the stressful situation must be obtained.

Mishel (1984) proposed four categories of uncertainty for the ill individual. These categories were based on the factor analysis of responses to Mishel's Uncertainty in Illness Scale (MUIS). Factor one, ambiguity, indicates that the person's perception of the illness experience lacks clarity. Factor two, complexity, denotes that the patient percieves constantly changing cues concerning the treatment regime and the pattern of care. Factor three,

deficient information, signifies a patients lack of information concerning her/his diagnosis. Factor four, unpredictability, refers to a perceived fluctuating course of illness and the unpredictability of prognosis.

Mishel (1986b) appraises uncertainty as either a danger or an opportunity. When uncertainty is appraised as a danger, a threatening state exists and the individual uses coping strategies in an attempt to eliminate the uncertainty. When uncertainty is appraised as an opportunity, coping strategies are used in an attempt to maintain the uncertainty since it is a beneficial state. According to Mishel (1986b), it has been suggested in the literature that some patients may prefer uncertainty to negative certainty, because it allows them an element of hope for a positive prognosis. If an individual is able to maintain beneficial uncertainty or reduce/eliminate threatening uncertainty then adaptation will occur. Inability to do the above will result in maladaptive signs of stress (Mishel, 1986b).

Figure 1. presents a schematic model of the conceptual framework guiding this investigation. Uncertainty experienced by the spouse of an ICU patient is a potential stressor. Primary appraisal determines whether the uncertainty is perceived as a danger or an opportunity.

During secondary appraisal coping strategies are selected in an attempt to maintain uncertainty perceived as opportunity and to eliminate uncertainty perceived as dangerous. Reported strategies are either cognitive, affective, or behavioral.

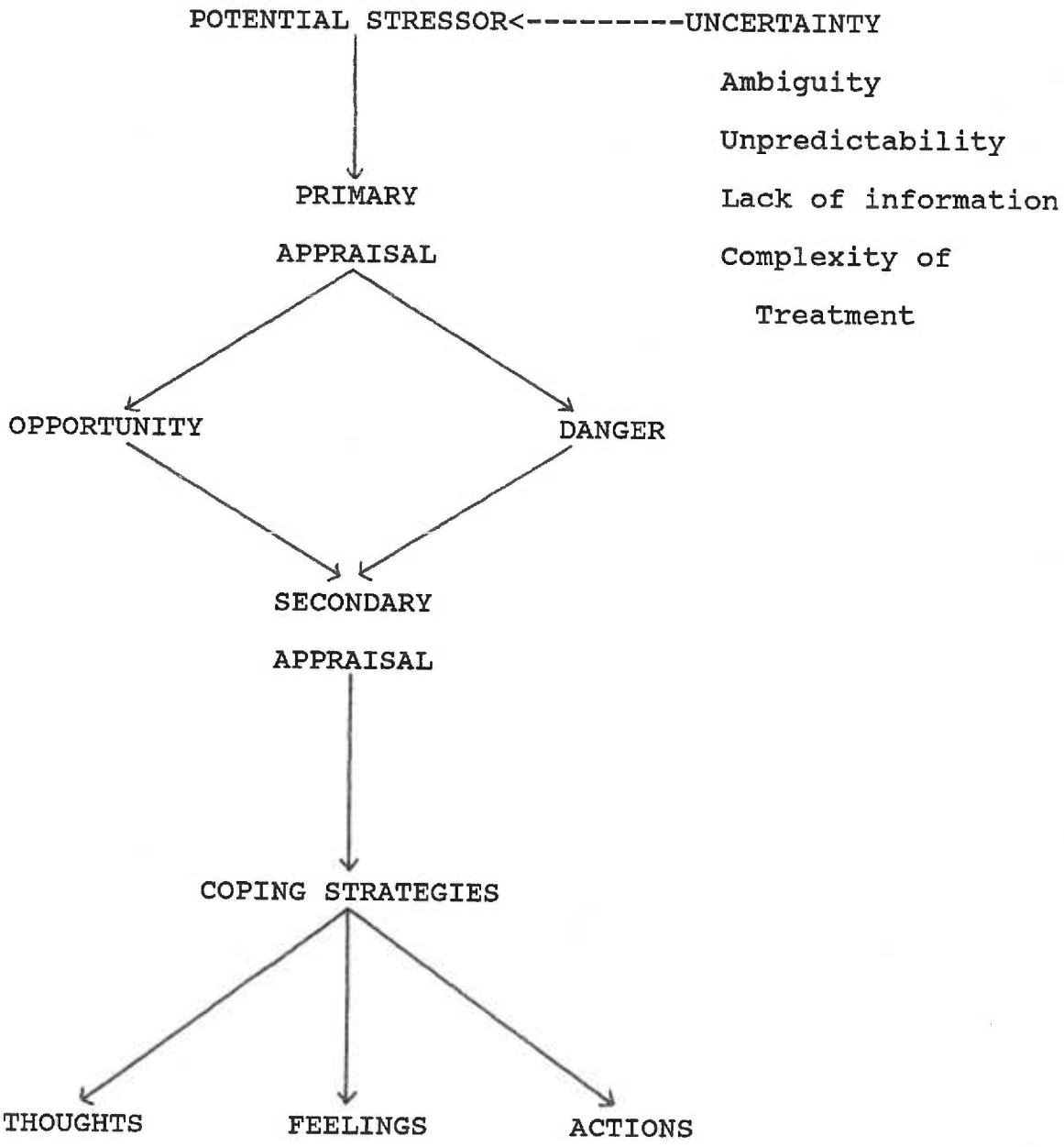

Figure 1. Schematic model of the conceptual framework.

Research Questions

Answers to the following research questions will expand the extent knowledge concerning appraisal of uncertainty and coping:

1) What uncertainty experiences are perceived by the spouses of patients in intensive care units?
2) Are these uncertainty experiences appraised as danger or opportunity?
3) What coping strategies are employed by these spouses in an attempt to manage the identified uncertainties?

Chapter III

Methods

Design

This descriptive study used nonexperimental, qualitative methodology. A qualitative study is appropriate when there is a paucity of information in the literature on the topic and when the study is to focus on the respondents' perceptions of the experience (Field & Morse, 1985). Both conditions existed for this study. There is disagreement in the field of qualitative research concerning the use of a preexisting conceptual framework with this methodology. For this investigation, which was preconceptually guided, the conceptual framework functioned to focus and guide the study, but the investigator was not bound to interpret the data in light of the conceptual framework (Miles & Huberman, 1984).

Sample and Setting

This investigation took place in a university-affiliated teaching hospital that houses three ICUs: a surgical ICU, a cardiac recovery room, and a coronary care unit. Patients with a medical diagnosis (other than cardiac-related) requiring intensive care are assigned to any of the three existing units depending on available beds and staffing levels.

Respondents (a convenience sample) were the spouses of patients being treated in each of the three units. In order to be included in the study, respondents had to be: a) legally married to the patient, b) English speaking, and c) 18 years or older. Additionally, the hospitalized spouse must have been in the ICU for at least 12 hours.

After an explanation of the study's purpose and design, a mental health nursing liaison specialist responsible for the adult ICUs familiarizd the researcher with the environments of each ICU and the waiting areas, and assisted in locating nearby potentially private areas where data could be obtained from subjects. The liaison specialists also introduced the researcher to the head nurses of the three units. After an introductory explanation of the study, the head nurses discussed appropriate strategies for accessing subjects via the nursing staff. The investigator consulted regularly with the units' charge nurses in order to identify and access prospective respondents.

Sixteen spouses participated in the study, nine wives and seven husbands. Two potential respondents, one husband and one wife, indirectly declined participation in the study. One did not keep an interview appointment and the other, after twice asking the researcher to return at a

later time, revealed to an ICU nurse that she did not wish to participate. For 43.75% of the respondents, the interview took place on the hospitalized spouse's second or third day in the ICU (range 2nd - 15th day).

Tables 1 and 2 contain demographic data for both the respondents and their hospitalized spouses. The mean age of the respondents was 53.43 years. All but one respondent had at least a high school education, and 87.5% were employed outside the home either part-time or full-time. Some religious affiliation was reported by 93.75% of the respondents; the majority were Protestant. The average length of time married was 24.04 years. Fourteen respondents (87.5%) reported some prior experience with an intensive care setting; 43.75% reported an experience within the last year. One-half of the respondents resided over 50 miles from the hospital location.

The mean age of the hospitalized spouses was 53.87 years. Fifty percent were employed outside of the home prior to admission. A religious affiliation was reported for 87.5%. There was equal representation of primary diagnosis classification among the spouses (medical or surgical). In 68.75% of the cases, the diagnosis or surgical procedure was cardiac-related.

Table 1. Demographics of spouse respondents.

AGE

mean 53.43 years

range 30-74 years

SEX

female 9

male 7

YEARS OF EDUCATION

mean 13.75

range 10-19

EMPLOYMENT

full-time (OOH)*	10
part-time (OOH)*	4
homemaker	1
retired	1

RELIGIOUS AFFILIATION

Protestant	13
Catholic	2
None	1

LENGTH OF MARRIAGE

mean 24.04 years

range 2months - 43 years

PRIOR ICU EXPERIENCE

yes 14

no 2

within past year 43.75%

MILES FROM HOSPITAL TO CITY OF RESIDENCE

Miles	no.
0-50	8
51-200	4
201-350	3
>600	1

* (OOH) - outside of home

Table 2. Demographics of hospitalized spouses.

AGE	
mean	53.87 years
range	31-68 years
SEX	
female	7
male	9
EMPLOYMENT	
full-time (OOH)*	7
part-time (OOH)*	1
homemaker	3
retired/disabled	4
medical leave of absence	1
RELIGIOUS AFFILIATION	
Protestant	12
Catholic	2
None	2
PRIMARY DIAGNOSIS CLASSIFICATION WHILE IN ICU	
medical	7
surgical	7
medical and surgical	2

* (OOH) - outside of home

Data Collection Procedures

After conferring with an ICU nurse(s) to identify a qualified respondent, the investigator approached a potential respondent and explained the purpose of the study. After assuring the respondent of confidentiality, and obtaining written consent; the respondent was interviewed in a private area near the appropriate unit. These semi-structured interviews were tape recorded with permission of the respondent. Open-ended questions (see Appendix A.) were developed to elicit the uncertainties experienced by these spouses during their husband's or wife's ICU admission. For those patients who had transferred directly from another hospital's ICU to an ICU in the teaching hospital, the respondent was instructed to include both experiences when reporting her/his uncertainties. This was the case for five of the respondents. For each experience of uncertainty identified, the respondent was asked whether she/he appraised the uncertainty as either a threat (danger) or as beneficial (opportunity). Next, for each perceived uncertainty, the respondent was asked about the coping strategies that she/he employed in dealing with that uncertainty. As suggested by Lazarus and Folkman (1984), these questions concerned the respondent's thoughts,

feelings, and actions. The interview sequencing varied when necessary to accomodate/facilitate particular respondents, their style of reporting information and their anxiety.

Focused interview techniques and interview schedule development were guided by recommendations from Merton, Fiske, and Kendall (1956). The process of retrospection was used to assist the respondent to place themselves mentally in the situation when uncertainty was perceived. This process facilitated obtaining more accurate data. If the content of discussion drifted from the respondent's experience of uncertainty in relation to their spouse's illness, refocusing techniques were used to redirect the interview. This refocusing was not abrupt (so as not to add any additional anxiety to the respondent's experience). An attempt was made to connect any strayed discussion to the question of interest so that the respondent did not perceive the interviewer as judging the strayed discussion content as irrelevant.

Situational and demographic data were collected during the first part of the interview in an attempt to build rapport, to decrease anxiety, and to familiarize the interviewer with the respondent's circumstances. This

information was later used to develop a profile of the study's respondents and their hospitalized spouses.

Because of personal and situational variables, more than one interview session was sometimes required to complete the data gathering process. Reasons for interruption included: the respondent was requested by a nurse or the patient to return to the ICU (an ICU nurse was always informed of where the interview was being held), or the respondent wished to return to the ICU to check on his/her spouse. When any situation arose necessitating postponement of the interview, an attempt was made to schedule a time (within 24 hours) to complete the interview. This was possible with each of the three interrupted interviews.

Prior to commencing data collection, the interview schedule was submitted to expert reviewers for evaluation of content validity and clarity of questions. The interview schedule was then piloted with colleagues and a layperson to obtain feedback concerning the schedule's understandability.

Protection of Human Subjects

A potential risk to respondents was that they might experience an increase in their stress level due to the interview process and the discussion of emotion-ladened

issues. In actuality, having the opportunity to discuss these issues with a non-judgmental professional not connected to the unit was reported by several respondents as having reduced their current level of stress. While a few respondents shed tears for brief periods of time during the interviews, no respondents became so emotionally distraught that postponement or discontinuance of the interviews was suggested or requested. The moderate risk to the respondent, in terms of increased anxiety, seemed outweighed by the future benefits to other spouses of ICU patients once a greater understanding of the perceived uncertainties and coping strateiges involved in this situation were described.

Chapter IV

Results

An overview of data analysis procedures introduces this chapter with more specific details given within the appropriate section. The report of results has been divided into six sections: uncertainty, appraisal, coping, affective response, coping with uncertainty, and appraisal and coping.

Data Analysis Procedures

Tape recordings of each interview were transcribed verbatim. Glaser and Strauss's (1967) strategy for delineating categories from raw data was used to extrapolate categories of uncertainty and coping strategy categories. In a pyramid-building fashion, data were initially coded using lower level concepts. As themes and patterns emerged from these lower level concepts, mid-range concepts with a higher degree of abstraction served as a conceptualization for a group of data. Finally, as the mid-range conceptualizations were analyzed, the resultant categorizations emerged.

A numerical coding system was used to identify each reported instance of uncertainty with the corresponding appraisal designation and coping strategies. Each reported instance of uncertainty was assigned a number and the same

number was used to identify the respondent's appraisal designation and the coping strategies employed by that respondent with that one instance of uncertainty.

After a colored marking was applied to the left border of the transcription (as an additional coding for the respondent interviewed), the transcription was cut and sorted into the lower concepts pertaining to the uncertainty instances, coping strategies, and uncertainty appraisals. Two copies of the transcription were made. The original copy was kept in a building other than the investigator's residence. One copy served as a working copy for coding data. The second copy served as a back-up reference once the workng copy had been cut and sorted.

A combination of latent and manifest content analysis was employed (Field & Morse, 1985). Latent analysis was used when themes and patterns were identified from the raw data in order to develop categories; manifest analysis was utilized in order to report frequencies and percentages of occurences.

The reliability and validity of qualitiative studies are frequently questioned (Field & Morse, 1985). To reduce the threats to reliability and validity, verbatim examples that provide evidence of the rationale for delineation of a particular category are presented in this chapter. Also,

selected data were submitted for peer and expert review of the conceptual scheme.

Uncertainty

Focused interviews that lasted an average of one hour were conducted with 16 respondents who reported a total of 83 instances of uncertainty perceived since their spouses's admission to an intensive care unit (mean 5.19 instances of uncertainty). Results are reported relative to this pool of 83 instances of uncertainty, not relative to the 16 respondents. These instances of uncertainty (the lower level concepts) were coded on the left margin of the transcription and each was assigned a number. The 83 instances of uncertainty clustered logically into 12 microcategories of uncertainty. These 12 microcategories were further clustered into three macrocategories of Spouse, Self/Children, and Health Care System (see Table 3).

Spouse. Of the 83 instances of uncertainty described, 41 (49.4%) pertained to the respondent's spouse hospitalized in the ICU. These instances clustered logically into the following four microcategories: Survival, Condition/Status, Diagnosis, and Future Functional Attainment.

Table 3. Macro/Microcategories of uncertainty.

	Number of Uncertainty Instances*	%
SPOUSE	41	(49.4)
Survival	14	(16.9)
Condition/Status	11	(13.3)
Diagnosis	8	(9.6)
Future Functional Attainment	8	(9.6)
SELF/CHILDREN	20	(24.1)
Role Performance	11	(13.2)
Coping Ability	6	(7.2)
Home Management	3	(3.6)
HEALTH CARE SYSTEM	22	(26.4)
Care Provision	7	(8.4)
Hospital System	5	(6)
Effectiveness of Treatment	4	(4.8)
Treatment Schedule	3	(3.6)
Procedures and Equipment	3	(3.6)

*n = 83 instances of uncertainty

The Survival microcategory refers to the respondent's uncertainty about whether his or her spouse would survive during the current admission. The greatest number of uncertainty instances (14 [16.9%]) collapsed into this microcategory. Following are exemplifying statements:

> The only uncertainty I've had, you know, is whether she's going to live or die.
>
> Well, the first uncertainty was whether she was going to make it or not.
>
> Just mostly, just A.'s [spouse's] health seemed uncertain to me, whether he was going to make it or not.

The microcategory containing the second greatest number of instances of uncertainty was Condition/Status (11 [13.3%]). Because of lack of available information, lack of access to information, conflicting information, or lack of knowledge; respondents were unsure about their spouse's physical condition/health status at some point(s) during the ICU admission or were unsure if a recurrence of a problem might again affect their spouse's health status at some point in the future.

> There are times when there is a long lapse of opportunity to see her. They have their work to do I'm sure, but I guess the spouse is not aware of exactly what's going on.
>
> Then when I get to the hospital I get four different versions. First, I don't know who exactly talked to me first, but one of the versions was they had discovered your husband not breathing.... I had questions in my mind. What's the real story?

> When he came back from the second surgery, I said can this happen again, as far as the bleeding?... He [doctor] said something about, 'No, it shouldn't, but,you know, there's always a possibility.' And that did leave me a little bit in limbo.

The Diagnosis microcategory includes instances where the respondent is uncertain about the spouses's exact diagnosis for either the primary or a secondary problem.

> We weren't sure at that time whether it was an infection, that the fever was causing an infection, which they suspected, or was it an early sign of rejection?
>
> Well, not knowing what it was to begin with. They brought him in as a stroke patient. Then after four days they said his mental alertness was too sharp to be a stroke, so they went on to the other two things [botulism or Guillain-Barre'] and ruled out a stroke.
>
> What hasn't been so precise ... is what was going on in the abdomen. And so, when you say uncertain, undecided, that's the nature of the injury here.

Future Functional Attainment refers to the respondent's uncertainty whether the spouse would be able to return to a previous (pre-hospitalization) level of functioning. Representative statements were:

> How much of his memory will come back? How much will he come back to his full - to being a productive human being?
>
> The uncertainty of what's the amount of brain damage that's involved and what will her condition be if she does survive?
>
> There was the uncertainty of him losing function [after surgery].... He's a 5-6 quad and when you're at that level, I felt like ... if he loses more functions I just don't know how I could do it.

Self/Children. The macrocategory of Self/Children contained 20 (24.1%) uncertainty instances that clustered into three microcategories. Two of the microcategories pertained to the respondent only, Role Performance and Home Management. One microcategory, Coping Ability, pertained to both the respondent and the respondent's children.

In the Role Performance microcategory, the perceived uncertainties existed in two areas, adequacy and attendance. In regard to adequacy, respondents questioned their ability and/or effectiveness as advocates and sources of support for their spouses and as representatives of their spouse's wants and needs. In regard to attendance, respondents experienced uncertainty about whether they should be present in the hospital near or with their spouse or, upon discharge to home, whether their constant presence would be required.

> And through this whole thing is the uncertainty of my role.... But, of course, he couldn't talk. And so that, again, made me feel that I wasn't sure whether I should believe him more or whether he was trying to tell me, was I giving him enough credibility? You know, was I advocating enough for him?... He was like no matter what I did he wasn't happy. I thought, am I going to go through all this stress and then at the end he's going to tell me that I've failed him?

> I am uncertain about how helpful I am to my wife. Like she, as far as I can tell if I read her right, she asked me to leave awhile ago. Now, I can interpret that a couple of ways. I can take it for the negative; she's angry I signed the consent form for surgery.

> She's tired; she needs to rest.... I've been in there a couple times in retrospect maybe even too long or too late feeling that I didn't want to leave, because I'd think she wants me with her. By the same token, I've evaluated and said, gosh, I don't know that I was really that much help.
>
> We stayed the first night. And the second night we did go home, and I got in bed and I couldn't go to sleep.... I felt like I was abandoning him or something for going home. [Were you unsure that night whether you should go home?] Yeah.
>
> Sometimes I'm gone 24 to 36 hours [from home because of his job]. My concern is now since this has happened, do I dare be gone from home that long?... Now should I take my retirement or shouldn't I? And I've been trying to decide this the last couple three days. When actually , I really don't want to.... I don't know if she should be left - if I should go and leave and be gone like I was before, you know, for so many years. I still have that uncertainty that I'm afraid to go off and leave her.

The Coping Ability microcategory is comprised of instances where respondents were uncertain about their own or their children's ability to cope with some actual or potential aspect(s) of their spouse's illness/injury situation.

> I have problems with my boys trying to let their emotions - express their emotions, which is natural. They want to be strong and all of those things. How are they going to take it if something does happen? There has been a lot of uncertainties in regard to this. And the uncertainty of how my children will handle it emotionally.
>
> I mean it was step one through ten all at once. And having to make some decisions that, you know, I was being asked to make decisions that I wasn't prepared to make. Looking back on them, I don't know if those decisions were all that critical really or important -

> could have been, like coming up here, see?... I just didn't want to make that decision at that particular time, you know? It's like you walk ... into a situation there and all of a sudden you have to make some decisions, and you don't have the opportunity to really look around and see what's going on, you see?

The Home Management microcategory is comprised of instances where the respondent was uncertain about necessary arrangements for the home care of the spouse or lacked knowledge of how to manage a situation that might arise at home post-discharge.

> Well, the only thing undecided is to whether I should have somebody come in - a nurse-type person to come in and stay with him while I'm working or will our married children be able to handle him? Will he listen to them when he can't do something?
>
> Right now my concern is, you see, he has a hiatal problem - hernia problem. Afterwards, how is he going to distinguish between that and angina?... [So, you have some uncertainty about when he gets back home how you as his support person might help him distingusih between angina and hiatal hernia?] Right.

Health Care System. Respondent's uncertainties that related to the health care professionals caring for their spouses and that related to the hospital environment comprise the macrocategory Health Care System. Twenty-two instances of uncertainty (26.4%) clustered into the five microcategories listed in this macrocategory: Care Provision, Hospital System, Effectiveness of Treatment, Treatment Schedule, and Procedures and Equipment.

Uncertainties in the microcategory Care Provision revolved around the issues of the quality of medical and nursing care the spouse was receiving and the competency of the health care professionals providing that care.

> You know, all through this whole thing I've had uncertainties about the care, but when you're a fellow professional, I think we tend to be much more critical.... They scratched his cornea sometime during the emergency, and so they had patches on both eyes after all this other stuff.... There was a discrepancy between the doctors, because one thought you patch one eye and one thought that they patch two.... Finally, J. [spouse] said he tore the dressings off. And the nurse finally took them off because they were aggravating him.

> The alarms went off and they [ICU staff] rushed into his room and you could see that they were genuinely scared. I could see that they were scared. Even the doctor here said he was scared when that happened and that was the first time that had happened to him as he was talking to a patient.... And when I could see that it scared them, naturally -.... I believed more that they could care for him than that they couldn't, but I just felt there's always that chance that maybe they couln't get his heart started or maybe it would stop this time or maybe they're not exactly right about what's wrong with him and life is so fragile.

> They [doctors] are very young, and I'm looking for Ben Casey and, you know, some of those. I'm looking for the guy with the whiskers.... Because when she was, ... I thought, dying, there was a young intern there and he said, 'Get an EKG stat!'... 'Get an xray machine down here stat!'... But the guy that saved her life was a breathing technician who came in and took one look. He didn't give any orders at all. He just jumped on top of her and began - went to work with a balloon and the oxygen and this and that and brought her -. So, I didn't have - I certainly have confidence that these guys are educated and all that, but I'm kind of looking for whiskers which I don't see.

The instances of uncertainty in the Hospital System microcategory related to the respondent's lack of knowledge/familiarity and/or confusion about various aspects of the hospital system's structure and/or function.

> I'm also not acquainted with a teaching hospital. That's given me a lot of stress. Dealing with all of these people that many of them don't communicate who they are and what their position - I don't know that I have a really good idea. I'm kind of getting ... to know the hierarchy of the people we're working with.... You get different stories, and then you learn finally that it's really only ... the doctor that you originally went to, see, that gives the final word.

> Uncertainty about who's in charge in the intensive care setting, and some of that relates to just who is it that you are suppose to get information from? Some people could give you information and other people it seemed like they couln't. You weren't quite sure how the system worked as to know who to approach about that.

The Effectiveness of Treatment microcategory refers to instances where the respondents were uncertain about the effectiveness/appropriateness of the treatment provided, underway, or planned for their spouses.

> And, of course, it'll be months he'll have the halo on until he knows whether it's [surgery's] relieved the pain or not.

> I've been unsure about the fluid level in his body.... They are beginning to get some of that off now so I think as it comes off the heart will settle down to its normal rhythm, but a little uncertain as to whether - and , of course, I'm no doctor - so, whether he needs to be dialyzed again, you know, in order to get it off quicker or that.

> The doctor had already told me that his situation is almost to the place where they're afraid to do surgery and whether it will help at all to do surgery, or they don't know if even the medication that is going to make him - to keep him from having chest pains if he goes home.

Uncertainty instances in the Treatment Schedule microcategory included experiences where the respondents were either unsure about some facet of the treatment timetable (i.e., implementation, continuation, discontinuation) or they lacked information or received conflicting information about what the actual/potential treatment plan was.

> She wants to go home, <u>badly</u>. She doesn't have to go home with a full set of teeth, and she doesn't have to go home articulate. We can get by. I hope the medical profession weighs this properly; I'm not sure. In other words, they seem to be keeping her here forever. Whereas, she thinks if she could go home she'd get well a lot faster. I'm not sure that she's wrong.... Or that they're putting the right values on getting her out of here. I think they are.

> Then the nurse said, 'We'd like to talk to you about alternatives, etc. One of which could be you could seek medical treatment closer to home and we could get your wife airlifted perhaps sooner than we anticipated.' Woah, that was really kind of neat. Since that person's talked to me, which has been now seven days, not a <u>word</u> has been said. Now I've talked with three doctors since then about it ... and all of them are very reluctant to even consider that because there's so many risks.

In the Procedures and Equipment microcategory, listed uncertainty instances described the respondents' uncertainties about lack of knowledge about hospital

equipment being used or to be used on their spouses and lack of knowledge about certain procedures ordered for their spouses.

> I didn't know - when they were going to put her on a respirator, I didn't know what that was. I pictured an iron lung.
>
> When I finally got in there, I was surprised at the number of things that were attached to her. And I wondered, ... good God, how can that woman breathe with all those things?... She had this tube down at this side, and she had a thing in her mouth to keep her from biting down, she had all these deals sticking around her head and her neck and her shoulders, everything like that.
>
> And even though there was a nurse in this room where they were doing this IVP, and I just thought, gosh, this seems to be going on forever. So, I guess they didn't tell me beforehand, or I guess I didn't understand if they did tell me, what the process was.

Appraisal

For each instance of uncertainty reported during the interview, respondents were asked if they appraised the uncertainty as threatening (danger) or as beneficial (opportunity). (See Appendix A., question 2. and related probes.) In reviewing the transcription, appraisals were coded and numbered corresponding to the instance of uncertainty to which it pertained. Descriptive data for the appraisal section were calculated on a sample of 82 instances of uncertainty.

Uncertainty appraisals were categorized as either danger, opportunity, a combination of danger/opportunity, or as neither danger nor opportunity. The vast majority of uncertainty instances were appraised as danger (59 [72%]), while 7 (8.5%) were appraised as opportunity. Four instances (4.9%) were appraised as containing elements of both danger and opportunity. Twelve uncertainty instances (14.6%) were appraised as neither danger nor opportunity. Following are quotes that expound on the appraisal as danger:

> No, no it's kind of threatening to me, because I can't really be satisfied either direction there. In my own mind I'm not satisfied just to go retire today, and, yet, I'm not satisfied not to. In other words, I'm kind of in a turmoil there. I don't want to and yet I feel like maybe I should have to.

> Yeah, I find that threatening, because I, of course, I have the problem - I want to plan, you know, a week ahead of time. And I realize they can't give me all those answers.

> To me personally it was a threat, because I would rather know what it was. Then you sort of know more what to expect. [Even if that would have been the worst?] Yeah, just to know one way or the other.

Uncertainty was appraised as opportunity for a variety of reasons, the most frequently reported was that it allowed for hope, for the chance of a positive outcome. Other cited reasons were that it permitted: a) avoidance of final decisions, b) speculation of the negative without

knowledge that it was truly so, and c) honest presentation of hope to the spouse. (See also uncertainty appraised as both danger and opportunity.) Representative quotations follow:

> The positive feelings in that - it being beneficial, that I'm glad I don't know... I don't know if I could cope with the next three months, ... or that I could cope now, if they're going to tell me that ... this [surgery] didn't improve him at all....

> [Was there anything good about being uncertain?] For me, yeah. [Can you describe how the uncertainty would be beneficial for you?] I didn't have to make any final decisions.

> I don't think I'd want to know [the total seriousness of spouse's injuries]. When you are there and you want to be by the bedside and be supportive you'd want to do it as forth right as possible, I'd think, and I don't want to chest my cards and I hope when I've said to my wife - hey, you are doing better - it has been based on fact, but to say that knowing differently, why -.

Four respondents appraised that some aspect of both danger and opportunity existed within four instances of uncertainty. The opportunity referred to a chance for a positive outlook (hope) or finding something positive in the situation, while the danger surrounded circumstances of not being able to have certain (sure) knowledge and, therefore, deal with the situation.

> Probably beneficial because it helps me to take my mind off of my other anxieties to direct my thoughts toward constructive things that I can do to help my children [opportunity].... I would rather be certain, because if you know what the outcome of something is going to be, you can find ways to handle those things if you know what's going to happen [danger].

> I think it was threatening because, well, in a way it's both. One it showed me there was a concern on the part of the staff that I appreciated [opportunity]. Threatening in that - what are they talking about [danger]?
>
> I can see an aspect of [good] - you know. I told you we weren't practicing Methodists, and it certainly put me on my knees, ... religious speaking.... I pray a lot and I went and saw the chaplain, ... so perhaps it softened me a little bit. So that would be a good - something good there. In fact, I feel deeper about such things than I did before. Perhaps I might be more sympathetic to other people because of this experience. I hope so.... [opportunity] Even if the outcome was going to be negative, I would want to know, rather than suspecting it. I would rather know and deal with it rather than treading water. [danger]

For twelve instances of uncertainty, eight respondents stated they appraised the uncertainty as neither danger nor opportunity. Respondents then either explained voluntarily or were prompted with questions to explain how they did appraise the uncertainty. In all but one instance, respondents proceeded to discuss their coping strategy (acceptance or suppression) versus their appraisal of the uncertainty under discussion. In the remaining uncertainty instance, the respondent, when questioned about his appraisal of the uncertainty as neither danger nor opportunity, described his affective response to the uncertainty. Following are exemplary statements:

> I don't see it either way, I guess.... Well, I can compare it with getting on an airplane. You know, I trust the pilots and I trust the plane, you know, but things can happen.

> No, I'd say it was more of an acceptance - just accept it. It was life. Life a lot of times deals pretty severe blows, and if you're not capable of handling them, you're in trouble.

For comparative purposes, the frequencies of appraisals were listed for each macrocategory and microcategory of uncertainty (see Table 4). Within each macrocategory (Spouse, Self/Children, and Health Care System), over 60 percent of the uncertainty instances were appraised as Danger. Each of the other appraisals (Opportunity, Danger/Opportunity, and Neither) were applied at least once in each of the macrocategories.

Coping

For each instance of uncertainty described, respondents were asked what thoughts and feelings they had and what actions they took in an attempt to manage the uncertainty experience. Coping data were coded on the right margin as thoughts, feelings, or actions (lower level concepts). These codings were also assigned a number that corresponded with the uncertainty instance to which the strategy pertained. These data bits were then analyzed to identify the coping strategies used by the respondents.

Analysis of the data revealed that 41 different coping strategies were used with the 83 instances of uncertainty. Each respondent used a variety of the 41 coping strategies

Table 4. Appraisal of 82* Instances of Uncertainty.

	UNCERTAINTY INSTANCE APPRAISAL			
	Danger	Opportunity	Both	Neither
SPOUSE (41 instances)	30 (73.2%)	3 (7.3%)	1 (2.4%)	7 (17.1%)
Survival	9	2	1	2
Condition/Status	9	1	0	1
Diagnosis	7	0	0	1
Future Functional Attmt.	5	0	0	3
SELF/CHILDREN (19 instances)	15 (78.9%)	1 (5.3%)	1 (5.3%)	2 (10.5%)
Role Performance	9	1	0	0
Coping Ability	4	0	1	1
Home Management	2	0	0	1
HEALTH CARE SYSTEM (22 instances)	14 (63.6%)	3 (13.6%)	2 (9.1%)	3 (13.6%)
Care Provision	4	2	0	1
Hospital System	3	0	1	1
Effectiveness of Tx	2	1	1	0
Treatment Schedule	2	0	0	1
Procedures & Equipment	3	0	0	0

*One instance (fitting Role Performance) inadvertently not appraised.

(mean 13.69, range 5-30) in an attempt to manage their uncertainty experiences. For each one of the 83 instances of uncertainty described, respondents used from one to 15 different coping strategies (mean 5.22).

The coping strategies were further clustered into four categories: Active Cognitive, Active Behavioral, Latent, and Avoidant strategies. Table 5 presents these four coping categories, the types of coping strategies in each, and the actual number of uncertainty instances in which each coping strategy was used. When using Active Cognitive strategies, the respondents attempted to deal with the perceived uncertainty by focusing their thoughts on the situation in either an anticipatory, reframing, or problem solving process. This category contained 19 out of the 41 identified strategies (46.3%). The four strategies from this category that were used to manage the widest variety of instances of uncertainty were: positive thinking, hoped for some positive aspect in the situation, developed own theory to explain the situation, and planned/prepared for future possibilites. An exemplary statement for each of the aforementioned strategies follows:

> I'd say it's been ... more positive thoughts than anything, that he could do it. He's done it before and now I knew with the medical profession anymore there's such marvelous medications and stuff and monitoring machines and they know exactly what's going on and everything.

Table 5. Coping Strategy Categories.

ACTIVE COGNITIVE STRATEGIES	Frequency of Use With Uncertainty Instances* (no.)
Positive thinking (selective attention/focus)	33
Hoped for some positive aspect in the situation	29
Developed own theory to explain the situation	25
Planned/Prepared for future possibilities	23
Prayed	17
Weighed potential positive and/or negative variables and possible alternatives	14
Self Talk	12
Decided health care professionals more knowledgable than self	6
Found something positive in the situation	5
Justified own actions	5
Upward comparison (better off than others or than in another situation)	5

Table 5. Coping Strategy Categories. (cont.)

ACTIVE COGNITIVE STRATEGIES	Frequency of Use With Uncertainty Instances (no.)
Questioned whether spouse's death may be better than present/future status	4
Learned about the hospital system via observation and experience over time	4
Speculated about positive and/or negative possibilities	4
Pictured future without spouse	3
Took things one day at a time	2
Reviewed circumstances of illness/ injury just prior to hospitalization	2
Tried to sort out whether problem existed or if perception faulty	1
Humor	1

Table 5. Coping Strategy Categories. (cont.)

ACTIVE BEHAVIORAL STRATEGIES	Frequency of Use With Uncertainty Instances (no.)
Talked to health care professionals to obtain/provide additional information	43
Sought/Utilized social support (family, friends)	32
Personally monitored spouse (care, physical status, mental status, equipment, response to visits)	20
Stayed at hospital	12
Advocated for spouse	11
Supported/Reassured/Prepared family, including spouse	11
Talked to spouse about the uncertain situation	10
Direct action to try to resolve the uncertainty	9
Sought/Utilized professional support	6
Telephoned unit to check on spouse	2

Table 5. Coping Strategy Categories. (cont.)

LATENT STRATEGIES	Frequency of Use With Uncertainty Instances (no.)
Trusted ICU staff (doctors and nurses) caring for spouse	16
Waited (wait and see)	16
Acceptance	13
Relinquished the burden (out of my hands, let husband take over, took advice)	8
Faith in God	3
AVOIDANT STRATEGIES	
Distraction (did activity to take mind off situation)	8
Suppression of thoughts/feelings	8
Left the situation	4
Utilized social supports as suggestors/supporters of avoidant behaviors	2
Avoided discussion of the uncertain situation	2
Coffee, cigarette to reduce the tension	1

Table 5. Coping Strategy Categories. (cont.)

AVOIDANT STRATEGIES	Frequency of Use With Uncertainty Instances (no.)
Put away personal reminders of spouse at home	1

*Reported frequencies of use for the coping strategies reflect the number of uncertainty instances (n=83) in which the strategy was used. No attempt was made to report a subject's multiple usage of the same strategy during one reported instance of uncertainty.

> Hopefully, I was able to be of some support, but I don't know. I hope so.
>
> And then I learned that it isn't a matter of a split second, that they [nurses] don't have to be right there [to answer the monitor alarm], that our bodies are resilient. They don't go to pieces just like that.... Your body does give you warnings, and if we heed these warnings, then we're not in trouble, but if we ignore them past time then we are in trouble. [Theory]
>
> I thought about him not surviving. I even thought about how I would take care of things, because, you know, it could ... get to that.

When using Active Behavioral strategies, the respondents attempted to manage their perceived uncertainty by focusing their actions on the situation in order to deal directly with the situation or the actual/potential effects of the situation. Ten (24.4%) of the coping strategies occurred in this category. The three used with the most instances of uncertainty were: talked to health care professional to obtain/provide information, sought/utilized social support, and personally monitored spouse. Exemplary statements follow in the same order as the aforementioned strategies:

> I'm trying to think which doctor I talked to first. I saw the anethesiologist in the cafeteria that afternoon, so I approached him and I said I heard this possibility. And he was the first to kind of temper my enthusiasm.... Then, I broached it with one of the head residents who had also followed S.'s [spouse's] case closely and then one of the team surgeons that operated on her.
>
> I called them [spouse's parents] and I just - well, I just broke down on the phone. And, you know, I told

> them I needed to make a decision here and I just don't know what to do.... But they helped me make the decision to bring her up here, and I needed that. I needed some ... impetus there. I needed some push.
>
> Dr. B. had mentioned early on that the fewer IVs and machines there, that's a good sign of improvement. Well, I sort of would case it out and see how many machines were working and I was very encouraged because they kept turning things off.... I would tend to look around and see if I could see anything in the trash can even or some indication -.... I looked to even see what they were hanging on to the IV to get an idea of the kinds of stuff. I'd noticed the third or fourth day this protein stuff that they were going to feed her and nobody had mentioned that. So, I asked about it.... And I would notice the machine, I could see that they were increasing the feeding. I kind of browsed.... I knew the various things that were bubbling on the side. I knew that there was a concern about blood in the urine, and, so, I'd take a peek at that. So, I was trying to piece things together on my own as opposed to leaning on doctors and nurses for that information.

The third coping category is Latent strategies. With these strategies, although the respondents thoughts were focused on the uncertain situation with an openness to new information, there was currently a resignation about or resignation from the situation in order to facilitate emotional self-preservation. Five (12.2%) of the coping strategies comprised this category. The three most frequently occurring strategies were: trusted ICU staff (doctors and nurses) caring for spouse, waited (wait and see), and acceptance. Examples follow, respectively:

> I'm just going to go by what - day by day what the doctor says. I'm sure that he will - he's trying everything, I know he's absolutely trying everything he can.

> I hate planning ahead, personally. I really do, because I would rather wait and see what, you know, what needs to be handled and handle it. So, I plan ahead and things change so then you've got to rethink everything and go through all the other emotions, and so I thought, ... let's just wait and see what happens.
>
> There are a lot of uncertainties that you have. I think I dealt with them by accepting the uncertainties and going on a day by day basis and hoping each day I would learn something, get an answer to some of these uncertainties. I just had to be patient.

The final coping category is Avoidant strategies. These strategies were used by respondents to avoid focusing their thoughts, feelings, or actions on the situation perceived as uncertain. Seven (17.1%) of the strategies comprised this category. Distraction and suppression were the strategies most widely used in this category.

> I busied my hands. Got my mind off of - [spouse's surgery]. I done a whole big stack of ironing.... I have rabbits, too, so I took care of them.... Just generally kept myself busy and my mind off of it.
>
> I'm not allowing any emotions. I just don't let that in there.... [So if some emotions start to come in, then you're pushing it out?] Well, I have to, sure. I mean I can't allow that to continue. That would drive me crazy.

The ten coping strategies used with the most instances of uncertainty were from the Active Behavioral, Active Cognitive, and Latent categories. In descending order they were: talked to health care professionals to obtain/provide additional information, positive thinking, sought/utilized social support, hoped for some positive

aspect in the situation, developed own theory to explain the situation, planned/prepared for future possibilities, personally monitored spouse, prayed, waited (wait and see), and trusted ICU staff (doctors and nurses) caring for spouse.

Affective Response. Respondents reported experiencing a variety of affective responses during the uncertainty instances (see Table 6). Fourteen negative emotions and five positive emotions were reported. The six emotional responses reported in the most instances of uncertainty were: fear (41%), hope (34.9%), anxiety (25.3%), worry (24.1%), frustration (21.7%), and sadness/depression (12%). (For this study, hope was assessed as a positive feeling state and in some circumstances, when a subject reported hoping for a certain positive aspect in a situation, it was also assessed as an Active Cognitive coping strategy.) Four respondents reported that they cried in response to an uncertainty instance(s). Although angry feelings were reported in nine uncertainty instances, only twice did respondents report expressing that anger directly to the person(s) that caused the feeling.

Coping with Uncertainty

Data were cross-tabulated in order to report which coping strategy categories were used and how frequently

Table 6. Affective Responses to Instances of Uncertainty.

NEGATIVE EMOTIONS	Frequency in Uncertainty Instances	
Fear	34	(41%)
Anxiety/Distress	21	(25.3%)
Worry	20	(24.1%)
Frustration	18	(21.7%)
Sadness/Depression	10	(12%)
Anger	9	(10.8%)
Guilt	8	(9.6%)
Discouragement/Disappointment	6	(7.2%)
Sense of loss	4	(4.8%)
Confusion	2	(2.4%)
Doubt	2	(2.4%)
Self-Doubt	2	(2.4%)
Helplessness	1	(1.2%)
Impatience	1	(1.2%)
POSITIVE EMOTIONS		
Hope	29	(34.9%)
Elation	6	(7.2%)
Thankful	4	(4.8%)
Confident	2	(2.4%)
Relief	2	(2.4%)

*n = 83 instances of uncertainty

each was used with the macrocategories and microcategories of uncertainty (see Table 7). Each of the coping strategy categories, Active Cognitive, Active Behavioral, Latent, and Avoidant were used at least once with each macrocategory of uncertainty (Spouse, Self/Children, Health Care System). Active Cognitive coping starategies were used most widely followed by Active Behavioral, Latent and Avoidant strategies. At the uncertainty microcategory level, three instances surfaced where only three of the four coping categories were used. No Avoidant strategies were reported for the Coping Ability, Care Provision, and Treatment Schedule categories.

Appraisal and Coping

For this analysis, data were again cross-tabulated in order to cite which coping strategy categories were used with each of the appraisal designations and how frequently there were used (see Table 8). For each appraisal designation, Danger, Opportunity, Danger/Opportunity or Neither; coping strategies from each category were used at least once. Active Cognitive strategies were used most frequently with each appraisal designation with the exception of the Danger/Opportunity appraisal, where Active Cognitive and Active Behavioral strategies were used equally. With each appraisal group, Latent strategies were

Table 7. Uncertainty and Coping.

Macro/Micro Uncertainty Categories	Coping Strategy-No. of Times Used			
	Act	Cog-Act	Bhv-Latent	Avoid*
SPOUSE	95	78	32	18
Survival	49	28	12	12
Condition/Status	19	22	5	2
Diagnosis	14	14	8	3
Future Functional Attainment	13	14	7	1
SELF/CHILDREN	53	32	11	4
Role Performance	31	18	7	3
Coping Ability	15	10	2	0
Home Management	7	4	2	1
HEALTH CARE SYSTEM	37	31	7	1
Care Provision	17	15	2	0
Hospital System	9	10	4	2
Effectiveness of Treatment	11	8	3	1
Treatment Schedule	9	8	2	0
Procedures and Equipment	1	5	2	1

*Active Cognitive, Active Behavioral, Latent, Avoidant

Table 8. Appraisal and Coping.

Appraisal Designation	Coping Strategy-No. of Times Used			
	Act Cog	Act Bhv	Latent	Avoid*
DANGER	128	118	30	12
OPPORTUNITY	27	12	4	6
DANGER/OPPORTUNITY	7	7	2	1
NEITHER	25	14	19	6

*Active Cognitive, Active Behavioral, Latent, Avoidant

used more frequenty than Avoidant strategies, except in the Opportunity appraisal where the reverse was true. In the uncertainties appraised as Neither (neither danger nor opportunity), Latent strategies were used with more instances of uncertainty than Active Behavioral strategies.

Chapter V

Discussion

In this chapter, findings are interpreted, discussed, and compared with previous research. The discussion is divided into four sections: uncertainty, appraisal, coping, and affective response.

Uncertainty

Findings indicate that the spouses of intensive care patients perceived a variety of uncertainties, not only related to their husband or wife specifically, but also related to themselves, their children, the health care professionals caring for their husband or wife, and the hospital environment. Some of the described uncertainty instances were brief, while others were long-standing. Some of the respondents' uncertainties had been resolved during the course of hospitalization, but others had perpetuated or had recently surfaced.

This study presents a different perspective in regard to uncertainty categories than was presented by Mishel (1984) and previously discussed in the conceptual framework. Each of Mishel's four categories, derived from quantitative factor analysis, seem to describe uncertainty generated by a particular source (i.e., ambiguity, deficient information). The current study's twelve

microcategories describe what the spouses' uncertainties were about, and the three macrocategories describe to whom or to what the uncertainty related. The uncertainty described by each microcategory may have generated from multiple sources (i.e., deficient information, conflicting information, lack of knowledge). Mishel's (1981,1983b) instruments for measuring uncertainty with the ill individual (MUIS) and with the parents of ill children (PUIS) have statements on them that relate to nine of the uncertainty microcategories identified in this study. The remaining three microcategories, Role Performance, Coping Ability, and Care Provision, seem to add a new dimension of information about the experience of uncertainty for spouses of ICU patients. Measures of uncertainty for spouses of ICU patients may need to include statements that relate to these three uncertainty microcategories in order to capture a true measure of a spouses's uncertainty.

Uncertainty instances specific to the intensive care setting were few. Reasons for this may include: a) anticipatory teaching/preparation of spouses by nursing staff (as frequently reported by subjects) and b) familiarity with the ICU setting because of media exposure or because of previous ICU experience. What did surface in the Role Performance, Care Provision and Hospital System

microcategories was that the teaching hospital environment contributed to some uncertainty instances in these categories. Some respondents had concerns about: the ill spouse misperceiving that permission had been given for them to be the subject of medical research, the experience level and abilities of the various doctors in the teaching hospital, and the general structure and function of the teaching hospital. While these microcategories also contained instances of uncertainty that did not relate directly to the teaching hospital situation, the ability to generalize these findings to other than a teaching hospital ICU may be limited.

All of the instances of uncertainty that related to the adequacy of role performance were reported by three of five respondents whose husbands or wives had been or were on ventilators. The inability to: a) verbally communicate with one's conscious spouse, b) receive verbal feedback about one's performance, and c) be sure of the spouse's lucidity and judgment capabilities seemed to contribute to these respondents' perceived uncertainty about their role performance. The generalizability of this finding is limited because of this study's small sample size and descriptive methodology.

Appraisal

This study lends partial support to Mishel's (1986b) Theory of Uncertainty in Illness with a sample of people other than ill individuals. Spouses appraised 80.5% of their uncertainty instances as either danger or opportunity as predicted by the theory. The majority (72%) of uncertainty instances were appraised as danger. Perhaps this high percentage of danger appraisals exists because the spouses of ICU patients may not have adequate time to become familiar with their spouses' illness/injury process within the intensive care situation (lack of event familiarity) (King & Mishel, 1986). Four uncertainty instances (4.9%) were appraised as having elements of both danger and opportunity. One possible explanation for this combined appraisal may be that the uncertainty instance may have been continually appraised/reappraised over the duration of the uncertainty experience. Appraisal of a situation may change from danger to opportunity and vice versa as circumstances change (i.e., an individual's coping strategies are judged ineffective (Mishel, 1986b), new information is received, the spouse's condition changes). Therefore, in some uncertainty instances, respondents may have reported that they appraised an uncertainty instance as both danger and opportunity at some time during the experience.

Perhaps the respondents' inability to label twelve instances of uncertainty (14.6%) as either danger or opportunity lies in the conscious appraisal process. When questioned, respondents were unable to provide alternative terminology that reflected how they did appraise the uncertainty. Lazarus and Folkman (1984) stated that cognitive appraisal is not necessarily conscious. Perhaps respondents unconsciously appraised the uncertainty as danger, opportunity, or both. An analysis of the coping strategies used may shed some light on this. When respondents appraised the uncertainty as neither danger nor opportunity, the coping strategies used may have eliminated/decreased or perpetuated the uncertainty. This suggests that the uncertainty may have been unconsciously appraised as danger (elimination desirable), opportunity (perpetuation desirable), or as both danger and opportunity (combinations of strategies utilized that might eliminate or perpetuate the uncertainty). Thus, there may be occasions where consciously reported appraisal is inaccurate or incomplete and, therefore, may limit the validity of consciously reported appraisals.

The validity of these findings that relate to the respondents' appraisal of the uncertainty instances is also threatened because of the difficulty that some respondents

experienced in understanding and answering this question (see Appendix A. - question 2. and related probes). Respondents required varying degrees of explanatory comments from the interviewer in order to understand this question. While a few respondents seemed to understand the question readily, others required exacting information about what the researcher was trying to ascertain. Therefore, appraisals may have been influenced, because there was an inconsistency in the amount of information and detail given to respondents before they appraised their uncertainty instances. Another difficulty was that respondents sometimes appraised the <u>situation</u> they had described as danger or opportunity versus appraising their <u>uncertainty</u> about that situation as danger or opportunity. While the researcher became aware of this possibility and clarified with respondents when this was suspected, there may have been instances where this appraisal of the situation versus the uncertainty was not recognized and corrected.

<u>Coping</u>

This study supports previous findings (Lazarus & Folkman, 1980) that individuals use a variety of coping strategies to manage life events. One to fifteen coping strategies were used per instance of uncertainty, and five

to 30 of the 41 coping strategies (mean 13.69) were used by each respondent in an attempt to mangage their described uncertainties.

This study's categorization of coping strategies in no way attempted to label certain categories of strategies or individual strategies as adaptive or maladaptive. Latent and Avoidant strategies may be very adaptive strategies when: a) other more active approaches are blocked or are ineffective in resolving the uncertainty or emotional distress and/or when b) an individual is striving to maintain hope versus the discovery of negative certainty.

Active Cognitive strategies were most frequently used by the spouses of ICU patients in an attempt to cope with their uncertainties. Next most frequently used strategies were Active Behavioral, Latent, and Avoidant strategies, respectively. This differs from the findings of Billings and Moos (1981). They reported that an illness event in the family elicited the most frequent use of Active Behavioral strategies. Possible explanations for this difference may be : a) The sample size of the current study was much smaller than the Billings and Moos study. b) In Billings and Moos' study, subjects were limited to selecting from 18 coping strategies perhaps limiting

full disclosure of all strategies used. c) The differences in the sample characteristics and setting, married couples in a community setting versus spouses of ICU patients, may account for the variation. d) Billings and Moos' study looked at how subjects coped with many reported life events, including an illness event; the current study focused only on the situation of perceived uncertainty in the intensive care situation. For this situation-specific sample, perhaps fewer behavioral strategies as opposed to cognitive strategies were seen as available options to deal with their circumstances of uncertainty.

In analyzing the ten most frequently used coping strategies, all except sought/utilized social support seemed to fit either in the problem-focused or emotion-focused categorizations described by Lazarus and Folkman (1980) and Billings and Moos (1981). Problem-focused strategies would include: talked to health care professionals to obtain/provide additional information, developed own theory to explain the situation, and personally monitored spouse. Emotion-focused strategies would include: positive thinking, hoped for some positive aspect in the situation, planned/prepared for future possibilities, prayed, trusted ICU staff caring for spouse, and waited. Sought/utilized social support might

fit into either category depending on the reason for usage. Referring back to the frequencies reported in Table 5 for these ten strategies (and excluding sought/utilized social support because of its dual nature), emotion-focused strategies (used 127 times) were more frequently used for coping with uncertainty than problem-focued strategies (used 63 times). This concurs with Lazarus and Folkman's (1980) finding that health-related stressors more frequently elicited emotion-focused coping, but varies from Billings and Moos' (1981) finding that an illness event in the family elicited problem-focused coping most frequently. In the Folkman and Lazarus (1980) study, although the sample and setting differed from the current study, a wider variety of coping strategy options (68) than were provided in the Billings and Moos' (1981) study were available for subjects to choose from.

Molleman et al. (1984) reported that self-instruction strategies were most frequently used by cancer patients to cope with uncertainty. Eight of the ten coping strategies most frequently used by the spouses in the current study subscribed to Molleman et al.'s definition of self-instruction strategies. For example, some respondents developed their own theories to explain the uncertain situation. Only sought/utilized social support and waited

did not relate to self-instruction strategies. Thus, two differing samples of persons in health care situations used similar strategies when coping with their experiences of uncertainty.

Talking to health care professionals (doctors and nurses) to obtain/provide information was the strategy most frequently used by spouses to cope with their uncertainties. Molleman et al. (1984) found communicating with professionals to be cancer patients' most effective way of reducing uncertainty. Daily (1984) reported that the ICU patient's family members' second most frequent need was for information. While this study was not designed to assess the effectiveness of utilized coping strategies, some comments by respondents during the interview process and the repeated use of this strategy by 50% of the respondents seem to suggest its perceived effectiveness or perceived potential for effectiveness for resolving or decreasing a spouse's uncertainty. This reinforces Daily's (1984) study that documents these spouses need for information.

The fourth most frequently used coping strategy was an Active Cognitive strategy (hoped for some positive aspect in the situation). Attempting to find something to be hopeful about seemed important for some of these spouses

regardless of how the uncertainty instance was appraised. This concurs with Molter's (1979) finding that the number one need of the relatives of the ICU patients was to feel there is hope.

Mishel (1986b) theorized that particular uncertainty appraisals would lead to particular coping strategy category usage (mobilizing and immobilizing strategies to eliminate uncertainty appraised as danger and buffering strategies to perpetuate an uncertainty appraised as opportunity). In the current study, strategies from each coping category (Active Cognitive, Active Behavioral, Latent, and Avoidant) were used with both the danger and the opportunity uncertainty appraisals (refer back to Table 8). This finding suggests support for that evolving portion of Mishel's (1986b) theory that describes a reappraisal loop (discussed previously in the Appraisal section). Some of the uncertainty instances consciously appraised as danger or opportunity may actually have been unconsciously appraised/reappraised as both danger and opportunity at some time during the experience. Perhaps this explains the use of two types of coping strategies (those that attempted to eliminate/decrease the uncertainty as well as those that would have perpetuated the uncertainty) with a single appraisal designation (danger or opportunity).

Affective Response

The spouses of patients in an ICU frequently ride an emotional rollercoaster. Spouses reported that they experienced not only a variety of negative emotions, but also reported occasional peaks of positive emotion which then sometimes ebbed as a negative emotional state became overriding. Fear and anxiety were the most frequently reported negative emotions experienced during the uncertainty instances. This concurs with previous studies by Daily (1984), who found that an ICU patient's family members priorty reported need was for the relief of anxiety, and Bedsworth and Molen (1981), who found that anxiety and anger were the most frequently reported affects of a sample of wives of myocardial infarction patients.

Chapter VI

Summary

Because the patient's illness experience impacts and is impacted by the family's reaction to that experience, nurses should aim toward holistic provision of care whereby they assess and intervene with the patient's support system as well as the patient. The literature pertaining to the uncertainties experienced by the families of ill patients is scarce, as are studies that discuss how these individuals may cope with these uncertainties. Because of this deficit, nurses may lack knowledge concerning the varying categories of uncertainty perceived by the spouses of ICU patients, how they appraise their uncertainties, and what coping strategies they may be utilizing in an attempt to manage their uncertainties.

Numerous health-related research studies have dealt with the variables of stress and/or coping (Lazarus and Folkman, 1980, 1984; Mason, 1985). In the nursing literature, Mishel has worked with and reshaped the conceptualization of uncertainty since 1981. She has developed an instrument to measure uncertainty in illness (MUIS) which has enhanced the study of this concept. Adaptations of this instrument have sparked studies with individuals with particular disease states (King & Mishel,

1986) and with the families of ill children (Mishel, 1983b). Mishel (1986b) has developed a Theory of Uncertainty in Illness that is continually being refined.

The uncertainty variable has not been specifically studied in relationship to the families of intensive care patients. Studies by Molter (1979) and Daily (1984) focused on the needs of families with a member hospitalized in an ICU. A third investigation, which studied wives of patients hospitalized in a coronary care unit (Bedsworth & Molen, 1982), addressed the variables of threat, coping strategies, and affects.

Uncertainty experienced by the spouse of an ICU patient is a potential stressor. Primary appraisal determines whether the uncertainty is perceived as a danger or an opportunity. During secondary appraisal, coping strategies are selected in an attempt to maintain uncertainty perceived as opportunity and to eliminate uncertainty perceived as danger. Reported strategies are cognitive, affective or behavioral.

This descriptive study of perceived uncertainty and coping in the spouses of ICU patients used nonexperimental, qualitative methodology. The investigation took place in a university-affiliated teaching hospital that houses three adult ICUs. Spouses of patients being treated in each of

the three units constituted a convenience sample. Sixteen respondents (nine wives and seven husbands) participated in semi-structured, focused interviews that were tape recorded. Verbatim transcriptions were analyzed via manifest and latent content analysis.

From 83 described instances of uncertainty perceived by the spouses of ICU patients, twelve microcategories of uncertainty were identified and defined. These microcategories were further clustered into macrocategories of Spouse (contained 49.4% of the uncertainty instances), Self/Children (contained 24.1% of the uncertainty instances), and Health Care System (contained 26.4% of the uncertainty instances). Four of the microcategories pertained to the respondent's spouse hospitalized in the ICU: Survival, Condition/Status, Diagnosis, and Future Functional Attainment. The macrocategory of Self/Children contains two microcategories that pertain to the respondent, Role Performance and Home Management, and one microcategory, Coping Ability, that pertains to both the respondent and the respondent's children. Microcategories that related to the respondents' uncertainties about the health care professionals caring for their spouses and about the hospital environment comprise the macrocategory Health Care System: Care Provision, Hospital System,

Effectiveness of Treatment, Treatment Schedule, and Procedures and Equipment.

The majority (72%) of uncertainty instances were appraised as danger. Opportunity appraisals occurred with 8.5% of the uncertainty instances. Respondents appraised that both danger and opportunity existed within 4.9% of the uncertainty instances, and that neither danger nor opportunity existed within 14.6% of the uncertainty instances.

Content analysis revealed that 41 different coping strategies were used with the 83 instances of uncertainty. The coping strategies were further reduced into four categories: Active Cognitive, Active Behavioral, Latent, and Avoidant strategies. Overall, Active Cognitive strategies were most frequently used by respondents in an attempt to manage their uncertainties. As an individual strategy, talked to health care professionals to obtain/provide additional information (an Active Behavioral strategy) was used most frequently to cope with uncertainty. The most frequently reported affective response was fear.

Findings indicate that the spouses of ICU patients perceived a variety of uncertainties, not only related to their husband or wife specifically, but also related to

themselves, their children, the health care professionals caring for their husband or wife, and the hospital environment. Three of the microcategories identified, Role Performance, Coping Ability, and Care Provision, seem to add a new dimension of information about the experience of uncertainty as it relates to the spouses of ICU patients and has not been previously discussed in reference to the ill individual's experience.

This study lends partial support to Mishel's (1986b) Theory of Uncertainty in Illness with a sample other than ill individuals. Of the instances of uncertainty described by spouses of ICU patients, 80.5% were appraised as either danger or opportunity as predicted by the theory. Possible explanations for other appraisal designations are discussed, as are difficulties with the appraisal question that may effect its validity.

This study supports previous findings (Lazarus & Folkman, 1980) that individuals use a variety of coping strategies to manage life events. Contrary to findings of Billings and Moos (1981), Active Cognitive strategies, as opposed to Active Behavioral strategies, were most frequently used to cope with uncertainty.

Of the ten most frequently used coping strategies, more emotion-focused than problem-focused coping strategies were

used by respondents. This is in agreement with Lazarus and Folkman (1980) and contrary to Billings and Moos (1981). The most frequently reported negative affective responses were fear, anxiety, and worry. This concurs, generally, with affects reported in studies of families of ICU patients by Daily (1984) and Bedsworth and Molen (1981). Additionally, hope, a positive emotion, was described as present in some respect in 34.9% of the uncertainty instances.

Nursing Implications

Findings, based on the respondents' perception of their uncertainty experiences, provide nurses with a key for understanding this element of the spouses' ICU experience. They also provide direction for assessment of and intervention with spouses' stress. In dealing with the spouses' experiences of uncertainty, nurses may have the opportunity to: validate the uncertainty experience for the spouse, assess coping strategies currently being used, suggest additional or alternate coping strategies, provide information that may decrease uncertainty, clarify misperceptions, provide anticipatory teaching, be emotionally supportive, and initiate appropriate referrals.

As previously mentioned, instruments developed to measure the uncertainty of spouses of ICU patients may need

to include statements that relate to all of the microcategories described in order to obtain a true measure of spouses' uncertainty. This study lends partial support for the applicability of Mishel's Theory of Uncertainty in Illness to a sample of people other than ill individuals. A theory's credibility is strengthened if it can provide guidance for research and practice and withstand testing with a wide range of populations.

Limitations of the Study

The ability to generalize the findings presented in this study is limited because the sample size was small and may not have been representative. Additionally, generalizability is limited because all of the ICUs providing respondents were housed in a teaching hospital.

As discussed previously, the validity of the findings in relation to the appraisal question was threatened because of the difficulty that some respondents experienced with this question. Also, the validity of the findings was threatened because of the problems inherent in interviewing respondents experiencing a situational crisis. Some of the respondents experienced memory and concentration difficulties during the interview process, but the focused interview techniques utilized in the interview sessions were a means to offset this potential threat.

Recommendations for Future Research

Development of an instrument to measure uncertainty with this population is needed in the future. Perhaps Mishel's instrument (MUIS) could be adapted for this purpose with the addition of data newly described in this study. Further testing of Mishel's Theory of Uncertainty in Illness with spouses of patients in ICUs is also recommended.

A replication of this study is suggested with a sample of spouses whose husbands or wives are hospitalized in other than an ICU. Findings from such a study may determine if the perceived uncertainties experienced by the spouses in this study are similar or dissimilar to the experience of spouses of other hospitalized patients. Triangulation of methodology is suggested when trying to ascertain how respondents appraise their uncertainties.

Is there a relationship between a spouse's perception of uncertainty about the adequacy of their role performance and the fact that their husband or wife is on a ventilator? Further study is recommended to discern whether or not these variables are related.

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Appendix A

Interview Schedule

Interview Schedule

Subject Number_____

Situational Data

When was your wife/husband admitted to the ICU?

Why was she/he admitted?

Demographic Data

SUBJECT'S age____ years of education completed____

sex____ employment/occupation_____

religious affiliation_____

length of time married____

city of residence_____

prior ICU

experience_____

PATIENT'S age____

employment/occupation_____

religious affiliation_____

1. As you think back over the time that your husband/wife has been in the ICU (CCU/CRR), can you recall any times, including now, when things have seemed uncertain in relation to your husband's/wife's illness or the intensive care setting/situation?

Synonyms for uncertain unsure, hazy, indefinite, changable, iffy, undecided, indecisive, unexplicit, debatable, obscure, cloudy, fuzzy, questionable, not understandable, confusing

Probes

1. Looking back to when your husband/wife was first admitted to the ICU, was there anything that seemed uncertain to you?

2. Is there/was there anything else about this intensive care situation that has made you feel uncertain?

3. Is there/was there anything else about your husband's/wife's illness that has made you feel uncertain?

4. Is there/was there anything that stood out as uncertain in that episode you just described?

5. At present, as you think about your husband's/wife's illness, is there anything that seems uncertain to you?

6. I am going to say a few words that other people sometimes use instead of uncertain. Keeping in mind this ICU experience, stop me if the word reminds you of a situation where things were uncertain.

2. Going back to when you described (an uncertain experience), did you believe that the uncertainty you experienced was a threat or was it a benefit?

Synonyms for threat: danger, risk, hazard, negative, scarey

Synonyms for benefit: advantage, favorable, helpful, positive

Probes:

1. In this episode you just described, where _____, was the uncertainty, at that time, threatening or beneficial?

2. As you are experiencing this _____, does it seem threatening or beneficial?

3. Sometimes people, even though they are stressed by the uncertainty will say that there is an aspect of good about it. As you think of this experience of uncertainty, is there any aspect of good about it?

4. If you had the choice, would you rather maintain the uncertainty or be certain, regardless of the outcome?

5. If it doesn't seem to fit either of those categories, how would you describe it?

3. In that situation of _(describe)_, what were you thinking as you tried to cope with the uncertainty?

In that situation of _(describe)_, how were you feeling emotionally as you tried to cope with the uncertainty?

In that situation of _(describe)_, did you take any actions/do anything as you tried to cope with the uncertainty?

Synonyms for think: believe, imagine, ponder, ideas, speculate

Synonym for feelings: emotions

Synonyms for action: doing, behave

Synonyms for cope: manage, handle, overcome

Probes:

1. As you are experiencing this _____, what (how) are you thinking (feeling,doing) as you try to cope with the uncertainty?

2. Were there any other thoughts that you had (feelings that you had, things that you did) to manage the uncertainty?

3. Did you think (do) anything else about it?

4. Did you have any other feelings about it?

Appendix B

Consent Form

Oregon Health Sciences University

School of Nursing

Consent Form

You are being asked to participate in a research study entitled "Perceived Uncertainty and Coping in the Spouses of Intensive Care Patients." This study is being done in partial fulfillment of the requirements for a Master's degree in Nursing for the principal investigator, Deanna Drazan, RN, BSN. She is working under the direction of Virginia P. Tilden, RN, DNSc. The purpose of this study is to provide health care professionals with knowledge about the uncertainty that the spouses of patients in intensive care units experience and how the spouses cope with the uncertainty. This information will assist health care professionals to get a better understanding of what the intensive care experience is like for the spouse and how health care professionals can then be more supportive of the spouses.

I understand that if I agree to participate in this study that Ms. Drazan will be asking me questions during an interview that may take about one hour. This interview can be divided into more than one session if I choose to or need to. The interviews will be tape recorded and some

notes will also be written during the interview. All information (on tape and in writing) will be handled to ensure confidentiality. Tape recordings will be erased and all names will be removed from written data upon completion of the study. Ms. Drazan has agreed to answer any questions that I might have about the study. You may contact the investigator through the Mental Health Nursing Department, Oregon Health Sciences School of Nursing at (503) 225-7827.

I understand that I may not benefit directly from participating in this project, but that it might help other people in the future. Some of the questions may touch on painful experiences which are upsetting to me.

There may be some benefits from participating in this study. It may be helpful to talk about the uncertainties I am experiencing and how I am handling them with a nurse who has experience in working with family members experiencing distress because a loved one is hospitalized.

It is not the policy of the Department of Health and Human Services, or any other agency funding the research project in which you are participating to compensate or provide medical treatment for human subjects in the event the research results in physical injury. The Oregon Health Sciences University, as an agency of the State, is covered

by the State Liability Fund. If you suffer any injury from the research project, compensation would be available to you only if you establish that the injury occurred through the fault of the University, its officers or employees. If you have further qwuestions please call Dr. Michael Baird, M.D., at (503) 225-8014.

I understand I may refuse to participate, or withdraw from this study at any time without affecting my relationship with, or treatment at, the Oregon Health Sciences University.

I have read the foregoing and agree to participate in this study.

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signature date

AN ABSTRACT OF THE THESIS OF

DEANNA DRAZAN

For the MASTER OF SCIENCE

Date receiving This Degree: June 12, 1987

Title: Perceived Uncertainty and Coping in the Spouses of Intensive Care Patients

Approved: [redacted]

Virginia Peterson Tilden, R.N., D.N.Sc.
Thesis Advisor

A descriptive, qualitative study of 16 spouses (nine wives and seven husbands) of intensive care patients was undertaken to determine what uncertainty experiences they percieved, how they appraised those uncertainty experiences, and what coping strategies they employed in an attempt to manage their identified uncertainties. An urban teaching hospital housing three adult ICUs was the setting for the study. Respondents (a convenience sample) were selected from each of the three units. Data were collected via semi-structured, focused interviews that were tape recorded. Verbatim transcriptions were analyzed via manifest and latent content analysis. Respondents described 83 instances of uncertainty that clustered logically into 12 microcategories of uncertainty. These microcategories were further clustered into macrocategories

of Spouse (contained 49.4% of the unceertainty instances), Self/Children (contained 24.1% of the uncertainty instances), and Health Care System (contained 26.4% of the uncertainty instances). Four of the microcategories pertained to the respondent's spouse hospitalized in the ICU: Survival, Condition/Status, Diagnosis, and Future Functional Attainment. The macrocategory of Self/Children contains two microcategories that pertain to the respondent, Role Performance and Home Management, and one microcategory, Coping Ability, that pertains to both the respondent and the respondent's children. Respondents' uncertainties that related to the health care professionals caring the their spouses and that related to the hospital environment comprise the macrocategory Health Care System: Care Provision, Hospital System, Effectiveness of Treatment, Treatment Schedule, and Procedures and Equipment. The majority (72%) of uncertainty instances were appraised as danger. Opportunity appraisals occurred with 8.5% of the uncertainty instances. Respondents appraised that both danger and opportunity existed within 4.9% of the uncertainty instances,and that neither danger nor opportunity existed within 14.6% of the uncertainty instances. Forty-one coping strategies were identified

that clustered logically into four categories: Active Cognitive, Active Behavioral, Latent, and Avoidant strategies. Overall, strategies from the Active Cognitive category were most frequently used by respondents to cope with their perceived uncertainties. As an individual strategy, talked to health care professionals to obtain/provide additional information (an Active Behavioral strategy) was used most frequently to cope with uncertainty. The most frequently reported affective response was fear. Generalizability may be limited because the sample was small and, therefore, unlikely to be representative. The study's descriptions provide a key for understanding the uncertainty element of spouses' ICU expereince. It also provides direction for assessment of and intervention with the spouses'uncertainty stressors. Descriptions provided may also enhance uncertainty instrument development for this population. This study lends partial support to Mishel's (1986) Theory of Uncertainty in Illness with a sample of people other than ill individuals.