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Date Dec. 29, 1993
Abstract

This descriptive correlational study was designed to determine the level of uncertainty perceived by family members of adult ICU patients. The study investigated the relationship between the perceived level of uncertainty and illness severity. In addition, the study sought to explore family members’ subjective perceptions of factors which were related to uncertainty during the ICU experience. The Mishel (1988) theory of Uncertainty in Illness guided this study.

A convenience sample of 30 family members of critically ill ICU patients completed the Family Member Version of the Parents Perception of Uncertainty in Illness Scale (PPUS-FM), the Visual Analogue Scale (VAS) for illness severity, and a demographic information sheet. In addition, 12 of the 30 family members participated in a semi-structured interview.

The findings demonstrated wide variability in the family members’ perceived level of uncertainty. However, the majority of family members of ICU patients perceived moderately high levels of uncertainty. The nature of the uncertainty experienced appears to be primarily generated in response to ambiguity and unpredictability of the situation.
The relationship between perceived uncertainty and illness severity was not statistically significant. Mishel's (1988) theory of Uncertainty in Illness supports the possibility that this finding may be a function of the family member's appraisal of the illness situation. Additional negative correlations, although not statistically significant, were found between the uncertainty factors of lack of clarity and lack of information and severity of illness. This suggests family members' who receive less information may have a more positive, although not necessarily accurate, appraisal of the illness situation.

The guided interviews revealed family members of ICU patients perceive similar uncertainties during the ICU experience. Uncertainty was related to the unpredictable illness or treatment situation, the unfamiliar environment and system of care and changes in family member functioning. The family member functioning theme is not accounted for in the Mishel (1988) framework, and appears to be primarily related to changing roles. Although a number of positive beliefs were used by family members to promote a hopeful outlook, responses indicated that most family members' appraisal of uncertainty fluctuated between a danger and an opportunity appraisal.
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Acknowledgements

I would like to express my gratitude to the members of my thesis committee, Dr. Anna Marie Hughes and Dr. Carol Jillings. Their enthusiasm, guidance and encouragement were invaluable to the completion of this challenging project. I would also like to thank Gloria Joachim for her thoughtful critique of the research proposal and the completed manuscript.

Special thanks are due to the Assistant Head Nurses and Head Nurses at both study hospitals who so generously gave of their time and energy to assist in the recruitment of family members for the study. Their dedication to this project was truly overwhelming.

I also wish to extend my appreciation to my family, friends and colleagues who continually provided me with encouragement, support and ideas. Thank you to Dr. Chris Bradley and Roberta Swanson for their helpful suggestions and assistance in setting up my data files. A special thanks to Will, Maureen and Sarah, whose support and understanding helped me to complete what, at times, seemed an insurmountable task.

Finally, I am indebted to the family members of ICU patients who shared their experiences with me. Without them, this study would not have been possible.
Dedication

I dedicate this manuscript to my parents, Telford and Joan, whose love and support have given me the strength to complete whatever I have set out to do in life.
CHAPTER ONE

Background to the Problem

Life-threatening illness requiring admission to an intensive care unit (ICU) is usually a highly stressful event replete with uncertainty for the hospitalized individual and his or her family member (Artinian, 1991; Breu & Dracup, 1978; Daley, 1984; Hilton, 1992; Leske, 1986; McDonald, 1992; Moos & Tsu, 1977). Few events in the critical care illness experience are recognizable or familiar. In addition, critical illness is fraught with set-backs and new complications which may magnify the uncertainty which is experienced. A number of research studies conducted in a variety of hospital and community settings have demonstrated that unresolved uncertainty can result in emotional distress or anxiety for both the ill individual and his or her family members (Christman, McConnell, Pfeiffer, Webster, Schmitt & Ries, 1988; Mintun, 1984; Mishel, 1981, 1984; Mishel, Hostetter, King, & Graham, 1984; Mishel & Braden, 1988; Webster & Christman, 1988).

Several studies have also supported a significant association between uncertainty and poor adaptation by individuals who are ill (Christman et al., 1988; Ford, 1988; Mishel, 1984; Simurda, 1988).

Nurses have begun to recognize the importance of supporting families to cope with the critical illness
of a family member. Family members who are unable to cope with the uncertainty associated with critical illness may have an adverse effect on the patient's emotional state and ultimate recovery (Doerr & Jones, 1979; Gardner & Stewart, 1978; Halm, 1990). Furthermore, family members who experience unresolved uncertainty and anxiety are often unable to provide support for the patient, and in addition may be unable to support each other (O'Keeffe & Gilliss, 1988; Rasie, 1980). A better understanding of family members' perceptions of uncertainty would provide an essential basis upon which nurses could begin to plan effective nursing interventions for family members of ICU patients.

The topic of uncertainty is frequently alluded to in the critical care nursing literature (Burke & Nagle, 1993; Caine, 1989; Cozac, 1985; FitzGerald, 1990; Gardner & Stewart, 1978; Mirr, 1991; Rasie, 1980). However, the emphasis has been on documenting the needs and stressors experienced by family members of critically ill patients (Breu & Dracup, 1978; Leske, 1986; Mathis, 1984; Miles, Funk & Kasper, 1991; Molter, 1979; Potter, 1979; Stillwell, 1984). In fact, much attention has been focused on a single area of research, namely family needs. Family needs research suggests that uncertainty is a major variable which
influences the needs of family members of ICU patients. In addition, numerous observations made by health care professionals suggest that uncertainty may be a significant stressor for family members.

Minimal attention has been directed to determining family members' perceptions of the uncertainty experienced in the ICU. Very few studies have been conducted whose primary purpose was to investigate uncertainty in family members of ICU patients. The studies which have been done provide inconsistent findings about the degree of uncertainty which may be experienced. In addition, it is difficult to glean specific information from these studies about family members' perceptions of factors which are related to uncertainty during the ICU experience.

Statement of the Problem

It is recognized that the experience of having a family member in the ICU is one potentially full of uncertainty and that uncertainty can have a negative impact on the family member and the patient. Yet, there has been little systematic investigation of the uncertainty experienced by family members of ICU patients. It is not clear what level of uncertainty is experienced by family members. It is not known if the family member’s perception of illness severity influences the perceived level of uncertainty. In addition, exploration of family members’ perceptions
of factors which may be related to uncertainty during the ICU experience have received only minimal consideration.

**Purposes of the Study**

The purposes of this study were to:

1) determine the level of uncertainty experienced by family members during the first week of their relative’s admission to the ICU;

2) investigate the relationship of perceived level of illness severity to the perceived level of uncertainty;

3) explore the family member’s perceptions of factors related to uncertainty during the experience of having a critically ill relative in the ICU.

**Research Questions**

This study was designed to answer the following research questions for family members of critically ill patients in the ICU:

1. What is the perceived level of uncertainty?

2. What is the relationship between perceived level of uncertainty and the perceived level of illness severity?

3. What are the perceptions of factors related to uncertainty specific to the ICU experience?
**Definition of Terms**

**Family Member:** Any relative, 19 years or older who has visited the bedside of the critically ill patient at least one time, and is identified by health care professionals as having a significant relationship with the patient. Only one family member per patient was selected for the study.

**Critically Ill Patient:** Any individual who has been admitted to the general medical-surgical ICU. The patient must have been in the ICU at least 48 hours and no more than 7 days.

**Intensive Care Unit:** A specialized unit within the hospital which is structured to care for individuals experiencing life-threatening physiological crises. These units will include general medical and surgical intensive care units which care for adult patients.

**Perceived Uncertainty:** The cognitive state occurring because of an inability to determine the meaning of an event as measured by the Family Member version of the Parents' Perception Uncertainty In Illness Scale (PPUS-FM).

**Perceived Illness Severity:** The family member’s estimate of the seriousness of the critically ill patient’s illness as measured at the time of the interview by the Visual Analogue Scale (VAS).
**Significance of the Research**

Exploration of family members' perceptions of uncertainty has provided information which increased understanding of this experience, and which can be communicated to nurses and other health care professionals. The identification of specific factors which are related to uncertainty during the ICU experience may help nurses and other health care professionals to design and implement interventions which assist family members to cope with the uncertainty which is prevalent in the ICU experience. In turn, this has potential for a positive impact on the ICU patient's recovery.

**Assumptions**

For the purposes of this study the following assumptions were made:

1. Critically ill patients admitted to the ICU present situations in which uncertainty may be experienced by family members;
2. Subjects will respond honestly to the scales and semi-structured interview guide used in the study.

**Theoretical Framework**

The theoretical framework which will provide the direction for this study is the nursing theory of Uncertainty in Illness as developed by Mishel (1988). This theory evolved from Lazarus' and Folkman's (1984) theory of Stress and Coping, and Moos' (1977) theory of
Coping with Illness. Mishel (1981) states uncertainty is one of the conditions which will produce a stress response in physical illness.

Mishel's theory has evolved from a large number of studies designed to develop and validate the Mishel Uncertainty In Illness Scale (MUIS) in a number of different clinical populations. These studies have primarily focused on the individual's perception of uncertainty in illness. There is also a small, but growing body of nursing research which has investigated the uncertainty perceived by parents and family members about another's acute or chronic illness using the Parental Perception of Uncertainty in Illness Scales (PPUS) or the family member version of the Parental Perception of Uncertainty in Illness Scales (PPUS-FM).

Mishel's theory, as displayed in Figure 1, describes three variables which are antecedents of uncertainty, and explains the relationship between uncertainty, appraisal and coping. The three antecedent variables are stimuli frame, cognitive capacity, and structure providers. These variables influence the information processed by the family member, and ultimately shape the degree of uncertainty which is perceived in response to the patient's illness-treatment situation. Uncertainty evolves when the family member lacks sufficient information or cues to adequately appraise the situation.
Figure 1. Mishel's Model of Perceived Uncertainty in Illness (1988)
Uncertainty is a neutral experience until appraisal occurs. Uncertainty is appraised as a danger or an opportunity utilizing the processes of inference and illusion. Following appraisal, coping strategies are implemented to manage the uncertainty and influence adaptation.

**Antecedents of Uncertainty**

The major antecedent variable, stimuli frame, refers to the form, composition and structure of the stimuli which are processed in an effort to develop a mental picture of the illness event. According to Mishel, uncertainty occurs when a clear cognitive appraisal cannot be achieved related to the unclear or ill-defined nature of the stimuli. The stimuli frame has three components: symptom pattern, event familiarity, and event congruence.

The first component, symptom pattern, refers to the extent to which symptoms are present in a reliable, consistent pattern. A variable symptom pattern, or an inability to distinguish between disease and treatment symptoms creates an ambiguous situation where the family member has difficulty making sense of the symptoms.

The second component, event familiarity, refers to the extent to which events within the health care environment are familiar or recognizable in relation to past experience. The intensive care environment is
novel and complex related to the extensive use of complex technology and frequent diagnostic tests. Treatments and procedures are ever-changing making it difficult for family members to establish a familiar frame of reference.

The final component of the stimuli frame is that of event congruence. Event congruence refers to the stability or consistency between what is expected and what is experienced in illness. Life-threatening illness is often characterized by setbacks or new complications which may increase the uncertainty perceived by the family member of the critically ill patient. An example of event incongruence occurs when the critically ill patient's unstable condition continues to deteriorate, despite continuing or escalating treatment, creating an incongruence between the expected recovery and the actual deterioration which occurs. Event incongruence can also occur when the timing of an illness event is not synchronous with usual events in the life cycle (Lazarus & Folkman, 1984).

The individual's cognitive capacity and structure providers influence the way in which the three components of the stimuli frame are appraised (see Figure 1). Cognitive capacity refers to the "information-processing capabilities" of the family member (Mishel, 1988, p. 225). Mishel indicates
information-processing capabilities may be impeded by the presence of stress, fatigue, pain, unclear or insufficient information, confusion or medications. For example, the family member may have difficulty accurately processing information related to shock and disbelief, extreme stress or fatigue, or the sheer sensory overload of the complex, technological environment.

Structure providers refers to the "resources available to assist the person in the interpretation of the stimuli frame" (Mishel, 1988, p. 225). Structure providers help the family member make sense of the unpredictable symptom pattern, unfamiliar events, and incongruencies which result when that which is expected is in variance with that which actually occurs. Mishel (1988) identifies structure providers as credible authority, social support, and education.

Credible authority "refers to the degree of trust and confidence patients have in health care providers" (Mishel, 1988, p. 228). Health care providers can decrease uncertainty by providing information about symptom patterns, the expected progression of treatment and illness and the unfamiliar health care system in a consistent and reliable manner.

Social support provides reassurance that someone is there to provide assistance related to financial, emotional or practical concerns thereby reducing the
uncertainty that arises secondary to an unpredictable future (Lazarus & Folkman, 1984). Mishel (1988) also indicates that social support can come from other individuals who have been or are going through a similar illness experience. Mishel indicates the sharing of information about symptom patterns or treatment experiences can reduce uncertainty by helping individuals to make sense of illness or treatment events and to formulate plans of action.

In addition to the structure providers of credible authority and social support, the individual's level of education also assists to interpret the stimuli frame (Mishel, 1988). Studies have shown that individuals with lower levels of education have been shown to have higher levels of uncertainty which may be related to increased difficulty in making sense of the health care system and complex medical terminology (Christman et al., 1988; Mishel 1981, 1984).

Appraisal

Mishel indicates that stimuli which are complex, unpredictable, unfamiliar or ambiguous result in uncertainty related to the inability to accurately recognize and give meaning stimuli. The presence of uncertainty impedes the appraisal process (Lazarus & Folkman, 1984; Mishel, 1988). When the uncertain event lacks clear form or structure this paves the way for multiple, diverse interpretations. Mishel states
that appraisal in an uncertain situation involves either the process of illusion or inference (See Figure 1).

Inference refers to the evaluation of uncertainty in accordance with past experience. According to Mishel, it is mediated by personal commitments and beliefs, general knowledge and experience and contextual cues. If the inferences are viewed as positive, then uncertainty will be appraised as an opportunity. If the inferences are viewed as threatening, the uncertainty will be appraised as a danger. Uncertainty in critical illness is likely to be appraised as a danger if the family member is unable to obtain a clear perception of what will occur.

Illusion is a process whereby beliefs are developed which are generally positive. Ambiguity, which is an integral part of uncertainty, fosters the construction of positive beliefs or illusions, which allow uncertain events to be appraised as positive or an opportunity. This illusion is valuable in helping family members maintain hope in situations which seem hopeless, and in assisting them to manage devastating information in the initial stages of a severe, critical illness of a family member (Hilton, 1992; Lazarus & Folkman, 1984; Mishel, 1988). Thus, uncertainty may be viewed "as an opportunity when the alternative is negative certainty" (Mishel, 1988, p. 231).
Coping and Adaptation

Appraisal is followed by coping strategies that enable adaptation to the situation. Coping is defined "as constantly changing cognitive and behavioral efforts to manage specific internal and/or external demands that are appraised as taxing or exceeding the resources of the person" (Lazarus & Folkman, 1984, p. 141). Uncertainty can make coping difficult in illness situations as the very nature of uncertainty precludes an accurate assessment or appraisal of the situation.

According to Mishel (1988), coping strategies are implemented in response to the type of appraisal. Coping mobilizing strategies, such as direct action, vigilance and information seeking are initiated to minimize the uncertainty and potential harmful outcome associated with a danger appraisal. If these strategies are ineffective, affect-management strategies, such as avoidance, are utilized to manage emotions. These may include fantasizing, faith, and disengagement (Mishel, 1988).

When uncertainty is appraised as an opportunity, coping strategies are designed to buffer or maintain the uncertainty. Buffering is designed to block any stimuli which would alter the positive view of the situation. Strategies include avoidance, neutralizing or avoiding information, and ignoring any information
which does not support a positive outcome (Mishel, 1988).

Mishel (1988) indicates that adaptation occurs when coping strategies are effective in managing the uncertainty which has been appraised as a danger or an opportunity. Coping strategies are considered effective if uncertainty is reduced in a danger appraisal and maintained in an opportunity appraisal. Mishel’s (1988) theory does not view adaptation in terms of long-term effects such as psychosocial adjustment or health. In addition, the impact of a continued danger or opportunity appraisal on long-term adaptation is not clear.

This study primarily explored the relationship between the antecedent variables and the family member’s level of perceived uncertainty in the ICU experience. In addition, the relationship between the family member’s perception of severity of the patient’s illness and the level of perceived uncertainty was explored. Coping and adaptation was not directly investigated; however, this portion of the framework was addressed during the analysis of the family member’s perception of factors related to uncertainty specific to the ICU experience.

Summary

This chapter has presented background information and a problem statement related to the study which
investigated the uncertainty experienced by family members of critically ill patients in the ICU. The purposes, research questions and significance to nursing have been discussed. In addition, operational definitions pertinent to the study have been given and assumptions and limitations have been outlined. Mishel's (1988) theory of Uncertainty in Illness, which will guide the study, has been explored. Chapter Two will present a review of literature pertinent to the study.
CHAPTER TWO

Review of the Literature

Introduction

The purpose of this chapter is to present an exploration and analysis of selected literature which is pertinent to the study. First, an historical tracing of the literature related to ICU patients and their families will be outlined. Then, research and non-research based reports of the needs of family members in the ICU will be presented to reflect this large area of research and link the findings with uncertainty. This will be followed by an overview of the literature which explains the perception of uncertainty. Finally, the literature pertinent to uncertainty in illness will be presented, with particular emphasis on studies of family members of ICU patients.

Historical Perspective

The literature has long acknowledged that critical illness presents a serious stressor and potential crisis for some family members of critically ill patients (Caplan, 1964; Hill, 1965; Moos & Tsu, 1977). The crisis of the patient's physical illness may be extremely potent for family members related to the uncertainty associated with serious illness and the hospitalization experience (Moos & Tsu, 1977). However, the critical care nursing literature has only recently
begun to study the impact of critical illness on family members.

Specialization and technology prompted the evolution of critical care units in the late 1950’s and 1960’s (Dracup & Marsden, 1990). Nurses within these settings primarily focused on interventions to restore emotional and physiological stability in the life-threatened individual and directed minimal attention to meeting the needs of family members (Bedsworth & Molen, 1982; Daley, 1984; Gaglione, 1984; Gardner & Stewart, 1978). The critical care nursing literature reflected this patient-centred perspective in the vast majority of publications. Early research tended to focus on the nature of the ICU environment, the patient’s psychological responses to critical illness within the ICU setting, and the patient’s physiological response to illness (Compton, 1991). Research studies which specifically focused on family members in the ICU did not commence until the mid-1970’s.

Literature in the 1960’s and early 1970’s reported mixed feelings about the presence of family members in the ICU. For example, Kornfeld, Maxwell & Momrow (1968), in a discussion of psychological hazards in the ICU, contended that family members may be a source of comfort or a source of anxiety for critically ill patients. These authors also indicated "constant
questioning by family members could interfere with staff functioning" (p. 48). These authors advocated that nurses control the presence of visitors to decrease patient anxiety and to improve the nurse's functioning. Strauss (1968), in a description of social relationships, agreed the reactions of family members could be a source of stress for nursing staff. She, however, felt emotional reactions, such as anxiety, might be attributed to tactics which nursing staff used to minimize family involvement in the ICU.

A number of authors began to speculate in the late 1970's, that, similar to patients, family members might experience unique stressors and needs in response to critical illness in the ICU setting (Breu & Dracup, 1978; Gardner & Stewart, 1978; Molter, 1979). Numerous stressors for family members of ICU patients were cited in a number of reports which primarily included the clinical observations of various health care professionals. Only a few research studies were located which specifically investigated family members' perceptions of stressors in the ICU (Bedsworth & Molen, 1982; Doerr & Jones, 1979; Potter, 1979).

Some authors then began to promote increased involvement of nursing staff with family members as an intervention to reduce the stress experienced by patients, family members and staff (Chatham, 1978;
Doerr & Jones, 1979; Gardner & Stewart, 1978; Rasie, 1980). Two research studies investigated interventions for family members with the goal of reducing the negative impact on patients which results from emotional distress in family members. These studies suggested preparation of family members, in the form of verbal or written instructions, decreased patient stress in coronary care unit (CCU) patients (Doerr & Jones, 1979) and decreased post-operative confusion in open heart surgery ICU patients (Chatham, 1978).

Research studies of the late 1970's and the 1980's began to emphasize that critical illness impacts on the entire family as well as the patient. A number of authors advocated that critical care nurses expand their role to care for family members (Bouman, 1984; Gaglione, 1984; Rasie, 1980). The literature emphasized however, that most critical care nurses did not have a strong knowledge or understanding of the needs and concerns of family members (Bouman, 1984; Daley, 1984; Geary, 1979; Jillings, 1981; Molter, 1979). Consequently, a series of research studies were undertaken whose primary purpose was to address the question: What are the needs of family members of critically ill patients? This intense activity has resulted in an extensive knowledge base in one focused area of research, namely family needs. This research was also driven by the evolution of a Critical Care
Family Needs Inventory (CCNFI) originally developed by Molter in 1976. Recently, the focus of research has been expanded to include a few qualitative studies which have explored family members' subjective perceptions of needs during the ICU experience.

The Needs of Family Members of ICU Patients

Researchers who investigated the needs of family members acknowledged that family members must struggle to reorganize roles and functions to cope with the serious illness of one member (Bouman, 1984; Daley, 1984; Leske, 1986; Molter, 1979). These researchers have worked from the assumption that identification of needs would eventually facilitate the development of interventions to meet those needs, and prevent the development of a crisis situation for family members of critically ill patients. Literature that pertains to the needs of family members of ICU patients falls into two categories: 1) studies which have used the Critical Care Family Needs Inventory (CCNFI) to identify and rate the importance of family needs; and 2) studies which have used a qualitative approach to explore family needs. Selected studies which have focused on ICU patients will be presented to demonstrate how the type of information obtained is tied to the uncertainty prevalent in the situation.
Studies Using The CCFNI

Molter (1979) constructed a needs instrument which consisted of a 4-point Likert scale with 45 needs statements developed through a literature review and a survey which investigated the opinions of 23 graduate nursing students. Molter then conducted a research study to investigate and rank the importance of the needs of family members of ICU patients within 48 hours of the transfer from the ICU. Information concerning the patient's condition and prognosis, the need for hope, and a caring attitude by hospital personnel were rated as the most important needs.

Subsequent studies used a slightly modified version of Molter's original instrument which was then referred to as the CCFNI. Daley (1984) investigated the needs of 40 family members of 28 patients who had been in the ICU less than 72 hours. Daley noted family members' needs for information and relief from anxiety were greater than in Molter's study. The need for hope was slightly lower. Daley suggested these findings may have been related to the fact that Molter collected data retrospective to the ICU phase. An open-ended question added to the scale did not identify any new needs.

Although the ranking of needs varied slightly across studies which used the CCNFI, the 10 needs consistently identified as important were: 1) to have
questions answered honestly; 2) to know specific facts regarding what is wrong with the patient and the patient's progress; 3) to know the patient's prognosis; 4) to be called at home about changes in the patient's condition; 5) to receive information once every day; 6) to receive information in understandable terms; 7) to feel hospital staff care about the patient; 8) to have hope; 9) to know exactly what things are being done for the patient; 10) to have reassurance that the best possible care is being given to the patient (Hickey, 1990). The need for hope was consistently valued as most important by family members in several studies (Leske, 1986; Molter, 1979; O'Neill Norris & Grove, 1986). Family members rated needs which referred to the patient, as significantly more important than personal needs in a number of studies (Daley, 1984; Molter, 1979; O'Neill Norris & Grove, 1986). The large number of studies producing similar results support the view that these findings are important needs for family members of critically ill patients in the ICU.

Recent studies which used the CCFNI, have reported that nurses may rate the importance of family needs differently than family members of critically ill patients in the ICU (Jacono, Hicks, Antonioni, O'Brien, & Rasi, 1990; O'Neill Norris & Grove, 1986). The discrepant findings of these studies underscore the importance of ensuring research is conducted to
determine family members' perceptions of needs. The studies which used a qualitative approach to explore family members' perceptions of needs began to appear in the mid 1980's.

**Qualitative Studies of Needs**

The review of the literature identified four studies which examined family members' subjective perceptions of their needs during the experience of having a critically ill relative in the ICU (Cozac, 1985; FitzGerald, 1990; Mirr, 1991; Rasie, 1980). Each of these studies used a qualitative approach to collect and analyze data from family members of ICU patients with a variety of medical diagnoses.

Many of the findings supported the conclusions of previous family needs studies which had used the CCNFI. Needs which were not previously identified included the need to relive the incident (Rasie, 1980) and the need to distract themselves from the situation (Cozac, 1985; FitzGerald, 1990). All of the reported qualitative needs studies indicated that family members desired more information but experienced uncertainty about obtaining it. This uncertainty was either because they did not know what questions to ask (Cozac, 1985; FitzGerald, 1990; Rasie, 1980), they experienced difficulties communicating with health care providers who were perceived as unapproachable (Cozac, 1985), or it was not clear who could provide what information.
Several of the researchers indicated family members required information about relevant medical and nursing interventions (FitzGerald, 1990; Cozac, 1985; Rasie, 1980) and directions about what to do at the bedside (FitzGerald, 1990; Cozac 1985). FitzGerald (1990) attributed this latter finding to the highly technical environment and complex treatments required to support the care of the patient in the ICU.

The qualitative family needs research studies and the studies which used the CCNFI provide support for the problem being addressed in this study. These studies suggested that uncertainty may be a variable contributing to the some of the needs of family members of ICU patients. Some of the findings appear to be linked with uncertainty as previously identified by Mishel (1981, 1983, 1984). For example, the consistent need for information appears to be related to the uncertainty associated with the patient’s condition or severity of illness and the unfamiliar hospitalization experience. The need for hope may be related to the uncertainty related to the patient’s prognosis and potential for future mental or physical disabilities.

The limitation of the above literature with respect to the proposed study is the significant lack
of investigation which specifically addresses family members' perceptions of factors which may contribute to uncertainty. Findings specifically reported as related to uncertainty have included lack of information and uncertainty about prognosis. Further research is required to determine if other findings specific to the ICU experience, such as changes in family roles, create uncertainty for family members. Thus, the second section of this review will specifically focus on discussion of the literature regarding uncertainty and studies which have explored the uncertainty experienced by family members of ICU patients.

Uncertainty

Perception of Uncertainty

Uncertainty is best defined by Mishel (1988) as the "inability to determine the meaning of illness-related events" (p. 225). It is the cognitive state that occurs "in situations where the decision-maker is unable to assign values to objects and events and/or is unable to accurately predict outcomes" (McIntosh, 1974, p. 170). Uncertainty evolves when the individual is unable to adequately structure and classify events because of insufficient cues or information (Budner, 1962; Hilton, 1992).

Several authors have identified ambiguity as a key factor which contributes to the development of
uncertainty (Lazarus & Folkman, 1984; Hilton, 1992; Mishel, 1984; Shalit, 1977). Budner (1962) stated situations which create ambiguity include: completely novel situations which contain few familiar cues; complex situations which contain a great number of cues to be considered; and contradictory situations in which different cues suggest different structures. Lazarus and Folkman (1984) differentiated between ambiguity or a lack of situational clarity, and uncertainty, which is the state which occurs when the individual is unable to determine the meaning of environmental stimuli.

The perception of events is also influenced by factors within the individual, such as commitments, beliefs, previous experience, and cognitive abilities (Lazarus & Folkman, 1984; Mishel, 1988). According to Lazarus & Folkman (1984), one of the crucial factors influencing appraisal is commitment which "expresses what is important to the person" (p. 56). Uncertain events prevent the individual from creating a clear perception of what is happening or what will occur (Budner, 1962; Duncan, 1972; Hilton, 1992; Mishel, 1981, 1984; Wiener, 1975). Uncertainty ultimately limits the individual's ability to adequately appraise a situation and implement appropriate actions or coping responses (Mishel, 1984; Hilton, 1992).
Uncertainty As A Stressor in the ICU Experience

The literature suggests illnesses which are life-threatening, serious and difficult to control are replete with uncertainty for family members as well as patients (Comaroff & Maguire, 1981; Lazarus, 1974; Hilton, 1992; McDonald, 1992; Mintun, 1984). Mishel (1988) stated the events which surround illness rarely have the necessary components to allow individuals to develop a cognitive structure which enables them to subjectively evaluate the treatment or illness experience. This situation may be magnified in the ICU where the hospitalization experience is very unfamiliar and complex, and involves significant threats to survival and health.

Uncertainty is usually evaluated as a threat in illness situations (Lazarus & Folkman, 1984; Hilton, 1992; Mishel, 1988). The inability to resolve uncertainty which is perceived as threatening can result in emotional distress, anxiety, and worrying (Hilton, 1992). Research studies have shown that uncertainty is associated with emotional distress and/or anxiety in hospitalized patients with medical diagnoses, in parents of children admitted to the ICU (Mintun, 1984) and in patients with myocardial infarctions (Christman et al., 1988; Webster & Christman, 1988).
Uncertainty is evidenced in the numerous examples of stressors which pervade the literature related to family members of ICU patients. The majority of these examples are primarily clinical observations from the perspective of the health care professional. Only three studies were located which specifically investigated family members’ perceptions of stressors in the ICU. Although the literature rarely identifies uncertainty per se, it appears characteristics of uncertainty are attributes of many of the cited stressors. The stressors identified in the research and non-research based reports relate to selected characteristics of uncertainty. The characteristics identified include: ambiguity, lack of clarity, lack of information and unpredictability.

**Ambiguity.**

A major source of ambiguity for family members of ICU patients lies in the highly technological nature of the ICU (Mishel, 1983; Miles et al., 1991). A number of authors have observed that family members may not be able to discern the purposes for many of the complex procedures, treatments and unfamiliar pieces of equipment (Gardner & Stewart, 1978; King & Gregor, 1985; Mishel, 1983; Rukholm, Bailey, Coutu-Wakulczyk, & Bailey, 1991; Roberts, 1976). In addition, family members may have difficulty comprehending the effect of
the various treatments and procedures. According to Mishel (1983), the inability to determine cause and effect is characteristic of ambiguity.

King & Gregor (1985) cited the mechanical ventilator as one type of technology which is of particular concern to family members because it prevents communication between the family member and the patient. In addition, these authors stated the ventilator may serve as tangible evidence that the patient is seriously ill, thereby heightening uncertainty about the patient's outcome.

The meaning of technology was explored in a qualitative study conducted by Burke & Nagle (1993). These investigators explored 9 spouses' perceptions of technology in the ICU environment. They determined that spouses used technology to monitor the progress of the patient. The authors reported all spouses experienced an initial uncertainty and fear about the technology, especially alarms and changes in the monitor. Many spouses, however, came to associate the technology with a sense of security. It was felt "knowing that the patient was being closely monitored by the nurses and the machine was reassuring" (p. 26). In addition to technology, numerous clinical examples indicated that family members may experience ambiguity related to difficulty in interpretation of the patient's symptoms (Mishel, 1983). The patient who
is unconscious or unresponsive was cited as a major source of uncertainty for family members (Cozac, 1985; Elliott & Smith, 1985; King & Gregor, 1985; Mathis, 1984). In general, this finding is attributed to the patient’s inability to communicate and increased uncertainty about progression of illness. Pain, or the fear of future pain which may be experienced by the patient, was cited as a symptom which is distressing for family members of ICU patients (King & Gregor, 1985; Miles et al., 1991; Roberts, 1976; Rukholm et al., 1991). Finally, the clinical examples indicated family members may experience ambiguity when they have difficulty distinguishing between symptoms which are the result of the illness and symptoms which are the result of treatment.

A study conducted by Rukholm et al. (1991) suggested that ambiguous symptoms, such as pain or level of responsiveness, can be a major source of stress for family members. As part of a larger study which investigated the relationships between family needs and anxiety in a convenience sample of 165 family members of ICU patients, these investigators concluded that the relative’s pain, followed by level of responsiveness and the number of tubes created the most worry for family members. The least upsetting worries were physical environmental factors such as the sight of other patients, staff conversations and noise.
The investigators suggested the common nursing practice of providing information at the bedside may have explained the subjects’ lack of concern for elements in the physical environment. Subjects may have experienced other worries but conclusions cannot be drawn as the investigators did not report specifics of their investigator-constructed scale.

Lack of clarity.

Family members may experience a lack of clarity when there is insufficient explanation or a lack of comprehension. A stressor which is frequently cited appears to be uncertainty about establishing relationships with unfamiliar health care providers. Family members may also experience uncertainty about obtaining information from health care providers who are perceived as unapproachable or "too busy" to communicate (Gardner & Stewart, 1978; King & Gregor, 1985; Miles et al., 1991; Mirr, 1991, Mishel, 1983). Lack of clarity may also exist when family members do not receive adequate explanations or if the explanations provided are conveyed in unfamiliar medical jargon (Davis, 1960; Mishel, 1983). Family members may have difficulty comprehending related to fatigue or limited education (Mishel, 1983). In addition, family members of critically ill patients may experience a wide range of physical and/or emotional responses, such as anxiety, disorganization, and
difficulty eating, sleeping or concentrating (Caine, 1989; Gardner & Stewart, 1978; Gilliss, 1984; McDonald, 1992; Mintun, 1984; Potter, 1979; Rukholm et al., 1991). These responses contribute to fatigue and stress which may decrease the family member’s ability to comprehend information.

**Lack of information.**

Mishel (1983) stated a lack of information can occur when information is not shared or known. Uncertainty evolves when there is insufficient information to recognize or classify events (Budner, 1962; Hilton, 1992; Sadowsky, 1982). Insufficient information is frequently cited as a major stressor for family members of ICU patients (Caine, 1989; Chavez & Faber, 1987; Comaroff & Maguire, 1981; Elliott & Smith, 1985; Gardner & Stewart, 1978; Hodovanic, Reardon, Reese, Hedges, 1984; Miles et al., 1991). Although the literature reviewed indicated family members desire more information on virtually every aspect of the patient’s treatment and illness experience, very few factors are actually cited as contributing to the family member’s perception of insufficient information.

Lack of information about the patient’s diagnosis and prognosis is the one factor which is consistently cited as creating uncertainty for family members (Burke & Nagle, 1993; King & Gregor, 1985; FitzGerald, 1990, Mirr, 1991). Mirr (1991) noted that family
members of ICU patients who were not competent to make their own decisions, often experienced difficulty making decisions in their role as proxy decision makers. These family members indicated a lack of information about the patient's eventual outcome made it extremely difficult to make decisions. This difficulty may be explained by Sadowsky (1982) who described uncertainty as "the gap between what is known and what is unknown to make correct decisions" (p. 342).

**Unpredictability.**

A final characteristic of uncertainty may be unpredictability about the outcome of the patient's illness and the changes that may be necessary in the roles and responsibilities of family members. Family members may be unclear on what they can or cannot do to help the ill family member and often lack markers by which to assess the patient's progress or recovery (Comaroff & Maguire, 1981; Hilton, 1992; Mishel, 1983).

A descriptive study by Potter (1979) suggested that uncertainty about changes in family responsibilities may be a major stressor for family members of ICU patients. Potter investigated 75 family members' perceptions of sources of stress in 3 different ICUs. The sampling procedure was not described. Potter constructed a 5-point Likert response scale to measure sources of stress related to: 1) environmental stimuli;
2) information and visitation; 3) family roles and responsibilities; and 4) the patient’s body image.

Potter proposed that environmental stressors would be most distressing for family members. Findings, however, suggested that factors threatening changes in family responsibilities were perceived as sources of greatest concern. It is not clear what factors may create uncertainty in family members’ roles, as the investigator did not describe the specific factors which composed the 4 subscales of her instrument.

In summary, it appears that uncertainty may be an attribute of many of the stressors identified in the research and non-research based reports of family members of ICU patients. However, the link between uncertainty and the identified stressors is primarily made by this investigator and rarely overtly described in these reports. In addition, most of the information related to stressors experienced by family members of ICU patients is based on the perspective of health care professionals. Studies which reveal family members’ own perceptions may be more accurate.

Studies of Uncertainty in Family Members of ICU Patients

The majority of research related to uncertainty in illness has focused on individuals either in the hospital or community. Research studies which have investigated the uncertainty experienced by family members and, specifically family members of ICU
patients are limited. The literature reviewed falls into two categories: 1) studies which used the family member version of the Mishel Uncertainty in Illness Scales (MUIS) to measure the uncertainty experienced by family members of ICU patients; and 2) studies which used a qualitative approach to explore family members' perceptions of uncertainty during the ICU experience. An adapted version of the original MUIS was used to measure uncertainty in this study. Thus, it is appropriate that, prior to reviewing these categories, pertinent background about the MUIS will be discussed.

**Background About the MUIS**

Mishel's (1988) nursing theory of Uncertainty in Illness, as described in the preceding chapter, was based on the work of several theorists. Mishel's theory evolved over time from the results of a number of studies which measured uncertainty using the Mishel Uncertainty in Illness Scales (MUIS) or various modified versions of the MUIS. In 1981, the MUIS was developed from an exploratory interviews of 45 hospitalized patients to determine their experiences with hospitalization. The interviews centered around four illness-related tasks which were a part of Moos' (1977) theory of Coping with Illness. The tasks were: dealing with symptoms, managing technical environments and establishing relationships with health care
providers, dealing with special treatments and side effects, and assessing the future and independence (Moos & Tsu, 1977; Mishel, 1981). A list of statements from the interviews was compiled and submitted to a group for judgement to determine which statements reflected uncertainty. Information was not provided about the composition of the group which evaluated the list of statements. This resulted in a 54 item scale which was administered to 259 hospitalized patients and factor analyzed.

Mishel (1981) reported the findings of three validation studies which were conducted with the MUIS. The first study tested the proposition in the previous 259 patients, that patients undergoing "rule-out" diagnostic procedures perceive more uncertainty than medical or surgical patients with confirmed diagnoses. As expected, the total uncertainty score was greater in the undiagnosed group than the groups with confirmed diagnoses. The second validation study tested and supported the hypothesis that uncertainty would be strongly related to the degree of stress experienced by 100 medical patients as measured by the Hospital Events Scale (Volicier, 1977). Construct validity was determined in the third validation study by converging the scale with a different scale measuring the same construct. The hypothesis that uncertainty would be related to a lack of comprehension was tested and
supported when the MUIS and the Comprehension Interview adapted from the Recall Test (Cassileth, 1980) were administered to 26 cancer patients on their first day of treatment.

The original MUIS measured the uncertainty which individuals experienced about their own illness. In 1983, Mishel proposed to modify the instrument to allow individuals to evaluate the uncertainty which was experienced in response to another’s illness. Mishel modified the instrument to specifically measure the uncertainty perceived by parents of hospitalized children. The modified instrument was called the Parent Perception of Uncertainty in Illness Scales (PPUS). The modified instrument underwent procedures to establish validity and reliability which are described in Chapter 3.

Mishel recommends slight adaptations to the PPUS to measure the uncertainty perceived by family members of ill individuals. The adaptations to create the family member version of the PPUS (PPUS-FM) are also described in Chapter 3. Mishel does not indicate any subsequent testing to establish validity or reliability has occurred with the PPUS-FM (Mishel & Epstein, 1990).

Multiple studies, primarily of individuals in contrast to family members, have used the MUIS to investigate uncertainty in illness. These studies have resulted in a large normative data base from
which to draw conclusions about the relationships
between uncertainty and demographic variables such as
age, education, gender and previous ICU experience
(Mishel & Epstein, 1990). A significant relationship
between lower levels of education and higher levels of
uncertainty has been suggested (Mishel, 1984;
Mishel & Epstein, 1990). Uncertainty scores do not
appear to differ by age or gender (Mishel & Epstein,
1990). The data base for studies using the PPUS or the
PPUS-FM is too preliminary to draw firm conclusions
about relationships between uncertainty and
demographic variables (Mishel & Epstein, 1990).

Studies Using the Family Member Version of the MUIS

Three studies were located which measured
uncertainty using the PPUS-FM in a variety of ICU
settings. In the first study, Mintun (1984)
hypothesized parents of children admitted to the
pediatric intensive care unit (PICU) on an unplanned
basis would perceive higher levels of uncertainty than
parents of children admitted on a planned basis. The
planned admissions group consisted of 21 parents, while
the group of unplanned admissions consisted of 28
parents. The total uncertainty score for all 49 family
members was at a moderate level (M = 77.57, SD = 18.8;
range 31-155; scale range = 31-155; midrange
uncertainty score = 93). Findings supported the
expected hypothesis. Subjects who had no opportunity to
plan for their child to be a patient in the PICU experienced higher levels of uncertainty than the group who were able to plan. Analysis of covariance determined the uncertainty subscores of Lack of Information ($F = 6.59$, $p = .0136$) and Unpredictability ($F = 14.37$, $p = .004$) were statistically significant in the unplanned group. Mintun explained these results could have been due to the types of patients in each group. The planned group was comprised of parents of children hospitalized for a relatively predictable course of surgery, while the unplanned group was comprised of parents of children with medical problems which often did not have a definitive diagnosis or clear treatment plan. Other factors, in this investigator’s opinion, which may have contributed to the increased perception of uncertainty in the unplanned group were: a greater percentage of children under the age of 6, and a greater number of children who may have been more severely ill as reflected by higher percentages of comatose and/or ventilated patients. A strong but not statistically significant relationship was noted between uncertainty and State Anxiety scores.

In the second study, Steffan (1988) used a non-experimental descriptive design to measure uncertainty in a convenience sample of 43 family members of critically ill adult patients in the
medical-surgical ICUs of two different hospitals. The sample consisted of 79% females and 21% males. Sixty-nine percent of the sample were either a spouse or adult child of the patient. Steffan investigated the relationships between uncertainty and the variables of prior hospitalization, medical diagnosis, familial relationship to the patient, and seriousness of illness. The time of data collection in relation to patient stay in the ICU was not stated.

Total uncertainty scores suggested a moderate level of uncertainty ($\bar{M} = 78.79$; range = 54 - 98; scale uncertainty score range = 29 - 145; scale midpoint score not reported). This finding was not expected nor explained by the investigator. Multifactor analysis of variance (MANOVA) demonstrated interaction between the variables of medical diagnosis, prior hospitalization, familial relationship, and seriousness of illness. None of the variables significantly explained variations in uncertainty levels of family members. However, significant relationships were suggested between subgroups. Family members of respiratory illness and myocardial infarction patients and family members of patients with a hospitalization experience within the previous six months perceived higher total uncertainty scores than other subgroups. This latter finding is consistent with other studies which have reported an increased association between recency of
hospitalization and uncertainty (Webster & Christman, 1988; Mishel, 1984). However, one-way ANOVA contrasting subgroups was not statistically significant. Findings also indicated that subgroups of spouse and adult child within the variable of familial relationship experienced the most uncertainty. Findings within the spouse and adult child subgroups were statistically significant. Overall, findings should be viewed with caution as the small sample size ($n = 43$) may not be sufficiently large for the number of investigated variables. In addition, this is the first study where family members completed the instrument without any investigator to provide instructions or answer questions. This may have affected the accuracy of the responses given the stress experienced by many family members in ICU.

In the third study, McDonald (1992) employed a descriptive correlational research design to explore the relationship between uncertainty and hope within the first six days in the ICU (Time 1) and approximately two weeks later (Time 2) on the ward setting. The original sample consisted of 30 family members of 30 patients at Time 1. This sample was reduced to 20 of the original subjects by Time 2, related to patient death or transfer and/or family member unavailability. Uncertainty was measured using the PPUS-FM and hope was measured using the Herth Hope
Scale (HSS). Findings suggested family members of brain-injured ICU patients experience relatively high levels of uncertainty overall at Time 1 (M = 98.2, SD = 12.26, range = 61 - 116) and at Time 2 (M = 91.4, SD = 14.04, range = 63 - 123). The total uncertainty range for the scale was reported as 31 - 155; midpoint scores were not available. Using a paired t test, uncertainty scores approached statistical significance between Time 1 and Time 2 (t = 2.23, p < .057). Pearson's Correlation determined a statistically significant negative correlation between uncertainty and hope at Time 1 (r = -.64, p < .003). At Time 2, the correlation approached but did not reach a correlation of statistical significance (r = -.44, p < .053). No significant relationships were found between uncertainty and the variables of gender, age, trauma/nontrauma, occupation, and relationship to patient.

The study by McDonald (1992) provides statistical support that, regardless of relationship to patient, family members of brain-injured patients experience high levels of uncertainty in the ICU phase. This finding is different than the previously discussed study by Steffan (1988) which found certain subgroups of family members of general medical-surgical ICU patients experienced more uncertainty than other
subgroups within the variable of familial relationship. McDonald explained the finding of high levels of uncertainty for all family members may be related to the unresponsive nature and incredibly uncertain prognosis of the majority of brain-injured patients. It is not clear if this finding will be reflected in other studies of family members of general medical-surgical ICU patients.

In addition to investigating the correlation between uncertainty and hope, McDonald (1992) also explored family members’ perceptions of the ICU experience by asking subjects a series of open-ended exploratory questions to obtain more qualitative data. Subjects were asked to describe the "worst" and "most helpful" things about the experience of having a brain-injured relative in the ICU. At Time 1, subjects were interviewed within 72 hours of the patient’s admission to the ICU. The investigator used content analysis to classify responses to the exploratory questions into categories. Categories were ranked according to the frequency of occurrence. The purpose of the interviews was to explore the overall ICU experience, in contrast to specifically exploring uncertainty. However, eighty-five percent of the responses to the description of worst things reflected uncertainty at Time 1. Examples of worst things included: not knowing the future, not having enough information about the brain
injury and potential brain damage, and dealing with the unfamiliar environment. The investigator did not describe the method used to determine the category of uncertainty. Description of helpful things included: expert care, supportive people, and information. A limitation of the study findings, in relation to the proposed study, is the minimal description of factors which were classified in the uncertainty category.

Qualitative Studies of Family Members' Perceptions of Uncertainty

One study was located which specifically explored family members' subjective perceptions of uncertainty in the ICU. Turner, Tomlinson, & Harbaugh (1990) used a modified grounded theory method to explore the dimensions of uncertainty in 13 parents of critically ill children in the pediatric intensive care unit (PICU). Ages of children ranged from 3 months to 16 years, with the majority of children's ages ranging from 3 - 6 years. The children had a wide variety of medical and surgical diagnoses and all but one child was intubated and mechanically ventilated. Data were collected 2 - 4 days after the child's admission to the PICU. Data were coded and categorized into emerging themes. The investigators concluded that family members in the PICU experienced four categories of uncertainty.
The first category was environmental uncertainty which was related to uncertainty about the location of resources and physical layout in the PICU, rules of conduct, unit management or routines, and the staff hierarchy. The second category was illness uncertainty. The majority of themes in this category were very similar to those identified by Mishel (1983). Findings which were different from previous studies included specific concerns about the use and function of equipment in the PICU and whether or not treatment was really necessary.

The third category of uncertainty encompassed the caregiver role. Parental uncertainty was minimized if parents perceived there was sufficient staff to provide quality care and if the caregiver was perceived as competent and empathetic. The parent's concern over caregiver competency also intensified with the perceived severity of the child's condition.

The final category of uncertainty was within the family as a system. Four themes emerged within this category. First, parents experienced role ambiguity relative to overlap between roles in the family system and roles related to caregiving by staff. In the second theme, parents experienced uncertainty about how well they performed their parental role with the sick child and the children who remained at home. Parents described a sense of helplessness that stemmed
from their inability to comfort their child. Thirdly, uncertainty was experienced about juggling multiple role demands such as child care, work and personal needs. Finally, parents expressed concerns about the future impact of the child's illness on each member of the family.

Although the study by Turner et al. (1990) was conducted in a pediatric ICU, many of the categories of uncertainty appear relevant for family members of critically ill adult patients. This is the only study conducted in ICU which specifically addressed family members' perceptions of uncertainty related to family roles. The study design and methods are described in detail and represent a careful application of grounded theory. A limitation is the modification of the grounded theory method to eliminate a reinterview with parents to confirm data. However, measures to ensure content validity included colleague review and comparative coding by 2 investigators.

Uncertainty and the Perceived Seriousness of Illness

It is clear that admission to the ICU is usually viewed as a life-threatening situation by patients and their family members. The literature consistently cites concerns about the the outcome of the patient's illness as a major stressor for family members of ICU patients. In addition, some authors have noted that
the perceived severity of illness may influence the ranking of the importance of needs perceived by family members (FitzGerald, 1990; Stillwell, 1984). For example, in one study which investigated the relationship between the perceived importance of visiting needs and perceived seriousness of illness, Stillwell (1984) found a statistically significant positive correlation between the perceived condition of the patient and the "need to see my relative frequently" ($r = .63, p < .05$).

It seems reasonable to assume based on the preceding examples that seriousness or severity of illness would be positively correlated with the perceived level of uncertainty. However, two studies which have investigated the correlation between uncertainty and perceived level of illness severity suggest this relationship is not clear. Both studies used a visual analogue scale to measure perceived severity of illness. In the first study, Mishel (1983) investigated uncertainty with the PPUS in parents of hospitalized children. She concluded total uncertainty scores were significantly related to the parent's perceived seriousness of the child's illness ($r = .16, p < .004$). In addition, the subscale factor labelled lack of information was negatively associated with the parental perceived seriousness of illness ($r = -.12, p < .03$). Mishel concluded, with more information,
judged seriousness of illness increased, and with less information family members were able to maintain an optimistic or hopeful outlook. In the second study, Mishel et al. (1984) measured uncertainty using the MUIS as part of a larger study which examined the predictors of psychosocial adjustment in 54 women newly diagnosed with gynecological cancer. In contrast to the 1983 study, Mishel found that although there was a weak positive relationship of seriousness of illness with uncertainty, it was not statistically significant. This finding was not explained by the investigator. Mishel reported that while uncertainty, less optimism, and loss of control over physical function were predictors of adjustment difficulties, perceived seriousness of illness was not supported as a major variable influencing adjustment. She also noted that more information about the illness situation, even if it was life-threatening, was associated with greater optimism about the future. She concluded that women who had a better understanding of their illness situation were better able to activate coping resources which resulted in a more positive frame of mind and fewer adjustment difficulties.

Summary of the Literature Review

It is apparent from the selected review of the literature that the life-threatening nature of critical illness and its associated unpredictable illness
trajectory is an experience which is potentially filled with uncertainty for family members as well as patients. The literature suggests this uncertainty may be magnified in the complex and unfamiliar ICU experience. The historical overview of the literature indicated nurses have only recently begun to study the impact of the ICU experience on family members. Much of this research has focused on the investigation of family needs, with a few studies conducted on the stressors experienced by family members. The findings of these studies frequently alluded to the uncertainty experienced by family members, however this phenomenon has received minimal investigation in family members of adult general medical-surgical ICU patients. The literature presented demonstrated a significant gap in the area of family members' subjective perceptions, particularly in the area of uncertainty.

Only two studies were located which measured the perceived level of uncertainty in family members of adult ICU patients, specifically general medical-surgical ICU patients and brain-injured ICU patients. Both studies demonstrated inconsistent findings related to the level of uncertainty perceived by family members of adult ICU patients. Further investigation to determine the level of uncertainty perceived by family members of general medical-surgical ICU patients was determined to be warranted.
The literature reviewed consistently cited concerns about the patient's condition and prognosis as major stressors for family members of ICU patients. Several studies indicated that perceived seriousness of illness may have a major impact on the ranking of the importance of needs by family members of ICU patients. It seemed reasonable to assume that perceived seriousness or severity of illness would be positively correlated with uncertainty. However, the two studies which were located that investigated this relationship reported inconsistent findings. Therefore, investigation of the relationship between uncertainty and perceived level of illness severity was needed.

The literature presented primarily represents the perspective of health care professionals. Only two studies were located which explored family members' perceptions of uncertainty in the ICU experience. These studies were conducted with parents of children in the PICU and family members of brain-injured persons. No studies were found which specifically investigated family members' perceptions of factors which are related to uncertainty in the adult medical-surgical ICU. This research study specifically addressed the need for increased understanding of family members' perceptions of uncertainty during the ICU experience.
The following chapter will present the methods used to guide this research study.
CHAPTER THREE

Methods

Introduction

This chapter describes the research design, sample, data collection procedure, instruments for data collection, ethical review process, and the approach used in data analysis.

Research Design

A descriptive correlational design was used in this study. The investigator sought to answer the questions regarding the level of uncertainty perceived by family members of critically ill patients in the ICU and to describe the relationship between the variables of uncertainty and perceived illness severity. The relationship between the level of uncertainty and the demographic variables was also determined. In addition, the investigator explored family members' perceptions of factors which related to uncertainty during the ICU experience.

Setting

The study took place in two large tertiary referral hospitals located in Vancouver, British Columbia. Subjects were recruited from the general medical-surgical ICU located in each of the two hospitals. Both ICUs admit patients who are severely ill and often referred from other centres in the province. Each of the units admit approximately
600 patients per year. The average length of stay in 1991 was 7 days with a range of 3 - 50 days.

The ICU setting in each hospital varied slightly. In Hospital A, the ICU consisted of 10 general ICU beds and 4 step-down ICU beds. The ICU in Hospital B consisted of 12 general ICU beds. Both ICUs admitted critically ill patients with a wide variety of medical and surgical diagnoses. In addition, the ICU of Hospital B admitted patients with transplantation of organs and patients with burns.

Sample

A convenience sample of one family member for each of 30 critically ill patients was selected for the study. This was based upon the number of family members which could be assisted to complete the questionnaire and interview within an 8 week time constraint of the investigator. This sample size was similar to other studies which used the PPUS-FM to measure uncertainty in the ICU setting (McDonald, 1992; Steffan, 1988). Specific criteria established to select the subjects for inclusion in the sample were as follows:

1. The family member was either a spouse, parent, adult child, or other person who had a significant relationship with the patient as identified by the Assistant Head Nurse (AHN) and validated by the investigator.
2. Only one family member for each patient was interviewed.
3. The family member was 19 years of age or older.
4. The family member had visited the patient in the ICU at least once prior to the data collection.
5. The family member was able to read and write English.
6. The family member was not experiencing severe emotional distress as identified by the Head Nurse (HN) or AHN.

As indicated in Chapter One, the critically ill patient was defined as any individual admitted to the general medical-surgical ICU, who was in the ICU for a period of at least 48 hours and no more than seven days. This definition was altered to exclude patients on whom treatment was being withdrawn or who were potential organ donors. The criterion of exclusion of patients who were terminally ill was established because the investigator wished to focus on family members of individuals who, at the time of the study, were considered critically ill as opposed to terminally ill.

The criterion of selection of family members who were not experiencing severe emotional distress, as identified by the AHN, was established to avoid further burdening family members who appeared to be having difficulty coping with the ICU experience. To further
prevent any undue stress on family members, it was also established that family members who met the criteria would only be contacted after initial emergency procedures were completed and the patient was stabilized.

Data were collected over a period of seven weeks. The relationships of subjects to patients varied. There were 14 spouses, 4 parents, 9 adult children, 1 adult sibling, 1 cousin, and 1 subject who, although not related to the patient, confirmed with the investigator that he had a very significant or "close" relationship with the critically ill patient.

Data were collected on each of the 30 subjects within the first nine days of the patient's admission to the ICU. Family members of patients who had been in other ICUs prior to the patient's admission to the study ICUs (23%) were included in the study sample. The investigator felt this was appropriate as these patients were transferred as their situation became more critical. Thus, their family members perceived admission to the study ICU as a "new situation".

Data Collection Instruments

The instruments that were used for data collection in this study are as follows:

1) Parents Perception of Uncertainty in Illness Scale - Family Member Form (PPUS-FM).

2) Investigator-developed Visual Analogue Scale (VAS)
to measure the perception of illness severity.

3) Investigator-developed Demographic Information Sheet.

4. Investigator-developed Interview Guide of semi-structured questions to explore family members' perceptions of specific factors in the ICU experience which are associated with uncertainty.

Family Member’s Uncertainty in Illness Scale (PPUS-FM)

The family member form of the Parental Perception of Illness Scale (PPUS-FM), (see Appendix A) is a modified version of the Mishel Uncertainty in Illness Scale (MUIS) developed in 1980 and discussed in the literature review. The MUIS was originally designed to measure the patient’s perceptions of uncertainty during hospitalization. In 1983, the MUIS was modified to measure the uncertainty experienced by parents of ill children. The modified scale was called the Parental Perception of Uncertainty in Illness Scale (PPUS).

The PPUS was reviewed to ensure content validity in terms of the pediatric hospitalization experience. This resulted in a 34 item Likert-format scale which measured the factors of ambiguity, complexity, lack of information and unpredictability. This scale was administered to a sample of 272 parents of children hospitalized for surgical, medical or diagnostic purposes. Data obtained was used to establish reliability and validity for the new form.
Factor analysis resulted in a 31 item four-factor scale with the 31 items loading at .40 or greater. Standardized alpha was .91. Nunnally (1970) indicates reliability ratings greater than .7 are considered acceptable for psychosocial instruments. Preliminary support for the construct validity of the scale was provided by the finding that the surgical treatment group experienced less uncertainty than the medical or diagnostic treatment groups. This finding was expected in light of the more stable, predictable course of treatment for surgical patients as compared to medical patients.

A normative data base has been established for multiple populations of parents of ill children. Coefficient alphas are in the moderate to high range (α = .86 - .93).

The PPUS has been adapted to a family member form (PPUS-FM) to measure the uncertainty experienced by family members. The PPUS-FM (see Appendix A) was used in this study to measure the uncertainty experienced by family members of adult ICU patients. For the purpose of the study, the PPUS-FM was modified in accordance with guidelines established by Mishel. Items were changed by the investigator to reflect the relationship of family members of adult patients in the ICU. Mishel also indicates items referring to "pain" can be changed to "symptom" or to the type of symptom most
prevalent in the patient's illness. This change was not made by the investigator as the unchanged items were more applicable to the diverse patient population in the ICU.

Only four studies with family members of patients are cited as contributing to the normative data base for the PPUS-FM (Mishel & Epstein, 1990). Samples have included family members of patients with diagnoses of cancer or "rule out" myocardial infarction and patients undergoing hemodialysis. Total scale reliabilities are in an acceptable range from .71 to .91, however, the data set is too small at present to determine consistency in sample means (Mishel & Epstein, 1990).

**Visual Analogue Scale (VAS)**

A visual analogue scale was developed by the investigator to measure the family member's perception of the ICU patient's severity of illness. (see Appendix B). The scale was patterned on other visual analogue scales used to gather information about internal perceptions or sensations, such as pain, which may be difficult to measure on scales with predetermined intervals (Lee & Kieckhefer, 1989). Visual analogue scales represent a type of measurement technique which can be used to obtain interval level data (Woods & Catanzaro, 1988).

The typical VAS is composed of a 100 mm or greater
horizontal line with end anchors that allow for the entire range of sensations regarding the phenomenon being studied (Lee & Kieckhefer, 1989). For the purpose of this study, the VAS that measures perceived severity of illness was 100 mm in length with end anchors of not serious to very serious. Subjects were asked to mark a line vertically through the point on the scale which represented how seriously ill he or she perceived the patient to be at the time of the interview. Perceived severity of illness was determined by measuring the point on the line and comparing to the predetermined total length.

Demographic Information Sheet

The demographic information sheet used in the study was designed by the investigator to collect relevant data about the subject and the patient (see Appendix C). Data collected from the family member of the ICU patient included information about the subject’s age, gender, relationship to the patient, employment status, education level, primary language, religious affiliation, understanding of the reason for the patient’s admission to the ICU, and whether the ICU admission was anticipated or not anticipated by the family member. Data collected from the medical record which concerned the patient included the patient’s age, gender, number of days in the ICU, and medical diagnoses. The participating agency
was also identified as Hospital A or B on the demographic information sheet.

**Interview Guide**

An investigator-developed interview guide was used for the collection of data related to family members' perceptions of specific factors which contribute to uncertainty in the ICU experience (see Appendix D). Mishel (1981) indicated uncertainty occurs in response to 1) illness concerns, such as symptoms or discomfort; 2) unfamiliar treatments or symptoms; 3) the complex system of care, including technical environments and relationships with health care providers; and 4) concerns about the future. These four classes of events were used to develop semi-structured questions to guide the interview process. An additional question was developed to investigate factors related to uncertainty about family roles or function as this was an identified concern in the review of the literature which examined the stressors experienced by family of ICU patients. The intent of the interview was to describe the family member's perceptions of factors in the ICU experience which are associated with uncertainty.

The interview questions were reviewed for clarity by a colleague, who had investigated uncertainty in brain-injured ICU patients, and by the supervisory committee. Feedback from these reviewers was used to
revise the guide prior to conducting interviews in the clinical setting.

**Ethical Considerations**

This study protected the rights of its subjects and was conducted in an ethical manner. Prior to conducting the study, permission was obtained from the University of British Columbia Behavioral Sciences Screening Committee for Research and Other Studies Involving Human Subjects and the two participating agencies. The initial contact of all family members was conducted by the Assistant Head Nurses (AHNs) of each of the ICUs according to a written protocol developed by the investigator (see Appendix E). The protocol was designed to ensure family members were not unduly burdened by actual or potential participation in the study. The protocol emphasized that family members who, in the opinion of the Assistant Head Nurse, were in severe emotional distress should not be contacted about participation in the study. Thus, family members who were especially vulnerable were not approached about the study unless their stress appeared to be under control within the time frame set for data collection. In addition, family members were not contacted about the study until all emergency procedures required by the patient were completed and the patient was stabilized. Once these criteria were met, the Assistant Head Nurse provided the family
member with a simple explanation about the study and a letter of information (see Appendix F). Family members were informed that participation in the study was voluntary and were given time to consider whether or not they wished to participate. The AHNs of each ICU maintained a record of family members who had been contacted and whether they wished to meet with the investigator or not. This record was maintained to avoid duplication of initial contact which could have created increased stress for family members.

The investigator maintained daily contact with the AHN of each ICU to determine which potential subjects could be contacted. The investigator did not contact potential subjects until the patient had been in the ICU for at least 48 hours. Written consent (see Appendix G) was obtained after the subject was provided with a detailed explanation of the study by the investigator. The consent form was designed to allow family members to consent to completion of the questionnaires and interviews or just the questionnaires. When the desired number of interviews were completed, the information letter and consent form were altered to ensure the family member was informed about and agreed only to completion of questionnaires. Prior to obtaining the consent, the investigator reviewed with subjects that participation was voluntary, and that refusal to participate or
withdrawal from the study at any time would not impact on the care received by their ill relative. Risks and benefits to participation in the study were described by the investigator and outlined in the consent form. Assurances of confidentiality were also provided. Each subject was assigned a code number to ensure anonymity of the data. The investigator, two faculty advisors, and two secretaries who transcribed the data and performed computer data entry were the only individuals who had access to the data. Subjects’ names were known only to the investigator and the consent forms were kept separate from the data. Subject’s names were not identified on the audiotapes, written transcripts of the interviews, or on the questionnaires.

Completion of the questionnaires and interviews was conducted in a quiet room located near to the ICU. Nursing staff were made aware of the location of the interview and encouraged as necessary to contact the family member. All subjects were offered the opportunity to discuss any feelings, concerns or questions elicited through participation in the study at the completion of either the questionnaires or interviews.

Data Collection Procedure

Following ethical approval to conduct the study, the investigator sent letters to the HNs and AHNs of each of the participating ICUs describing the study and
requesting their assistance in selecting and contacting potential subjects (see Appendix H). Meetings were held with the AHNs and HNs of both agencies to outline the protocol for subject selection and initial contact. In addition, the investigator sent letters to the Medical Directors of each ICU to inform them of the study (see Appendix I). At the request of the Ethical Review Committee of Hospital A, the investigator also sent letters to each of the Associate Directors of the ICU and ensured any questions about the study were addressed prior to proceeding with data collection. The investigator also met with the social worker and pastoral care representative of the ICU of Hospital A to describe the study and address any potential concerns. At the request of the HN, an information package describing the study procedures was provided for the social worker at Hospital B.

For the first week of the study, the investigator had approval to proceed at only one agency, Hospital A. The investigator came to the ICU on a daily basis and was available to assist as necessary with questions about subject selection and contact. The investigator encouraged the AHN to exclude family members from initial contact until the AHN felt comfortable approaching the family member about potential participation in the study. The decision to approach a
potential subject and the timing of the initial contact was ultimately the responsibility of the AHNs.

Initially, subject recruitment had been restricted to within the first week of the patient's admission to the ICU. Ninety percent of the subjects met this criterion. However, either because initial contact was delayed or because the family member was not yet ready to meet the investigator, this criterion was altered to include 3 subjects with an ill relative in the ICU for a period of up to 9 days. These subjects were enrolled in the study as the subjects' relatives remained critically ill. In addition, these family members expressed a strong desire to be involved in the study.

Once the names of potential subjects were obtained from the AHN, the investigator approached family members in the ICU or the ICU waiting room to establish an interview time. This approach was only moderately successful as family members tended to either want to meet with the investigator immediately following recruitment by the AHN or were only available to meet when they planned to visit the patient in the ICU. Subject recruitment was facilitated by the AHN determining an interview time with the family member which matched the family member's visiting schedule and availability established by the investigator. The investigator was informed of
interview times by a daily telephone call to the AHN. In addition, the AHN left messages on the investigator's answering machine if additional interviews were scheduled after the daily telephone call. The investigator also ensured that family members who could only meet at a time outside of the preestablished availability were not lost to the study by altering this availability as required.

Four family members decided not to meet with the investigator after the interview times had been established. One family member indicated she was "not up to it". Two family members did not meet with the investigator as their ill relatives died subsequent to establishing the time to meet with the investigator. The fourth family member chose to reschedule the time related to a deterioration in her relative's condition. The fourth family member then chose to meet with the investigator when her relative's condition stabilized.

The data collection procedure followed for each subject was consistent, following the guidelines discussed in the ethical considerations. At the beginning of the interview, the investigator reviewed the purpose of the study and subjects were also given an opportunity to ask questions. Once all questions were answered, the researcher obtained the family member's written consent, and a copy was given to the family member.
At the time of the interview, two family members decided not to participate in the study at the suggestion of the investigator. The first family member has just received "bad news" from the physician and appeared very upset. The second family member had signed the consent but indicated she would "rather just talk". Both family members used the interview time to describe their feelings and concerns related to the experience of having a critically ill relative in the ICU.

Once written consent was obtained, the investigator provided instructions on completion of the study questionnaires. The investigator provided detailed instruction on completion of the PPUS-FM and observed the family member complete the first two questions of this scale. The investigator then remained with the family member during completion of the scale to provide assistance or clarification as required. Most family members were able to readily complete the questionnaire with only minor clarification, generally on items which were negatively worded. During completion of the questionnaires, some family members verbalized factors which created uncertainty for them. Initially notes were not kept of these comments. In later interviews, if the family member was willing, the investigator made brief field notes of these comments.
Several family members had difficulty completing the PPUS-FM related to an inability to concentrate or to comprehend the scale items. Two of these family members had attained an educational level of Grade 8 or less, while the third family member appeared to be in a state of disbelief. One of the three family members asked the investigator to read each item and then to write her verbal response on the questionnaires. Despite assurances from the investigator that they were free to withdraw from the study if they desired, all three family members chose to continue. The majority of participating family members were eager to complete the uncertainty questionnaire.

After completion of the PPUS-FM, each subject completed the VAS to measure illness severity. Subjects were asked to base their responses on their perception of the present situation. None of the subjects experienced difficulty completing the VAS.

Subjects then completed the demographic information sheet which concerned information about the family member. Following completion of all the questionnaires, the investigator interviewed those subjects who had agreed to be interviewed up to a total of 12 interviews. The semi-structured interview guide developed by the investigator was used to guide the interviews. Once again, family members were advised they could stop the interview at any time or refuse to
answer any question. With the exception of one subject, all subjects were able to respond readily to the exploratory questions used in the interview guide. The investigator endeavored to ask all the questions on guide. Additional questions were asked by the investigator as the interview progressed to validate the family member’s perception of the situation or to have the family member elaborate on examples of events which appeared to relate to uncertainty. The subject who had difficulty responding to the questions was the same subject who had difficulty completing the PPUS-FM due to an apparent state of shock or disbelief. Despite the ongoing assurance from the investigator that he was free to withdraw from the study, this subject appeared to want to talk and chose to continue the interview. The investigator listened to the subject’s concerns and tried to support the subject during the interview.

Completion of the study questionnaires took approximately 15 - 30 minutes, with the exception of the three family members who had difficulty completing the PPUS-FM. These three family members took approximately 45 minutes to complete the study questionnaires. The interviews ranged from 30 - 45 minutes in length. The majority of subjects indicated they were pleased to have an opportunity to share the experience of family members of ICU patients with
the investigator. Most subjects chose to participate in the questionnaires and the interview until only the option of the questionnaire was offered. At the completion of either the questionnaire or the interview, the investigator asked family members if they had any concerns or feelings related to the study procedures which they would like to discuss. Family members then described a wide variety of concerns which were related to the ICU experience as opposed to study procedures. In situations where the family member appeared to be requesting further support, the investigator asked the family member if they would like assistance with specific concerns. If the family member did not wish any assistance, the investigator listened to their comments and empathized with their situation. Two family members requested assistance from the investigator to meet with the social worker and the physician. With the family members' permission, these requests were passed on for follow-up by the Head Nurse. All information from the interview remained confidential.

Data Analysis

Data from the questionnaires were coded, entered into the computer file and analyzed using the SPSS-X computer program. Measures of central tendency were used to organize the data related to the demographic variables which describe the study sample. Total scores
and subscale scores on the family member version of the Perceived of Uncertainty in Illness Scale (PPUS-FM) were calculated to determine the level of uncertainty. Cronbach’s alpha coefficient was also calculated for the total uncertainty scale. Then, measures of central tendency were calculated for each subscale and total scale of the PPUS-FM and the Visual Analogue Scale (VAS).

The Pearson Product Moment Correlation was used to determine the correlation between the total level of uncertainty and the perceived level of illness severity. In addition, correlations were performed between the total level of uncertainty and the demographic variables of family member age, sex, and education level, the relationship to patient, previous ICU experience, and whether or not the experience was anticipated. Correlations were also determined between each subscale and these variables.

The taped responses to the semi-structured questions were transcribed verbatim by a typist. The transcriptions were then checked for accuracy by the investigator by reviewing the recordings. The data was then subjected to qualitative content analysis following a method recommended by Polit and Hungler (1985). First, the investigator reviewed the responses to identify themes that related to uncertainty. In addition, notes were made as relationships between the
themes became evident. Then, the themes were collapsed into larger categories. The investigator went back to the data to see if the categories fit and revised themes as necessary. The investigator then tabulated the frequency with which the themes were supported by each subject's data. The investigator then described the understandings gained from the content analysis. Quotes from the data were used to illustrate the investigator's findings. The draft content from the descriptions of each of the themes was then compared to the frequency information. Negative cases were then reviewed to identify their impact on the investigator's findings. Finally, the descriptions were revised as necessary by interpreting the insights derived from the preceding validity check.

Summary

This chapter had described the methods which guided the research study. The criteria and process for selection of participants were outlined. In addition, the processes of data collection and analysis were discussed in detail. Finally, ethical considerations were described. The following chapter will present the findings of the study.
CHAPTER FOUR

Presentation of the Findings

Introduction

Chapter Four consists of two sections. The first section provides a description of the characteristics of the sample. This description includes characteristics of the patients as well as the family members. The second section presents the research findings related to each of the three research questions.

Characteristics of the Sample

The sample consisted of 30 family members of 30 critically ill patients who were hospitalized in the general medical-surgical ICU of one of two tertiary care hospitals in the lower Vancouver Mainland. Quite incidentally, fifteen family members (50%) were recruited from each of the two participating hospitals. Characteristics are reported first in terms of the study sample of family members and then the associated critically ill ICU patients.

Demographic Characteristics of the Family Members

Demographic data collected from the family members of the ICU patients were gender, age, relationship to the patient, occupation, educational level, country of birth, primary language, and religious affiliation. Of the 30 family members in the sample,
19 were female (63.3%) and 11 were male (36.7%). The age of the subjects ranged from 29 to 73 years (M = 47.1, SD = 14.16).

Twenty-nine of the 30 of family members (96.7%) were related to the patient by kinship or marriage. One subject was an "extremely close" friend and considered himself to be the "only family of the patient." The majority of subjects were either spouses (48.7%) or adult children of the ICU patient (30.0%). The subjects' relationship to the ICU patients is presented in Table 1.

Table I

<table>
<thead>
<tr>
<th>Relationship</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wife</td>
<td>11</td>
<td>38.7</td>
</tr>
<tr>
<td>Daughter</td>
<td>5</td>
<td>16.7</td>
</tr>
<tr>
<td>Son</td>
<td>4</td>
<td>13.3</td>
</tr>
<tr>
<td>Husband</td>
<td>3</td>
<td>10.0</td>
</tr>
<tr>
<td>Mother</td>
<td>2</td>
<td>6.7</td>
</tr>
<tr>
<td>Father</td>
<td>2</td>
<td>6.7</td>
</tr>
<tr>
<td>Other (Cousin, Friend)</td>
<td>2</td>
<td>6.7</td>
</tr>
<tr>
<td>Brother</td>
<td>1</td>
<td>3.3</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>30</strong></td>
<td><strong>100.0</strong></td>
</tr>
</tbody>
</table>

The family members' occupations were categorized by the researcher (see Table II). The majority of subjects 36.7% were employed in the professional or administrative/manager category. Homemakers represented another 16.7%.
Table II

Occupation of the Family Members

<table>
<thead>
<tr>
<th>Occupation</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Professional</td>
<td>6</td>
<td>20.0</td>
</tr>
<tr>
<td>Administrative/Manager</td>
<td>5</td>
<td>16.7</td>
</tr>
<tr>
<td>Homemaker</td>
<td>5</td>
<td>16.7</td>
</tr>
<tr>
<td>Technician/Trades</td>
<td>3</td>
<td>10.0</td>
</tr>
<tr>
<td>Sales/Business</td>
<td>3</td>
<td>10.0</td>
</tr>
<tr>
<td>Retired</td>
<td>3</td>
<td>10.0</td>
</tr>
<tr>
<td>Unemployed</td>
<td>3</td>
<td>10.0</td>
</tr>
<tr>
<td>Student</td>
<td>1</td>
<td>3.3</td>
</tr>
<tr>
<td>Office Worker</td>
<td>1</td>
<td>3.3</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>30</strong></td>
<td><strong>100.0</strong></td>
</tr>
</tbody>
</table>

The educational level of the sample of family members is presented in Table III. Eighteen of the family members (60.0%) were educated at the university or college level. A total of 5 family members (16.7%) had attained less than a high school education.

Table III

Education Level of the Family Members

<table>
<thead>
<tr>
<th>Education Level</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>University/College</td>
<td>18</td>
<td>60.0</td>
</tr>
<tr>
<td>High School Graduate</td>
<td>7</td>
<td>23.3</td>
</tr>
<tr>
<td>Grade 9 - 11</td>
<td>2</td>
<td>6.7</td>
</tr>
<tr>
<td>Up to Grade 8</td>
<td>3</td>
<td>10.0</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>30</strong></td>
<td><strong>100.0</strong></td>
</tr>
</tbody>
</table>

The majority or 23 family members (76.7%) were born in Canada. Of the remaining 7 family members, 5 were born in Great Britain (16.6%), 1 was born in China (3.3%) and 1 was born in Tanzania (3.3%). The latter group of family members emigrated to Canada between the years of 1920 and 1972. English was the primary
language of 27 of the family members. (90.0%). All family members were fluent in English, including the 3 family members (10.0%) who did not consider English to be their primary language.

Table IV displays additional data re: previous ICU experience and location of family members during the patient's ICU experience. Nineteen family members (63.3%) had previous experience in the ICU either through personal experience or with another ill family member or friend. The remaining 11 family members (36.7%) had no previous ICU experience.

Eighteen of the family members (60.0%) lived outside the lower Vancouver Mainland. Family members were not asked if they had relocated at the time of data collection. This data was retrospectively recorded from the investigator's knowledge of each family member's situation as discussed at the time of data collection.

Table IV

Other Characteristics of the Family Members

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>ICU Experience:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Previous experience</td>
<td>19</td>
<td>63.3</td>
</tr>
<tr>
<td>No previous experience</td>
<td>11</td>
<td>36.7</td>
</tr>
<tr>
<td><strong>Location during ICU stay:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Remained in hometown</td>
<td>18</td>
<td>60.0</td>
</tr>
<tr>
<td>Relocated to Vancouver</td>
<td>12</td>
<td>40.0</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>30</td>
<td>100.0</td>
</tr>
</tbody>
</table>
Demographic Characteristics of the ICU Patients

Patient data collected from the medical record were age, gender, number of days in the ICU, and medical diagnoses. Twenty patients were male (66.7%) and 10 patients were female (33.3%). Age of the patients ranged from 23 - 83 years (M = 54.07, SD = 17.81). Table V displays the number of days the patient had been in the ICU at the time the family members responded to the questionnaires. The number of days ranged from 2 to 9 days (M = 5.03, SD = 1.89).

Table V

<table>
<thead>
<tr>
<th>Days</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>2</td>
<td>1</td>
<td>3.3</td>
</tr>
<tr>
<td>3</td>
<td>7</td>
<td>23.3</td>
</tr>
<tr>
<td>4</td>
<td>6</td>
<td>20.0</td>
</tr>
<tr>
<td>5</td>
<td>2</td>
<td>6.7</td>
</tr>
<tr>
<td>6</td>
<td>8</td>
<td>26.7</td>
</tr>
<tr>
<td>7</td>
<td>3</td>
<td>10.0</td>
</tr>
<tr>
<td>8</td>
<td>2</td>
<td>6.7</td>
</tr>
<tr>
<td>9</td>
<td>1</td>
<td>3.3</td>
</tr>
<tr>
<td>Total</td>
<td>30</td>
<td>100.0</td>
</tr>
</tbody>
</table>

The ICU patients had a wide variety of medical diagnoses which were categorized according to the most specific reason for ICU admission (see Table VI). At the time of data collection, 22 of the 30 patients (73.3%) had multiple medical complications in addition to the primary admission diagnosis.
Table VI

Primary Reason For Admission to the ICU

<table>
<thead>
<tr>
<th>Disease Category</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Cardiovascular/Vascular</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cardiac Arrest x 1</td>
<td>6</td>
<td>20.0</td>
</tr>
<tr>
<td>Open Heart Valvular/Bypass Surgery x 2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Peripheral Artery Bypass Surgery x 1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Abdominal Aneurysm Repair x 2</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Respiratory</strong></td>
<td>9</td>
<td>30.0</td>
</tr>
<tr>
<td>Adult Respiratory Distress Syndrome x 2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pneumonia x 2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Respiratory Arrest x 1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pulmonary Emboli x 1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lung Transplant x 1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Respiratory Neoplasm x 2</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Trauma</strong></td>
<td>5</td>
<td>16.7</td>
</tr>
<tr>
<td>Multiple Trauma (including burns) x 4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Head Trauma (no multiple trauma) x 1</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Gastrointestinal</strong></td>
<td>4</td>
<td>13.3</td>
</tr>
<tr>
<td>Gastrointestinal bleeding x 1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gastrointestinal perforation/rupture x 2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pancreatitis x 1</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Miscellaneous (Sepsis, Metabolic)</strong></td>
<td>4</td>
<td>13.3</td>
</tr>
<tr>
<td>Septic Shock x 2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Drug Overdose x 1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diabetes x 1</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Neurologic</strong></td>
<td>2</td>
<td>6.7</td>
</tr>
<tr>
<td>Subarachnoid Hemorrhage x 1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Guillian Barre x 1</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>30</td>
<td>100.0</td>
</tr>
</tbody>
</table>
Findings

The level of uncertainty and level of illness severity were examined using descriptive statistics. The Pearson Product Moment Correlation Coefficient was used to examine the relationship between uncertainty and illness severity. Following reporting of the findings related to the first two research questions, findings related to the interviews or the third research question will be reported.

Research Question 1: What is the perceived level of uncertainty of family members of critically ill ICU patients?

To establish the level of uncertainty perceived by these subjects, scores obtained on the uncertainty scale were calculated. In addition, scores for each of the factors on the uncertainty scale were calculated to determine which factors reflect the highest uncertainty.

The total score on the uncertainty scale (PPUS-FM) ranged from a low of 53 to a high of 119 ($M = 86.8$, $SD = 16.26$). These findings indicated the majority of family members perceived moderately high levels of uncertainty. Uncertainty scores were treated as a continuous variable for data analysis. However, uncertainty scores are arbitrarily grouped in intervals of eight for ease of data presentation (see Table VII).
Table VII

Total Uncertainty Scores for Family Members

<table>
<thead>
<tr>
<th>Total Score</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>53 - 60</td>
<td>2</td>
<td>6.7</td>
</tr>
<tr>
<td>61 - 68</td>
<td>3</td>
<td>10.0</td>
</tr>
<tr>
<td>69 - 76</td>
<td>2</td>
<td>6.7</td>
</tr>
<tr>
<td>77 - 84</td>
<td>6</td>
<td>20.0</td>
</tr>
<tr>
<td>85 - 92</td>
<td>5</td>
<td>16.7</td>
</tr>
<tr>
<td>93 - 100</td>
<td>5</td>
<td>16.7</td>
</tr>
<tr>
<td>101 - 108</td>
<td>5</td>
<td>16.7</td>
</tr>
<tr>
<td>109 - 119</td>
<td>2</td>
<td>6.7</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>30</strong></td>
<td><strong>100.0</strong></td>
</tr>
</tbody>
</table>

Note. The PPUS-FM consists of 31 items each scored from 1 - 5. The minimum possible score is 31 and the maximum possible score is 155. Midrange uncertainty score is 93.

There are four subscales of the uncertainty scale. Factor means and item means for each subscale identify areas of higher and lower uncertainty (see Table VIII).

Table VIII

PPUS-FM Factor and Item Means

<table>
<thead>
<tr>
<th>Factor</th>
<th>Items in the Factor</th>
<th>Factor Mean</th>
<th>SD</th>
<th>Item Mean</th>
</tr>
</thead>
<tbody>
<tr>
<td>I Ambiguity</td>
<td>13</td>
<td>40.13</td>
<td>8.3</td>
<td>3.09</td>
</tr>
<tr>
<td>II Lack of Clarity</td>
<td>9</td>
<td>19.57</td>
<td>5.79</td>
<td>2.17</td>
</tr>
<tr>
<td>III Lack of Information</td>
<td>5</td>
<td>11.90</td>
<td>3.35</td>
<td>2.38</td>
</tr>
<tr>
<td>IV Unpredictability</td>
<td>4</td>
<td>15.20</td>
<td>3.09</td>
<td>3.80</td>
</tr>
<tr>
<td><strong>Total Scale</strong></td>
<td><strong>31</strong></td>
<td><strong>86.8</strong></td>
<td>20.53</td>
<td></td>
</tr>
</tbody>
</table>

Note. Possible range of scores in each factor are as follows: Factor I (13 - 65), Factor II (9 - 45), Factor III (5 - 45), Factor IV (4 - 20). Item means are scaled 1 - 5.
The item means for the factors of ambiguity and unpredictability reflected the highest uncertainty.

Research Question 2: What is the relationship between uncertainty and the level of illness severity perceived by family members of critically ill ICU patients?

The family member's perceived level of illness severity for their critically ill ICU patient was measured with a 100 mm visual analogue scale which ranged from not serious to very serious. The frequency and distribution of the subjects' overall perception of illness severity were examined (see Table IX). Subjects' rating on the visual analogue scale ranged from 34 mm to 100 mm ($M = 83.8, SD = 17.63$). The majority (76.6%) of the 30 subjects rated their perception of illness severity 81 mm or greater. Four subjects (13.3%) perceived an illness severity with ratings of below 61 mm.

Table IX

<table>
<thead>
<tr>
<th>Rating</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 - 10 (not serious)</td>
<td>0</td>
<td>0.0</td>
</tr>
<tr>
<td>11 - 20</td>
<td>0</td>
<td>0.0</td>
</tr>
<tr>
<td>21 - 30</td>
<td>0</td>
<td>0.0</td>
</tr>
<tr>
<td>31 - 40</td>
<td>1</td>
<td>3.3</td>
</tr>
<tr>
<td>41 - 50</td>
<td>1</td>
<td>3.3</td>
</tr>
<tr>
<td>51 - 60</td>
<td>2</td>
<td>6.7</td>
</tr>
<tr>
<td>61 - 70</td>
<td>1</td>
<td>3.3</td>
</tr>
<tr>
<td>71 - 80</td>
<td>2</td>
<td>6.7</td>
</tr>
<tr>
<td>81 - 90</td>
<td>10</td>
<td>33.3</td>
</tr>
<tr>
<td>91 - 100 (very serious)</td>
<td>13</td>
<td>43.3</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>30</strong></td>
<td><strong>100.0</strong></td>
</tr>
</tbody>
</table>
The relationship between perceived level of uncertainty and perceived level of illness severity using Pearson's Product Moment Correlation Coefficient was \( r = -0.02, p = 0.914 \). This indicated there was no statistically significant relationship between the family member's total uncertainty score and the perceived seriousness of their relative's illness. However, the direction of the correlation was negative. Correlations between perceived severity of illness and scores on Factor II (\( r = -0.06, p < 0.74 \)) and Factor III (\( r = -0.22, p < 0.226 \)) of the uncertainty scale, although not statistically significant, supported this negative trend.

Additional Findings

Other analyses were performed for the purpose of identifying relationships between uncertainty and family member age, gender, educational level and patient age and gender. The Pearson Product Moment Correlation was used to correlate the relation between the continuous variables of uncertainty scores and age in years. Point biserial correlations were used to correlate the relationships between uncertainty and the family member categorical data related to gender, education level, relationship to patient and ICU experience. Point biserial correlation provides a measure of relationship between a continuous variable and a two-categorized, or dichotomous variable
Ferguson, 1966). Categorical data for education level and the family member’s relationship to the patient were converted to dichotomous data because of the small number of participants in each category. Education level was changed to above and below high school and the family member’s relationship to the patient was grouped as spouses and other. The findings of these correlations are summarized in Table X.

Table X

**Correlations of Total Uncertainty and Uncertainty Factors and Other Demographic Variables**

<table>
<thead>
<tr>
<th>Demographic Variable</th>
<th>Uncertainty Factors</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1</td>
</tr>
<tr>
<td><strong>Pearson’s r:</strong></td>
<td></td>
</tr>
<tr>
<td>Family Member Age</td>
<td>.15</td>
</tr>
<tr>
<td>Patient Age</td>
<td>.10</td>
</tr>
<tr>
<td>No. of ICU days</td>
<td>.02</td>
</tr>
</tbody>
</table>

| Point Biserial rpbij:|   |     |     |     |       |
| Family Member        |   |     |     |     |       |
| Gender               | -.09| -.37*| -.09| .05 | -.19 |
| Education Level      | .10| -.13| -.03| .39*| .07  |
| Relationship to      |   |     |     |     |       |
| Patient              | .07| .39*| .09 | -.20| .16  |
| ICU Experience       | .00| .16 | -.04| -.10| .03  |
| Patient Gender       | .05| .23 | .04 | -.05| .11  |

**Note.** Two-tailed significance, * p < .05

Uncertainty Factor 1 = Ambiguity,
Factor 2 = Lack of Clarity
Factor 3 = Lack of Information
Factor 4 = Unpredictability

No significant relationships were found between uncertainty and age and uncertainty and previous ICU experience (see Table X). Three statistically
significant relationships were found between the uncertainty factors and the variables of gender, education level and relationship to patient. First, a positive correlation was found between spouses' uncertainty scores and the uncertainty factor of lack of clarity ($r_{pbi} = .39$, $p = .035$). In addition, there a negative correlation was found between males' uncertainty scores and the uncertainty factor of lack of clarity ($r_{pbi} = - .37$, $p = .042$). Finally, a positive correlation was found between the uncertainty factor of unpredictability and the uncertainty scores of family members who had less than Grade 12 education ($r_{pbi} = .39$, $p = .033$).

**Research Question 3: What are family members' perceptions of factors related to uncertainty specific to the ICU experience?**

Content analysis of the data was used to determine the factors related to the uncertainty perceived by family members of critically ill ICU patients. Responses which reflected not knowing, not being sure, not being clear, vagueness, being in doubt, being undecided, and unable to rely or count on someone or something were used to identify uncertainties perceived by the family members. Sixty four uncertainties specific to the ICU and general illness experience were identified (see Appendix J). The list of uncertainties
is helpful to visualize the wide range of uncertainties experienced by family members during the ICU experience. However, this list does not adequately reflect specific factors which contribute to family members' perceptions of uncertainty. Thus, the data were further explored to identify common themes. Three major themes related to family members' perceptions of uncertainty were identified from the interview data: the illness/treatment situation, the environment and system of care, and family member functioning. A number of subthemes which reflected factors related to family members' perceptions of uncertainty were identified in each of the three themes. Table XI on the following page displays the themes and factors which were related to family members' perceptions of uncertainty. The factors in each major theme will now be presented in the context of the supporting family members' perceptions of uncertainty.

Illness/Treatment Situation

The first major theme included those factors which influenced family members' perceptions of uncertainty related to the patient's illness or treatment situation. Factors included: the critical condition of the patient, the cause of the condition, the expected course and treatment plan, monitoring the patient's progress, making treatment decisions, and future outcome.
Table XI

**Themes and Factors Related to Family Members’ Perceptions of Uncertainty**

<table>
<thead>
<tr>
<th>Themes</th>
<th>Factors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Illness/Treatment Situation</td>
<td>Critical condition</td>
</tr>
<tr>
<td></td>
<td>Cause of the condition</td>
</tr>
<tr>
<td></td>
<td>Expected course/treatment plan</td>
</tr>
<tr>
<td></td>
<td>Monitoring patient’s progress</td>
</tr>
<tr>
<td></td>
<td>Making treatment decisions</td>
</tr>
<tr>
<td></td>
<td>Future outcome</td>
</tr>
<tr>
<td>The Environment and System of Care</td>
<td>Quality of care</td>
</tr>
<tr>
<td>Family Member Functioning</td>
<td>Relationships with health care providers</td>
</tr>
<tr>
<td></td>
<td>Locating resources</td>
</tr>
<tr>
<td></td>
<td>Physical/emotional responses</td>
</tr>
<tr>
<td></td>
<td>Supporting the ICU patient</td>
</tr>
<tr>
<td></td>
<td>Supporting family members</td>
</tr>
<tr>
<td></td>
<td>Role conflict</td>
</tr>
<tr>
<td></td>
<td>Uncertain future</td>
</tr>
</tbody>
</table>

**Critical condition of the patient.**

Family members spoke of the patient’s condition as: "really bad, very critical, unstable, very serious, potentially fatal, a delicate balance". Most of the family members directly or indirectly acknowledged the possibility that the patient might not survive. All family members but one acknowledged the patient’s condition was serious. The fact that the patient was in ICU underscored the precariousness of the patient’s condition. One family member described the admission of the patient to the ICU as both overwhelming and comforting:
"It had sort of a double meaning....to see all this equipment and know that skilled people are here to use it and understand it and do all that was wonderful ... but the fact that he had to be here was something else again, because it really did point that he was very, very ill to have to be here".

The occurrence of unpredictable complications, such as infections, relapses and secondary organ failure, contributed to the family members' perceptions that the patient's condition was critical. Although over half of the family members had a clear perception of the patient's complications and treatment plan, the remaining family members were vague about the complications that existed or how they would be treated. Ambiguity seemed most prevalent when the information about the condition was unclear or did not exist. The following response by a daughter whose mother experienced one complication after another illustrates this perception:

"they don't seem to know, I don't know what information they could give me, yeah I guess it would really help if they could find something and then provide me with the information".

The extent of the complications was particularly worrisome if the family member perceived vital organs, such as the brain or liver, were involved. Some family members actively sought information on the extent of the complications while others openly admitted to avoiding such information. One family member whose
father appeared to have developed a growth in his lungs said "maybe if I don’t ask it will go away".

The degree of uncertainty appeared to be related to the extent to which complications or changes in the patient’s condition could be controlled by health care providers. One family member who perceived her father’s situation as extremely precarious indicated "...there’s so many other things that are going on that they feel like they’re not on top of them all". Another family member whose husband’s condition had stabilized stated "the technicians and doctors they really didn’t know what they were working with at first...a lot of things were out of control, but then it did settle down one thing at a time as it was brought under control".

Cause of the Condition.

Uncertainty appeared to increase when family members did not know the cause of the patient’s condition. Most family members were able to clearly state the patient’s primary diagnosis. However, a number of family members did not know what caused the patient’s original problem or subsequent complications. The following responses from two different family members illustrate the family members’ desire to know what caused the patient’s condition:

"Knowing that, now that he has the cancer and that there is a chance with the chemotherapy that he could respond to it, gives us some hope... it’s still a waiting game, but I do feel more positive ... I feel now that at least we have something to go on..."
"I'm unsure of what's happening and it's because they're not sure what's happening with her ... and that's worrisome, cause I guess they haven't got down to the underlying cause..."

In a similar vein, family members of two patients who were trauma victims struggled to identify a reason for the trauma. The attempt to make sense of the situation by one of these family members is reflected in the following response:

"my husband has always been there, he's been an excellent husband really and a very good father, I think that's why my kids are all so upset they don't understand why this happened... in fact, I don't understand either, and I know this is a question we'll never have answered... why did it happen?"

In the situations where the cause of the illness or reason for the injury remained unclear, family members struggled for answers. Feelings related to an appraisal of the situation as a threat, such as anxiety, stress, and occasionally guilt were evident.

Expected course and treatment plan.

All family members in the study were eager to obtain information which would help them to predict the expected course of illness and treatment. The majority of family members perceived they were as well-informed as they could be given the uncertainty and complexity of the patient conditions. Family members felt particularly well-informed about the expected treatments and procedures in ICU. However, they perceived a lack of information about the expected course of illness, particularly in the long-term. Some
family members acknowledged it was not always possible for health care providers to predict this information with any certainty. The wife of one ICU patient said:

"I think really the questions that I want answered are questions that they can’t answer yet, like they don’t know if his voice box... has it been damaged is he going to have to learn to talk all over again... things like this I wonder about but they can’t answer that there is too much swelling... it's too soon to tell"

Responses to the uncertainty associated with "not knowing" the expected course ranged from resignation to frustration. Two family members who felt very uninformed about the future course of illness and treatment had been coping with the patient’s chronic illness prior to the ICU experience. A third family member who also expressed an intense desire to know the expected course did not yet have a definitive diagnosis despite a total stay in hospital of nine days. All three family members expressed uncertainty about the patient’s progress.

Family members varied in their preoccupation with the uncertainty associated with not knowing the patient’s future course or treatment. For the most part, the family members of patient focused on obtaining information about the immediate course and treatment plan. Family members found it helpful to know the expected stages or steps which might occur during the patient’s ICU stay. One family member found it reassuring to predict what steps
might occur next:

"reassuring to, the goal in my mind was to find out what was wrong and then we found out what was wrong, the next goal is to see how he manages with the chemotherapy and if that progresses fine, then the next goal to see him get off the ventilating machine, we're doing it step by step"

**Monitoring the patient’s progress.**

Monitoring the patient’s progress to draw conclusions about condition and treatment constituted the fourth factor which influenced the family members’ perceptions of uncertainty in the illness/treatment situation. Family members assessed the patient’s progress by observing for signs that the patient was returning to "normal". These observations primarily centered about everyday signs such as the patient’s physical appearance, level of responsiveness, and ability to eat, drink or breathe. In addition, a few family members attempted to interpret treatment changes, such as a decrease in the amount of pain medications. Family members usually relied on physicians and nurses to clarify their questions about the patient’s progress. However, at times, some family members placed more emphasis on their own assessment of the patient’s progress or depended on the observations of other family members to form conclusions. The accuracy of their conclusions varied. Signs which were ambiguous tended to result in uncertainty, while more distinct signs decreased family members’ perceptions of
uncertainty. Responses from two different family members illustrate these findings:

"Today for the first time I picked up his hand and gave a supportive squeeze like I’ve done in past days and received no response but today I received a squeeze back that said he’s there and he looks, you can see his eyes, there’s life and presence behind his eyes, it’s not doing slates [sic]...we know it’s a positive progression, it seems to be that he’s making positive steps"

"His legs kind of thrash and he keeps lifting his arm, trying to get it to his face so we know that there is pain in the face...I don’t really know at this point, how much he really knows its pain or just an agitation, like hair falling on your face"

Family members experienced particular difficulty in interpreting symptoms related to the patient’s level of consciousness or responsiveness. Family members became anxious or worried if they concluded there was a possibility that the patient might be in pain or emotional distress.

In addition to monitoring the patient’s physical signs, family members sought to evaluate treatment effectiveness through their knowledge of the expected course, time frames and the results of tests.

Two family members commented:

"I’m anxious to see what the cat scan shows, and if there are any new things that we have to think about or be concerned about or new things to decide...it’s one of those things we like to say, we’ll know more after the scan, so you let the scan be the milestone..."

"By the end of this treatment by Sunday or Monday we should have some indication of how well he is responding..."
Making treatment decisions.

Another factor which related to uncertainty in the illness/treatment situation was the making of difficult treatment decisions by family members. Several family members in the study expressed doubts about decisions they had made to commence or continue treatment. Family members wondered if they had sufficient knowledge about the patient's wishes and the eventual prognosis to make decisions which were in the patient's best interests. In addition, these family members questioned if it was morally right for them to make critical life and death decisions on behalf of the patient. Decisions were particularly difficult if the family member perceived there was a possibility that the patient was suffering or might suffer. The agony experienced by one family member is captured in the following quote:

"We know mum's seriously ill and we say that we have doubt whether we should have allowed her to go peacefully or continue giving her treatment, the bottom line is how much is she hurting, how much is she aware, is she still angry at me?.... right now its okay for a few days....let's carry on but make sure she doesn't hurt, make sure she doesn't hurt, make sure she doesn't hurt, its all we ask..."

Future outcome.

The final factor related to uncertainty in the illness/treatment situation which was acknowledged by all family members was uncertainty about the patient's
outcome. This uncertainty varied widely from vague statements about "not knowing the future" to specific questions about future complications, disability or quality of life. A number of family members directly or indirectly indicated the prevailing concern related to future outcome was not knowing if the patient would live or die. This uncertainty so overwhelmed several family members that they had difficulty moving beyond the present to contemplate the future. One family member’s comments illustrate this finding:

"this could be it, he might not come out this time, so its, I mean when he comes out then it will be a bonus to have him home again. I haven’t even really thought about that, even just getting out of the ICU up to another ward, I haven’t even..."

A number of family members wondered if the patient would have future complications or disabilities. Most family members acknowledged it was "too soon to know". Some of these family members tried to put these concerns to the "back of the mind", while others monitored the patient’s condition for signs that the patient was returning to "normal".

Four family members had been alerted to the possibility that the patient might have suffered a brain injury. This uncertainty was perceived as disturbing for the family members who collectively had very negative beliefs about brain injury. In addition, these ICU patients had varying levels of responsiveness
making it difficult for the family members to interpret progress.

Almost all of the family members expressed doubts about the patient's eventual quality of life. Family members' responses indicated a good quality of life involved "returning to normal activities, no major mental or physical disability, no major pain or suffering". Doubts were primarily related to the family member's perception that the patient was or had been so seriously ill that they may never be able to achieve full recovery. In addition, the family members who had expressed doubts about making treatment decisions for the patient were particularly concerned about the present and future quality of the patient's life.

The Environment and System of Care

The second major theme related to family members' perceptions of uncertainty was the critical care environment and system of care. Responses indicated that the majority of family members perceived minimal uncertainty about unfamiliar routines, procedures or technology. Family members attributed this perception to "feeling comfortable, informed, reassured" in the ICU setting. Factors which influenced family members' perceptions of uncertainty about the environment and system of care included: quality of care, relationships with health care providers, and locating resources.
Quality of care.

Family members' responses indicated the perception of a high quality of care in ICU was related to health care provider competency, caring approach, and the use of high technology. Most family members perceived that health care providers in the ICU were highly knowledgable and competent. They relied on health care providers to maintain "control" over the patient’s precarious condition. Some family members felt reassured by the presence of highly visible staff in sufficient numbers to handle sudden changes in condition or emergencies.

The majority of family members also perceived a high quality of care related to the caring and empathetic attitude demonstrated by health care providers towards the critically ill ICU patients. Talking to the patient who may or may not be aware, relieving the patient’s pain, and touching the patient were examples of behaviours viewed as caring by family members. Uncertainty was modified when this caring approach was extended to family members as well as patients. The importance of a caring approach towards family members is reflected in the following response:

"they’re concerned about us, this is their job, we are almost one, a larger group than my brother, he’s the patient and of course the main concern, but they are embracing the whole family as a unit ...they’re there to help and its very supportive"

Receiving regular updates about the patient’s condition
and progress, being allowed access to the patient and feeling that the staff were concerned about the family member were viewed as caring behaviours towards family members.

Family members also perceived the high quality of care in ICU was related to the use of technology. Most family members acknowledged that seeing the patient in ICU surrounded by tubes and monitors was initially overwhelming. Family members spoke of technology as "having a purpose, a necessary procedure, keeping things under control, providing information." In addition to relying on health care providers' interpretations of technology and related changes in the patient's condition, some family members acknowledged attempting to interpret monitor readings on their own. Some family members used this information to draw conclusions about the patient's condition and progress; others drew no conclusions but felt a sense of control when they attempted to "make sense of what was going on".

Some family members perceived that they felt "much safer when the patient was hooked up to machinery". This perception was particularly evident in the uncertainty expressed about discontinuing "life support" technology, such as the mechanical ventilator. While the majority of family members expressed faith in technology, one family member who had previously
experienced the death of a child in a pediatric ICU, expressed doubts about the use of technology to prolong life.

The majority of family members expressed great confidence in the overall quality of care provided by ICU staff. However, a few family members had doubts about the specific actions of some health care providers. For example, one family member expressed concern about an "unexpected" complication in the operating room. She was not sure she was receiving the "full story" about this complication and indicated she was not "totally happy with the physicians and their approach to the family". Some family members perceived doubts when they observed behaviour which was not congruent with their expectations of ICU staff. For example, one daughter was uncertain when the physician and nurse did not appear to collaborate on the plan of treatment. She commented:

"How come she [the nurse] didn’t know that, how come you guys [physicians and nurses] don’t get it together, he [the physician] told me not to do it and now you’re doing it..."

Although family members rarely criticized the quality of care provided by ICU staff, they were less reluctant to express concerns about the quality of care delivered outside the ICU setting. Several family members were perplexed how the patient reached such a "state of crisis" on the ward before they were
transferred into the ICU. Other family members perceived uncertainty and anxiety about the eventual transfer of the ICU patient to the ward. They doubted that there would be sufficient staff or technology outside the ICU setting to adequately assess or monitor their ICU patient.

**Relationships with health care providers.**

Family members depended on the health care providers to manage the patient’s critical condition, to keep them informed, and to allow them access to the patient. Some family members placed their trust globally in all health care providers; while others felt more comfortable when they interacted with a consistent physician or group of nurses.

Uncertainty increased for some family members when they were unsure of the health care provider’s identity or scope of responsibility within the staff or hospital hierarchy. One family member commented:

"it would be nice to have a nametag or RN or JP or whatever, whatever their name is...I wonder who they are, what they’re objectives are..."

Information from health care providers played a major role in modifying the uncertainty experienced by many family members. Unanswered questions primarily related to future complications or prognosis. Most family members perceived they had received "lots of information" during the ICU experience. One family member commented:
"I’m beginning to learn all kinds of medical knowledge I never knew before, being that you can understand some of the equipment and know what they’re doing when they are doing it, not really knowing, but kind of having an idea what is going on...And I think that’s because while they’re doing things, they’re giving you information and I think that’s really important..."

A number of factors influenced the extent to which family members felt they could rely on the information conveyed by health care providers. All family members in this study indicated they wanted to hear honest and accurate information from health care providers. The majority of family members stated they wanted to hear the "good news and the bad news", although responses indicated that one or two family members avoided asking questions if they thought the response might be negative. Reports which were inconsistent tended to increase uncertainty about the reliability of information. The perception of inconsistency seemed to emerge when family members were receiving information from a number of different health care providers. Some family members perceived that although the content of the information was essentially the same, the tone of communication or degree of optimism varied with different health care providers. The responses of two family members reflect this perception:

"the doctors would come in and say you’re making lot of progress...and another one would come in oh, there’s not much change, they might be talking about relatively the same thing its just that it seems one person sees it different from another ...I don’t quite know what, who I should really believe"
"this doctor said, its almost like he said the same things that the doctor said yesterday only he looks... I don’t know maybe he just looks at the silver lining, not the clouds and stuff".

The latter family member monitored the patient’s appearance in an attempt to reconcile conflicting information:

"you know, its like the doctor saying that he’s better today and when I look at everything, everything seems to be the same...everything looks the same and he looks worse so I try to straighten it out in my own head"

The majority of family members indicated they wanted to hear specific information about the patient’s treatment or condition. Some family members were distressed when they perceived information was "glossed over" or the health care provider simply stated "don’t worry" in response to specific questions about the patient’s treatment or changes in condition. In these instances, family members felt their right to full disclosure of information had not been acknowledged.

Family members relied on physicians to provide them with information about the patient’s condition, treatment plan, and prognosis. In contrast, family members relied on nurses to provide them with information on the patient’s current status, changes, procedures and the daily treatment plan. Most family members perceived that information was offered freely and regularly by medical and nursing staff. The following comments by two family members reflect
this perception:

"whenever anybody comes in they usually explain to my father or to us what they are doing...its almost like they’re teaching a class on the side"

"the doctor came over and introduced himself and wondered if we had spoken to any of the staff that day and he was just bring us up to date and I thought that was really great you know, that he came over to us without us having to go search him out"

Although most family members perceived there was an abundance of information, the occasional family member experienced uncertainty which primarily seemed to be related to accessing specialists within the ICU setting. One daughter whose mother was cared for by multiple specialists stated:

"I’m not sure who is in charge of her [the patient] they don’t tell you which specialty they are with and that makes it difficult as there are a number of them...so its difficult to get questions answered"

Family members also depended on health care providers for support. Support for many family members meant being made to feel welcome and "involved". This meant they were free to ask questions, had frequent access to the patient, and were considered an important part of the patient’s illness experience by health care providers. The following responses made by different family members of ICU patient illustrate the importance of this involvement:

"making us feel comfortable to be close to him and not saying don’t touch this or that, its very supportive...making us feel like we’re not intruding, not in her working space, and we have a right to be here and we feel welcome"
"I realized I was involved and I could ask them almost anything...and I thought that was good...I don't feel totally as if I'm somebody who comes in now and then...I have some understanding of what is going on and what the plan is"

The family members relied on nurses to facilitate access to the patient. The majority of family members experienced conflict between their desire to be with the patient and not "bothering" health care providers who were providing essential care to the patient. Some family members felt uncomfortable using the intercom or phone to obtain access to the ICU. Uncertainty about the patient's condition tended to increase when family member's perceived they had been waiting an unduly long time or if they had been "forgotten" in the waiting room.

**Locating resources.**

In discussing the final factor about the environment or system of care, almost all the family members in the study experienced uncertainty related to locating resources in the unfamiliar health care environment. Receiving an orientation to the physical layout of the hospital seemed to minimize uncertainty for some family members. Some of these family members were not sure how to find reasonably inexpensive and accessible facilities to eat, sleep or park, or where to turn to for spiritual or emotional support. Others appeared hesitant to ask for help or information.
Some family members relied heavily on friends and family to help them meet practical concerns such as transportation or childcare or for emotional support. Those family members who came from large families or close-knit communities commented on the importance of this support. One family member demonstrated reliance upon support from family members which seemed to be related to his cultural background. He perceived he could count on "extended family", who were "flying in from all over the globe", to help him with future care of his mother as long as necessary.

Particularly striking were situations in which family members had to relocate to be near their family member. These family members experienced uncertainty related to an unfamiliar hospital environment and city. In addition, some family members spoke of "missing their usual family and friends". One family member who was from a small town and alone in the city stated: "if I didn’t have a place to stay, what would I do, sleep on a park bench?...the first few days I was so scared, scared to walk to the bus stop, scared to get on the bus...".

Family Member Functioning

The third and final major theme identified was family member functioning. Family members' responses revealed that all family members experienced disruptions in family roles, responsibilities and
functions in response to the critical illness of a family member. Common factors in the theme of family member functioning which related to uncertainty were: physical and emotional responses, supporting the patient, supporting family members, role conflict, and an uncertain future.

Physical and emotional responses.

The subjects experienced a wide range of physical and emotional responses to the stress of having a family member in the ICU. A number of family members spoke of experiencing a state of disbelief. One family member commented: "I dwell between the reality of it and the unreality". Emotional responses primarily included worry, anxiety, fear, helplessness, confusion and despair. Associated physical responses included exhaustion, gastrointestinal upset, nervous tension, and difficulty sleeping or eating. Family members worried about the impact of the illness on their own physical and emotional health. Some family members were not sure they could keep going to support the patient and other family members. The daughter of one of the ICU patients stated "I just about passed out, I haven’t had that before and I’m thinking I’ve got to keep my own health, so many people depend on me".

Although most of the preceding responses reflect a negative appraisal, some family members spoke of
feeling hope. In particular, they expressed the belief that a positive outcome was possible.

Supporting the patient.

All family members in the study perceived their role as protecting and supporting the patient. Personal needs and concerns were submerged as family members focused all their energies and concern on the patient. Family members were primarily concerned with "being there" for the patient. One family member, speaking on behalf of his family, stated that just being there "put us at ease, to know we're in a position of control or at least know we're doing all we can". Family members experienced less uncertainty about performing this role when, as described previously, they were made to feel welcome and "involved".

Family members also viewed an important part of their role in supporting the patient was to protect the patient. Family members perceived uncertainty about the patient’s ability to cope with the impact of the illness. The family members made every effort to protect their ICU patient from information or decisions which might be upsetting. The family members spoke of "being strong, controlling emotions, and communicating an optimistic outlook" to the patient. Some family members experienced a sense of helplessness about protecting the patient when they perceived the patient might be in pain or distress.
Supporting family members.

Subject responses indicated that the threatened potential loss of a member impacted on all members of the family. Subjects talked about disrupted home routines, the emotions of other family members, and shifting family responsibilities. Some subjects experienced uncertainty about the impact of the illness on the physical and emotional health of other family members, particularly children. Others experienced uncertainty about communicating information which they did not fully comprehend at times to other family members. The subjects varied in their ability to extend their support beyond their ICU patient to include other family members.

Role conflict.

Family members’ responses indicated that most of the family members experienced role conflict as they tried to balance multiple roles such as going to work, supporting the patient, supporting other family members, and meeting their own needs. Most family members experienced doubts about leaving the patient to fulfill other responsibilities. Family members were afraid that the patient might not survive or might be frightened if they awoke in the ICU environment. The role conflict experienced by one of the family members is reflected in the following comment:
"when I'm here I think about the kids, and when I'm with the kids, I think I should be next to her....I hate to think that there's no one around her when she becomes somewhat aware"

**Uncertain future**

Family members varied considerably in their ability to project the impact of an uncertain future. Some family members spoke of "not being able to predict the future", while others spent considerable time anticipating changes that might be required in their own life and by the family as a whole. Family members' uncertainty about the impact of the illness on their future seemed to be related to their role and the patient's role in the family unit. For example, the family members who had been primary caregivers to the patient prior to the ICU admission were not sure they would be able to care for the patient in the future. One family member whose husband was self-employed was particularly concerned about the financial impact of potential long-term disability.

Most family members talked about placing their "lives on hold" for the present. Not being able to predict the future impacted on the ability of family members to make decisions for themselves or the family as a whole. Some family members perceived uncertainty about making major decisions without the input of the hospitalized family member. Other family members perceived uncertainty about having to take over
shifting responsibilities. In general, only the most essential decisions or changes had been made at the time of the interview.

Summary

A description of the characteristics of the sample and the findings of the study has been provided in this chapter. First, demographic characteristics of the family member sample and the associated ICU patients were reported. Findings related to each of the three research questions were also presented. In the chapter to follow, the findings which have been presented will be discussed in relation to the theoretical framework, research studies, and problems inherent with the study methods.
CHAPTER FIVE
Discussion of Findings

Introduction

The findings of the present study, representing family members’ perceptions of uncertainty during the ICU experience, are discussed in relation to the theoretical framework, other research studies and problems related to the study methods. The discussion consists of five sections. In the first section, characteristics of the sample are discussed. The second section addresses findings related to the level of uncertainty perceived by family members. The relationship between illness severity and uncertainty is discussed in the third section. This is followed by a discussion of the factors within the ICU experience which influenced perceptions of uncertainty. The chapter concludes with a discussion of the family members’ appraisals of uncertainty.

Characteristics of the Sample

The sample, with respect to age, gender, and previous ICU experience, appears representative of the typical sample accessed in the majority of family needs studies. The sample was predominately female (63.3%), had experience in the ICU setting (63.3%), and reflected a wide distribution of subjects’ ages (M = 47.1, range = 29 - 73 years).
The study sample appears dissimilar from previous family needs research samples with respect to the level of education and relationship to patient. Almost half (48.7%) of the study sample was represented by spouses, while the category of parents was quite small (13.4%). It is difficult to explain this finding as no details were available to the investigator on the reasons why some family members chose or did not choose to participate in the study. The investigator noted during discussion with family members that a number of families selected the family member to participate who was viewed as "closest to the family member" and/or was the family spokesperson. In addition, the family member who "needed to talk" may have been encouraged to participate in the study. It may be that this person is typically the spouse of the ICU patient.

The educational level of the sample was high. Eighteen family members (60.0%) of the sample had attained an education at the university or college level. As the education level of those family members who did not participate is unknown, it is difficult to know if education level influenced participation in the study. The majority of the subjects were employed (80%). This finding is consistent with the mean age of the sample (M = 47.1 years).

Subjects in this study were primarily Caucasian despite an attempt to recruit subjects from different
cultures. The responses of one family member who had emigrated to Canada a number of years ago suggested some differences in the dimension of culture. Overall, however the sample was very limited from a cultural perspective. It is possible the criterion of fluency in English may have limited recruitment of family members from other cultures. The subjects who were born outside of English speaking countries considered English to be their primary language.

Many family members in the study sample (40%) had relocated on a temporary or permanent basis from their hometown to the Vancouver region. Five subjects (20%) spent considerable time travelling between their hometown and the hospital.

The patient sample in this study is representative of the typical ICU patient population at Hospital B. ICU statistics at Hospital B, for the period from April 1, 1992 to March 31, 1993, indicate patients' ages (n = 657) ranged from 16 - 92 years of age (M = 52, SD not reported). These statistics also indicate a wide variation in the types of medical diagnoses admitted to the general medical-surgical ICU. No statistics were available from Hospital A.

The Perceived Level of Uncertainty

This section will discuss the perceived level of uncertainty for family members of critically ill adult ICU patients and possible reasons for variations in
perceived uncertainty. It concludes with a discussion of the uncertainty instrument in terms of reliability and difficulties which were encountered with data collection.

**Total Uncertainty Scores**

This sample of family members of adult critically ill ICU patients perceived levels of uncertainty that ranged from 53 - 119 \((M = 86.8, \ SD = 16.3)\). Subjects scores on the PPUS-FM appear to reflect moderately high levels of uncertainty compared to normative data (Mishel & Epstein, 1990). The range and standard deviation of family members' scores reflect wide variability in the measured level of uncertainty.

It appears subjects' scores in this study fall somewhere in between the mean uncertainty scores perceived in the studies reported by Mishel & Epstein (1990) and McDonald (1992). Mishel & Epstein (1990), reported 42 parents of critically ill newborns perceived mean uncertainty scores of 76.3 \((SD = 20.4)\) as measured by the 31 item Parent Perception of Uncertainty Scale (PPUS). In contrast, McDonald (1992) reported family members of critically ill adult brain-injured patients in the ICU perceived high levels of uncertainty as measured by the 31 item PPUS-FM \((M = 98.2, SD = 12.26, \text{ range} = 61 \text{ to } 116)\).

One factor that may explain the moderately high levels of uncertainty in this study may be related to
the events in the critical care illness experience which are novel and unfamiliar. Mishel (1988) suggests familiarity with the health care environment is developed over time and through experience in a setting. The level of uncertainty in the present study was measured within the first 7 days of the ICU experience, with the exception of 3 subjects where uncertainty was measured at 8 or 9 days. Study findings indicated that uncertainty was not correlated with previous ICU experience. While some subjects reported previous ICU experience was very helpful, other subjects perceived the current ICU settings as alien to their past ICU experiences.

Another factor which may have contributed to the moderately high levels of uncertainty may be the intense emotional states experienced by family members. Similar to other research studies which have studied family members’ perceptions of the critical care illness experience (McDonald, 1992; Mirr, 1991; Titler, Cohen, & Craft, 1991), family members in the present study experienced emotions such as disbelief, anxiety, helplessness, and fear. High threat situations can impair the individual’s ability to process information which may ultimately elicit uncertainty (Mishel, 1988).

As noted in Mishel’s (1988) theory, another reason for the uncertainty may be a function of the incongruence between what is expected and what is
experienced. Family members may have initially held the view that a positive outcome was possible (McClowry, 1992). However, as time went on family members who were interviewed (n = 12) acknowledged that the patient's illness situation was fraught with unpredictable complications and setbacks. Uncertainty may have been generated as family members realized the patient's situation may not be readily cured, and thus expectations and experience were incongruent.

The moderately high levels of uncertainty may also have been related to the subjects' difficulty in interpreting or making sense of the patient's ambiguous symptoms or complications. Many of the patients in the study were unconscious or unable to communicate which may have made it difficult for family members make sense of the patient's condition. Interviewed subjects' reports also suggest that moderately high levels of uncertainty may have evolved when family members received information which conflicted with their view of the patient's appearance or condition.

The moderately high levels of uncertainty may have also been a function of how aware the family members in this study were of the clinical uncertainty associated with illness. Davis (1960) states that "as in all applied fields of endeavour, medicine deals in probabilities rather than absolutes" (p. 43). Clinical uncertainty is related to actual difficulties in
determining diagnosis and prognosis (McIntosh, 1974). Many of the subjects who participated in the exploratory interviews acknowledged the inability of medicine to provide all the answers. Comments such as "I don’t know but then nobody knows ....the questions I want answered [refers to outcome of multiple injuries] they can’t answer yet" illustrate family members’ awareness of the clinical uncertainty associated with critical illness.

An additional explanation for the moderately high levels of uncertainty may be related to the significant number of spouses (48.7%) in the sample. There was a statistically significant positive relationship between spouses and the uncertainty factor of lack of clarity ($r_{pb1} = .39, p = .035$). Although all subjects in the study acknowledged a close relationship to the ill family member, it is possible the high degree of commitment perceived by most spouses may have contributed to high levels of uncertainty and threat.

Although the levels of uncertainty in the present study were moderately high, they were significantly lower than those obtained in McDonald’s (1990) study which measured levels of uncertainty in family members of critically ill brain-injured patients ($M = 98.2$, $SD = 12.26$). The differences in levels of uncertainty may be related to family members’ perceptions of the the adequacy of information. Most subjects in the
present study perceived that information was frequently offered and that they were "well-informed". In contrast, subjects in McDonald's study perceived they received "inadequate information". It is not clear if the differences in perceptions in the two studies are related to the acknowledged lack of information associated with acute brain injury resulting in ambiguous situations, or differences in the manner in which information was communicated.

Although the uncertainty scores were fairly evenly distributed above and below the mean (M = 86.8, SD = 16.26), there was variability in the levels of uncertainty perceived by some subjects in the present study. One reason for variation in the levels of uncertainty may be a function of the degree of social support perceived by family members. Mishel (1988) indicates supportive persons are essential for emotional and practical support and to facilitate the sharing of information about the unfamiliar illness experience. Over 40% of the family member sample had relocated to be near the patient in Vancouver. Family members' responses to the exploratory interviews indicated that some family members were isolated from their usual support persons and experienced difficulty in establishing links to tap into available spiritual, financial or shelter resources. The lack of available social support may have generated high levels of
uncertainty for these family members. On the other hand, other family members who spoke of their reliance on family and friends to help them "get through the ICU experience" may have perceived lower levels of uncertainty.

Another possible reason for the variation in levels of uncertainty may be related to the degree to which family members perceive they can rely on or trust health care providers. Mishel & Braden (1987) report that trust and confidence in the health care provider is one of the major means of reducing levels of uncertainty. The majority of family members who were interviewed expressed a high level of confidence in the "expert care" provided by ICU staff. However, a few family members who perceived they could not rely on health care providers may have perceived higher levels of uncertainty.

The variability in uncertainty scores may have been related to the educational level of the sample. A statistically significant positive correlation was found between the factor of unpredictability and family members who had less than Grade 12 education ($rpbi = .39, p = .033$). This suggests family members in the study who had less education perceived more uncertainty related to an inability to predict the course of illness or outcome. This finding supported previous studies (Mishel 1981, 1984) which found individuals
with lower levels of education perceive higher levels of uncertainty related to illness and the system of care. The findings of this study should be viewed with caution, however as the high education level of most subjects in the study sample may have skewed the distribution.

A final reason for the variability in uncertainty levels may have been an actual or perceived lack of information. According to Mishel (1990), there is an expectation in the Western world that "the cause of the illness can be determined with certainty and the illness can be controlled" (p. 257). The interviews revealed that some family members may have perceived uncertainty when physicians had difficulty providing a definitive diagnosis or prognosis. In addition, some family members may have experienced difficulty comprehending information which was provided. This may have been related to their previously discussed intense emotional states or the nature of the information. One family member who perceived she received inconsistent reports from multiple specialists stated: "I don't quite know what, who I should really believe". Some family members members who received "bad news" may not have acknowledged this information. According to Lazarus & Folkman (1984) paying selective attention to confirmatory information is a common response to threatening information.
Four Factor Uncertainty Scores

According to the item means of each of the four factors of the PPUS-FM, family members' perceptions of uncertainty were primarily related to unpredictability. This was followed by ambiguity, lack of information, and finally, lack of clarity. McDonald (1992) also reported that unpredictability reflected the highest level of uncertainty. Comparison of this study with McDonald (1992) is difficult because subscales scores were reported as percentage means.

The item means with higher scores suggested that family members perceived uncertainty related to their inability to predict or control the patient's illness or treatment situation or eventual outcome. Item means with lower scores generated the least uncertainty for family members in the study. The low scores on these items suggested that most family members perceived they received adequate, understandable information and that they could rely on health care providers during the ICU experience.

Discussion of the PPUS-FM

The PPUS-FM had an internal consistency alpha co-efficient of .87 reflecting high reliability. The four factors had internal consistencies ranging from .55 to .87 indicating medium reliability. This finding is consistent with four other studies which used the PPUS-FM and determined coefficients of .71 to
.91 and internal consistencies which ranged from .55 to .89. Thus, there is reasonable confidence in the reliability of the scales. However, Factor 3 (lack of information) and Factor 4 (unpredictability) have low alphas which may be a reflection of the small number of items in each of these factors.

Some subjects experienced difficulties in interpreting some of the items in the uncertainty scale. Subjects found it difficult to respond to items which referred to both doctors and nurses in the same item. In addition, the term doctor was ambiguous as it could mean resident, interne, specialist, or ICU physician. Some subjects also found it difficult to disagree with a negatively worded item. Finally, subjects' comments may indicate one or two items were not representative of the uncertainties experienced by this sample of family members.

The accuracy of the uncertainty scale in conditions of high threat may be questionable. The investigator noted that some family members found some of the items to be threatening. Consequently, some of these family members responded to some items according to what they wished to believe as opposed to what they actually felt or perceived. Mishel (1988) indicates that illusions, or beliefs constructed out of uncertainty, may help individuals to maintain an opportunity appraisal. It may be that some family
members misinterpreted some items to maintain their fragile optimism.

Uncertainty and Illness Severity

The family members perceived high levels of severity for their critically ill ICU patients with a mean score of 83.8 mm and a range from 34 mm to 100 mm. Findings revealed that there was no statistically significant relationship between perceived level of uncertainty and perceived level of illness severity. This finding supports the results of Mishel et al. (1984) who found no relationship between uncertainty and perceived illness severity in women diagnosed with gynecological cancer.

The results clearly indicate that the majority of family members perceived the ICU patient to be severely ill. It was therefore surprising to the investigator that no relationship was found between perceived illness severity and uncertainty. The finding may be attributed to a conceptual difficulty in explaining how appraisal is interrelated with illness severity and uncertainty. The level of illness severity may be vary with the type of appraisal as opposed to being related to uncertainty. For example, family members who perceive an opportunity appraisal may perceive the patient is less severely ill. However, the level of uncertainty may be low, moderate or high. This conclusion should be viewed with caution as the sample
was very positively skewed with respect to illness severity.

It is interesting to note there is a negative correlation between Factor II (Lack of Clarity), Factor III (Lack of Information) and perceived illness severity. Similar to Mishel (1983), these findings imply that with more information and understanding of the illness and system of care, judged seriousness of illness increases. This suggests that a lack of information may allow family members to maintain a more optimistic, although possibly less accurate, appraisal of the illness situation.

Family Members' Perceptions of Uncertainty

The fourth section of the discussion of findings relates to the factors which influenced family members' perceptions of uncertainty during the ICU experience. Numerous factors related to uncertainty were identified through analysis of the exploratory interviews. Many of these factors were highly individualized according to each family member's unique perception of the illness situation. However, three common themes emerged from the family members' responses which were: the illness/treatment situation, the environment and system of care, and family member functioning (see Table XI, p. 90). The first two themes fit within the Mishel (1988) theory of Uncertainty in Illness.
However, the family functioning theme is not considered within this theory.

The themes and the factors which emerged in the present study were very similar to the uncertainty themes identified by Turner et al. (1990) who explored parents' perceptions of uncertainty in the pediatric ICU. These results suggest that overall family members experience many similar uncertainties during the first week of the ICU experience, despite differences in the age of the patient.

**Role Ambiguity and Environmental Uncertainty**

There were some differences in the areas of role ambiguity and environmental uncertainty. Turner et al. (1990) found that parents perceived a high degree of uncertainty with respect to the physical environment and role performance in the ICU. In contrast, family members in the present study perceived minimal uncertainty in these areas. The subjects in both studies perceived a need to protect the ill family member. However, this need may have been felt more intensely by parents of critically ill children who perceived less confidence in the competency of health providers. In contrast, the majority of subjects in the present study perceived a high degree of confidence in the ability of health care providers to care for their ICU patient. This perception may have resulted in less environmental or role performance uncertainty.
Cognitive Schema or Map

Family members experienced difficulty in creating a cognitive schema or map by which they could interpret the illness or treatment situation (Mishel, 1988). Unexpected complications, relapses and changes in condition resulted in an unreliable and ambiguous symptom pattern which was difficult to interpret. Comaroff & Maguire (1981) state that persons who are in the hospital "seek to systemize information and construct norms against which to guage their present state and future prospects" (p.117). Family members in this study used expected stages, time frames, and their expectations of everyday norms to guage the patient's progress. Uncertainty resulted when the patient's progress was not congruent with the norms expected by the family member. In addition to their monitoring of the patient's progress, family members' were also preoccupied with knowing the cause of the patient's condition. These behaviours may have been an attempt to control or create the illusion of control over the patient's illness/treatment situation. Hilton (1988) indicates "a causal search may be an effort to predict, understand, and control threat" (p. 233).

Technology and Procedures

The family members' perception of minimal uncertainty related to technology or the physical environment may be related to their perception of
receiving adequate information. A comment made by one of the family members supports this conclusion: "it's all quite, quite clear [refers to ICU environment] they tell us everything...they're always explaining procedures as they do them". Numerous studies of family members' concerns in the ICU have identified that family members desire more information (Daley, 1984; FitzGerald, 1990; McDonald, 1992; Mirr, 1991, O'Neill Norris & Grove, 1986). Similar to conclusions found by Rukholm et al. (1991), the present study suggests it is now becoming common practice for nurses to explain the physical environment to family members at the bedside.

Social Support

Mishel (1988) indicates that social support can provide assistance which reduces uncertainty. It is interesting to note that while some family members commented on the importance of support from family and friends, others did not seem to acknowledge this area. Although some family members had benefited from interactions with pastoral care or the social worker, others perceived uncertainty related to accessing resources in the complex system of care. It may be that health care providers who were focusing on the needs of the patient may not have provided the family member with information in this area. In addition, some family members who were "in limbo" following the
impact of life-threatening illness may have been powerless to mobilise resources (Jillings, 1990). Finally, similar to family needs studies (Daley, 1984; Molter, 1979; O’Neill Norris, 1986), some family members may have viewed their needs as minor compared to patient needs. Family members who were reluctant to "bother" health care providers were concerned that they might be detracting from necessary patient care.

**Relationship with Health Care Providers**

The family member’s relationship with health care providers was critical to reducing perceptions of uncertainty about the environment and system of care. Most family members expressed great confidence or trust in the "expert care" provided by health care providers in the ICU. According to Washington (1990), trust is "seen as only possible in familiar environments" (p. 418). Therefore, the level of trust perceived by most family members was a surprising finding.

It is possible family members perceived less uncertainty as they felt they could trust the actions or words of ICU staff because they viewed the ICU staff as credible authorities (Mishel, 1988). Establishment of trust may also have been fostered by the observation of a caring and empathetic approach which was extended to family members as well as patients. Comaroff & Maguire (1981) note that "the hospital specialist may
become the object of optimistic faith" (p. 117). It is not surprising that family members were sometimes reluctant to express concerns about the competency of health care providers to the investigator. Family members' faith or belief in the health care providers was integral to maintaining their hope for a positive outcome. The majority of family members tended to minimize or excuse situations in which they doubted the actions or words of ICU staff.

**Family Member Functioning**

Many of the factors in the category of family member functioning, with the exception of the role ambiguity previously discussed, bear some similarity to the family system uncertainty reported by Turner et al. (1990). However, as aspects of family member uncertainty have received minimal investigation, differences which existed between the two studies will be highlighted.

In contrast to the caregiver role perceived by parents in the Turner et al. (1990) study, family members in the present study were more concerned with protecting and supporting the patient. Family member uncertainty evolved when family members were unable to carry out this role due to conflicting role demands or factors within the ICU setting. Family members in both studies experienced helplessness and uncertainty in situations where they were unable to comfort or
interact with the ICU patient. The importance of the protective and supportive role was particularly evident in the responses of one family member in the present study who represented a different culture. He believed the support of the extended family might be the factor which promoted a positive outcome for the patient. This finding suggests the cultural dimension related to family member uncertainty should be explored in greater depth.

The concept of family members protecting and supporting the critically ill patient is not unique. Mishel & Murdaugh (1987) noted partners caring for patients prior to heart transplant blocked their own needs and "pledged themselves to the welfare of the patient" (p. 334). In addition to monitoring the patient's physiological state, partners protected the patient by filtering information which might be upsetting. Family members in the present study performed similar protective actions.

Family members experienced uncertainty associated with making proxy treatment decisions. Family members were concerned about their ability to make decisions in the best interest of the patient, particularly as it relates to quality of life. Similar to Mirr (1991), family members experienced uncertainty related to making proxy treatment decisions when there was a lack of information about eventual prognosis. Turner et
al. (1990) did not report uncertainty related to proxy decision making. It is possible parents were more comfortable in the proxy decision maker role than family members of adult ICU patients. Family members experienced uncertainty when they made proxy decisions which could potentially prolong patient suffering. It is possible this activity conflicted with their role to protect and support the ICU patient.

Family members in both studies perceived uncertainty related to their ability to support other family members. Turner et al. (1990) noted that parents were concerned about how well they cared for children at home. Family members in this study who were parents also expressed this uncertainty. However, as family members played multiple diverse roles, such as adult children or siblings, their uncertainty was a function of their role in the family. For example, one adult son whose mother was critically ill was predominately concerned about supporting his elderly father. Given that all members of a family are impacted by the illness of a member (Jillings, 1990), it is not surprising that many of the family members felt a need to support one another. Their ability to do so may have varied because of the "tendancy of family members to focus all their energy and concern on the critically ill patient" (McClowry, 1992, p. 561).

Both Turner et al. (1990) and the subjects in the
present study did experience role conflict between their need to be with the patient and their need to perform other roles. Turner et al. suggested that the parents' role conflict was related to their doubts that health care providers could adequately care for the child in their absence. However, the family members' role conflict appeared to be related to their need to support the adult patient. This need is possibly a reflection of the intense commitment towards the ill patient which was reflected in all the family member interviews. McClowry (1992) suggests family members who feel intense cohesion or love and affection for one another are highly motivated to support the critically ill patient.

A final aspect of family member uncertainty involved predicting and managing role changes which were necessitated by the absence of the ill family members. Most family members who were interviewed had put their "lives on hold" and were making only the most essential changes. However, some family members in this study perceived uncertainty related to anticipating role changes or actually taking over essential roles traditionally performed by the ill family member. In contrast, Turner et al. (1990) perceived less uncertainty in this area. Although parents anticipated future changes, it is doubtful
they would have to take over any major responsibilities from their ill children.

**Family Members' Appraisal of Uncertainty**

Mishel (1988) notes uncertainty is a neutral state until appraisal occurs. Given the importance of appraisal in determining the family members' perception of uncertainty, this final section will briefly discuss key factors which influenced family members' appraisal of uncertainty during the ICU experience.

Each family member's appraisal of uncertainty was related to individual variables such as past illness experiences, developmental stage, personal beliefs and commitments. In addition to these unique variables, the responses of family members revealed a number of common factors which appeared to influence appraisal during the ICU experience.

The family members' need to maintain a hopeful or opportunity appraisal was consistent with the family needs studies (Leske, 1986; Molter, 1979; Daley, 1984). Miller (1991) defines hope as "a state of being characterized by an anticipation for a continued good state, an improved state, or a release from a perceived entrapment (p.307). The family members in the present study primarily focused on the specific hope that the patient would survive, although two family members expressed hope that the patient would not suffer.

The process of illusion, or the construction of
beliefs with a positive outlook (Mishel 1988), may have permitted some family members to appraise uncertainty as an opportunity. Some family members believed the expertise which was present in the ICU in the form of skilled staff and technology would "pull the patient through" the ICU experience. The belief that God or a higher being was in charge of the situation promoted hope for other family members. A few family members believed their own inner strength would in some way support the patient through the experience. Finally, most family members held the belief that a positive outcome was possible.

The belief in a positive outcome was most evident in family members who were interviewed within the first few days of the patient’s admission to ICU. In some cases, this belief appeared to slowly disintegrate over time making it difficult for the family member to maintain an opportunity appraisal. McClowry (1992) suggests family members initially hold the view that the illness is time limited and may expect a complete cure. This view is initially protective, but may be difficult to maintain as the family member develops a more realistic appraisal of the situation.

A number of family members who were interviewed perceived that uncertainty was dangerous resulting in a threat appraisal. This type of appraisal was particularly evident in family members of patients who
had been chronically ill prior to the admission to the ICU. One elderly spouse stated: "this [the ICU experience] is just one piece of being sick for many years...I'm worn out, I can't take much more". Family members of ICU patients who had been chronically ill may have had previous negative experiences with illness which contributed to a threat appraisal. In addition, these family members may have realized that full recovery was not possible. These conclusions are supported by Mishel & Murdaugh (1987) who reported that, over time, partners of heart transplant patients gradually realized that returning to normal was not possible.

Other family members may have perceived a threat appraisal related to their sense of helplessness or lack of control over the situation. For the most part, family members' responses indicated that most family members vacillated between an opportunity and a threat appraisal. One family member stated:

"it makes it confusing...to be so up and then so down, I mean I'd rather have the hope but if it goes up and down...like tomorrow if we have a different doctor and its way worse again...I found that really hard to bounce up and down"

In the appraisal coping section of the Mishel (1988) theory of Uncertainty in Illness, individuals can only chose a danger or opportunity appraisal. Thus, the model does not account for the fluctuations in appraisal that were evident in family members' accounts
of their experience. Mishel (1990) notes the theory needs reformulation to reflect the changes in appraisal which occur over time.

Summary

The findings of the study were discussed in relation to the Mishel’s (1988) theory of Uncertainty in Illness and other research studies. First, the characteristics of the sample were discussed. Then, the level of uncertainty perceived by the family members and problems inherent with the uncertainty instrument and study methods were reviewed. This was followed by a discussion of the factors which influenced family members’ perceptions and appraisal of uncertainty during the ICU experience. The final chapter will present a summary of the findings, conclusions, and implications that arise from the the study.
CHAPTER SIX

Summary, Conclusions and Implications

Introduction

This study was designed to answer questions regarding the level of uncertainty perceived by family members of critically ill patients at one point in time during the first week of the ICU experience. The study also sought to describe the relationship between the family members' perceived level of uncertainty and the level of illness severity. In addition, family members' perceptions of factors which were related to uncertainty were explored. An overview of the study and its conclusions are presented in this chapter. This is followed by discussion of the study implications for nursing practice, education, and research.

Summary of the Study

This study was undertaken to describe and explore family members' perceptions of uncertainty and illness severity during the ICU experience. The impetus for the study came from the investigator's observations that family members experienced a high level of stress which may be related to uncertainty which evolved in response to the critical illness experience and the ICU environment. The findings of studies which investigated family needs and stressors during the critical care experience suggested
uncertainty might be a significant phenomenon which influences the perceptions of family members. There are, however, a significant lack of studies which have investigated family members' subjective perceptions, particularly in the area of uncertainty. It was recognized that a study was needed which would provide health care professionals with a better understanding of the uncertainty experienced by family members during the ICU experience.

This descriptive correlational study was conducted in two large tertiary referral hospitals located in Vancouver, British Columbia. Data were collected from a convenience sample of one family member for each of 30 critically ill patients who met the sample criteria. Subjects were contacted by the Assistant Head Nurses of the study ICUs according to a written protocol developed by the investigator. The subjects completed the Parents Perception of Uncertainty in Illness Scale - Family Member Form (PPUS-FM), the Visual Analogue Scale (VAS) to measure illness severity, and a demographic information sheet. In addition, 12 of the 30 family members were interviewed according to a semi-structured interview guide developed by investigator. A number of considerations were employed to ensure anonymity and confidentiality of the data. Perceptions of
uncertainty and illness severity were measured at one point in time.

The age of the family members at the time of the study ranged from 29 to 79 years. There were 19 females and 11 males. The majority of the family members were spouses (48.7%) or adult children of the ICU patient (30%). The family members had a wide variety of occupations which were primarily in the professional, administrative/manager, or homemaker categories. Most of the family members were educated at the university or college level (60.0%). The sample of family members demonstrated limited cultural diversity as the majority of subjects were Caucasian, had been in Canada at least 20 years, and considered English to be their primary language.

The age of the associated ICU patients ranged from 23 - 83 years. Twenty of the ICU patients were male and 10 were female. The number of days the patient had been in the ICU at the time of data collection ranged from 2 to 9 days. The vast majority of patients had multiple diagnoses and complications.

The Uncertainty in Illness theory of Mishel (1988) served as the theoretical framework for the study. According to this theory, the processes of uncertainty, appraisal and coping work together to determine the meaning individuals construct for illness
Three variables (stimuli frame, cognitive capacity, and structure providers) precede uncertainty and offer the information that is processed by the individual. The process of appraisal plays a key role in determining the impact of uncertainty. Uncertainty evolves when the individual lacks sufficient cues or information to adequately appraise the illness situation. Uncertainty can be appraised as a danger or an opportunity. Coping strategies are efforts generated in response to the type of appraisal to manage uncertainty and influence adaptation. The study primarily explored the relationship between the antecedent variables and the family members' perceptions of uncertainty in the ICU experience. Coping was only briefly discussed in relation to the appraisal of uncertainty process.

Answers to the three major research questions were examined using the Mishel (1988) Uncertainty in Illness theory to explore the family members' perceptions of uncertainty and illness severity. Overall, family members of ICU patients perceived moderately high levels of uncertainty as measured by the uncertainty scale. Subjects' uncertainty scores fell between the levels of uncertainty reported in two research studies which addressed uncertainty in family members of critically ill newborns and critically ill adult brain-injured patients. The
uncertainty appeared to be generated primarily in response to ambiguity and unpredictability of the situation.

Findings demonstrated wide variability in the family members' perceived level of uncertainty. The Mishel (1988) theory of Uncertainty in Illness was useful to explain possible reasons for the variations in levels of uncertainty found in the study sample. The moderately high levels of uncertainty appeared to be associated with factors such as event familiarity, event congruence, ambiguous symptoms or complications, the subjects' degree of commitment to the patient, intense emotional states, and the clinical uncertainty associated with critical illness. Variations in level of uncertainty appeared to be associated with the amount of social support, the degree of trust established with health care providers, educational level, and characteristics of the information which was provided and received.

Findings also indicated that there was no statistically significant relationship between uncertainty and illness severity. This finding was not expected by the investigator who had expected to find a positive correlation between uncertainty and illness severity. This finding may be related to a conceptual difficulty in explaining how appraisal is interrelated with illness severity and uncertainty.
The level of illness severity may vary with the type of appraisal as opposed to being related to uncertainty. Additional negative correlations, although not statistically significant, were found between uncertainty factors of lack of clarity and lack of information and severity of illness. This suggests a lack of information and understanding may be linked to a more positive appraisal of the illness situation, a finding which is supported by other research studies which have investigated uncertainty. The findings which are related to uncertainty and illness severity should be viewed with caution as the sample was highly positively skewed with respect to illness severity.

Qualitative content analysis of the family members' responses to the exploratory interviews revealed a number of factors which were related to uncertainty during the ICU experience. Many of these factors were highly individualized for each family member according to their unique perceptions and appraisals of the situation. However, three common themes and associated factors were identified which suggests family members experience similar uncertainties during the ICU experience.

Factors related to uncertainty with the first major theme, the illness/treatment situation, seemed to be primarily related to the unpredictability of the patient's condition, illness, or future outcome.
Uncertainty appeared linked to the family members’ perception of the degree to which the situation was under control. Unpredictable complications, changes in condition, lack of medical certainty about the illness or treatment and deviations from expected norms increased the uncertainty perceived related to the illness/treatment situation.

The environment and system of care constituted the second major theme related to the family members’ perceptions of uncertainty. Contrary to that which was expected by the investigator, subjects experienced minimal uncertainty related to the unfamiliar routines, procedures or technology. Perceptions of uncertainty within this setting seemed to be modified by the belief that the patient was receiving expert care, faith in technology and the supportive, caring approach of health care providers. A major factor associated with perceptions of uncertainty seemed to be the extent to which family members could rely on or trust the actions or words of health care providers. In addition, a number of family members perceived uncertainty related to establishing links to practical, emotional and spiritual resources.

Family member functioning was the third and final theme related to family members’ perceptions of uncertainty. Uncertainty was primarily generated in relation to the family members’ roles in supporting
the patient and other family members, role conflict and changing roles. A unique finding was the uncertainty family members experienced in relation to their role of making treatment decisions for the patient. Further research is required to explicate this finding.

The responses revealed that family members fluctuate between an opportunity or hopeful appraisal and a danger appraisal. Positive beliefs were critical to maintain an opportunity appraisal. A danger appraisal seemed to be related to previous negative experiences, intense emotions, and lack of progress over time.

The Mishel (1988) theory of Uncertainty in Illness was found to be appropriate to study family members' perceptions of uncertainty during the critical care illness experience within the illness/treatment situation and environment and system of care themes. The theory needs to be expanded in the areas of family roles and appraisal over time in order to adequately explain the theme of family member functioning and fluctuations in uncertainty over time.

Limitations

The generalizability of this study's findings is limited by the small sample size which may have contributed to the lack of significant correlations. The use of a convenience sampling method, the measurement of uncertainty at only one point in time,
and restriction of the sample to two ICU settings and
to those who can read or write English also limit
generalizability. It is not known if the family
members who participated in the study are significantly
different from family members who did not participate.
Family members may have given socially desirable
responses related to their vulnerability and dependency
on health care providers during the ICU experience. In
addition, family members' responses to the uncertainty
scale may not always have been accurate related to
their intense need to give responses which maintained a
hopeful appraisal.

Conclusions

The findings of the study suggest some tentative
trends and conclusions:

1. Family members of critically ill ICU patients
describe many similar factors which are related to
perceptions of uncertainty during the illness
experience.

2. Overall, family members perceived moderately high
levels of uncertainty. However, there were wide
variations in these levels which may be explained
by the antecedent variables which influence
uncertainty in Mishel's (1988) Uncertainty in
Illness theory.

3. Family members' perceptions of the level of
uncertainty and illness severity do not appear to
be related. This may be a function of the relationship between illness severity and appraisal.

4. The appraisal of uncertainty by family members of ICU patients may fluctuate over the illness course between an opportunity and danger appraisal.

5. Positive beliefs, such as faith in the expertise of the health care provider, appear to be major factors which are critical to the family members' perceptions of a hope appraisal. Other significant beliefs which influenced a hope appraisal included faith in God or a higher being and belief in a positive outcome.

6. Access to the patient appears to be a major factor which reduces the uncertainty perceived by family members.

7. During the ICU experience, family members may require assistance to establish links with emotional, practical and spiritual resources.

8. Family members experienced a number of distressing physical and emotional responses during the ICU experience which are associated with a danger appraisal.

9. Exploration of family members' perceptions during the ICU experience was perceived to be a positive experience by the majority of family members. However, investigators in future studies should continue to be sensitive to the fact that not all
family members wish to or are emotionally ready to participate.

Implications

Although the findings of this study are tentative they suggest many implications for the provision of care to family members of critically ill ICU patients. Implications for nursing practice, education, and research are presented in the following sections. In addition, the Mishel (1988) theory of Uncertainty in Illness is discussed in light of this study's findings. The focus of the discussion is directed towards nurses, however, implications for other health care providers are included as appropriate.

Nursing Practice

The findings suggest that family members of critically ill patients perceive similar factors which are related to uncertainty during the ICU experience. However, there is sufficient evidence to suggest that a number of factors unique to each individual play a significant role in family members' appraisal of uncertainty. In addition, although many subjects had moderately high levels of uncertainty, there was wide variation in the levels of uncertainty perceived by family members. Therefore, nurses should not assume that all family members of critically ill ICU patients experience uncertainty in the same way. There is a need to develop and implement family
assessment tools which allow for quick, individualized assessment of each family member's unique situation and perception of uncertainty. Specifically, these tools should gather information on previous family illness experiences, cultural beliefs and practices, a brief history of the roles of each family member, demographic data and immediate concerns. In addition, assessment should include evaluation of social supports, specifically related to practical, emotional, and spiritual concerns. It is also important to collect data on how the family wishes to receive information: what family member(s) should receive the information, what type, how often and from whom. The data collected from the assessment could be used to develop a plan of care, which includes interventions to manage uncertainty. The plan of care should be validated with the family member and shared with other health care providers to ensure consistent implementation which is congruent with the expectations of the family member.

Nurses need to recognize that the family members' appraisal of uncertainty may fluctuate over time. Therefore, it becomes important to repeat the assessment at regular intervals to determine if the family members' perceptions of uncertainty have changed and if coping strategies are adequate to manage the uncertainty. Nurses should become familiar with the
factors which are common to the development and management of perceptions of uncertainty in most family members during the ICU experience. This understanding could assist nurses to anticipate and manage some of the major factors discussed below which generate uncertainty for family members.

The relationship with the health care provider is a major factor which influences the development of uncertainty. The findings suggest family members view nurses as important support persons with whom feelings and concerns can be ventilated and received in a nonjudgemental manner. Family members also count on nurses to provide expert care, information, and access to the patient. These interventions are within the realm of all nurses at the bedside and are essential to reducing perceptions of uncertainty. First, it should be recognized that family members’ uncertainty is reduced when nurses focus on patient care needs. Given the intense requirements of the ICU patient, it may be useful to assist nurses and other members of the team through implementation of the clinical nurse specialist (CNS) role. The CNS could assess and provide additional support to manage family members’ perceptions of uncertainty.

Second, nurses and other health care providers in the ICU need to acknowledge the importance of the relationship between health care providers and family
members. The findings suggest that family members have a critical need to trust health care providers. Family members rely on health care providers to provide expert care and information within the ICU setting. In addition to the provision of information, health care providers could implement other interventions which may promote a trust relationship. These may include changes in practice to facilitate the provision of consistent information, access to patients, increased interdisciplinary collaboration, increased support and information at transition times of discharge or transfer from the ICU, and a family focus of care. Implementation of any of these interventions should be simultaneously evaluated through research to determine their impact on family members’ perceptions and appraisal of uncertainty.

Third, it is apparent that family members have a critical need for consistent information from health care providers. However, the content and manner in which information is relayed should differ within the context of the family members’ appraisal of the situation. Health care providers must collaborate with the family member to determine what type of information is most helpful for them and how they wish to receive that information. The findings suggest family members are most interested in receiving consistent, reliable information about the patient’s symptoms, expected
course and treatment plan, changes in condition and prognosis. Information about the physical environment, routines and procedures is considered of lesser importance. As family members often develop misperceptions of extremely threatening information which may require further clarification, it would be helpful for nurses to be present when physicians provide information about diagnosis, condition or prognosis. Finally, health care providers must be sensitive that some family members are not ready to receive "bad news" and this may be a protective strategy to maintain a hopeful appraisal. The effects of providing any information should be monitored and evaluated.

Fourth, the findings suggest family members rely on nurses and other health care providers for emotional support. Nurses could provide emotional support by meeting with family members to clarify which uncertainties exist and to determine if those uncertainties should be reduced, alleviated or maintained. Findings suggest that family members primarily perceived uncertainty related to unpredictability and ambiguity of the situation. The nurse may be able to reduce uncertainty through the provision of knowledge or clarification of inaccurate conclusions or misperceptions. The findings suggest listening to the concerns of family members may
eliminate some of the stress associated with a danger appraisal and may help family members to clarify which uncertainties can be altered and which cannot.

Study findings suggest access to the patient is an important factor which provides support and reduces uncertainty. Visiting policies should be revised if necessary to ensure that access to the patient by the family member is as unrestricted as possible. The findings suggest family members are concerned about "bothering" staff and may be uncomfortable with the current communication systems available to gain access. It might be helpful to have a volunteer in the waiting room who could assist family members to gain access to the patient.

The findings suggest uncertainty may be related to the difficulties experienced by many family members in establishing links with emotional, practical and spiritual resources. Written information about available resources within the hospital and community could be developed and made available to family members. In addition, individuals such as the social worker, pastoral care worker and clinical nurse specialist (CNS) could work as a team to provide emotional, spiritual and practical assistance as required. It is important that these individuals be accessible and visible to family members as many family members who would welcome assistance do not actively
seek resources in the initial ICU phase. In addition, it would be useful to provide family members with written information about unit routines and the staff hierarchy. This information would clarify the misperceptions some family members have about the roles and responsibilities of health care providers in the ICU.

Nurses should recognise the importance of facilitating a hopeful perspective to family members in the ICU experience. Some family members may need to maintain uncertainty in order to maintain hope. The findings suggest that the provision of expert care, a empathetic and caring approach to patients and family members, providing anticipatory guidance on what to expect, ensuring access to patients, and facilitating spiritual support are interventions which may promote a feeling of control and hope for family members. All family members need to feel there is hope for a positive outcome. In addition, some family members feel hope when they perceive health care providers will ensure the patient is kept comfortable and does not suffer.

The wide range of physical and emotional responses associated with a danger appraisal, such as anxiety, worry and helplessness should also be addressed by nursing staff. Nurses should acknowledge these responses and help family members to understand that
families of critically ill patients often feel strain. It is important to anticipate that family members of patients with chronic illness or who are geographically isolated from usual supports are most likely to feel this strain. In addition, family members of ICU patients who have symptoms which are very ambiguous, such as altered level of consciousness, may develop a danger appraisal. Anticipatory guidance related to the need to deal with changing family roles, multiple responsibilities and inevitable role conflict could be provided. Family members also would benefit from receiving as much information as possible to make treatment decisions in the best interests of the patient. Nurses should acknowledge the strain associated with this role. In addition, development of a trust relationship may allow family members to feel more comfortable with occasionally leaving the hospital to meet other responsibilities or personal needs. The nurse could assist to schedule a family meeting to facilitate airing of concerns amongst family members and to promote the division of responsibilities among family and friends. Finally, nurses should recognise that the ongoing uncertainty associated with a danger appraisal may require more intensive assessment and referral which necessitates the involvement of other members of the team, such as the CNS, social worker, chaplain, or psychiatric liaison.
Nursing Education

In addition to teaching nurses the technical skills required to work with critically ill patients, a nursing curriculum needs to incorporate concepts related to uncertainty and the appraisal process, coping, crisis and chronic illness. Nurses should also begin to understand these concepts in relation to family nursing theory. Nursing education should facilitate students' learning and practice of the psychosocial assessment skills and communication skills which are important to interacting with families of critically ill patients. It is also critical that the nurse learn strategies such as negotiation, conflict resolution and team building in order to facilitate interdisciplinary practice which may promote consistency of care. The need for provision of information suggests nurses should develop an understanding of the principles of adult learning and communicating in times of stress. Nurses should also be provided with learning opportunities to develop the skills necessary to prepare and present materials for family education.

Nursing Research

This descriptive correlational study provides only a beginning knowledge related to understanding family members' perceptions of uncertainty in the critical illness experience. There is an need for a significant
body of research to provide direction for nurses caring for family members of during this experience. The most pertinent suggestions which have evolved from the study are as follows:

1. The present study measured family members' perceptions of uncertainty at one point in time, and as such, did not allow for measurement of changes in uncertainty over time. A longitudinal study design would provide a more comprehensive assessment of changes in the degree and nature of uncertainty experienced by family members of critically ill patients over time. The study could be designed to follow family members of ICU patient through the ICU experience, immediately post transfer to the ward setting, and then following discharge into the home setting.

2. Reading and comprehension of the English language was required in the present study to complete the study questionnaire. Thus, a clear picture of the impact of the cultural dimension on uncertainty was not possible. There is a need to replicate the study with individuals from a variety of cultures to increase understanding of the cultural beliefs and experiences which may be related to uncertainty.

3. The study suggests there are clinical variables which may influence family members' degree of uncertainty. These include: patient diagnosis,
actual illness severity, the family members' relationship to the patient, history of recent hospitalization or chronic illness. Given the difficulties associated with probability sampling in the critical care clinical setting, it would be useful to proceed with a number of research studies which investigated the phenomenon of family members' uncertainty in a variety of clinical settings. Meta-analysis of the data from multiple studies would permit more accurate conclusions to be drawn about the clinical variables which may alter the degree of uncertainty perceived by family members.

4. The levels of uncertainty experienced may have varied in relation to the instrument used to measure uncertainty. The PPUS-FM should be refined to revise items which are difficult to interpret, to remove items which do not apply to the critical care illness experience, and to incorporate items which reflect the family role uncertainty. Given the fact that the original factor analysis of the instrument was conducted with parents, it would be useful to establish construct validity of the scale for family members.

5. Although not statistically significant, a negative correlation was found between perceived illness severity and uncertainty in this study. The
investigator concluded that illness severity is more likely to be associated with the process of appraisal than the level of uncertainty. Further study is warranted to explore the relationships between uncertainty, perceived illness severity and appraisal.

6. The current study specifically focused on the antecedent variables which led to the perception and appraisal of uncertainty. Studies should be conducted with family members of critically ill patients which specifically investigate the relationship between uncertainty and coping strategies and the situations in which uncertainty facilitates a hopeful appraisal.

7. The study explored an individual family member's perceptions of uncertainty. Findings suggest the family as a whole is impacted by the critical illness of members and its view may be different from that of the individual family member. It is important for qualitative research to be undertaken to describe and explore the phenomenon of uncertainty in the critical care illness experience from the perspective of the family as a whole.

8. There is an urgent need for nurses to develop and evaluate efficient and effective family assessment tools in the critical care setting. It would also be useful to design intervention studies which
specifically develop and test interventions that may impact on the degree of uncertainty and adjustment experienced by family members. This study’s findings suggest areas which should be examined include: the provision of orientation programs or educational materials; the use of support groups or stress management techniques; the impact of interdisciplinary collaboration; and the implementation of different care delivery systems, such as primary nursing or family focused care.

Nursing Theory

The Mishel (1988) theory of Uncertainty in Illness was useful to explain specific factors in the ICU experience which were related to family members’ perceptions of uncertainty and appraisal. The idea that nurses can influence factors which are related to uncertainty and coping, such as promotion of a trusting relationship, is worthy of further study. Mishels’ (1988) theory should continue to be used in guide future research endeavours in clinical practice.

The theory may require modification for future use with family members. The theory lacks the necessary time dimension to fully account for the changes in uncertainty, appraisal and coping that evolved in family members over time. In addition, the Uncertainty in Illness theory and the PPUS-FM require modification to incorporate the processes
of family member uncertainty related to role changes and role conflict. It would be beneficial if the PPUS-FM was tested and modified to more accurately measure family member uncertainty and uncertainty specific to the critical care illness experience.

Summary

This chapter concludes the report of the research study which sought to describe and explore family members' perceptions of uncertainty during the ICU experience. The study has been summarized, major conclusions have been highlighted, and implications for nursing practice, theory, education and research have been presented. It is this investigator's hope that the study findings will be useful for health care providers who seek a better understanding of the uncertainty experienced by family members during the critical care illness experience.
References


Appendix A

Mishel Uncertainty in Illness Scale - Family Member Form
Mishel Uncertainty in Illness Scale - Family Member Form

Instructions: Please read each statement. Take your time and think about what each statement says. Then place an "X" under the column which most closely measures how you are feeling about your family member TODAY. If you agree with a statement, then you would mark under either "Strongly Agree" or "Agree". If you disagree with a statement, then mark under either "Strongly Disagree" or "Disagree". If you are undecided about how you feel about your family member, then mark under "Undecided" for that statement. Please respond to every statement.

1. I don't know what is wrong with my family member.

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<th>Strongly Agree</th>
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2. I have a lot of questions without answers.

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3. I am unsure if his/her illness is getting better or worse.

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4. It is unclear how bad his/her pain will be.

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5. The explanations they give about my family member seem hazy to me.

Strongly Agree (5)  Agree (4)  Undecided (3)  Disagree (2)  Strongly Disagree (1)

6. The purpose of each treatment for my family member is clear to me.

Strongly Agree (1)  Agree (2)  Undecided (3)  Disagree (4)  Strongly Disagree (5)

7. I do not know when to expect things to be done to him/her.

Strongly Agree (5)  Agree (4)  Undecided (3)  Disagree (2)  Strongly Disagree (1)

8. His/her symptoms continue to change unpredictably.

Strongly Agree (5)  Agree (4)  Undecided (3)  Disagree (2)  Strongly Disagree (1)

9. I understand everything explained to me.

Strongly Agree (1)  Agree (2)  Undecided (3)  Disagree (4)  Strongly Disagree (5)

10. The doctors say things to me that could have many meanings.

Strongly Agree (5)  Agree (4)  Undecided (3)  Disagree (2)  Strongly Disagree (1)

11. I can predict how long his/her illness will last.

Strongly Agree (1)  Agree (2)  Undecided (3)  Disagree (4)  Strongly Disagree (5)
12. My family member’s treatment is too complex to figure out.

Strongly Agree (5) Agree (4) Undecided (3) Disagree (2) Strongly Disagree (1)

13. It is difficult to know if the treatments or medications are helping my family member.

Strongly Agree (5) Agree (4) Undecided (3) Disagree (2) Strongly Disagree (1)

14. There are so many different types of staff, it’s unclear who is responsible for what.

Strongly Agree (5) Agree (4) Undecided (3) Disagree (2) Strongly Disagree (1)

15. Because of the unpredictability of my family member’s illness, I cannot plan for the future.

Strongly Agree (5) Agree (4) Undecided (3) Disagree (2) Strongly Disagree (1)

16. The course of my family member’s illness keeps changing. He/she has good and bad days.

Strongly Agree (5) Agree (4) Undecided (3) Disagree (2) Strongly Disagree (1)

17. It’s vague to me how I will manage the care of my family member after he/she leaves the hospital.

Strongly Agree (5) Agree (4) Undecided (3) Disagree (2) Strongly Disagree (1)

18. It is not clear to me what is going to happen to my family member.

Strongly Agree (5) Agree (4) Undecided (3) Disagree (2) Strongly Disagree (1)
19. I usually know if my family member is going to have a good or bad day.

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20. The results of my family member's test are inconsistent.

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21. The effectiveness of the treatment is undetermined.

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22. It is difficult to determine how long it will be before I can care for my family member by myself.

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23. I can generally predict the course of my family member's illness.

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24. Because of the treatment, what my family member can do and cannot do keeps changing.

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25. I'm certain they will not find anything else wrong with my family member.

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26. They have not given my family member a specific diagnosis.

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<tr>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Undecided</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
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</table>

27. My family member's distress is predictable. I know when it is going to get better or worse.

<table>
<thead>
<tr>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Undecided</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
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28. My family member's diagnosis is definite and will not change.

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<thead>
<tr>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Undecided</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
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</table>

29. I can depend on the nurses to be there when I need them.

<table>
<thead>
<tr>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Undecided</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
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<tr>
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</table>

30. The seriousness of my family member's illness has been determined.

<table>
<thead>
<tr>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Undecided</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
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</table>

31. The doctors and nurses use everyday language so I can understand what they are saying.

<table>
<thead>
<tr>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Undecided</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
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</tbody>
</table>

Reference: Mishel PPUS for Family Members of Adult Critically Ill Patients Adapted According to Instructions By Mishel.
I request permission to copy the Parent/Child Uncertainty in Illness Scale for use in my research entitled, [MEASUREMENT OF UNCERTAINTY IN]

In exchange for this permission, I agree to submit to Dr. Mishel, upon completion of the study a printout of the uncertainty data or a 5½ inch disk containing the data with a data dictionary. The data must contain information on each subject's age, sex, education and diagnosis, along with the raw data on the uncertainty scale. This data will be used to establish a normative data base for clinical populations. No other use will be made of the data submitted. Credit will be given to me in reports of normative statistics that make use of the data I submitted for pooled analyses. I also agree to send Dr. Mishel a copy of my findings. I understand that my report will be used to compile information on the theory of uncertainty in illness. Credit will be given to me in any reports referring to my findings.

(Signature)

(Date)

Position and Full Address of Investigator.

Thesis Committee Chairperson: Dr. Ann Marie Ayho
University of British Columbia
Vancouver, B.C. Canada

Permission is hereby granted to copy the MUIS for use in the research described above.

(Signature)

(Date)

Please send two signed copies of this form to Merle H. Mishel, Ph.D., College of Nursing, University of Arizona, Tucson, Arizona 85721.

MMH:pw
revised 1/89
Appendix B

Visual Analogue Scale (VSS) – Perception of Illness Severity
Visual Analogue Scale - Perception of Illness Severity

Instructions: Below is a picture of a scale which will be used to determine how ill you view your family member to be. The left side of the scale represents NOT SERIOUSLY ILL and the right side of the scale represents VERY SERIOUSLY ILL. Please draw a vertical line through the point on the scale which represents your view of your family member's condition TODAY:

Not Serious

Very Serious

Scale developed by Pamela Miller, April, 1993.
Appendix C

Demographic Information Sheet
Code _____

Demographic Information Sheet

From the Family Member:

1. Relationship to the ICU patient:
   Spouse   Parent   Sibling   Adult child   Other
   ______   ______   _______   ___________   _________

2. Sex of the family member: Male _____ Female _____

3. Age of the family member: _____

4. Number of days the patient has been in ICU: ____ days

5. Occupation of the family member:
   _________________________________
   _________________________________

6. Education of the family member:
   _____ 1. Up to Grade 8   _____ 4. College or University
   _____ 2. Grade 9 - 12   _____ 5. Graduate Degree
   _____ 3. High School Graduate

7. Country of birth of family member: ________________

8. If not born in Canada, year of emigration to Canada: _______

9. If English is a second language, what is the primary language of the family member: _______________________

10. Religious Affiliation of family member (Specify)
    _________________________________

11. Previous ICU experience: No _____ Yes _____
    If yes, please describe _______________________________

12. Family member’s understanding of the reason his/her ill relative is in the ICU:
    _________________________________
Code: _____

From the Medical Record:

1. Institution: Hospital A _____ Hospital B _____
2. Date of admission to the ICU: ____________________
3. Patient’s age: ____ years
4. Patient’s sex: Male _____ Female _____
5. Medical Diagnoses: ____________________________________
   ____________________________________
   ____________________________________
Appendix D

Interview Guide
Interview Guide

I would like to ask you a few questions that will help me get a better understanding of the uncertainties you may be experiencing while having a family member in the ICU. Your answers to the questions will be tape-recorded. Take the time to answer the questions and feel free to add additional comments.

1. What is your understanding of your family member’s condition at this point in time?

2. Are there things about your family member’s illness that are unclear or worrisome to you? If so, could you please describe these to me?

3. Are there things or events in the ICU environment which are unclear or worrisome to you?

   Probe: Some family members have told me the unfamiliar ICU setting or hospital setting can be very confusing. Have you found this?

4. What information would help you to have a better understanding of this situation?

   Probe: Some family members often have many unanswered questions related to the experience of having an ill family member in the ICU. What questions would you like answered?

5. What kind of changes are you experiencing as a result of your family member’s illness? What do you anticipate in the future?
Appendix E

Protocol for Initial Contact of Family Members
Protocol For Initial Contact of Family Members
By The AHN/HN

Title: Uncertainty in Family Members of Adult ICU Patients

1. Family members who are eligible for the study include:
   a. Spouse (Married or Common-law), Parent, Adult Child, Sibling or other person who has a significant relationship with the patient.
   b. Family members who are 19 years of age or older.
   c. Family members who can read and speak English.
   d. Family members of patients who have been in the ICU less than 7 days.

2. Family members who, in the opinion of the AHN/HN are in severe emotional distress, should not be contacted about participation in the study.

3. Family members should not be contacted until initial emergency procedures are completed and the patient is stabilized. Initial contact should be completed as close as possible to within 48 hours of the patient’s admission to the ICU.

4. The HN or AHN should provide the family member with a simple explanation about the purpose of the study. The family member should be given a copy of the information letter describing the study.
   Note: The HN who is designated as an agency contact person is excluded from initial contact of subjects.

5. Ask the family member’s permission to be contacted by the investigator who will provide a more detailed explanation of the study and obtain consent. Please ensure family members have sufficient time to consider this request. Also, it is very important that family members are aware that refusal to participate in the study will not jeopardize their family member’s medical or nursing care.

6. To avoid duplication of initial contact, the AHNs and HN should keep a list of family members who have been contacted and whether they wish to participate or not. The investigator and HN who is designated as an agency contact person will not have access to this list.

7. The investigator will maintain daily contact with the AHN to determine which potential subjects may be contacted.
Appendix F

Information Letter for Family Members
Title: Uncertainty in Family Members of ICU Patients

Principle Investigator: Pamela Miller, Ph. 277-5819
[Agency Contact Person: Name, Phone no.]

Dear Family Member:

As a Registered Nurse who has worked in intensive care units (ICUs) for the past fourteen years, I am concerned about family members with a relative in the ICU. As part of my course work for graduate studies, I am conducting a research study to find out more about how family members with a relative in the ICU view the uncertainties related to their relative’s illness or treatment.

Participation in the study is entirely voluntary. You may decide not to participate or may withdraw from the study at any time without affecting your family member’s current or future treatment. All information resulting from this study will be kept strictly confidential. The study questionnaires will be coded so only the investigator will be aware of your identity. Your name and any other identifying information will not be associated with any published or unpublished reports arising from this study.

Participation in the study involves approximately 20 minutes to complete questionnaires. Although the study will not directly benefit you, the information provided may assist nurses to help other family members during this difficult time.

If you are interested in participating or finding out more about the study, please let the Assistant Head Nurse of know of your interest, and what is the best time to meet with you. I will then be in touch with you and can answer any questions or concerns you may have prior to proceeding. Thank you for taking the time to consider taking part in my research study.

Sincerely,

Pamela Miller, R.N.

Faculty Advisors
Anna Marie Hughes, Ed.D., CRN,
Assistant Professor, Ph. 822-7437
Carol Jillings, R.N., PhD,
Associate Professor, Ph. 822-7479
Appendix C

Consent Form
Informed Consent

Title: Uncertainty in Family Members of Adult ICU Patients

Investigator: Pamela Miller, R.N., M.S.N. Student
[Agency Contact Person: Name and Phone No.]

You have been asked to participate in a research study. Participation in this study is entirely voluntary. You may decide not to participate or may withdraw from the study at any time without affecting your family member’s current or future treatment.

Purpose
Family members of patients who are in the intensive care unit (ICU) often experience increased stress during this difficult time. One factor which may increase family members’ stress may be uncertainty about the patient’s illness or treatment situation. The purpose of this study will be to find out more about how you as a family member view the uncertainty which may occur during the first week of your relative’s admission to the ICU. The study will also determine how seriously ill you view your family member’s condition to be.

Procedures
Participation in the study involves completion of 2 questionnaires. The questionnaires take approximately 20 minutes to complete. You have the right to refuse to answer any question in the questionnaires. You may also withdraw from the study at any time.

Risks and Benefits
Although there is no direct benefit to you in this study, the information you provide may assist nurses and other health care providers to gain a better understanding of some of the concerns experienced by family members of ICU patients. This information may be useful to assist other family members during this difficult time. The investigator will be available to assist you with the completion of the questionnaires. It is possible completion of the questionnaires may make you feel uncomfortable. You will be given the opportunity at the end of the questionnaires to discuss any concerns, questions or feelings which may have occurred as a result of the study procedures.
Monetary Compensation

There will be no monetary compensation for participating in the study.

Confidentiality
All information resulting from this study will be kept strictly confidential. The questionnaires will be coded so that only the investigator will be aware of your identity. Your name and any other identifying information will not be associated with any published or unpublished reports arising from this study.

If you have any questions or concerns about the study, you may contact the investigator, Pamela Miller at 277-5819 or her two faculty advisors listed below. In addition, you may also contact [Name and phone no. of agency contact person]

Faculty Advisors
Anna Marie Hughes, Ed.D., CRN,
Assistant Professor, Ph. 822-7437
Carol Jillings, R.N., PhD,
Associate Professor, Ph. 822-7479

I have read the above information and I have had the opportunity to ask questions to help me understand what my participation would involve. I freely consent to participate in the study and acknowledge receipt of a copy of the consent form. I agree to completion of the study questionnaires.

Signature of the Participant

Signature of the Witness
Appendix H

Information Letter for the Head Nurse
and the Assistant Head Nurse
Re: Research Study - Uncertainty in Family Members of Adult ICU Patients

Dear [insert HN or AHN name]:

I am requesting your assistance to conduct a nursing research study in the ICU. The purpose of the study is to investigate the uncertainty experienced by family members of ICU patients. Family members with a critically ill relative in the ICU experience many uncertain events. A better understanding of family members' perceptions of uncertainty may facilitate the development of interventions which provide direction for more specific support of family members during the ICU experience.

I have proposed that the initial contact of family members be undertaken by the HN and/or the AHN. The HN who is designated as an agency contact person would be excluded from initial contact of subjects. I would specifically like to discuss this protocol with you to ensure what is proposed meets with your approval.

I will be in contact with you to arrange a meeting as soon as possible to answer any questions or concerns you may have. I am also willing to inform any of your staff about the study.

Your assistance in helping to facilitate this research study is greatly appreciated.

Sincerely yours,

Pamela Miller, R.N.,
B.Sc.N, MSN Student
Ph. 277-5819

[Agency Contact Person
Name, Phone No.]

Faculty Advisors
Anna Marie Hughes, Ed.D., CRN,
Assistant Professor, Ph. 822-7437
Carol Jillings, R.N., PhD,
Associate Professor, Ph. 822-7479
Appendix I

Information Letter for the ICU Medical Director
Re: Research Study - Uncertainty in Family Members of Adult ICU Patients

[Medical Director
Intensive Care Unit
Agency Name ]

Dear Dr. [insert name]

I am writing to inform you about a nursing research study which I will be conducting in the ICU. The purpose of the study is to investigate the uncertainty experienced by family members of ICU patients. Family members with a critically ill relative in the ICU experience many uncertain events. A better understanding of family member’s perceptions of uncertainty may facilitate the development of interventions which provide direction for more specific support of family members during the ICU experience.

I have met with the Head Nurse and Assistant Head Nurses of ICU to describe the study in greater detail and to discuss the protocol for participant selection and informed consent. They have agreed to undertake initial contact of family members as outlined in the attached protocol.

I would be most willing to meet with you should you feel that there are medical implications which need to be addressed or if you have questions which arise following review of the attached information.

Sincerely yours

Pamela Miller, R.N.
B.Sc.N., MSN Student

[Agency Contact Person: Name, Phone no.]

Faculty Advisors
Anna Marie Hughes, Ed.D., CRN,
Assistant Professor, Ph. 822-7437
Carol Jillings, R.N., PhD,
Associate Professor, Ph. 822-7479
Appendix J

Uncertainties Perceived by Family Members of ICU Patients
# Uncertainties Perceived by Family Members of ICU Patients

## Illness Situation

1. Unsure if the patient will recover from surgery
2. Unsure if complications can be controlled
3. Unable to predict if patient's condition will change - a "time bomb"
4. Don't know what caused the patient's condition
5. Can't predict future complications
6. Can't predict if the patient will get back to normal
7. Unsure of future prognosis
8. Unsure if the patient will survive
9. Unsure if the patient has developed brain damage
10. Unsure if the patient is in pain
11. Unsure if the patient is in physical distress
12. Unsure if the patient is in emotional distress
13. Unsure if the patient will survive without the ventilator
14. Unable to interpret changes in the patient's condition

## Treatment Situation

1. Not confident doctors know the cause of the problems or how to treat them
2. Doubts chronic medical problems can be corrected by surgery
3. Unsure the treatment will be effective
4. Uncertain about the speed of diagnostic tests
5. Can't predict if side effects will occur
6. Unsure if the patient will survive treatment
7. Doubts decision to encourage parent to have surgery
8. Not sure about making decision to commence chemotherapy treatment for patient
9. Doubts decision to continue aggressive treatment
10. Vague about results of tests
11. Can't predict discharge time
12. Unsure if the patient will be discharged home or to another hospital
13. Unsure of treatment plan to manage care at home
Environment/Health Care System

1. Not clear re discharge arrangement
2. Not clear about location of future treatment if the patient survives
3. Unable to rely on available bed for patient
4. Unsure where the money will come from to stay in Vancouver
5. Unsure where to find inexpensive parking or accommodation
6. Not clear on where to find affordable long-term stay accommodation
7. Unsure how to access social worker
8. Unsure if should approach social worker with personal concerns
9. Not clear why ICU so noisy
10. Not clear on the purpose of ICU rounds
11. Unsure about changes in monitor readings, alarms
12. Doubts use of technology to prolong life
13. Can't predict when patient changes will occur
14. Insecure about the initial appearance of ICU patient
15. Unsure who answers the intercom system
16. Unsure if questions from family member "bother" staff
17. Can't decide whether to use intercom system to access patient or just to go in
18. Not clear "what is going on" while in the waiting room

Health Care Provider

1. Unsure if health care providers are always aware of changes in the patient's condition
2. Unsure if can rely on nurse who doesn't explain change in treatment
3. Unsure if can rely on doctor to communicate new complications to family doctor
4. Wonders if complications could have been prevented if detected earlier
5. Unsure why it took so long to transfer the patient from the ward to the ICU
6. Doubts can rely on ward staff to know if the patient develops a complication or relapse
7. Unsure why information staff not aware of location of patient
8. Doubts reliability of conflicting reports from different physicians
9. Doubts condition reports which do not match the patient's appearance
10. Wonders why physician and nurse gave conflicting reports
11. Not confident when the nurse performed an action which the physician had indicated should not be done
12. Can’t rely on getting access to physician for information on the patient’s prognosis
13. Not clear who to talk to or whose information to rely on when dealing with numerous specialists
14. Not sure who to talk to about potential concerns about managing care of patient at home
15. Not confident an unfamiliar nurse can detect changes in the patient’s condition
16. Doubts if the patient’s medical condition has been treated appropriately in the past
17. Doubts staff can take care of patient when they appear “tired"

Family Member Functioning

1. Doubts ability of patient to cope with the impact of multiple injuries/future disabilities
2. Wonders if information about seriousness of the illness frightened spouse
3. Doubts ability to support patient emotionally if entire family is not able to provide support
4. Doubts ability to control emotions at the bedside
5. Unsure how to manage husband who insists he will go home instead of to another hospital
6. Doubts ability to care for patient at home
7. Cannot decide whether to stay with the patient or with children
8. Cannot decide whether to attend to personal concerns or stay with the patient
9. Doubts ability to maintain own physical health
10. Doubts ability to cope with work, taking care of family, and taking care of self
11. Doesn’t know if can emotionally cope with death of patient
12. Can’t decide if parents should move in with family member [adult child] in the future
13. Adult child unsure if parent can cope with further "bad news" about his ill spouse
14. Cannot decide if should make a major move to new house at present (Reluctant to leave hospital)
15. Unsure about future plans or changes for self or other family members
16. Wonders why initial accident happened to patient
17. Doubts ability to communicate patient condition to other family members
18. Cannot predict how children will respond to seeing father in ICU
19. Doubts if other family members are honest about the patient’s condition