WHAT IS THE IMPACT OF ICU SYNDROME EXPERIENCED BY A CRITICALLY ILL PATIENT FROM THE PERSPECTIVE OF THE FAMILY MEMBER?

By

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Abstract

ICU Syndrome: Its Impact on Family Members of Critically Ill Patients

ICU syndrome is a mental syndrome of acute onset that occurs in some patients in a critical care unit. This syndrome continues to occur frequently and serves to increase both morbidity and mortality in affected patients. Despite the continued occurrence a limited amount of information is known about the effects on the patients, and nothing is known about the effects on family members. A literature review indicates no specific qualitative studies had been conducted in this area. Some related research studies indicated that a critical illness affects not only the patient but family members as well. A critical illness compounded by ICU syndrome, can have the potential for long-term effects for both the patient and the family.

This study was designed to gain an understanding of ICU syndrome from the perspective of the family members. A qualitative descriptive methodology was used to guide this study. This approach was guided by the assumption that people do make order and sense of their environment although this world may appear disoriented and nonsensical to others. Ten family members of patients who experienced ICU syndrome agreed to participate in this study. Interviews were conducted on two separate occasions. Analysis of the data revealed that participants identified 12 major categories of responses in relation to ICU syndrome. The participants identified some responses similar to the literature reviewed, but also brought forth several findings that moved beyond the current literature. These findings indicated that ICU syndrome caused them to take on greater
roles in the family unit. Respondents exhibited great strength, cared a great deal for the patient, and demonstrated caring, helpful and supportive roles. These roles were maintained throughout the hospitalization. The occurrence of the syndrome meant that the respondents would need to reassess their plans for the future. Information was needed by the respondents specifically related to the syndrome and this need was not always met adequately by the health care team. The patients exhibited a great deal of trust in the respondents to help them while they were ill and/or suffering from the syndrome. The respondents felt it was important for them to try to make some meaning of the behaviours noted during the syndrome and to pass on this information to the staff who did not know the patient as they did.

The findings are discussed in relation to the framework and literature reviewed. Areas that move beyond the information currently known about family members responses are discussed and recommendations for nursing practice included.
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CHAPTER ONE
INTRODUCTION

Background To The Problem

Intensive care unit (ICU) psychosis is a syndrome that can occur in any critical care setting. Although this syndrome is often referred to as a form of delirium, it is considered both transient and acute in nature (Geary, 1994). This syndrome, with an acute onset that results in the impairment of intellectual functioning, occurs in a patient in a critical care unit. Symptoms associated with ICU syndrome include the following: a loss of reality perception, fatigue, distraction, attention abnormalities, confusion, disorientation, a clouding of the consciousness, incoherence, an increase in psychomotor activities, hallucinations, delusion, and a disordered sleep-wake cycle (Easton & MacKenzie, 1988; Eisendrath, 1982; Fisher & Moxham, 1984; Lipowski, 1980). It is observed as a temporary confusion state that is an adverse reaction to the critical illness, subsequent treatment, and results directly from the stressful critical care environment (Foreman, 1992; Geary, 1994; Kleck, 1984). Variation in the terminology used in its description is noted in the literature ranging from confusion, post-cardiotomy delirium, intensive care unit syndrome, and postoperative confusion or delirium (Bouman, 1984; Crippen & Ermakov, 1992; Geary, 1994; Marshall, 1993). In this paper, this acute confusional state will be referred to as ICU syndrome in an attempt to encompass the many factors that cause it and the variety of symptoms exhibited by those affected.
The discussion and interest in this syndrome is first noted in the literature beginning in the late 1970's through the 1980's (Belitz, 1983; Dracup, 1988; Easton & MacKenzie, 1988; Fisher & Moxham, 1984; Gardner & Stewart, 1978; Hansell, 1984; Helton, Gordon, & Nunnery, 1980; Kleck, 1984; Lipowski, 1987; Owens & Hutelmyer, 1982; Ramsay, 1986; Roslaniec & Fitzpatrick, 1979; Schnaper & Cowley, 1976; Sime & Kelly, 1983; Siros, 1988; Smith & Dimsdale, 1989; Thomas, Cameron, & Faugs, 1988; Weddington, 1982; Williams et al., 1979; Wilson, 1972). The ongoing interest and ensuing need to understand and treat this syndrome is evident in the literature published within the past few years, which indicates that this syndrome remains a significant problem in our ICUs (Briggs, 1991; Clark, 1993; Crippen & Ermakov, 1992; Foreman, 1992; Geary, 1994; Krozek, 1991; Lloyd, 1993; Marshall, 1993; Mirka, 1993; Murphy, Forrester, Price, & Monaghan, 1992; Rasin, 1990; Scherubel & Tess, 1994; Stanley, 1991; Tess, 1991). As a practicing critical care nurse, this author observes that the syndrome is indeed an ongoing problem in the critical care environment.

This study will examine the impact of the ICU syndrome on family members in several different critical care units, not solely dealing with cardiac surgical patients. The diagnosis of confusion post-operatively was seen in the 1960's as open heart surgery became a more commonplace mode of treatment for heart disease. Reports of psychiatric disturbances after this surgery have continued to increase (Owens & Hutelmyer, 1982; Smith & Dimsdale, 1989). Possible causes of this confusion, later determined to be ICU syndrome, have included the cardiopulmonary bypass, length of
time on bypass, micro-emboli showers due to the surgery, and an increase in serotonin levels (Owens & Hutelmyer, 1982). Other contributing factors such as age, preoperative emotional stability, and type of cardiac disease have been explored (Smith & Dimsdale, 1989). These authors list several other potential causes of ICU syndrome such as the intra-operative nature of cardiopulmonary bypass, use of an oxygenator, lowest arterial pressure while on the bypass, increased anesthesia time, increased pump time, the number of units of blood given, and hypothermia during the surgery. Despite this exhaustive list of potential causes of ICU syndrome in the cardiac surgery patient, a literature review conducted by Smith and Dimsdale (1989) covering a 25-year period failed to reveal "reliable predictors or risk factors" for the postcardiotomy delirium or ICU syndrome. Their research remains "conflicting" regarding the potential causes (p. 452). Due to the lack of reliable predictors in the post-operative cardiac surgical patient, this researcher has sought to include several critical care units to widen the scope of the research.

The disorder may be accompanied by a disturbance in the sleep-wake cycle and is often exacerbated during the evening (Lipowski, 1987). Lipowski (1987) also found that the resultant cognitive disorientation leads to impairment in a person's ability to receive, select, process, and retain both internal and external information and to integrate this information meaningfully. This syndrome hampers an individual's awareness of the environment. One of the earliest symptoms observed by the nurse is a disorganization of thinking or a reduced ability to maintain attentiveness (Crippen & Ermakov, 1992). The
patient may then become restless, agitated, and/or combative (Easton & MacKenzie, 1988; Geary, 1994). While exhibiting this syndrome, the patient cannot integrate coherent streams of thought or deduce meaningful information from them. Memory retention is defective; short-term memory is impaired as a result of the short attention span (Crippen & Ermakov, 1992).

In contrast to the agitated patient presented by Crippen and Ermakov (1992), Geary (1994) presents another type of delirium, one of a hypoactive variation. Individuals affected with this type will be quiet, sleepy, and slow to respond. They may also demonstrate a decrease in psychomotor activities and will mumble to themselves or make inappropriate gestures. The individual with a hypoactive form of the syndrome may remain undiagnosed as this patient is quiet and does not disturb anyone, in contrast to the hyperactive, restless, and agitated patient (Lipowski, 1987). A mixed variant, characterized by features of both of the forms mentioned, can be present. These patients can alternate between the two forms in both an “irregular and unpredictable manner,” often in the same day (Geary, 1994, p. 53).

The psychosis state that erupts is caused by many factors of a psychosocial and psychologic nature within the critical care environment. Fisher and Moxham (1984) postulate the syndrome results from the stress experienced by the patient while in the critical care unit. It is short-lived, sudden and transient, with a cause-and-effect relationship being found within the environment or could arise from some factor within the patient themselves (Easton & MacKenzie, 1988; Fisher & Moxham, 1984; Geary,
As an iatrogenic complication, such environmental factors as sensory deprivation, sensory overload, sleep deprivation, disorders of the sleep-wake cycle, loss of day-night orientation, immobility, communication impairment, use of restraints, noise, isolation, and finally pain and discomfort have all been identified as potential contributors to the syndrome (Belitz, 1983; Briggs, 1991; Clark, 1993; Crippen & Ermakoff, 1992; Dracup, 1988; Fisher & Moxham, 1984; Foreman, 1992; Geary, 1994; Hansell, 1984; Helton, Gordon, & Nunnery, 1980; Kleck, 1984; Lloyd, 1993; Mirka, 1993; Rasin, 1990; Tess, 1991; Wilson, 1972).

Intra-personal variables that are thought to contribute to ICU syndrome are metabolic factors, acute withdrawal from drugs or alcohol, drug or poison intoxication, head injury, low mean arterial blood pressure (MAP) (MAP < 50 mmHg), and chronic cardiovascular or respiratory illness (Clark, 1993; Crippen & Ermakov, 1992; Easton & MacKenzie, 1988; Geary, 1994; Kleck, 1984; Lipowski, 1987; Tess, 1991).

ICU syndrome is manifested in many patients between the second and seventh day following admission to the critical care unit (Easton & MacKenzie, 1988). The incidence of this syndrome is estimated to be as low as 10% (Kleck, 1984), while as high as 40% is noted by Geary (1994). Briggs (1991) reports that the syndrome occurs as frequently as in 70% of the ICU population. Additionally, the incidence of ICU syndrome in the elderly population appears to be consistently higher than in those patients less than 65 years of age. The syndrome is reported to occur in approximately 50% of cases where individuals are more than 65 years of age (Geary, 1994; Williams et
al., 1979). Foreman (1992) specifically examined the elderly population (those individuals older than 65 years of age) and their psychological responses to a critical illness. His study reported that as many as 80% of the elderly population will have some degree of confusion or ICU psychosis subsequent to hospitalization and treatment in a critical care unit. He promotes the key role that nurses can play in the prevention, identification, and management of these acute confusional episodes through constant and intimate contact with the patient.

ICU syndrome may vary in severity. In a mild form, some patients can be reasoned with and may in fact trust the reasoning of others during the confusion manifested with the syndrome. In cases of severe delirium associated with the syndrome, the patient is no longer able to reason deductively or solve problems and usually cannot perceive reality, even with the aid of an unaffected individual (Rasin, 1990). Delusions or hallucinations tend to develop as a result of the altered perceptions and may be individualized; some patients can misinterpret the actions surrounding them as life threatening. The hallucinations tend to be fleeting, changeable and poorly organized or consist of incomplete thoughts (Crippen & Ermakov, 1992; Lipowski, 1987). For example, the sound of falling glass could be mistaken for a gunshot, or oxygen might be mistaken for poisonous gas (Crippen & Ermakov, 1992). Some patients have been noted to be amnesic during the period of the syndrome and have no recall of the time at all (Easton & MacKenzie, 1988).
The presence of this syndrome has been reported to increase both morbidity and mortality in hospitalized patients. As early as 1982, Weddington reported a "significant mortality" (p. 1232) associated with the syndrome in patients of all ages. A chart review conducted by Weddington (1982) revealed that one third (33%) of patients with delirium as a psychiatric diagnosis in addition to a physical disorder or condition died, compared to 2.3% of the patients seen with a primary diagnosis of depression. Weddington's (1982) study, despite the limitations of a chart review, indicates a relationship between patients exhibiting the syndrome and a high mortality rate.

Following the report presented by Weddington, a prospective study was conducted by Thomas, Cameron, and Fahs (1988) to examine the contribution of a psychiatric diagnosis as a comorbidity factor, such as delirium, during the hospitalization and the contribution this had to the length of hospital stay. One hundred fifty-three consecutive admissions to a medical ward during a two month period were eligible for inclusion in the study. A total of 133 patients were followed daily until they were either discharged or died. All patients were evaluated for the presence of delirium on admission and following discharge, with all diagnoses coded according to the International Classification of Diseases (9th revision). A statistically significant prolongation of the hospital stay of delirious patients was found (delirious group mean actual hospital stay 21.6 ± 23.7 days, compared to the non-delirious group mean length of stay 10.6 ± 10.1). This study clearly indicates that delirium is associated with a poorer health outcome, and even an increased rate of mortality. In a similar light, Crippen and
Ermakov (1992) found that delirium is a multifactorial syndrome, and can be associated with a range of metabolic and organic disorders. When this stress-induced ICU syndrome is observed after multiple organ failure or an organic and metabolic cause, it is an "ominous sign of a bad outcome" (p. 55).

Kleck (1984) observed that the syndrome is stressful not only to the patient, but to many members of the nursing and medical staff as well. Recognition of the agitated patient is not difficult, but does present management problems for the nursing staff and can be a challenge (Geary, 1994). Furthermore, Geary (1994) advocates that if the syndrome is stressful for nurses, families will likely be affected by the syndrome. It is important for nurses to recognize the effects of the syndrome on the family, as it can be very frightening and stressful for a family member to observe the delirious and unusual behaviours manifested in ICU syndrome. The diagnosis of ICU syndrome can be made if the onset is acute, involving an intellectual impairment in functioning following admission to a critical care unit. Furthermore, ICU syndrome is resolved following the discharge from the critical care environment.

Significance Of The Problem

This study is designed to provide information about family members of critically ill patients who experience ICU syndrome. While ICU syndrome continues to be a prevalent syndrome in critical care, a limited amount of information is known about its effects on the patient, and nothing is known about its effects on family members. At present, no single etiology has been identified, and the syndrome is neither preventable
nor readily alleviated. As the syndrome continues to occur in our modern critical care units, the information gained about its impact on family members should be considered crucial to providing care not only to the patient but to family members. At the very least, the knowledge gained from this study can be used to facilitate nurse-family interactions; the nurse can learn about the impact of this syndrome on the family members. Beyond this basic level of awareness, the nurse may then use the information in this study to develop care plans that incorporate family members’ needs and perhaps plan for counselling or support systems to be put in place to aid the family members.

Interest in this syndrome was first noted in nursing and medical journals in the late 1970’s, continuing into the 1980’s. The research by Geary (1994) and Williams et al. (1979) clearly indicates an increase in the incidence of delirium in the elderly population. Additionally, Kleck (1984) found that alcohol and non-prescription drug withdrawal or even withdrawal from prescribed medications can prove to disrupt the patient’s normal coping processes, thus producing delirium in the intensive care unit. As this problem continues to arise, with limited understanding of the causative factors, interest in ICU syndrome remains high. As we move forward into the 21st century, and as the patient population continues to evolve and reflect societal trends of an aging population and an increase in drug and alcohol usage, the problem of ICU syndrome will continue to surface in critical care.

The information obtained from this study can be used by critical care nurses to increase their knowledge about the impact of the syndrome on a patient’s family
members. A limited amount of qualitative research exists about this syndrome, and, in fact, very little describes the patient’s experience with the syndrome (Easton & MacKenzie, 1988; Owens & Hutelmyer, 1982; Williams et al., 1979). Moreover, only one of these studies has been conducted within the past ten years (Easton & MacKenzie, 1988), and for reasons previously stated, the patient samples used in these studies may now be unrelated to our current patient treated in a critical care unit. Furthermore, none of the studies reviewed indicated the family member’s perception or impact of the syndrome on them. Owing to the prevalence of this syndrome and the lack of research to tie the family member’s experience with not only a critical illness this is a timely study. The information gained from this study is crucial to our abilities as nurses to provide care for our patients and families.

Theoretical Framework

An important component of this study is the emphasis on the inclusion of the family in the nurse’s perspective of care. Historically, hospital nurses have tended to view the individual patient as the recipient of care, particularly in critical care units. Family members have neither been viewed as an important component of care by the nurses nor been given much consideration. In the past, the conception of family, according to Whall and Fawcett (1991), has often been limited to the control of disease within a family unit, or the family members in the home when making a home visit. Admission of a family member to a critical care unit often represents a crisis situation for both the patient and the family members (Artinian, 1991). The illness, however
disturbing to the patient, is also a “disruptive event” for the family (Reider, 1994, p. 272). Reider also reports a high level of anxiety in family members following admission of the patient to a critical care unit. Coping with a critical illness is made more difficult by the occurrence of ICU syndrome, placing further stress upon the family members and increasing their levels of anxiety. As Marsden (1992) asserts, patients do not abandon their relationships when they become ill, and therefore a nurse must include the family members in the perspective of patient care. Family members should also be viewed as a source of support for a critically ill person (Simpson, 1991).

This research study is based on the premise stated by Logan (as cited in Knafl & Grace, 1978) that “the individual cannot be understood completely in isolation from the family and other social networks of which they are part” (p. 11). Traditional beliefs about family have held the family as a nuclear unit, comprised of a father, mother, and two children (Logan & Dawkins, 1986). The operational definition of family for this study is a self-identified group of two or more persons whose association is characterized by special terms, who may or may not be related by blood lines or law, but who function in such a way that they consider themselves to be a family. This definition promotes a broader, less traditional definition of the family than provided by Logan and Dawkins (1986). Current standards of practice have changed to reflect an increased interest in the health care consumer as not only an individual but as a part of a family and/or significant other who accompany the patient (Whall, 1986). This shift in practice is similarly reflected in Marsden’s (1992) proposal that nurses are not only professionally
but morally obligated to support changes in family visitation regulations in critical care units to allow more family time with the patient and to promote a more liberal vision of the family unit. A similar argument is put forth by several authors who identify family members as a source of support for the critically ill patient (Artinian, 1991; Gardner & Stewart, 1978; Simpson, 1991).

Providing family-centred care has not always been seen as practical or recognized as a worthy pursuit for nurses. In addition, some authors propose that “nurses and families often had differing notions about what constituted a family-centred approach” (Logan & Dawkins, 1986, p. 33). For example, in the pediatric setting, it has been found that nurses may frequently demonstrate a narrow view of how parents define and participate in their child’s care while in the hospital. The individual cannot be isolated from the family unit, despite a critical illness. All persons come from a family background and will remain a part of this unit despite the hospitalization (Gardner & Stewart, 1978). These patients will not abandon their relationships when an illness affects them, and families remain an important component of recovery (Marsden, 1992).

The current notion of family used in this study is best viewed from a systems perspective; one in which the family members represent a diverse background and may interact with many internal and external factors (Whall, 1986). In this view, the patient is in the foreground of the nurse’s perspective, with family in the background (Robinson, 1995). As Robinson (1995) proposes, at this level an individual/family member is chosen as the focus of nursing attention by the virtue of his or her response to an actual
or potential health problem, such as the ICU syndrome. Commonly seen in acute care, the nurse may interact with other members of the same family for the purpose of gaining information relevant to the patient’s situation. Further to this perspective offered by Robinson, some key elements outlined by Wright and Leahey (1990) are used to guide this study. First, the family system is part of a larger suprasystem and is composed of many subsystems. This is based on the notion that the whole unit is greater than the sum of its parts. Second, any change that affects one family member, such as the ICU syndrome, affects all family members (Wright & Leahey, 1990). In this study, it is assumed that the encounter with ICU syndrome does not only affect the patient, but all family members. It remains to be seen what that effect will be on the family members.

Recognition of the family as a constant in the patient’s life brings forth the issue that the nurse needs to practice a form of family-centred care. Family-centred nursing care involves the recognition by the nurse that the family is a constant in the patient’s life. Thus, the patient is seen as the main figure in a picture, but the family members remain a constant in the background (Freidman, 1992; Robinson, 1995). Such a focus keeps the family members within the scope of a nurse’s practice. The family members may serve as a secondary resource to this critically ill patient and even to the nurse. This perspective provides the nurse with the guidance to assess the patient not only as someone who is critically ill, but as a family member. Nurses must include the family in the assessment, and observe the effect that the health status can have on the family roles and relationships (Robinson, 1995). The nurse may assume that a patient experiencing
ICU syndrome will have some effect on the family members to some degree. For example, a change in the patient's behaviour will often result in the inability of the other members to respond as previously, due to the change in that one member's behaviour. Using a systems perspective to view the family provides the critical care nurse with the direction to look beyond the individual in the bed for whom they will provide care during their shift. Due to the acuity of a critical care patient, nurses have often thought that it was difficult if not impossible to provide care for more than their assigned patient. Yet, a systems perspective advocates that as a change occurs in the individual patient, a similar, reactive, or complementary process will occur in the family members. In family-centred care the nurse must recognize and respect of the pivotal role that families play in the lives of others in the family.

Research Question

This study will seek to answer the following question:

What is the impact of ICU syndrome experienced by a critically ill patient from the perspective of the family members?

Definition of Terms

A number of key terms used in this study are defined as follows:

**Critical care patient**

"The critical care patient is one who is experiencing a life-threatening health crisis. This life-threatening crisis may occur as a result of serious injuries from accidents or fires; a major operation involving vital organs such as brain, heart or lungs; or failure of one or
more of the body's vital organs as a result of disease, infection or complication from treatment" (CACCN Standards, 1992, p. 4).

**Critical care nurse**

“A highly skilled health professional who works in a critical care unit in collaboration with physicians, respiratory therapists, physiotherapists, nutritionist, and many other health care workers. The critical care nurse utilizes the nursing process consistent with a conceptual model of nursing practice. The critical care nurse provides patient care twenty-four hours a day” (CACCN Standards, 1992, p. 4).

**Critical care unit**

“A highly technological and specifically designated area within a hospital that is established for the care of critically ill patients” (CACCN Standards, 1992, p. 4).

**ICU syndrome**

“An acute state which is transient. This results in a mental syndrome of an acute onset, which involves an impairment of intellectual functioning, in a patient in a critical care unit. This impairment may be associated with a loss of reality perception, fatigue, distraction, attention abnormalities, confusion, disorientation, a clouding of the consciousness, incoherence, and an increase or decrease in psychomotor activities, hallucinations, delusions, and a disordered sleep-wake cycle” (Easton & MacKenzie, 1988; Eisendrath, 1982; Fisher & Moxham, 1984; Lipowski, 1980).
Family
A self-identified group of two or more persons whose association is characterized by special terms, who may or may not be related by blood lines or law, but who function in such a way that they consider themselves to be a family (Whall, 1986).

Family-centred care
A recognition that the family is a constant in the patient's life in spite of the critical illness or ICU syndrome. Some of the key elements of family-centred care are the facilitation of family/professional collaboration at all levels, exchanging complete and unbiased information between families and professionals in a supportive manner, recognizing, and respecting different methods of coping and appreciating families as families. This supports the expectation that there will be an effect on family members. (Adapted from: Shelton & Stepanek, 1994).

Assumptions
It is also assumed that family members undergo a concomitant process as the patient experiences the ICU syndrome. It is anticipated that these family members are willing to openly share their thoughts and feelings about the syndrome with the researcher. The researcher is dependent upon the family member's ability to honestly articulate and share these feelings that have occurred during the patient's experience with ICU syndrome during the interview conducted for this study.
Limitations

One limitation of this study is that family members are selected from one hospital within the Lower Mainland. These family members may represent a unique group of individuals, different from all other family members found in other hospitals in the Lower Mainland.

Summary

Intensive care unit syndrome is an acute form of delirium or confusion, transient in nature, and occurs following admission to a critical care unit. Specific features of the syndrome include a clouding of the consciousness, a decreased ability to maintain attention, difficulty with orientation, memory problems, and a labile affect. ICU syndrome can be caused by environmental factors and may be considered iatrogenic. Several intra-personal factors such as alcohol or drug withdrawal or an imbalance within the body itself may cause the syndrome. Two forms of the syndrome have been noted in the literature: a restless, agitated, and confused state; and a second form that is a hypoactive variation, in which the individual is quiet and sleepy.

A critical illness, however disturbing to the patient, also represents a disruptive event to the family members. The admission of the patient to a critical care unit often represents a crisis situation for not only the patient but the family members. Coping with a critical illness is made all the more difficult by the manifestation of the ICU syndrome, serving to place further stress upon the family members, and could lead to an increase in anxiety for the family members. An important aspect of this study will be the emphasis
placed on the focus of care that concentrates on the family members and the impact ICU syndrome can have on them. This study is designed to provide information about the impact that this syndrome can have on the family members of a patient who experiences ICU syndrome while in the hospital. It is hoped that by obtaining this information about the family members and the impact that this syndrome can have on them, nurses will at the very least have some awareness of the thoughts and feelings of family members. Beyond this basic understanding, the information can be used to provide some nursing interventions aimed at the family members designed to alleviate the stress and anxiety that this syndrome places on the family members.
CHAPTER TWO
LITERATURE REVIEW

Introduction

In order to understand the impact of ICU psychosis on family members, several issues must first be clarified. It is important that the researcher fully understand what the syndrome is, and how to determine its presence. These issues have been covered in the first chapter. In order to help family members during this time period and develop nursing interventions that will facilitate coping with an unpredictable event such as ICU syndrome in addition to a critical illness, it is necessary to develop a knowledge base of how the syndrome affects the family members. The purpose of this literature review is to understand and focus more on the emotional impact and stresses experienced by family members of critically ill patients who undergo ICU syndrome.

As this author began to explore the literature regarding this syndrome, it became apparent that there is a limited amount of literature concerning ICU syndrome. In the past, researchers have been interested in gaining an understanding of this syndrome from a cause and effect perspective, with the need to identify the symptoms of the syndrome being clearly identified. Early works exploring the syndrome focused primarily on the incidence of delirium post cardiac surgery. Researchers sought to determine the factors that would predispose the cardiac surgical patient to post operative confusion (Farrimond, 1984; Owens & Hutelmyer, 1982; Smith & Dimsdale, 1989). Following an extensive review, Smith and Dimsdale (1989) reported that there is no single precise risk
factor that consistently appears to lead to the delirium. Additionally, despite a high prevalence of delirium noted post cardiac surgery 25 years ago, improved surgical techniques have neither led to a decrease in the incidence nor shed further light on the etiology. The focus of these articles has been of a clinical nature, including causative factors, manifestations, diagnostic criteria, and possible mediating factors for post-operative confusion. None of the articles reviewed explored the experiences or recollections of the cardiac surgical patient during the delirious period.

The focus of this research study is the impact of this syndrome on family members. There is much literature to support that a critical illness can have a significant impact on families (Cohen, Craft, & Titler, 1988; Covinsky et al., 1994; Gilliss, 1984; Halm et al., 1993; Kleiber et al., 1994; Koller, 1991; Reider, 1994; Titler, Cohen, & Craft, 1991). Evidence clearly indicates that a critical care hospitalization is not only threatening to the patient but also represents a "disruptive event for the family" (Reider, 1994, p. 272). However, few studies have investigated or sought to understand the emotional responses of, or toll on family members of the critically ill patient during hospitalization.

Based on the limited number of nursing studies linking the family members' perspective and emotional responses to this specific syndrome, the literature review was broadened to examine some of the other fields thought to be relevant to this study. First, the literature relating to the patient's experience with an acute confusional episode or delirium was reviewed. Second, the literature concerning family needs and stress during
a critical illness was reviewed. Third, studies of the needs and stress experienced by spouses of patients who suffered a myocardial infarction (MI) were reviewed to provide some insight into the reactions to this sudden critical event. Finally, the literature on post traumatic stress disorder and its effects on the spouse and family members was used to provide some insight into the meaning of a traumatic event, the relationship to stress, and the potential development of psychological problems in the future.

Patient’s Experience with Acute Confusional Episode

Regardless of the cause, ICU syndrome remains a common occurrence in critical care units. A limited amount of research exists to provide insight into the experience and impact of this syndrome on the individual. Patients who were interviewed by researchers following an experience with confusion described the experience as very frightening and terrifying (Easton & MacKenzie, 1988). The experience with confusion is seen as a disorienting and terrible experience. Almost all of the studies reviewed indicated that either visual or auditory hallucinations were commonly experienced by the patient during the period of confusion (Easton & MacKenzie, 1988; Edmands, 1995; Neelon, 1990; Owens & Hutelmyer, 1982). Indeed, one woman reported that she had witnessed “a murder” while in a drug-induced delirious state (Edmands, 1995, p. 111). This hallucination could be recalled with remarkable vividness at the time of an interview some 13 years later. Initially after the episode, the subject shared her experience with her spouse, but fearing the consequences of repeating such a story, she and her husband agreed to never speak of the experience again (Edmands, 1995). This silence and fear of
repercussions were thought to act as contributing factors in the development of severe psychological problems many years later in this individual’s life.

Of those individuals who experienced a confusion state, many reported altered body sensations and a feeling of decreased alertness (Easton & MacKenzie, 1988; Neelon, 1990; Owens & Hutelmyer, 1982; Williams et al., 1979). A general lack of alertness and disorientation were reported by some respondents (Andersson, Knutsson, Hallberg, & Norberg, 1993; Williams et al., 1979). Some of the most common responses of the participants related to a feeling of disorientation, for example, one patient felt “as if she had spoken about things that were like fantasies” and that she knew she was mixed up about various “things” (Andersson et al., 1993, p. 244). Williams et al. (1979) reported responses such as “didn’t know where I was,” “can’t keep track of things,” “don’t know where I want to go,” “things are fuzzy at times, kind of fogged up” (p. 32). Neelon (1990) reported similar findings of respondents feeling lost; for example, some reported “can’t find a way out ....,” and “afraid to go to sleep” (p. 585).

Individuals experiencing visual hallucinations, despite some level of awareness that things were not really there, had no control over these events (Andersson et al., 1993; Neelon, 1990). Williams et al. (1979) found that the confused patients they interviewed were able to describe a variety of responses such as being mixed up, a lack of awareness, disorientation, a feeling of depression, worry, and anxiety. In this study, the self reports of mental nonclarity and the observed behaviour by the nursing staff were related. In addition visual hallucinations had occurred for some respondents. The vast
majority of those individuals who do experience some confusion “suffer in silence” (Easton & MacKenzie, 1988, p. 234), and do not share this experience with hospital staff for fear of being labelled as crazy (Andersson et al., 1993; Edmands, 1995; Neelon, 1990; Owens & Hutlemyer, 1982).

The available studies that record the patient’s perspective with confusion indicate that confusion is a terrible experience for every individual, with a loss of all normal markers or cues in the environment to help provide orientation to the immediate surroundings. The unusual feelings and experience with confusion are phenomena that patients are reluctant to share with health care providers, and even perhaps with their families. It is apparent that these events do represent a major psychological impact for the individual. The findings of these studies provide some insight into the personal experience with a confusional state as a component of ICU syndrome. This information is important in increasing the nurse’s awareness of the patient’s experience with ICU syndrome and can be used to guide nursing interventions that promote a safe hospitalization for a confused patient.

### Family’s Needs During Critical Illness

Leahey and Wright (1987) list some basic assumptions about families with a life-threatening illness. These assumptions are (1) the diagnosis of life-threatening illness occurs within a social context, (2) a life-threatening diagnosis changes the family’s life trajectory, (3) families need to review a life-threatening event, (4) family members’ reactions influence the course of a life-threatening illness, (5) family function is often
altered by life-threatening illness, and (6) family members’ beliefs about a life-threatening illness influence how they and the patient cope with the situation (p. 46-49). Using these assumptions, it is clear that admission to a critical care unit will be stressful to family members. Therefore, it is appropriate at this time to try to identify, in this study, what some of these stressors might be, specifically to determine the effect or impact of ICU syndrome on the family members. The purpose of this literature review is to understand and focus more on the emotional impact and stresses experienced by family members of critically ill patients who undergo ICU syndrome. As Hickey and Leske (1992) suggest, it is now time to look beyond the descriptive studies of the past.

Anxiety related to critical illness.

It is clearly outlined by Bozett (1987) that a life-threatening illness will be stressful to families, and that admission to "intensive care units whether planned or not, causes acute anxiety" (p. 13). This anxiety can be transferred to the patient increasing his or her stress levels (Bouman, 1984) and is a family’s response to the stress (Hodovanic Reardon, Reese, & Hedges, 1984; McShane, 1991; Reider, 1979). Some of the reasons for the increased anxiety are that the hospitalization threatens the integrity of the family system, separates family members, restricts the duration and number of visits, restricts the visits of children, and finally, results in a lack of privacy for the hospitalized individual (Bozett, 1987). A life-threatening illness places a family under "unusual stress"; and the illness of one family member can "uncover" interpersonal problems
within the family, lead to fiscal ruin, and obstruct emotional and educational plans (Bahnson, 1987, p. 26).

The perspective offered by McShane (1991) advocates a contemporary approach to the view of a family unit. This author believes that the family is the centre of care. She states that nurses should be expanding their concept of family and work to reduce the stress experienced by family members that results from the hospitalization of one individual in that family unit. A life-threatening illness and admission to a critical care unit will no doubt produce stress in the family unit according to this author. Therefore, the critical illness can potentially represent a crisis situation for the whole family.

**Determining family needs during critical illness.**

Families’ needs during a critical illness have been well documented. Studies have focused on identifying a number of needs such as having a waiting room near the intensive care unit, having a washroom near the unit, receiving calls at home regarding changes in the patient’s condition, knowing the course of treatment, being assured the best care is being given, feeling hopeful, talking to the physician daily, knowing the staff, having a hospital contact person, having visiting hours begin on time, and having questions answered honestly (Hickey, 1990). Most of these studies have not provided information of nursing practices or the unit characteristics that could potentially affect families’ need during a critical illness (Hickey, 1990). According to Hickey future research needs to be aimed at providing nursing interventions that satisfy family needs and the long-term effects of a critical illness on the family.
Developed by two nurses, the Critical Care Family Needs Inventory (CCFNI) is one of the most well known tools used to assess family needs in critical care (Hickey & Leske, 1992). The tool was initially developed in 1976 with need statement items generated from a survey of graduate students in nursing. These nurses were asked to list needs of family members of critically ill patients that they had either observed or cared for in their practice. This inventory was developed to provide nurses with a reliable, practical, and useful instrument that could be applied in a clinical setting to determine the specific needs of family members of critically ill patients. The tool covers a range of needs and places them in order of importance by the respondents. The focus of the instrument has remained on meeting the cognitive needs, informational needs, and physical needs of families (Bouman, 1984; Kleinpell & Powers, 1992).

In a recent literature review, Kleinpell (1991) critiques the tendency of past studies, which have examined only physical needs and the predominant use of the CCFNI to ascertain these predetermined family needs during the time of a critical illness of a loved one. Kleinpell’s (1991) review of 12 nursing research studies prioritize the needs of family members. She found that the need for information was identified as a top priority for family members, followed by the need to have hope. Kleinpell feels that the nurse should act as a primary source of information for family members and that the ability to meet the need for information as well as others can serve to reduce stress and provide support to both the family and the patient. Factors in a critical care unit such as the lack of physical space, the vast amount of equipment, the staff efforts solely directed
at the patient, the lack of communication with and support for family members, the unmet informational needs can result in a disruption in family members’ coping. This, in turn, can lead to a high level of stress within the family and even hostile interactions between the family members and staff (Lammon, 1985).

In a summary of nursing research studies over the past 15 years, Hickey and Leske (1992) advocate that the patient is not the only “victim” of a critical illness but that family members should be considered an important component of the nursing assessment of a critically ill patient. In fact, these authors believe that the family members may be affected to a “greater degree” than the patient (p. 645). They likewise propose that the stress of a serious illness of one member will exert a powerful reciprocal influence on family functioning and that the usual behaviour patterns utilized by the family can affect the patient’s outcomes. Furthermore, Hickey and Leske (1992) note that minimal research exists to explain or delineate the actual changes that occur in the family during the critical illness of one family member. These authors noted the hesitancy by nurses to incorporate families in patient care. Reasons for this inability in critical care nurses to provide family support are, lack of conviction that the family constitutes part of the patient’s environment for recovery, few intensive care units that truly advocate a family centred philosophy, and lack of confidence of the nurses themselves in their ability to provide the care to family members in crisis. Moreover, time constraints serve as a barrier in completing family assessments, which are used as a guide to plan for family interventions.
The experience of a critical illness and the significant effects on family members are documented in a study by Cohen, Craft, and Titler (1988). One participant notes:

Things have been really hard being sick again and all. My husband even asked me for a divorce because he said he couldn’t handle all my sickness after all ... I reminded him my illness has been no picnic for me to go through ...

One month later the same patient stated “things like I went through really do have effects good and bad, on a family ...” (p. 154, 155).

Responses to a critical illness.

Several studies have explored the emotional responses of family members in terms of behavioural responses, anxiety levels, and coping methods when a family member experiences a critical illness (Halm et al., 1993; Kleiber et al., 1994; Koller, 1991; Reider, 1994). The study by Kleiber et al. (1994) was designed to describe the behavioural and role responses of family members to the hospitalization of another family member in a critical care unit. This study utilized a daily log with probe questions to elicit the emotional responses of family members during the period of critical care hospitalization. Data analysis revealed 17 major categories of emotional responses. The dominant emotion identified by the respondents on the first day of the ICU admission was that of fearfulness. Fear was in response to “the unknown, unexpected, and uncontrollable” situation (Kleiber et al., 1994, p. 72).

The study by Cohen, Craft, and Titler (1988) clearly indicated that families have strong emotions during the critical care hospitalization, fear being a common emotional response. The outcome of fear can be silence, which can have an impact on each family
member. As a result of this silence, many fears may go un-addressed. In a study of ten family members, Liddle (1988) used a questionnaire developed specifically for this study to determine some of the needs perceived by relatives of patients in two intensive care units in a teaching hospital. Eight of ten (80%) of the respondents replied that they were frightened when they entered the intensive care area; these respondents found the main cause of fear arose from “seeing your relative ill” (Liddle, 1988, p. 152). In a similar study conducted in a trauma unit, Kleeman (1989) found that fear arises when a traumatic injury is unknown and unexpected and is perceived as a severe experience by the family members.

Other family responses to a crisis situation such as trauma include anxiety, shock and fright, denial, anger, hostility, distrust, remorse, guilt, grief, depression, and hope (Kleeman, 1989). The impact of the trauma on the family is not only severe, but complex due to the family’s lack of experience with this type of event in the past. One’s previous repertoire of coping skills are inadequate in this type of situation, “even the most functional and resourceful families feel lost and more vulnerable that ever before” (Kleeman, 1989, p. 24). Figley (1983) documented similar responses exist in a sudden or catastrophic situation. Eleven factors that may influence a family member’s response are: (1) having little or no time to prepare, (2) previous experience with the stressor, (3) sources of guidance available to manage the stressor, (4) the amount of time in a “crisis” state, (5) the extent to which others have experienced the stressor, (6) the degree to which there is a sense of loss of control or helplessness, (7) loss, (8) disruption and
destruction, (9) danger experienced by people exposed to the stressor, (10) the quantity and quality of the emotional impact of the stressor, (11) medical problems associated with exposure to the stressor (Figley, 1983). According to Figley (1983), a catastrophe can be any sudden, unexpected, and often life-threatening event, which, when of a sufficient magnitude can cause a sense of disruption, loss or destruction, with a permanent and detailed memory of the event. It can also cause disruption to the lifestyle or routines of others. This type of event can be any illness that results in admission to a critical care unit.

Hospitalization in a critical care unit produces high levels of anxiety in all family members (Halm et al., 1993; Koller, 1991; Reider, 1994). This assumption has been put forth by several researchers (Halm et al., 1993; Koller, 1991; Reider, 1994). Halm et al. (1993) wished to determine the affective and behavioural responses of families to a critical illness event, based on the assumption that critical illness causes anxiety and acts as a source of stress for family members. The three main sources of psychological stresses that are related to a critical illness can arise from the disruption of community life, the loss of a loved one, the fear of a permanent disability, and, finally, the uncertainty regarding the ability to control one’s environment. In critical care units, the overwhelming prevalence of high technology equipment can serve as the main source of stress related to lack of control over one’s environment. A convenience sample of 52 adult family members participated in this study, which used a self-report tool, the Iowa ICU Family Scale (IIFS), developed by these researchers for the study. The behavioural
responses reported were in relation to sleeping, eating, and activity levels. Respondents reported reduced sleep, a poor quality of sleep, a higher consumption of fast food and snacking, and frequent gastrointestinal upsets. The stress response changes were measured over time and indicated that the highest levels of anxiety occurred at the beginning of the critical care hospitalization, gradually levelled off over time, and finally dropped considerably by the 28th day of hospitalization. These findings confirm that high levels of stress are evident early after admission to hospital. Additionally, these researchers noted a higher score for family members even when they perceived an improvement in the patient's condition, indicating that stress is not always associated with a negative event. Dracup (1993) similarly found families experience the greatest levels of anxiety in the early part of the critical care admission and that the stress levels will be modified as the patient's condition stabilizes or begins to improve.

Koller (1991) used three tools including an open-ended interview guide, known as the Family Member Structured Interview Guide (FMSIG), the Jalowiec Coping Scale (JCS), and the CCFNI to interview 30 immediate family members of critically ill patients. The results of this study also indicated that the critical illness was perceived as a stressful event. Reider (1994) similarly recognized that high levels of anxiety were present in family members of adult critically ill patients, which is consistent with other studies. Reider (1994) also studied family members of patients diagnosed with trauma, heart, respiratory, neurological, and other conditions (liver failure, diabetic ketoacidosis, sepsis, abdominal aortic aneurysm, and problems that required major abdominal
surgery). Family members (n = 11) of the trauma patients experienced the highest mean anxiety score (mean score = 12; scale 0 - 24 points), followed by heart disease, respiratory, neurological, and other conditions. Age appeared to be a factor in the anxiety levels, with the highest levels noted in the younger family members. Harvey, Dixon, and Padberg (1995) confirm that the multiplicity of stressors associated with traumatic events can prove to be overwhelming and can potentially provoke a crisis in any family unit. Furthermore, both fear and anxiety are common emotional reactions to this type of event (Harvey et al., 1995). The studies reviewed clearly indicate that family members of critically ill patients do undergo many stressors, anxiety, and fears during the course of the hospitalization, and have more than just the physical needs such as telephones, washrooms, and need for physical proximity to the patient (Curry, 1995; Dracup, 1993; Halm et al., 1993; Koller, 1991; Padberg, 1995; Reider, 1994).

Nurses’ attitudes to family needs.

Curry (1995) conducted a study to determine nurse’s attitudes about the needs of relatives in one critical care unit. This author felt it was clear that family members will undergo some form of psychological crisis while a relative is in the critical care unit. This author based the study on the works of Lazarus, which focused on the psychological stress and individual coping processes. The study by Curry (1995) demonstrated that while many nurses recognized the needs of relatives of the critically ill, many nurses also felt unable to provide care to relatives because they lacked the necessary skills and experience to do so.
Dracup (1993) believes that all nurses have a commitment to include family members in their scope of care. The belief that family members of the critically ill are also deserving of nursing care is reflected in the current standards of the American Nurse's Association Social Policy Statement, which indicates that the family is a necessary unit of service (Dracup, 1993).

The Impact of Myocardial Infarction on Spouses and Family

Several studies have examined the impact or social effects of a myocardial infarction (MI) on spouses and families. This area of research can lend further insight and information into the experience of a critical illness on the family unit because it deals specifically with the emotional responses of the family members to a sudden critical illness.

Mayou, Foster, and Williamson (1978) found that many wives of patients with MI's had major psychological effects. During the time of the hospitalization, 95% of those wives who participated in the study experienced some degree of anxiety, with as many as 38% suffering moderate or severe distress. Common symptoms of the anxiety and distress were crying, sleep disturbances, and appetite disturbances, followed by feelings of numbness and unreality. A tendency to cling to other people such as friends and neighbours also surfaced during this time of hospitalization. Two follow-up interviews were conducted, the first at two months and the second at one year post discharge from the hospital. At the time of both follow-up interviews, the participants related that the psychological symptoms (as judged by a mental state interview) were
"fewer but remained considerable" (Mayou et al., 1978, p. 699). The interview at one year post discharge still indicated that the wives showed "considerable" psychological distress (Mayou et al., 1978, p. 699). Furthermore, at the one year interview, 40% of the wives complained of ill health and 17 percent had made more frequent visits to their own physicians during this time. Female respondents with younger children did not display greater psychological distress, but felt a great strain by needing to keep a brave face during the acute phase. This study clearly demonstrates the psychological impact on spouses and the effects that can potentially extend far beyond the hospitalization phase of illness. This study and a similar study by Nyamathi (1987) emphasize not only the immediate impact of a critical illness, but serve as reminders that there are potential long-term impacts on a family unit faced with a critical illness.

Nyamathi (1987) proposes that studies such as those conducted by Mayou et al. (1978) clearly provide us with the knowledge that an acute MI is perceived as a crisis by both patients and families. This crisis can result from the suddenness of the event as well as the perception that this event represents a physical, personal, and psychologic threat. Nyamathi also believes that the effects of an MI should never be considered in isolation of the family members, as it is inevitable that the MI will have an appreciable impact on the spouse, who is most often the wife (Nyamathi, 1987). This study by Nyamathi (1987) determined that the spouses used behavioural, cognitive, and intrapsychic coping responses to deal with the myocardial infarction. Behavioural coping responses such as calling the doctor, calling for transportation, seeking help, and
praying were used. Cognitive coping responses were identified as thoughts of the illness being heart-related, being in control, hoping, self-questioning, and planning or setting goals. Intra-psychic coping responses included denial and avoidance, emotion-controlling and putting up a front, and, finally, fantasizing about and wishing for a miracle.

Using a semi-structured interview format, Bedsworth and Molen (1982) sought to describe the psychological stress of female spouses of MI patients in the period of 72 hours or less following admission to a critical care unit. The findings of this study concur with the findings that psychological stress is present in wives of patients with an acute MI. In this early phase of the hospital admission, the most common type of threat verbalized by the wives was that of loss—either the loss of the mate entirely or the loss of a healthy mate (Bedsworth & Molen, 1982). Additionally, anxiety, depression, guilt, shame, anger, fear, apathy, and helplessness were among the emotional responses reported by the spouses.

Marsden and Dracup (1991) reported not only the effects of a cardiac event on the patient, but indicated that the spouse lives through “a parallel experience of their own” (p. 287). This experience, according to these authors, may equal the patient’s own experience in intensity. The psychological impact of an MI may affect the spouse for up to one year post MI (Mayou et al., 1978). Marsden and Dracup (1991) now propose that a shift in nursing research should begin to evaluate nursing interventions in alleviating or reducing the distress of spouses in such an event.
Sirles and Selleck (1989) most clearly delineate the association between an MI and the effects on the family when they state “the experience of serious illness, especially when it is a sudden and life-threatening cardiac event, is a crisis to both the individual and the family. Such events challenge a family’s stability, adaptability, resources, beliefs, and assumptions” (p. 24). Using a systems perspective, which advocates interaction between the person and the environment, these authors view human beings as open systems, with semi-permeable boundaries, who are in a constant interaction state with the environment. A social system is composed of “an organized boundary system of social roles, behaviours, and practices developed to regulate the practices and rules” (Sirles & Selleck, 1989, p. 23).

Dhooper (1983) also examined the effects of a heart attack on spouses and other family members. Interviews were conducted with participants three times, the first during the hospitalization, and at one month and three months post discharge. He also found a significant impact on the emotional health of family members due to the suddenness and seriousness of the cardiac event. Immediate reactions to the event were shock, disbelief, fear of loss of a spouse, anger, and helplessness. The findings of this study indicated similar results to those of Mayou et al. (1978) that the stress felt by the family members as a result of the MI can persist for some time beyond the acute critical care phase of the hospitalization. The most common reaction was fear of losing the sick member of the family, a finding that is consistent with the study of Bedsworth and Molen (1982). Sleeplessness, loss of appetite, lack of concentration or forgetfulness, and
headaches were common symptoms reported during the acute phase of care. Anxiety levels remained high in spouses and children despite the progression of the patient to a step-down unit. The results of this study indicate that in addition to the immediate anxiety experienced by the spouse of the MI patient, there seems to a need to strengthen their own resources against harm (Bedsworth & Molen, 1982).

Post Traumatic Stress Disorder

The studies reviewed on family’s needs during a critical illness and the impact of a myocardial infarction on spouses and families indicated a potential for long-term effects as a consequence of a hospitalization which involved a stay in a critical care unit. It seems appropriate to examine the literature in the field of post traumatic stress disorders. A traumatic event can disrupt an individual’s relationship with the world and potentially result in PTSD (Allen & Bloom, 1994). Post traumatic stress disorder (PTSD) is a relatively new syndrome that was identified following the war in Vietnam. It was only in 1980 that it was added to the Diagnostic and Statistical Manual of Mental Disorders (DSM-III) of the American Psychiatric Association and given full recognition as a diagnostic category (Van Der Kolk, 1984). Essentially, PTSD is the development of characteristic symptoms that follow a psychologically distressing event (Dicks, 1990). Initial data regarding this syndrome stemmed from experiences with returning Vietnam veterans. Dicks (1990) interviewed many subjects, not only just the men in combat, but some spouses of the combat soldiers, and one nurse who served in Vietnam. An overwhelmingly consistent portrait was developed of these individuals suffering from
PTSD. The event precipitating the PTSD is one that is considered outside "the range of usual human experiences" (Dicks, 1990, p. 2). The event is usually associated with feelings of intense fear or helplessness, as in ICU experiences.

PTSD disturbs individuals and their families in a variety of ways and can have a substantial negative effect on the affected individual's life, and those around him or her. A symptom of this disorder includes the re-experiencing of the traumatic event in many ways including dreams (Hogancamp & Figley, 1983). Common responses to the disorder are depression, anger, anxiety, sleep disturbances, psychic or emotional numbing, headaches, irritability, memory impairment, poor concentration, constant change in jobs, emotional constriction, loss of interest in work and activities, and substance abuse (Dicks, 1990; Van Der Kolk, 1984). People affected by PTSD have few friends, tend to isolate themselves, and may believe that no one cares about them. Many PTSD sufferers have difficulty maintaining a partnership, and their children have more tendencies to behavioural problems both at home and in school. Therefore, this information indicates that long-standing trauma related problems can severely compromise the individual's social skills and social competency and could result in marital problems (Carroll, Foy, Cannon, & Zwier, 1991).

The characteristic sign of PTSD is a delayed response to some trauma that may not be manifested until months or years after the event. PTSD has been recognized in civilian groups such as victims of natural disasters, plane crashes, nuclear accidents, or explosions (Van Der Kolk, 1984). The definition put forth by Dicks (1990) indicates
PTSD is a delayed response to extreme stress. This allows the nurse to take into account other anxiety provoking situations besides combat situations as a potential precipitating factor for the development of PTSD. In addition, Van Der Kolk (1984) proposes that other factors such as inherent personality factors, the strength of character, and the developmental stage of life at the time of victimization might act as an influencing factor in the development of the disorder. Chronic overload, and therefore PTSD, may develop if coping resources are inadequate or continuously overwhelmed.

Families can also be affected greatly by PTSD. Carroll et al. (1991) reported several effects on the family, including difficulty in maintaining intimacy, difficulty with self-disclosure, increasing manifestation of hostility and aggression, and marital problems. Children in the family can be affected either directly as they become the target of this hostility, or indirectly through poor parental functioning of the affected individual with PTSD. In a study conducted in the Middle East, Baker and Kevorkian (1995) sought to not only determine the effects of subjecting an individual to chronic and varying forms of traumatic life events, but to determine if family members respond differently to the same stressors and traumatic events. Three groups of families were studied--those who were severely traumatized, moderately traumatized, and a control group of non-traumatized families. A combination of quantitative tools, all Arabized versions, were supplemented by interviews conducted by a research assistant. Findings of this study demonstrate that depression symptoms are associated with stress and trauma. Depression symptoms were more common among the women; however, most of
the husbands refused to be interviewed by the female research assistant. Overall, this study showed that the level of trauma produces concomitant levels of depression and even levels of anxiety (Baker & Kevorkian, 1995).

Allen and Bloom (1994) also found effects on the family as a result of trauma. The trauma can disrupt the attachment bonds within the family and sever the internal and external connections of the family unit, often spreading down through the generations (Allen & Bloom, 1994). Clinicians working with family members of PTSD have noted specific manifestations such as constricted intimacy and expressiveness, overt hostility, unpredictable verbal and physical aggression along with difficulty adjusting to recurrent crises (Allen & Bloom, 1994). These theorists conceptualize the psychological effects of trauma. Some of the psychological effects recognized by Allen and Bloom (1994) are uncontrolled anger, grief, depression, narcissistic vulnerabilities, and anxiety. This model maintains that each individual creates an “individual, internal representation of the world based on a relatively stable framework of assumptions” (Allen & Bloom, 1994 p. 426).

Summary

This chapter reviewed selected bodies of literature to provide information and insight into the impact of ICU syndrome on family members. Based on the lack of studies to specifically examine the family responses to such a syndrome, it was necessary to broaden the field of literature reviewed. It was thought that these bodies of literature would help to illuminate the research question in this study.
The subjective reports of an experience with acute confusion indicates that this experience is fearful and is associated with a feeling of loss of control. Many participants felt reluctant to talk about the period of confusion. But at the same time, they were aware that they were unable to control the course of events surrounding the confusional episode. The fear associated with the confusion was remarkable; most respondents feared reprisals such as being labelled as a result of the confusion.

Family needs during a crisis have been seen in relation to needs for comfort and more practical items such as telephones and waiting rooms near the unit. Family needs in past were determined primarily in terms of physical needs and have been intertwined with the patient’s own needs. Yet, the literature review clearly indicates family members are also affected psychologically as a result of a critical illness. Information remains insufficient to understand emotional responses and the depth of the impact of the critical illness on family members. It is probable that the critical illness is stressful for family members as well as the patient; many people will find the impact of a family member exhibiting ICU syndrome stressful and even more anxiety provoking.

The effect of an MI on family members, particularly spouses, lends more insight into how acute hospitalization can impact on family members initially and the long-term effects. Stresses were related to an actual loss or a potential loss of a partner. Many of these participants suffered considerable distress that can evolve into a host of physiological symptoms, including an decrease in health and thus more frequent visits to a physician. Similarly, it may be possible that a syndrome such as PTSD results from
some form of psychological trauma as first seen in war veterans and later identified in survivors of natural disasters. In analogous situations resulting from critical illness, unresolved trauma in an individual could have a major impact on the whole family unit by disrupting these family bonds. The literature reviewed provides some insight into how a critical illness can affect family members. This study will focus on the impact of the syndrome on the family members.
CHAPTER THREE

METHODOLOGY

Introduction

This study employs a qualitative research methodology. The nature of the research question lends itself well to this type of inquiry, as it is attempting to uncover the individual’s experiences with the phenomena under study (Strauss & Corbin, 1990). In this specific study, the family members’ encounter with ICU syndrome, little is known about the family members’ thoughts and feelings during the time the patient experiences ICU syndrome. According to Polit and Hungler (1991), qualitative methodology can be used to uncover this type of information. This study utilizes an inductive, from the ground up approach. This methodology uses data from interviews with respondents and “is based on the premise that gaining knowledge about humans is impossible without describing human experiences as it is lived and as it is defined by the actors themselves” (Polit & Hungler, 1991, p. 497). This study is guided by the assumption that people do make order and sense of their environment although this world may appear to be disordered or nonsensical to others (Hutchinson, 1986). This chapter includes information about participant selection, data collection, and a brief synopsis of data analysis. The researcher includes a description of strategies utilized to promote rigor of the research. Finally, a discussion of the ways in which the protection of study participants’ rights were ensured is included.
Selection and Recruitment of Participants

This type of study requires that sampling should be of a nonprobability sampling type. The purpose of nonprobability samples is to facilitate understanding, to collect information for description, and to elicit meaning (Morse, 1986). As this researcher was interested in understanding the concept of ICU syndrome from the family member’s perspective and making sense of the impact of the ICU syndrome, the sample size was determined by these factors (Morse, 1986). For this study, therefore, it was necessary to access a certain population, those who are able to provide this information to the researcher. All informants were deliberately selected by the researcher according to the direction of the research (Morse, 1986). A small sample size is appropriate for this type of study. To obtain the type of information required, family members were selected specifically due to their desire and ability to provide information regarding their experience with ICU syndrome. All family members who were able to be present at the interview and expressed an interest in participating in the study were invited to participate. These family members were identified as significant by the patient or were identified by the staff as those individuals who visited the patient.

Subject Selection Criteria

The family members selected for the study met the researcher’s criteria of having a family member in a critical care unit who demonstrated the ICU syndrome according to the operational definition provided. The researcher verified that the patient exhibited signs of ICU syndrome by speaking with the nursing staff in the unit before approaching
the family members. Some family members provided the information for the demographic sheet describing the patient's diagnosis and the symptoms of the syndrome exhibited. Most families selected were living in the Lower Mainland or were available for a follow-up interview by telephone or some other means such as by mail, should one be required. Each family member who wished to participate in the study and was fluent in English was included in the interview. The family members interviewed for this study were all adults and were able to articulate their feelings clearly to the researcher.

Exclusion Criteria

Family members were excluded from the study if the patient did not clearly meet the criteria provided by the operational definition for the ICU syndrome. Family members who did not live in the Lower Mainland were excluded, unless they agreed to some alternative arrangement for follow-up interviews.

Recruitment Procedure

The participants in this study were recruited by the following procedure. Initially, the unit managers for the Coronary Care Unit, the Cardiac Surgical Intensive Care Unit, and the Intensive Care Units in a Lower Mainland hospital were approached by the researcher to discuss the study. A copy of a condensed research proposal was provided to them. Following this meeting, a second meeting was held with the Assistant Head Nurses for the Intensive Care and Cardiac Surgical Intensive Care Units to explain the nature of the study, participant selection criteria, and recruitment procedure as these individuals would be the main contact between the researcher and the potential subjects.
The department head responsible for Critical Care was also provided with a copy of the research proposal and met with the researcher to discuss the study.

Following approval of the study by department head and unit managers, an application to conduct the research was submitted to Research Services at the Vancouver Hospital and Health Sciences Centre (VHHSC). A concurrent application was made to the University of British Columbia Behavioural Sciences Screening Committee For Research and Other Studies Involving Human Subjects. Once ethics approval was obtained from both the University and the study site selected, subject selection and recruitment began. In-service sessions were held with those nursing units requesting them to inform the nursing staff about the study and what would be required of them. As well, written information was left in each unit to inform the staff of the purpose of the study, the patient criteria for the syndrome, and the need to interview family members who were present during the syndrome. Potential subjects were first identified by either the nursing staff or the Assistant Head Nurses on each of critical care units. The researcher made regular visits to each nursing unit to meet with these individuals and follow-up on any potential candidates. Following this, the Assistant Head Nurse, Charge Nurse, or Staff Nurse explained the purpose of the study to the family members and asked their permission to be contacted by the researcher. An information letter for participants was prepared by the researcher and provided to interested family members (Appendix A). Once subjects agreed to participate, the researcher made contact with the family either in person or by telephone. Further explanation of the study was provided to
the family members at this time, if needed. If they agreed to participate in the study, the family members were given the choice of being interviewed in either their home or at the hospital, at a time convenient to them.

Informed consent was read and signed by the participants and a copy provided for them prior to initiation of the interview (Appendix B). Demographic information regarding the patient, including primary diagnosis and any secondary diagnoses, was collected from either the chart or from the family members in several instances (Appendix C). Demographic data were also collected from the participants of the study (Appendix D).

Data Collection

This study is a qualitative descriptive study based on the premise that when "little is known about a group of people, or a social phenomenon of interest, in-depth interviewing is a good way to learn about it (Polit & Hungler, 1991). This research is aimed at describing "how a group of people define, via social interactions, their reality" (Hutchinson, 1986, p. 112). The presentation of the data relies on the inquiring and analytic mind of the researcher, whose task it is to discover and describe the essence of complex interactions (Hutchinson, 1986). The information gained from this study is important to health care providers and can be used to develop appropriate interventions for family members.

The utilization of non-probability sampling was important in this study and remains consistent with a qualitative approach. The assumption is made that not all
“actors in a setting are equally informed” about the knowledge sought by the researcher (Morse, 1986, p. 183). Not all persons can provide information about the impact of ICU syndrome on family members, and subjects are selected for their knowledge base about the concept of study and receptivity. In qualitative research, a small sample size usually provides the researcher with the information necessary. Data collection and analysis occur simultaneously (Polit & Hungler, 1991).

Qualitative descriptive study data gathering follows a pattern of field research (Hutchinson, 1986). Once the data collection begins, the researcher is immersed in the social environment. It is important that once the data collection begins, that the researcher lay aside their own beliefs about the subject explored, and be aware at the same time of any personal values or beliefs that may affect the interpretation of the data. It is due to this self-awareness that a researcher can begin to understand another’s world (Hutchinson, 1986).

The initial interviews were conducted in the hospital for the majority of the respondents, during the time of the ICU syndrome. The researcher prepared a list of open-ended trigger questions, designed to be used in case of difficulties initiating the interview process (Appendix E). In fact, the interview guide was not used to any degree, and the study participants were able to provide rich information with very little prompting from the researcher. During the interviews, the researcher asked questions to clarify the meaning of any areas that were unclear, and asked questions to elaborate on certain areas that surfaced throughout the interviews. These interviews were conducted
in a small private family room outside of the critical care unit or in an office near the
unit. This was done to ensure privacy and eliminate interruptions. For one respondent,
the initial interview was conducted approximately one week following the patient’s
discharge from the hospital, and was held in the respondents home. For the majority of
the respondents the interview was an emotional experience. Some of the emotions noted
during the interview were crying, anger, and laughter. The interviews were audiotaped
and later transcribed verbatim by a transcriptionist.

A total of eight initial interviews were conducted, two of which were conjoint(i.e. 2
family members). Interview times ranged from 27 minutes to 64 minutes in length.
The mean length of the interviews was 45 minutes. All participants were given the
choice of being interviewed together, as a family unit or individually. Some family
members felt that they would share very different information with the researcher if they
were interviewed alone, and the choice was left to the respondents. All participants were
aware that the audiotape could be stopped anytime during the interview, but none
requested the researcher to do so. All participants completed the first interviews and did
not withdraw prior to the completion of the interview. Field notes were used to record
the venue, and background information regarding any emotions demonstrated by the
respondents during the interview.

Follow-up interviews were conducted approximately 8 to 12 weeks later. The
purpose of these interviews was to verify the information provided in the initial
interviews and to seek any additional information from the respondents that had surfaced
since the last interview. All follow-up interviews were conducted individually. The researcher was particularly interested at this time in determining the effect, if any, that the time period since discharge from the hospital had on the responses of the participants.

A variety of mechanisms were utilized to increase accessibility of the respondents including telephone interviews as well as interviews conducted in person. These face to face interviews were conducted in the home of the respondents. Field notes were kept to record the circumstances and setting of the interview. The patient who had suffered the ICU syndrome was present in the home for one of the interviews, but was in another room and did not participate in the interview. Those interviews conducted by telephone were audiotaped as well. A total of 5 follow-up interviews were audiotaped, and notes were taken by hand for one follow-up interview after the interview completed. The length of these interviews lasted from 25 minutes to 75 minutes. One respondent was not approached for a second interview as her spouse [the patient] had recently and unexpectedly passed away. Another respondent spoke informally with the researcher. When approached by the researcher for a follow-up interview she felt unable to make a commitment to meet again, as her father had recently been diagnosed with metastasis of his cancer and her concerns at this time were directed to this new illness.

Interestingly, for several of the respondents while the ICU syndrome was no longer present during the second interview many of the patients still suffered from some illness or had been chronically ill since the first interview, and unable to return to their
previous level of functioning. For these people, the syndrome was resolved, but they were still faced with the impact of the illness on their lives. The purpose of the second interviews was to validate the data analysis at that point, and to obtain any new data that had not been discussed in the first interviews. There did not appear to be any effect of the time period between interviews on the ability of the respondents to recall the initial interview and subjects discussed. Field notes were kept during the data collection process. These were used to record any circumstances that occurred during the interview, such as the participants fearfulness, or any information sharing that occurred before or after the interview session. The researcher documented observations related to each family member’s appearance, mental status, anxiety, and home environment if the interview was conducted in the home. The field notes were used as part of the data base to help facilitate interpretation of the data.

Data Analysis

In keeping with a qualitative methodology, data collection and analysis occurred simultaneously. Therefore, data analysis began following the first interview with each family. Once the interview was conducted, the audiotapes were transcribed by a transcriptionist. The audiotape was replayed and compared to the transcript for verification that transcription errors had not occurred. Any notes regarding changes in the respondent’s voice or emotion were noted on the transcript at this time. This indicated that an issue was very meaningful or emotionally charged to the participant (Morse & Field, 1995).
Following this initial step of verification, data analysis began by the constant comparative method of analysis (Polit & Hungler, 1991). In this methodology, coding represents the operations by which data are broken down and put back together again (Polit & Hungler, 1991; Strauss & Corbin, 1990). Analysis consists of three types of coding: a) open coding; b) axial coding; and c) selective coding. Open coding is the first basic analytical step during which the data are broken down into discrete parts, closely examined, and compared for similarities and differences (Strauss & Corbin, 1990).

Axial coding is used after the initial stage of open coding. This allows the researcher to make connections between categories and subcategories (Strauss & Corbin, 1990). The focus is on specifying a category in terms of the conditions that give rise to it, that is to say, the context in which it is embedded (Strauss & Corbin, 1990). It is anticipated that the researcher may be alternating between the two modes of coding as data analysis proceeds. Concepts and relationships arrived at through this deductive thinking should be verified against the actual data. Axial coding, therefore, is a process which relates subcategories to a category, using a complex process of both inductive and deductive thinking. It is during this phase that categories are developed (Polit & Hungler, 1991).

The final stage of this data analysis is the stage of analytic induction. According to Polit and Hungler (1991) the researcher strives to weave together the thematic pieces into an integrated whole. In this final stage for this descriptive study the researcher began to look for salient properties and similarities in the situations. This enables the
researcher to state that under certain conditions something can be expected to happen (Strauss & Corbin, 1990). Inductive and deductive thinking are used to systematize and solidify connections. This is seen as a constant movement between questioning, generating a hypothesis, and making a comparison (Polit & Hungler, 1991). Categories can be grouped according to the patterns discovered by asking questions and making constant comparisons.

Reliability and Validity

In qualitative research, methodological rigor must be addressed as well. The approach to qualitative inquiry emphasizes the standardization of language, rules, and procedures for obtaining and analyzing data to ensure replicability and validity (Sandelowski, 1986). Sandelowski promotes the strategies originally listed by Guba and Lincoln as a way to ensure the reliability and validity of qualitative research as; auditability, credibility, fittingness, followed by confirmability. Rigor in qualitative work, according to Sandelowski, (1993) places a greater emphasis on fidelity to the spirit of the work rather than an adherence to rigid rules.

Auditability

Auditability occurs when the researcher leaves a clear decision trail concerning the study (Sandelowski, 1986). Auditability, therefore, is a criterion of rigor that relates to the consistency of the findings (Sandelowski, 1986). This ensures that the reader can follow the progression of events and understand the logic in the study. A study is auditable if another researcher can clearly identify the decision trail in the study and
would arrive at similar and comparable conclusions using the same data (Sandelowski, 1986).

In this study, auditability is established by a written report of the findings of the study. Attention is given to the subject matter of the study, purpose of the study, selection criteria, data collection, analysis, and finally, interpretation.

**Credibility**

Credibility is a qualitative equivalent to internal validity in quantitative research. It is the criterion against which the truth value must be evaluated. A qualitative study is credible when it “presents such faithful descriptions or interpretations of a human experience that the people having that experience would immediately recognize it from those description or interpretations as their own” (Sandelowski, 1986, p. 30). A credible study is one in which other readers or researchers can recognize the experience after reading a report of the study (Sandelowski, 1986).

Credibility was established in this study by (a) checking for representativeness of the data as a whole and the coding of categories with faculty; (b) checking across data sources and data collection procedures to determine congruence with other relevant sources; (c) checking that the theories and descriptions contain typical elements of the data; (d) obtaining validation with the subjects themselves in a second interview. Participants were offered copies of the original transcripts during the second interviews, with the purpose of validation and confirming the data obtained during the interview. Only one participant actually desired the copy.
Fittingness

Qualitative research depends on human subjects who have a story to tell (Sandelowski, 1986). Representativeness in this type of research refers the data, not solely the subjects or settings (Sandelowski, 1986). The tasks of the researcher are to establish the behaviours or events as typical or atypical in the lives of the subjects. Fittingness is a qualitative criterion that determines if the findings of the study can actually fit into contexts “outside of the study situation” (Sandelowski, 1986, p. 32) and if the audience judges the findings of the study meaningful and applicable in its own experience. However, an effort was made to include family members from three separate critical care units and to include a wide range of family members.

Confirmability

Confirmability is “the degree to which the findings were determined by the informants” (Howell, 1994, p. 104). The contents of the study should be that of these informants, not the researchers. Confirmability is obtained by the use of a second interview to validate and confirm with the participants that the content, analysis, interpretation, analysis, and completeness are in fact correct representations of the first interview. Additionally, notes and memos of theoretical decisions promote a clear decision trail to enable other researchers to arrive at the same conclusions. Faculty members were utilized to validate the adherence to confirmability.
Ethical Considerations

Ramos (1989) outlines the main areas of concern in qualitative research as the participant-investigator relationship itself, the investigator's subjective interpretation of the data, and the emergent design. In this study, the participants were encouraged to share with the researcher their thoughts and feelings during a period when a family member was possibly confused and suffering from ICU syndrome. It was felt at the outset of study that by providing the participants with the opportunity to verbalize these thoughts and have them validated, that indeed there would be more benefit than harm.

Following the interview, all participants unanimously agreed, despite some episodes of crying, and the emotions seen throughout the interviews, that talking about their experiences and feelings during the time was helpful. Many also verbalized that having these feelings explored and openly expressed was therapeutic in itself. The participant-investigator relationship was viewed by the researcher as one of a privileged relationship. Each subject was treated with respect and listened to attentively. The researcher had a genuine desire to be attentive and to listen to what each participant viewed as important. The researcher was empathetic and fully prepared to meet again with and provide support for any individual who felt overwhelmed with the material discussed during the interview. Every effort has been made by the researcher to protect and promote the participants' rights to respect, dignity, information, autonomy, and privacy.

The investigator interpreted the data according to guidelines provided by qualitative research methodology. Faculty verified that indeed the coding and
categorization were representative, and provided feedback to the researcher during the interpretation phase. At the time of the second interview each participant was offered a copy of the transcript from the first interview, only one respondent requested this.

All potential participants were approached initially by a staff member in the critical care unit. They were provided with an information letter at this time (Appendix A). All participants entered into the study voluntarily and could withdraw at any time without repercussion. Once the interview was in progress, the participants had the right to have the audiotape stopped at any time and could have a portion of the interview erased if they should so desire. Potential participants were assured that failure to participate in the study would in no way affect the care provided to them or their family members.

Informed consent was obtained from all participants. Each individual was offered a copy of the consent. It was made clear in this consent that participation was voluntary, and that withdrawal was possible at any time. The contact number at the University Research Services was provided for any person who felt that they were not treated fairly (Appendix B).

The researcher protected each participant's right to privacy in respect to the data in several ways. First, all demographic data collected were coded with further reference to names deleted. The information collected by this means was used and reported in an aggregate manner only, as supplemental data to the interviews. Only the researcher had access to the coded documents. All audiotapes were coded, with only the researcher able
to identify them. Access to the data, audiotapes and transcripts, was limited to the researcher and her committee members. The transcriptionist signed an agreement or contract to maintain confidentiality and returned the computer disc at the end of the transcriptions (Appendix F). The contents of the disc were deleted at the end of the study by the researcher. Finally, all audiotapes and transcripts will be destroyed following the completion of the scholarly reports and thesis.

Summary

A descriptive qualitative methodology was selected for this study as it fits best with the purpose of describing and shedding light on the phenomenon of interest. This approach is based on an approach that works from the bottom up and uses everyday behaviours to help explain or describe a phenomenon. The use of this methodology will best help not only nurses but health care providers to understand and become aware of the impact that ICU syndrome has on family members. The data from the transcripts were analyzed following the interviews. The following chapter describes the results of the data obtained from these interviews.
CHAPTER FOUR

CHARACTERISTICS OF THE SAMPLE AND

PRESENTATION OF THE FINDINGS

Introduction

This chapter has two sections: characteristics of the sample, and the presentation of the findings. The participants in this study discussed their encounter with a family member who underwent ICU syndrome while in a critical care unit. The participants described several common themes that they experienced during the patient's phase of acute delirium associated with ICU syndrome.

These themes were conceptualized as discrete categories among respondents. They were shared by all participants, with varying degrees of impact on each participant. The participants tended to move between these categories in an individualized manner, in no predictable order. In addition, the intensity of these categories varied among each respondent.

The major categories identified by the respondents were; (1) the reason for being there, (2) maintaining strength, (3) the need for support—knowing who to turn to, (4) the respondents' need to know, and information seeking, (5) a questioning of how long, looking for a cause and effect relationship with the syndrome, (6) the respondents' trust in the staff or the patients trust in the respondent, (7) the need to look for the patient as the respondents know them, (8) dealing with the loss and planning, (9) the need to make meaning of the behaviours, and finally (10) the respondents emotional responses such as...
anger, guilt and feeling responsible, and blaming the patient or environment.

Accordingly, the presentation of the findings represents the aggregate descriptions of the thoughts and feelings that the participants shared with the interviewer concerning the time that their family member underwent ICU syndrome.

Characteristics of the Sample

Ten family members were interviewed for this study. Participants were initially approached by a staff member in the critical care unit and asked to participate in the study. In total, eight patients who experienced the syndrome were identified, and ten of their family members were interviewed. Only one family group did not wish to participate in this study. A further two patients were identified by staff as having met the criteria of ICU syndrome, but family members were not present during the critical care phase and, therefore, did not observe the syndrome.

The family members present in the hospital were approached as a group and were given the option of being interviewed either individually or as a group. This decision was left entirely to the participants. Those family members interviewed separately indicated that they might share different information with the researcher if other family members were present during the interview. The initial interviews, with the exception of one, were conducted during the period of ICU syndrome, in a room in the hospital. One participant was interviewed within one week of the discharge of her father, and the interview was conducted in her home. A second daughter was interviewed in the hospital, but almost one year following her father’s experience with ICU syndrome. The
memories, emotion, and impact of the syndrome remained vivid in her mind despite the time period that had lapsed.

Second interviews were conducted approximately 8 to 12 weeks after the initial interview. They were conducted either in person or by telephone. The use of other means of interviewing besides face-to-face contact, was employed to minimize disruption to respondents, to increase accessibility to respondent, and to allow the researcher to validate the findings of the first interviews. Participants themselves helped to validate findings as did the faculty on the thesis committee. It appeared that the time period between the first and second interview was not a crucial factor in recall, as all the respondents had excellent recollections of the discussion and points made during the first interview. One difference noted in the second interview was that almost all the subjects appeared much more relaxed and less stressed than during the first interview. That relaxation, however, did not prevent emotion or fearfulness from being expressed during many of the second interviews.

Participants (n=10) included five daughters, two wives, one husband, one daughter-in-law, and one son-in-law. The ages of these respondents ranged from 36 to 76 years of age. All the participants had completed high school. One daughter held a graduate degree. One interesting note was that two of the daughters and one spouse were registered nurses. The remainder of the participants had varied backgrounds and included an educational researcher, a teacher, a secretary, a truck driver, and two retired persons.
Overview of the Categories

The study revealed 10 major categories that clearly demonstrated the impact of ICU syndrome on the respondents and a discussion of these are presented in this section. The major categories demonstrated the depth of the respondents' emotions and were conceptualized as discrete entities that were common to all respondents. These categories were conceptualized as responses with varying degrees of importance for each respondent. There did not appear to be one singular overriding or central theme, but rather one category led to another for most respondents. These categories were conceptualized in a linear fashion, and neither occurred in the same order for all respondents, nor did they all have the same weight for each respondent.

The first category entitled "the reason for being there--their role" best describes the role that the respondents played related to ICU syndrome. All respondents played an important and active role in helping the patient through the syndrome. The role was often not unlike a previous role taken on in the family. All these roles involved offering support to the patient and ranged from basic comfort measures to helping connect the patient to reality.

Respondents in the study demonstrated and maintained tremendous strength of character throughout the period of the hospitalization including the period of ICU syndrome. This strength was an important point for them, and they tried to maintain it despite some difficult circumstances. In fact, if they broke down at all, this tended to happen after they left the hospital and many family members cried all the way home, or
upon arrival home. Having the support of others was an important aspect for these respondents as it allowed them some way of continuing their vigil at the hospital. These respondents also needed to know where they could obtain this support when they needed it. The respondents felt that support came in one of two forms, either physical or emotional. One daughter also found a source of spiritual support that she had previously developed. The support was important and tied in with the first category entitled “the respondent’s reason for being there” and the role that the respondents played related to ICU syndrome.

Needing to know information was another important category. Information gained from the health care professionals about the syndrome, was a modifying factor in their stress. Difficulty obtaining the information they needed served to be a stressor. Family members primarily obtained their information from the nurses caring for the patient, but outside friends were also utilized. Most family members felt that the information obtained from physicians was limited, and had difficulty accessing them. Several respondents thought that information about ICU syndrome should be provided as a component of the routine pre-operative teaching. Many family members knew that things were not going according to plan when the syndrome developed. Questions regarding the length that the syndrome and subsequent confusion could last were raised. Seeking information about the cause and effects of the delirium provided some comfort and control in this situation. Family members looked at possible drug interactions or another modifiable condition such as sleep deprivation as the cause for the syndrome.
Being forced to observe the effects of the syndrome demonstrated by the patient produced many questions and often led to feelings of uncertainty in family members. The patient's confusion represented an unknown phenomenon for most respondents, and they sought a cause and effect relationship. Family members were often not sure if this was a permanent or temporary situation, and they needed to know what to do to cope with the situation.

Trust was another category identified in this study. A great deal of trust was exhibited not only by the participants in this study but by the patients who demonstrated trust in the respondents. The trust varied somewhat between these two groups. First, the respondents had to learn to trust the medical staff to provide information to them and to care for the patient. Patients with the syndrome also showed an element of trust in the respondents who were often asked to make decisions regarding care on their behalf during the period of the syndrome. Some patients also turned to family members to validate feelings of paranoia or hallucinations that occurred during this time.

Many time family members could see and hear their loved one, but the unusual behaviours made it difficult to reach him/her. Looking for the person they knew despite the behaviours was a common theme. They were able to see the patient in the bed, recognized the voice, but did not recognize the behaviours they saw. Family members looked for a sign of the normal behaviours they would expect from the patient. They missed the role that the patient normally played in the family unit, and hoped for a speedy return of that person.
This syndrome prompted them to stop and take a little time to plan for the future. Planning by the respondents could include the incorporation of the patient in their own lives in the future, or even to plan for the future if the patient did not survive the hospitalization. Children of the patient with ICU syndrome took stock of their own lives and re-examined their own roles in the family unit. The planning that occurred may be related to their jobs, career plans, or even the need to make lifestyle changes. As the behaviours that accompanied the syndrome were previously unknown and at times bizarre, the family members looked at them as some type of message, perhaps covertly being presented to them by the patient. This was evidenced in the category of making meaning from the behaviours. It was sometimes possible for the respondents to identify subtle changes in the behaviours even before the staff were able to detect the syndrome. Family members felt that interacting with the patient helped to bring the patient back to reality, and helped the patient to focus on reality.

Not only were these family members at times responsible for decision-making, they also took the blame for the decisions they made. Many family members made difficult treatment decisions during this time on behalf of the patient. Conversely, some blame for the syndrome was directed at the patient as some family members felt it could have been controlled or avoided.

However, the behaviours or the situation could provoke some anger in the respondents. The situation of being faced with the syndrome or the close contact and continual strain of these unusual behaviours that were associated with the syndrome
could prompt the anger. The anger could be directed at the patient or at the situation itself. The family members felt frustrated at the situation that developed, and were helpless at times to do anything to help. Family members also expressed some anger when they saw other patients who progressed through the critical care units much more rapidly, and did not develop the syndrome. Anger was also directed at other family members who were not present to share the burden they felt.

Guilt and feelings of responsibility were perceived together in another category. These family members shouldered some of the guilt for enabling these unusual or negative behaviours. They also felt guilty and responsible for treatment decisions they made. Many of these respondents had encouraged the patient to chose the present course of treatment, or surgery, and now felt guilty because the outcome was not an expected one.

Discussion of the Findings

Reason For Being There -- Their Role

This category best describes the role or reason that all the family members present assumed during the hospitalization. Some of the family members present felt that they took on the roles of being present, caring, and helpful as a result of a role they had played in the past within the family. For others, these could also be new roles taken on since the illness and development of the ICU syndrome.

Individuals who had played a similar helpful or active role in the family in the past found that this type of role was consistent with this known role-- to help out the
family, to advocate on behalf of the patient, and to help the health care team better understand the patient or person that they knew. Those individuals who held a strong role within the family unit felt that this was just doing what had to be done for another family member. They felt that it was important to have family involved in the patient’s care and that their close involvement and contact would help to calm the patient:

... coming from and why you’re doing this because I keep thinking I’m doing this to help my dad get better. Get his feet back in reality ...

The role of being in the hospital, for family members was thought to be a part of “who they were.” Increasing their participation or interaction with family members in this situation showed them what families were all about.

... I don’t know I just come and see her and, you know, I love her, so that, you know, I will do it for anybody but for her. I’ll do it more because, you know, she’s in the family, so, you know ...

... that’s been, um, a part of who I am just, you know, as a - as a mother working with kids, it just is pretty natural ... I think it’s just natural that I would be like that with my parents too so ...

These respondents tried to keep calm or reduce the agitation for their family members.

One daughter had seen her father confused with previous hospitalizations and felt that it was important that her father have her present to help “anchor” him. This strong role of being present for her dad was an established role for this daughter.

... my situation is different, too, because of the number of times I’ve been to the hospital. I can’t count the number of times on my hands anymore that I’ve been to the hospital for my dad ...
All of the family members felt that their presence at the hospital would provide some stability for the patient and felt that they could do it better than the staff members or another family member present:

... you know she would take him and hold him and he doesn’t like that fussiness. And maybe they think I’m cold that I don’t do that all the time but, uh, he just gets mad. You know, maybe they think I don’t have any feelings but I do. It’ll be our 40, 45th anniversary coming up shortly...

They were prepared to do whatever was needed, be it holding hands, trying to keep the patient engaged in conversation, stimulating the patient to think about the past, or providing a necessary bit of history for the patient to try to bring them back to reality:

... and, you know he [the patient] needed a lot of support you know... he did and I, you know, like I was sort of -- the most I could do was sort of be there and talk about a bunch of shit, you know, like there was some funny story that happened and, you know, read in the paper and this political idea came up and at least that to him was very kind of meaningful...

... try to keep him engaged and try to keep him thinking and asking him questions... Get him to think about fishing or get him to think about the table he’s working on. He’s a cabinet maker...

... I’m here to hopefully -- can that be try connection to life outside this horrible place...

... that’s my bottom line is I -- the more we’re here I think the better it will be for him...

Physical comfort measures beyond hand holding were something that they felt they could provide because of that intimate knowledge they held about the patient from the past history. One wife provided some assistance to her husband, “and I know that he likes to have a pillow under his arm- under his arm. When he’s turned and... it wouldn’t
be there and he’d be floppy I’d do that because ....” If touch was not indicated, just a family presence was an adequate reason to be there. Many had a strong need to be there and had some difficulty in clearly defining the reasons they were there. However, being able to stay at the hospital with the patient provided that patient with a connection to life outside and reinforced to these respondents the importance of family holding together. For example, “family means being there, not always measured in time” or “yeah, we’re family.” Many of the daughters felt a strong bond with their fathers, and this bond made it even more important to be there during his time in need.

A new role emerged for some respondents. Many took on the role of a stronger, more independent person within the family unit and left behind a more dependent childlike role. The respondents might go so far as to turn their role into one of providing support for the other parent, usually the partner of the patient with ICU syndrome. One daughter said; “I’m in the role in the family being yeah, it’s almost like there’s something that I was that is just being expressed in my family for the first time.” The children felt that during this time they needed to be strong and provide the support rather than ask for that support from their parent. This temporary role as the “parent” came about because of the family connection. In the second interviews, most of the respondents felt that they had returned back to the role of the child within the family unit once the confusion and immediate illness had resolved for the patient.

A nursing background led two daughters to become interpreters of medical information for other family members as well as a contact person for the health care
team. This specific role was not a previous one for them within the family unit, but as they possessed the necessary medical knowledge to do this interpretation, they acted in this capacity once the patient was hospitalized. This proved to be an important role, as the remaining family members trusted them to provide explanations and information. Likewise, the health care team felt comfortable and confident that those daughters could help the others understand messages such as in this case, “I think in a situation like this where you’d have -- the nurses need, you know, somebody that they can talk to ... .” Another daughter had similar sentiments when she said, “well, my relationship with my parents has changed ... they sort of see me as the nurse kind of.”

In a follow-up interview, one spouse mentioned that she was dealing with several different specialists, none of whom told them anything nor communicated with each other. Both she and her husband, the patient, felt lost and were very frustrated and angry at the lack of communication. She thought that if her daughter, one of the nurse respondents, were present, she would sort them out and get some answers for them.

Maintaining Strength

Maintaining strength was an important theme throughout this study. The respondents described many ways in which they exhibited great strength, primarily emotional strength. These respondents described a long walk down the hall from the waiting room for cardiac surgery and the main intensive care units, after first having passed through a gate, which was the locked door to the visitors waiting room, to visit their relative. The actual distance was irrelevant; but the act of walking down this long
hall was the significant part. It meant that they had to pull themselves together during this walk. These respondents never knew what they would find once they turned the corner into the critical care unit. Even those family members who visited in the cardiac care unit (CCU) felt the same thing, even though there was no locked door or long hall to walk down to enter the unit. For many respondents there was an accompanying set of physiological symptoms such as a feeling of their stomach going up into their throat, or a tightening of the throat during this walk. This feeling was so overwhelming at times that they didn’t know how they got to the other end of the hall. They felt that this was a common feeling: “you know, everyone knows the anxieties and walk up to the gate saying can I come down now?” Other respondents indicated similar feelings:

... anxiety-- when you pick up the phone in the waiting room and ring and say “um can I see Mr. X? Is he alright? Can I come down? Can I come in?” And walking down the hall, your heart rate goes up and you think, oh God, is he going to know me, what’s he going to say, is he with it?

... I’m kind of scared to walk around the corner to see what’s there. What’s going to greet me. I kind of always send--and I kind of held back and let [husband] go first ... But, actually, when I was coming out of CCU one time and I was -- and there was another girl and another fellow there they were going in and the girl stopped and she just stopped, she took about three deep breaths and then she-- ...

Interviewer (I): Then you psych yourself up?
Respondent (R): Well, I stop before I go in and kind of take a deep breath saying, “What am I going to walk into? What am I going to walk into?

It was important for these respondents to be strong, to “hold it together” and control their emotions while they were in the hospital with the patient. They felt that it was very important to be strong and not to break down or cry in the room, but often were not sure if that was a good or bad thing when asked about it. In contrast, often on the
way home from the hospital these respondents did break down and “cried all the way home,” or cried on another family member’s shoulder upon returning home. Often, these respondents, when they felt they were pushed to what they saw as the very end, would break down and release some of the tension. The significance of the release meant that they could then return to the hospital and continue to hold it together and be strong. This need to be strong was so important that if they felt the need to break down, they would leave the critical care unit in order to cry:

... like—like—like I’ll, you know, a couple of times when I was talking to you and you knew that I almost had tears well up but it’s like, no, I’m fine here when I go home, I’ll deal with it ...

... Sure. I’ve had a few tears at home, off and on and I cry when I feel like it, I do. But, you know, there’s so much that’s happened to us ...

... Um, it—it– I didn’t cry, you know, when I was looking at him. I think he was so much, you know, because he was so sick ...

... Same with me. They can push me, push me they push right to the very end ...

... Oh–I said we’ve had such a—we’ve had a lot. We’ve had a lot. So I find, um, I’m strong, I think. I think I ‘m strong. But I’m, you know—I don’t want anybody to say you can’t falter ...

... take a deep breath and just go in and try and, you know, be strong and keep a stiff upper lip and everything. That’s what the girls kept saying to me, anyhow. “Mom why are you so strong, don’t be so strong.” And I said “Well I’ll hit my wall sooner or later”. And I did you know ...

... yeah, ... and it’s really hard ‘cause you’re standing and you--you go out of the room and you just—I mean I was strong enough not to break down in the room, um, but I don’t know if that’s good or bad.

... I know I can’t do this well without stepping away a little bit in the process to—to go and just release a bit and then I can go back--come back and --and be there for him. I think that—that is important to get away. That’s what changed things
was to go away and release the tension and release the fears, release the worry a bit and -- ...

Keeping a strong face to the family allowed them to hold up and reinforce the strength of other family members. They needed to be there for the patient and would be able to help the patient more if they remained strong. All of the family members had constant reminders that a loved one was in a critical care unit. Only rare instances occurred when they were able to briefly forget that the patient was sick and what they were going through:

... brief time I would forget that it was happening and then I would remember. Oh, yes. My husband’s in ICU and he’s in the DT’s and confused and not conscious and it’s a terrible thing and it certainly has been the worst—this is day 13—but I must say that that middle section was the worst week of my life ...

... it was such a change and it wasn’t him, so we were witness to this terrible struggle. It’s very hard to see anybody in your family uncomfortable, in pain, um, and the look, you know, that—in their eyes, and you know they are suffering and it’s very difficult. I didn’t get weepy until about the fourth or fifth day...

The strength demonstrated by the respondents was important, and this need for strength could often lead to silence. While family members often had concerns about the patient, and perhaps the confusion and ICU syndrome itself, they often did not talk about it, keeping silent for fear of upsetting others. Many of them had some suspicion that all was not right, but sharing it with the other family members would only serve to upset them, and perhaps impair their ability to keep the strength while in the hospital. Talking about these fears and suspicions made the situation worse. One daughter said about talking about it with her brother:
I: That he was afraid to make it worse. Do you think he was afraid to make it worse by talking about it?
R: He was afraid.

It was helpful for the respondents to try to keep an even level of emotions while at the bedside and not allow the stress to escalate. There were appropriate and acceptable times to release the stress, always away from the hospital and the bedside and often even at a later date. The needs of the patient and the other family members were held uppermost, and the need to release or show signs of weakness given much less priority. Previous experience with hospitalization and even with confusion made it easier to cope and to be strong. Being pessimistic was not seen to be helpful, but rather an optimistic outlook was thought to be important.

If the family members felt the need to keep up the strength, but felt their own strength dwindling, they sought some way to keep up their strength. Using internal resources such as spiritual ones could be one way, while not thinking of oneself as helpless was another way. There were times when that strength was tested, and just looking at the loved one in a confused state could produce some weakness. Yet, these people sought some mechanisms to re-energize and return to the bedside as a strong, supportive person:

... Um, yeah. My faith made it easier for sure. I think that I, um,-- yeah, I -- there were times when I could have gone downhill fast ....... Um but I remembered the resources -- or the resources came to me and, um, and so it helped strengthen me to , um, so just, um, strong people and ...even music ...
Support -- Knowing Who to Turn to

Having support available was important for all respondents who had experience with ICU syndrome. Support could be either emotional or physical in nature. The importance of support to these respondents was that without it, they felt they would be lost: "I'd be lost if I didn't have it." The presence of support enabled participants to go on and continue to provide care for their family member.

A typical response came from a woman who was staying with her mother during the hospitalization of her father. She lived out of town and leaned on her husband for much needed support during a short visit home. She said: "... and my husband, having the physical, um, emotional support was really important ..." She had a good cry on his shoulder:

... it was a wail, you know I can't -- I couldn't see myself doing that with anybody else but my husband. You know, it was like a right from my gut a let-it-all out and -- and that was really important for me anyway ...

She also placed a great deal of emphasis on her faith and had a spiritual source of support unique to this respondent.

... I remembered what I perceive to be true in terms of who else is involved in this whole process-- um--so it's not just on a human level. I believe that there are other events happening and it's not just on a -- human level that all this is transpiring. There's other levels, um, spiritual levels that are happening here. So I --and I. Those are the resources that helped me ...  

Friends and other family were also very important in providing support. They showed that they were concerned by calling to check on not only the patient, but the family members as well. It meant that others cared about their family members, and they
were not alone. Some family members who were from out of town stayed with their relatives. This again provided them with support during a difficult time. For example, one daughter stayed with her Mom and left her job for several weeks to do so. Her mother said about that daughter’s support: “... my daughter’s been great, coming here. She’s missed like I keep worrying about her work ...” Another man further emphasized the importance of support from family and friends in his experience with the syndrome when he said: “... that definitely helps but I’d say family and friends, if I was down staying in a hotel or motel somewhere ... if your friends are right there and everybody’s there so you won’t have any problem.” Friends and family allowed the respondents to falter, and let down their guard. For example as one wife said, “oh if I falter because I need to falter, you know, it’s me. Something’s saying, um, okay, collapse for a bit.”

The physical absence of family did not always mean a lack of support, as simply knowing that someone could be called on was helpful.

Support was often derived from assurances from the health care team that the patient would get better. This would once again provide the caregiver with a resolve and with the strength to go back to the hospital to continue offering comfort to the patient. One family member derived comfort and support just from hearing the nursing staff in the background, knowing that they were not alone and that the staff was there to care for their relative.

Many of these respondents turned to their own family or derived some support from their workplace. Those not at the hospital served to maintain the household and
picked up extra duties and childcare responsibilities at home that enabled the respondents to stay at the hospital. More than one employer provided time off without hesitation, again in order to provide the respondent the opportunity to be at the hospital. Overall, such actions were interpreted by the respondents as positive, supportive messages or gestures, thereby, enabling them to do what they had to do for the patient with ICU syndrome.

Respondents Need to Know; Information Seeking

Family members needed to know about ICU syndrome in order understand the behaviours exhibited by the patients, and prepare for what lay ahead. These respondents gained the majority of their information once the syndrome emerged, usually from the nurses caring for the patient. Information from staff was sometimes provided readily, at other times was thought to be held back, or only given out when directly sought by the family members. Many family members recognized that it might be difficult for the physicians to talk to them due to time constraints, but they also thought that a greater effort should be made to facilitate family/physician interactions. Furthermore, they felt that the time needed to provide explanations and answer their questions would be minimal “maybe 15 minutes or so,” and this information would help them prepare better and it would be less of a shock:

... I’m sure it’s hard for them to make the time when you’re there or maybe—but maybe there’s no—I don’t sense that there’s any effort made to say okay, maybe the nurse could come up and say, “When are you going to be here tomorrow, or this evening?
If ICU syndrome was a potential complication of surgery, family members felt they should have been informed ahead of time. Having this knowledge may prepare them better, even if this information was deemed to be frightening: “I mean maybe not everybody’ll go nuts, but tell people there’s a possibility that they may be off ...”. The need to prepare and have knowledge is seen here:

... I would have been prepared. It— it would have been exactly the same as the first evening going in and viewing the tapes [pre-op surgery tapes] ... and, um, if I’d know the— the problems I’ve mentioned earlier, it would have—I would have felt more at ease ...

The incidence and symptoms of the syndrome should be provided as a component of pre-operative teaching. Having this information would have made it easier for families to cope. One husband was reluctant to “step in,” but at the same time felt such a need for further information he spoke to his own physician about his wife’s impending surgery. Information and contact with physicians could be minimal for many respondents. One wife had no expectation of support from the physicians: “ I expect nothing from the doctors so I’m not disappointed. They have not talked to me once since the surgery.” In this case, the patient’s wife had seen the physicians and been present in the room with them, but they had made no attempt to speak to her. Respondents did not minimize the information provided by the nursing staff, but they felt the provision of such information should be a shared role between the physicians and nursing staff. They felt their questions were just part of the normal questioning, failure to obtain the information they needed left some people to make their own conclusions: “... left up to my own perceptions most often, I hope they are right ... I haven’t heard it won’t happen, so I’m,
you know, I’d like to know more ...” The difficulty in obtaining information could be frustrating.

Many friends called during this period to check on the progress of the patient, and on occasion these friends could provide some information about the syndrome. Family members found it reassuring to hear that someone else they knew and trusted had experienced this syndrome and a potential resolution.

Questions: How Long?/ Looking for a Cause and Effect Relationship

Many family members knew that things were not going according to plan when the syndrome developed. Questions regarding the length that the syndrome and subsequent confusion could last were raised. Seeking information and knowledge about the cause and effects of the delirium provided some comfort, and control in the situation.

This information helped families to plan and deal with the situation accordingly:

... I’m wondering whether something might have happened, whether it was permanent or not. And, um, whether there was a period in the operation that perhaps, not enough blood went to one part of the brain ...

... Well, I—I, um, was worried and, um, I was concerned about her, um whether you call it loss of memory or—confusion and not recognize me, um, and I—I feel that, um—l—wondered whether this was going to last any length of time, or whether it was just temporary ...

... what my concern was, is it the drugs, or did she not get enough oxygen to the brain? Is it permanent or is it temporary? That’s what I was really concerned about. And I thought if it’s permanent, ...

Family members began to look for some cause and effect of the syndrome. Being able to identify a causal relationship helped them to deal with the unusual behaviours that they saw. Many questions emerged as to why this was happening to the patient.
Family members attempted to relate these behaviours to something known to them from the past. Many family members had tried to help the patients early in the illness and had noted some subtle changes in their attitudes or behaviours even before they were labelled with ICU syndrome. They often had tried to forewarn the staff about these changes before the syndrome became full-blown:

... I knew that it was Fentanyl related. I knew it was ICU psychosis with, you know, sleep deprivation. He had all these reasons to have, you know... they didn’t seem to be too aware, they didn’t seem to be too concerned with--and I didn’t really get into too much with them ... so I thought I’m going to wait ’til he’s settled and have a word with the nurses ...

... I’m just a little concerned about Dad and, you know, I think he’s a bit confused. He said “Hey Mr. [patient] are you-? ...

Family members examined the physical layout of the unit and physiological factors in each patient as potential causes of the syndrome. Expectations were that if just that one thing could be fixed, then the syndrome would be gone. Family members then attempted to eliminate what causes they thought might contribute to the syndrome:

... and that’s what [the doctor] said was the worst part was the lack of sleep. She had to have the sleep so the body could start to get oriented ...

... Look it could last a week. You know, um, so get prepared for it so to speak. And I guess part of that was, well he might snap out of it if he has a good night’s sleep ...

... there was constant activity and he had no access to the light of the window and the nursing station right by him so there was a constant light there ...

... you don’t know if it’s a combination of morphine, or, you know, all those other things as well ...
Many family members looked for a connection between periods of lucidity and the time of the day and hoped to see the periods of lucidity become longer:

... I've been a little disappointed hoping that each day would be better but it seems right now--like there's a cycle, that in the morning it's bad. When he wakes up it's not great, ...he's just a big fog ...

To them, the syndrome meant that at some point it might be possible that the patient might not remember their conversation or even their visit that day. According to the family, the patients looked like themselves and had a physical resemblance to the person they knew, but exhibited behaviours of someone else.

Attempting to find a causative factor for the syndrome, family members looked as far back as several years to more recent events such as a drug interaction or some other contributing, perhaps controllable, factor:

... maybe some patients aren't scared for surgery, but he was petrified and that bothered me ... but, you know, when you look at him and--and see him so restless. I mean, he wasn't a good sleeper anyway but he was so restless and when he didn’t know where he was and didn’t communicate and ...

... well he might snap out of it if he has a good nights sleep ... if he could just sleep for 12 hours, he'd be fine ..

... and if there’s something we can do to control that electrical buildup by the fluid or whatever’s it’s related to ..

... you know my dad has, you know, I mean he has drank in his lifetime ... and also his history ... He had an infarct and an arrest and an angiogram and an angioplasty the week before. And plenty of blood product ... So um, and being back on the pump twice and the meds and um, history of alcohol was probably enough that he was in a high-risk category ...

Some family members were aware of the contributing factors to the delirium and sought clarification and information from the staff as to any other potential causes that they
were not aware of. Seeking the cause helped to make some sense of the behaviours and helped them to focus on what could be done or changed to bring back some normalcy and reality for the patient.

For one respondent, the reported cause of the delirium, according to the medical team, was alcohol withdrawal. Despite the other contributing factors for the delirium she suspected the team's focus remained alcohol withdrawal. This respondent also saw sleep deprivation and the inability to control the sleep/wake cycle as crucial factors that had contributed to the delirium:

... In my case, I would say that it was made a hundred times harder because of the supposed cause that I was told by his physicians, the surgeon, social workers, clinical nurse specialist and because I was told it was the DT's and he was the author of his own misfortune and unnumerable other things, I felt the confusion was a hundred times harder to bear ... I was told that this-that this had happened because he wasn’t awake, because he was in the DT’s and so he wasn’t able to do... It is our fault that this happened and that is still the way it’s being thought of ...

Trust in the Staff and That Person [Respondent]

Trust took several different forms. Primarily, family members felt some measure of trust in the staff. Secondly, the respondents thought the patients themselves felt trust in the family member(s) who were present in the hospital with them, despite the syndrome. Finally, most family members were hopeful and had trust that the patient would get better and felt optimistic that everything would be fine. This eternal hope or view that things will be better tomorrow was in relation to their hope that the syndrome was temporary. Despite sometimes limited information about ICU syndrome, these
family members felt it would turn out well, “Well, I-- I’m optimistic. I’ve told you, I was optimistic earlier but it’s still back of my mind.” Another respondent stated, “By talking, you know. Like I keep saying, “Oh, she’s going to be okay. Don’t worry. Tomorrow you’ll go she’ll be fine.” One daughter had been with her father on several previous hospitalizations in which he was also confused. She was one of the few individuals who had experienced this before and had hope because she had been through a previous experience with her dad. In fact, she was the one to offer reassurance to the nursing staff that her father would be fine in a few days:

...It’s not really clear to me, but I remember feeling like I was reassuring them that, “Oh, you know, we’ve been through this. It’s--it’ll be fine”. I just knew it ‘cause I’d been through it before. And I knew what--I knew to talk to him and centre him um, so I had no doubt. Or I didn’t let myself have any doubt ...

Additionally, family members often noticed small things such as a smile from the patient, that could be missed by the staff and interpreted these things as signs that the patient was improving. The family continued to look for some ray of hope or some sign of improvement:

... As I say, I can see big improvement and, um, speaking to you [daughter-in-law]and remembering your name, she--the other day she couldn’t remember anything... I thought for a moment, well, she’s not getting much better ... And yet she smiled at [daughter-in-law] and she said your name. I - I think she said ...

Learning to trust the staff was important for the family members. They needed to trust that the staff, primarily the nursing staff, could care for their family member and that they [the staff] knew best. This ability to trust staff was thought to be helpful by these respondents. Being able to trust the staff to continue to look after the patient,
despite the confusion, enabled respondents to get much needed rest, food or even at
some point to go on with their own lives. This trust meant that they didn’t have to
actually provide care for 24 hours a day and could “turn and walk away” for a short time.
If the family members did leave the hospital for a rest or to attend to personal things,
they often phoned in and spoke with the nurses caring for the patient to check on the
progress. In one case, trust was not present in the nurses, and that meant to that spouse
she could not stay at the bedside. As well, she encountered two physicians and the nurse
at her husband’s bedside, none who made an attempt to speak with her which resulted in
her being unable to stay at the bedside:

... the two doctors were there and they did not look at us or speak to us and I felt
this was, you know— it was very difficult. So I really felt like—not giving up—but I
felt a physical sensation of, you know, everything closing in, my head in a vice
and I was very upset. And because the nurse did not talk to me, I was standing
there, looking at him, and she didn’t—this was in a step-down unit—she just sort of
walked around me and did things and didn’t say anything. And I had to leave
because it was too much ...

Nurses provided some of the explanations about the ICU syndrome, but mostly
provided general information about the patient’s condition while they were caring for
them, and the family members trusted the nurses to give them this information.
Nurses were seen as knowledgeable. If the nurses felt that the patient was doing well or
“all right”, the family believed them. In general, the family members hoped that the
health care team would do the very best for their family member and believed that they
did not want to lose the patient and would work very hard to help him or her.
The family members also viewed a nurse's role as one that should or could support them. The violation of the role and trust was seen in the previous example when one spouse viewed the lack of communication by the nurse as the final straw, which forced her to leave. Family members expected the physician would provide them with the medical information about the patient in addition to the information provided by the nurses. Family members recognized the nursing role as one which should provide them with the means to go on and hoped that consistency in the shift reports and nursing care would somehow be ensured. This trust and knowledge in the nurse's role enabled them to relieve some of their anxieties.

Family members always tended to be hopeful. Family members hoped that the nurses would continue to care for the patient in a truly dedicated, caring manner, despite the confusion. Warmth and personality demonstrated by the nursing staff helped the family members to trust the nurses. If that trust was not present, the nurse-family relationship or the family member's ability to share information with staff could be impaired. Also, if this trust and relationship was present, then it might be possible for the family members to let down barriers and perhaps even cry in front of someone else:

... in the back of my mind, know that he was in the best place and he was getting the best care he could. Because, I mean, like I couldn’t do it for him. You know, it’s that trusting in someone else to do it for him ...

... I was useless. I couldn’t do anything for him. But the nurses seem to say he’s alright. He’s doing alright and I guess, you know, they’ve got the knowledge, which I don’t believe me. I only went to Grade 12 ...

... It took me a while to gain the confidence that someone was in charge. You know, I mean, in--I trusted the nurses more. ... they were there every minute every day.”... “and, you know, it’s like who is consistent? So there’s a worry for the
family there with—they might miss something that someone forgot the day before. Okay? And if they didn’t know the process well enough, I mean how guys do, crossover and changeover and, you know, all those things, they might be worried about that...

Lack of communication was seen in the following examples:

... obvious that she wished I would, you know, take a hike, and --you know what I mean, that sort of thing. And I thought, oh yeah I’m really going to be telling you that, you know, I’m worried about Dad. ... “the one from the special care nurse, well, she was a real problem. She wasn’t, I don’t know, I guess it shows you how much personality and warmth matters...

... And on that basis, we had that little meeting where they told me all these things, and then I realized how they--how hostile they were and how--how misinformed they were and, obviously a huge problem. ... I derived the most support when I felt they were truly--that their focus was to get him better and make sure he was alright. Then I felt supported.

The patients trusted many of these family members to care for their ongoing needs and even financial and practical concerns while in the hospital. Once again, this trust may have been based on some previous relationship of trust or it could be entirely new. The patients often felt that they could leave these concerns to the family members; in one case, the father left instructions and a Power of Attorney with his daughter because of a long-standing relationship of trust. Some of these children felt that because their parents had been there for them for many years and had taught them about life, it was now time to return this help to their parents. One daughter said, “It’s just me and my dad. I’m his lifeline sometimes. If I wasn’t there for him, it wouldn’t have gone the way it ... so well. That’s my effect on him.” Usually having a positive relationship with that parent in the past, would promote their involvement with the patient during the time of the ICU syndrome.
Family members were often asked to make decisions regarding care and treatment for patients. Family members could be asked to make some difficult decisions such as in the event of a cardiac arrest. Possibly having some knowledge of the patient's wishes regarding resuscitation measures to be used helped to make this easier for them. The patients also trusted the family members to validate some of their paranoid feelings, or to help them out of a situation in which they perceived they needed help. This trust was based on a feeling of oneness and the patient's belief that their family member would indeed help them out of this situation. At some level the patients believed that everything would be fine, and they knew the family members were helping. In the case of the man with the reported delirium tremens (DT's), the family members felt it was their duty to make sure that the patient was not made to feel like a bad person because of the syndrome and resulting delirium. In cases where the family members encouraged patients to consent to cardiac surgery, they subsequently developed ICU syndrome, the family members felt some responsibility. One daughter told her father, a cardiac surgery patient, that she would be "by him," and now things were not progressing as planned:

... I mean, the bottom line, it's terrifying. I mean, here's somebody you love totally nuts. And your feelings of guilt in terms of--I--I saw my dad into the OR, you know, up the elevator on his way and, It's okay, dad, you know, you'll come through it. And his trust in me. And then to think that he might die because of something like this, it was all, how did I let myself do it. And I knew there was no choice ...

These patients often trusted the family members so much that they were more likely to take medications for family members than the nursing staff. One daughter was asked to give her mother some medications, "Well, I had to give her some pills, too,
right? ... they brought them in and said can you get these into her? I said, no problem.

And she took them.” Another man looked to his daughter for help when he was suffering from some paranoia or possibly an olfactory hallucination:

... No, they’re poisoning me. Can’t you tell? Smell it. It’s not oxygen. Don’t you believe me. Don’t you trust me? And so my response, you know, uh--there’s two levels to that ...

At some level, the patient trusted the family members while confused or paranoid even when they could not trust the staff.

Looking For ...

While the patient displayed the ICU syndrome, many of the behaviours previously noted as typical of the syndrome were witnessed by the family members. For many of the health care providers, the unusual behaviours exhibited with ICU syndrome made it difficult for them to visualize the person the family members knew. Yet family members could still see that person they knew; “I can hear her, I can see her, I can see ... but she’s not there.” Some of the behaviours currently exhibited were likened to those that were normal behaviours for that person. One lady was very restless, picking at the sheets and fidgeting. Her daughter, however, said that: “my mom fidgets, always fidgets. She’s always doing that.”

Yet to most family members, the person that was in the bed at the time of the ICU syndrome was different from the person that they knew, and they spent time searching for that person. When they saw the patient agitated, even though it was difficult for them, most family members still stayed at the hospital. For example; “to see
my husband that way and he really did look awful ... they tell you what he’ll look like and what is being done but when you see all these things in the light ...” Another wife saw some other person in the bed in place of her husband:

... For me it wasn’t anybody I knew, it wasn’t my husband ... you hope it was somebody else and it wasn’t anybody I knew. I mean even his face looked different a little bit. There’s no recognition or awareness that I’m there or what he was ... I really felt that it was a stranger and that was a terrible feeling to be looking at your husband of 29 years ... and that he’s not there, he’s gone and that was very difficult ...

Many family members were looking for the strong person who they thought should be getting ready to go out, making decisions, working, or managing their own finances:

... like a strong figure, you know, like I never ... when I was a kid, you know, would never think about— worrying that somebody was going to protect you because he was quite, you know, kind of macho, kind of strong man. And to see him in a position of weakness he--it was totally disorienting to me ...

Undoubtedly, the person they knew should be doing things, not acting in the agitated, non-productive manner caused by the syndrome. In order to help bring back the person they knew, some family members reminded the patient of past courage and strength, and the history that they had together:

... that’s another thing I did with him in the hospital, too, and, um, even afterwards, and then the nurses started doing it, too. I would remind him of his strengths and his courage and his determination and, um, like when restless and agitated and I would--I’d say ...

This shared past and the knowledge of what the patient was capable of, made the potential loss of that person all the more difficult. After seeing her dad “like that,” one daughter started to yell at him and lost the caring interventions she had acquired as a
nurse. Family members kept looking at the person and trying to find the person they knew within this other person:

... he's very bright and intellectual, he seemed to want, you know, I mean everything—it's only natural but certainly not in our family but he wanted some emotional support, you know. It certainly wasn't how we knew Dad, you know...

Dealing With the Loss, Planning For the “What If’s”

Seeing this syndrome and not knowing if it was permanent caused many family members to look to the future. They started to make plans and even considered the loss of the role that the patient played within the family unit or the potential loss of the patient by death:

... you wonder if he's going to live or not, and I thought Oh God no ... it made me realize I had to start planning—I mean I'm in a situation where I’m not in the city I work in. But just planning, my God, alright, if he gets unwell, if he dies, what do I do then? How long am I going to be away, how do I look after Mom? My finances—cause I’d have to transfer money, how much, how long are they going to let me not work for, how am I going to manage my mortgage if I’m not working, how long do I need to stay with Mom is something ... if Dad goes ...

This planning continued for some time after hospitalization for some family members. One daughter whose father was no longer able to drive after his hospitalization continued to make plans well after he was home. In the second interview she verified that she had been planning and had made plans to buy a new house and have her parents live with her, even without consulting her parents. She found that this need for planning had stopped by the time of the second interview. Once she was sure in her mind that he had his memory back and that he could function, the need for planning
ended. However, this daughter also spoke of the need to help her aging parents and saw her involvement in their lives gradually increasing over the next ten years. She also planned to reduce her workload to help her parents once they needed more of her time. Another respondent spoke of the need to make some changes in diet and lifestyle for both herself and the patient. In the second interview, this respondent recalled that indeed she spoke of these plans during the first interview while her husband was in the hospital and thus far had stuck with them. She was also shopping very carefully and planned to attend a class offered by a dietician on how to read the food labels in the grocery store.

ICU syndrome caused a re-examination of the children’s role in the family unit. The children felt the need to take on more of a parenting role than they had in the past. They also considered the need to look after the remaining parent if the patient should die. They tended to look at the worst case scenarios and planned for the what if’s often very early in the phase of ICU syndrome.

Planning for the future resulted from seeing the ICU syndrome and perhaps the other illness. They examined the current situation and made plans in the event that the patient could not return home or died. The ICU syndrome also meant that they would need to make some lifestyle changes not only for the patient but for themselves. Many children recognized a genetic component, particularly in the cases of cardiac disease. They planned to take better care of themselves and a few respondents wanted to lose weight. Being present at the hospital helped them to deal with these potential and actual
losses of the patient or the role that they held in the family unit, and spending time with
the patient helped to alleviate some of these fears. There were feelings of loss when
they visited the hospital, often in terms of the past relationship they had experienced.

Considering the outcome and wondering about the “what if’s” was another aspect
of this category. The family members interviewed often wondered what the outcome
could have been for the patient if they had not been there at the hospital. They wondered
about how they would cope and deal with problems if the patient could not return home
and wondered if life would ever return to normal. They also wondered if the patient
would function normally upon his or her return home:

... I have noticed myself thinking is, is he going to be able to be at home? Is he
going to be able to function at home? Is life going to go fairly back to—to what
I’m used to? You know, is he going to be able to drive? Is he going to be able to,
um, do the banking? You know, is—is this—this kind of in and out doesn’t seem
stable enough to me for normal life ...

Similar sentiments were noted by another respondent: “you wonder whether he’s gonna
live or not and I thought oh God, dear God, no.”

It was important for these respondents to plan to keep some semblance of
normalcy in their own lives because they did not know how long this syndrome would
last. For some, despite the need to keep their lives in order, there was still some
hesitancy in going on with their previous activities: “I volunteer at [place]. And should I
keep on with it or should I not?” Other feelings of frustration were noted:

... you know, and so you’re getting nothing done and she’s just laying there and
you’re thinking, Oh God, I should be up there instead of at home, and doing what
you’re doing, but like I say, you can’t sit around, you have to do your own
things ...
... But there was one night where they said, no, you're stressed, we're not letting you back in and it was like--and Dr. says to me yesterday, he said, you know, "You need to get on with your own life, too" Cause I was asking how long is this going to happen? You know, like I need to deal with my life ...

Making Meaning of the Behaviours

When the respondents first noticed unusual behaviours and the syndrome was exhibited by the patient, the family members sought to find some meaning in these behaviours. They often saw some kind of connection between the current behaviours and those from the past. They even thought these behaviours could escalate into something more severe. If the patient talked to the staff about something that seemed inappropriate, the relationship the family members had with the patient often allowed them to make sense of the conversation. When one patient spoke of her mother, the family members initially expressed surprise, but then remembered that she had cared for her sick mother. When this patient told her husband and daughter-in-law that she was saving books and magazines for her mother, they realized that this was something she had always done for her mother. In this case, they were just surprised to hear her talk about her mother as she had been dead for two years. These family members were seeking to find some kind of connection with either the patient's current state or the past and the meaning of these behaviours. Making sense of the behaviour could result in some kind of questioning, as in the case of the patient who was restless and physically restrained:

... I could see him he'd be throwing them out of the way or hit him in the head. I wasn't about to let him sit there and go mental 'cause he was really agitated and talking about jail ... were you in jail Dad? And he says that he went with the
boxing to, you know, some prison as a you know -- when I was there with so and so and the I got thinking ... He had a pretty wild youth, I wouldn't be the least bit surprised, and, um, so he was going on and on about jail. He says its just like jail, you can't see the light, you can't see anything, you -- you know -- no wonder ... people go crazy in jail ...

... something to hold onto so he would think he was holding a pen and it calmed him down and he--I gave him my hand to write on. And. like, I know, Dad's accounts and all that stuff are really important to him. It centres him ...

... and I would say, "Well, what was your friend's name again?" And get him to try and remember it and, um, or the professor and what about the time when you and your sister did this or that?

Because of the syndrome many patients were restrained to prevent either self-harm, removal of intravenous lines, or getting out of bed. Often the patient was aware of the restraints and verbalized some awareness of this restriction to the family members. Family members offered reassurance to the patient. They also reassured staff members that they were not upset by the use of restraints:

... and because, I mean they--the nurses say they’re tying --and the doctor, too--they’re tying him down because he is confused and maybe he doesn’t know what’s going on and he could in fact end his life with that action ...

Moreover, the family members looked into the past to see if something in the past could be connected with being tied, such as being caught and held prisoner during wartime.

While displaying some confused thoughts another patient talked about special plates that were not selling. While this made no sense to the hospital staff, her daughter recognized this in relation to the past when her mother sold memorial plates. When another patient spoke about the "alcohol" (actually, water) given to him his daughter searched to find the meaning of this thought. She thought maybe there was something
real causing his confusion and that his taste buds could be affected. This same patient later thought he was being poisoned by his oxygen. The family members sought to make sense of his behaviours, wondering if “at some level that a drug interaction had occurred?” Consider the case of a man who developed pneumonia as a postoperative complication:

... he said three days ago that he had pneumonia [to his daughter] and now he has purulent sputum, and the nurse just sent a sputum sample, he kept saying something was wrong ...

Once again, this kind of thinking and reflection demonstrated the need for the family members to validate some of the patient’s behaviours and to justify the behaviours. There was often an attempt to look at some connection between a physiological aspect and make the connection to the confusion.

Interaction with the patient during the syndrome, particularly confused patients, the family members hoped to bring the patient back to reality, to gain clarity, and to help the patient focus on what was important. Giving the patient something to hang onto made the family members feel like they could help to decrease the agitated behaviours. One daughter said to the researcher; “… hallucinations or confusion seemed to be from the past, the brain’s confused right…?” At the same time, some patients talked about some things even the family members were unable to understand for whatever the reason: “oh yeah, she recognizes me, but she says stuff I don’t understand ‘cause I couldn’t know.”
Family members looked for some kind of message in these unusual behaviours that were exhibited as part of the syndrome. Despite the syndrome, they tried to determine if the patient was trying to tell them something. One patient had his hands restrained as he was restless and the nursing staff was concerned that he would pull out his temporary pacemaker wire. His daughter looked beyond the confusion to seek some meaning to his behaviours:

... He’s feeling he’s lived a good life. If he wasn’t confused and wanted to end it, he doesn’t know what’s going on and could end his life ... see this in connection, does he want to go? I’m not ready to let him go yet ...

In this particular case she was asked to sign the surgical consent for her father to have the permanent pacemaker inserted. In the conversation she was unsure if these behaviours displayed by her father were really some kind of message from him to her, saying that he did not want her to allow a permanent pacemaker to be implanted, and that he was ready to let go and die. She thought that it was her and not him that wasn’t ready to let him go.

Dealing with these behaviours often caused the family members to wonder how to explain this time period to the patient. At the time of the first interview they expressed doubts as to how they would fill in the gap in the patient’s life. The family members were concerned about how the patient would react to being told about the syndrome and the behaviours that they exhibited.
Emotional Responses of Blaming, Anger, Guilt and Feeling Responsible

Blaming.

Blaming could be visualized in various ways. Some blame was placed upon the patient, but the respondents also felt some blame in situations where they had made a difficult decision. Additionally, when one family member made a decision regarding the code status of the patient the family physician later telephoned them to question the decision. He implied the family members were to blame for an inappropriate decision that contradicted the patient’s wishes: “then my doctor phones as he got into his office and he said, what did you do -- change the code for?”

Many family members blamed the patient for the ICU syndrome. They felt that the patient may have brought it upon himself or herself by not sleeping at night. They continued to hope that after one good night’s sleep the syndrome would resolve. If the illness and subsequent delirium were thought to be preventable, then some family members were “furious” because it need not have occurred. In the case of the man who developed ICU syndrome possibly related to alcohol withdrawal, the health care team placed a great deal of blame on the patient, insisting that all his problems were self-induced. The patient’s wife noted that; “saying all his problems were related to the DT’s, his own fault--poor guy has problems with his blood pressure, yet this is always redirected to the DT’s.” When she was told that he was suffering from the syndrome in addition to his illness her thoughts were as follows;

... in the DT’s, they had very grave concerns and that he--you know--he might not make it. And they’re very guarded and they do not say but that was the
implication was that he might have done himself in—killed himself. And so I’m looking at him in his state, I can’t think—I wasn’t really thinking ...

This wife also reported that her daughter was made to feel responsible for the DT’s and made to feel that her father was a very bad man. The respondent voiced to the researcher that it was unfair for his daughter to be placed in this situation of blaming, and only served to increase her stress.

Anger.

Anger was another common response of family members. The anger stemmed from two potential sources—the patient or the situation. Family members felt angry that the syndrome developed and felt frustrated and helpless to do anything. This anger, frustration, and helplessness led to an increase in their stress levels, “I go so mad and went and had a couple of glasses of wine, which is wrong to do [I’m a diabetic too].” Other responses demonstrated some frustrations related to the cause of the syndrome in one case:

... here we are with a very sick guy and now was not the time to be hurling these accusations at me and my husband ...

...I mean to watch him so agitated, he couldn’t breathe, pulse rate went up, I’ve got the same parasympathetic nerveways too ...

Other family members either contributed to, or alleviated some of the anger during this difficult period. Historically, if family members had a strong bond amongst the family unit, the syndrome could further promote unity. Conversely, if a family member tended to have limited contact with either the patient or other family members interviewed for this study, the syndrome could cause some anger within the respondents
due to the seriousness of the situation and the lack of support from these other family members:

... he [her brother] could have come to see him, it’s pretty major what’s happened to Dad, he didn’t even come. I thought he would come, no point in getting into a discussion ‘cause it would hurt. If he had come his reactions would have been different. In fact, I would, this is probably mean, but I would go so far to say he couldn’t have cared less whether dad was in terrible pain or terrible confusion or whatever ... he would have just been the same cold, person ...

If a respondent normally was distant from the patient or family unit, now to be thrown into a situation of contact with the family members as well as dealing with the syndrome could create even greater stress. One daughter had recently tried to provide some health education and assistance to the patient prior to this hospitalization. She felt angry at this situation, “it created fury in me that all I tried to do was ignored, they didn’t listen to me and this could have all been prevented.” Similar sentiments were heard from another daughter who also had been trying to promote healthy dietary habits for her parents. Her father’s need for urgent cardiac surgery and subsequent development of the ICU syndrome prompted anger in her:

... you bastard, why didn’t you take care of yourself better— you know he liked to eat ... some anger towards him for not putting ... for being responsible for ... part of its genetic but part lifestyle. Why are you here in the first place? A lot of guilt around harping after my parents for watching how they eat you know ...

Coping with the syndrome itself was frustrating and often led to anger for many family members. The unknown time frame that the syndrome would last and the patient’s need for support meant that many family members could not get on with their
own lives. The unknown duration of the syndrome caused family members to feel that their own lives were on hold and they were never sure when life would return to normal and expressed thoughts such as, “I have a lot to do, and I’m getting mad because I can’t do any of my stuff I want to do ... let’s get better and get on with life”. The need to spend so much time at the hospital caused fatigue, which did not help the anger subside. Family members often found it difficult to rest even when they left. Many family members spent long hours in the waiting room and observed other cases where patients progressed through a critical illness and did not develop the syndrome. These respondents noted that patients who did not develop confusion often progressed more rapidly and moved out of the critical care unit sooner than their family member. As a result, family members asked why this wasn’t happening to them: “a shorter time frame for others to get better, why can’t it be my dad?” This situation also led to some anger and forced some people to become more assertive than they normally would be. As a result some anger and frustration came about from fears of being labelled “the bitch” or a “hostile family member,” and fears of having information withheld emerged. It was important to them that they be kept informed and aware of any change in the patient’s condition:

... I’ll be labeled and they won’t keep me informed. They’ll just read me as the bitch, you know, family member and, um be hostile and not be informative and I won’t know anything. And I literally got no sleep all night. I kept waking up, waking up and then first thing in the morning I phoned the ICU to see how he was ...

... so, um, I expect, I said, Okay,[to daughter], expect nothing and we--because we’re not going to get it, other than civility ...
Guilt and feeling responsible.

Family members felt guilt either because they had encouraged the patient to proceed with a surgical procedure or because they had made some decisions on the patient’s behalf. They also felt some guilt surrounding the behaviours that the patient exhibited while confused. If these respondents made a decision on behalf of the patient, they wondered if they had made the right decision at the same time hoped that the patient would agree with the decision. For instance, by signing a consent form for a permanent pacemaker on behalf of her father, one daughter felt guilty, “he could have all these parts and live another 20 years or so and he doesn’t want to.” Being asked to make decisions or guide the care of the patient meant these family members had to live with the consequences and might feel ambivalent about the decisions made:

... I don’t want him to die like this, I don’t want to ... I don’t want it this way, no—like I would rather him go home and have a heart attack ‘cause it’s just too painful to watch day after day ...

If they knew the patient’s wishes regarding the use of life support or a prolonged illness, guilt could arise if “it wasn’t going the ways she wished.” One daughter felt guilty because her father was very strong and aggressive with the syndrome and was worried that he might hurt one of his caregivers. She would feel responsible if a nurse did get hurt as a result of her father’s behaviours, even though she knew these behaviours were directly related to his syndrome. Guilt could also emerge if at some point in the hospitalization, if the family members no longer felt the same degree of grief or intense
emotion that they initially felt. They worried when they no longer cried: “I got a problem dad ... I’m not crying anymore when I see Grandma.” The family members thought this reflected some sort of acceptance on their part of the syndrome.

The family members interviewed felt a great deal of responsibility. They may have encouraged the patient to have surgery and now things had gone terribly wrong. They also may have tried to promote healthy behaviours and now as a consequence of lifestyle habits the patients became ill. Family members felt that perhaps there was something more they could have done to encourage lifestyle changes or prevent the illness from happening. During the syndrome, family members felt that some of the behaviours the patient exhibited were inappropriate and not typical behaviours for the person they knew. They felt it was their responsibility to help the health care providers see the person they knew:

... he would not do that in his right mind-I mean call me if you need the least little... last thing I want is some poor nurse up on compo that could be me, you know taking a shot to the head from this guy ...

One wife described the guilt and feelings of responsibility placed on her by the health care team for her husband’s behaviour, which was labelled as alcohol withdrawal by the physicians: “... felt bad too. I enabled his behaviour and I’m bad because I am part of the family, we’ve let everybody down.”

Family members were also responsible for being present and providing support to the patient. If information was to be given to the patient, they felt responsible for directing the amount, type, or timing of the information to be given. Many family
members were responsible for making patient care decisions and, in one case, providing surgical consent. This responsibility weighed heavily on some family members:

... oh, I didn’t really think of it as a choice, actually. Like I said to my husband that night when I came home, you know, they asked me to sign for the surgery. What if I hadn’t?

Summary

In summary, this chapter presents the study’s findings in relation to the impact of ICU syndrome on family members. The findings revealed that the participants in this study moved through or encountered several emotional responses related to the syndrome. These responses or themes were experienced by all participants in no sequential order, with varying degrees of impact for each participant. The common themes were the reason for being there—their role, maintaining strength, support—knowing who to turn to, the respondents’ need to know and seeking information, a questioning of how long, the cause and effect relationship of the syndrome, trust in the staff and the patients’ trust in the respondent, looking for ..., dealing with the loss and planning for the “what if’s”, making meaning of the behaviours, and finally the emotional responses of blaming, anger, guilt and feeling responsible. The information presented in this chapter represents the collective responses of the participants that were shared with the interviewer during a series of two interviews.

In the first category presented, the reason for being describes the roles that the participants took on during this time. They took on roles of caring, being present, and helpful roles often dependent on previous roles they had held in the family unit. Some
respondents held similar active roles within the family unit already, and this behaviour was an extension of this role. Many believed that the need to be at the hospital and be supportive was not an unusual role for them to take on. Conversely, some respondents felt that this situation created a need for them to take on a less dependent roles on their parents. Two daughters, who were nurses, became the contact person for the health care team during this time who served to interpret and translate the messages from the team to other family members. The health care team trusted these daughters to be able to understand their messages, and, in turn, the family members trusted and understood the explanation and guidance these daughters provided.

These respondents demonstrated tremendous strength throughout their time in the hospital. In fact, they felt it was crucial that they hold themselves together and be strong while they were there. If they broke down and cried this usually happened on the way home from the hospital. Many respondents used the time during a long walk down the hall from the waiting room to compose themselves and prepare themselves for what they would find once they met the patient. All family members had constant reminders the patient was in a critical care unit. The need for strength could be reflected in a negative manner with many family members hesitant to talk about the syndrome for fear of upsetting others.

Support and knowing who to turn to were important aspects. The importance of the support meant that the participants would be lost without it. Support came from other family members or friends. Having support meant that these respondents could
once in a while falter, let go, and then return to the hospital in order to continue providing support to the patient.

Needing to know information was a huge component of being able to deal with the syndrome. Family members sought information from the staff, primarily nurses, but even outside sources such as friends and other physicians were utilized. These respondents experienced limited contact with physicians in the hospital. In one case even when the physician was present at one point in the room, he made no effort to speak with the family member. Most respondents felt more effort should be directed at facilitating physician/family interactions. Explanations needed to be provided regarding the syndrome, preferably pre-operatively.

Family members knew things were not going according to plan when the syndrome developed. This led to a questioning and search for a cause and effect relationship for the syndrome. The possibility that the condition could be permanent arose in many of the respondent’s minds, and they needed to know what had happened in order to cope with the situation. Being able to pinpoint some cause helped family members with some possible interventions. Some family members were able to identify potential causes and questioned the health care team regarding other potential causes. Having this information helped to explain the confusion and alleviate fears.

It was important for the respondents to have trust. The respondents felt trust in the staff or trusted that the patient would get better and improve. These respondents needed to learn to trust that the staff would support the patient when they were not
present. This trust enabled them to leave for a time and not worry. Conversely, if that trust in the staff was not present, it became more stressful for the family members. Making decisions regarding care and treatment for the patient was a component of this trust. Also, the patients often looked to and trusted the respondents to validate some feelings of paranoia and might be more likely to take medications for the family members.

Looking for the person that they knew despite perhaps bizarre behaviours was common for respondents. They often saw the person lying there, recognized the voice and wondered where they were. Family members searched for them but often had difficulty recognizing them. Family members looked for signs of normal behaviours—the person who could manage money, get ready for work, or pursue a hobby. They missed the person that they knew.

Many respondents looked beyond the immediate situation to the “what if’s” and began to deal with a loss of that person. They made plans for the future, in some believing that their lives might change dramatically. They made many plans regarding their jobs, worried whether they could be able to return to work, made plans to support the remaining parent, and made plans to make lifestyle changes. Respondents experienced some feelings of loss during this time, particularly in terms of loss of the role that patient played in the family unit. They made plans to take over that patient’s role if it became necessary.
When the respondents became aware of the behaviours, they sought to make meaning of the aberrant behaviours. Making sense of these behaviours could be likened to the questioning or wondering if there was some connection with the past to explain these behaviours now. Sometimes when the patient spoke of something that did not appear to make sense the staff, family members were able to reflect on the past, and help clarify the meaning of the statement made by the patient. Family members were continually looking for some sort of message in the behaviours. Family members thought that interacting with the patient was important, and helped the patient focus on the present.

Family members blamed the patient for the situation, thinking it was preventable. Difficult decisions evolved regarding a code status for one family, and blame was placed on them for the decision they did make. Blame was placed on one patient for experiencing what was labelled self-induced delirium, precipitated by alcohol withdrawal. His wife was made to feel partially responsible and was blamed for being a co-facilitator of his alcohol usage.

Some family members felt anger, directed at the patient or the situation. They felt frustrated by the complication, often felt helpless to do anything about it. They also felt angry at other family members who were not present as they felt that they could share some of this burden or stress. Being placed in this role and dealing with this situation meant that many respondents could not get on with their own lives. This was compounded with the inability to predict how long the syndrome would last. If they
normally did not take on an assertive role in the family, they felt frustrated at being placed in this situation. Finally, they felt angry and frustrated when they saw other patients progress rapidly without the syndrome.

Guilt and feelings of responsibility for decisions surrounding care arose. If family members made treatment decisions, they could feel guilty and responsible for making the right decision. Often these respondents had encouraged the patient to go through with surgery, and felt responsible for encouraging this course of action when things went wrong.
CHAPTER FIVE
DISCUSSION OF THE FINDINGS

Introduction

In this chapter, the findings of the research study will be explored in relation to the impact on family members whose significant other experienced ICU syndrome. It was hoped that this study would provide some information and insight into an area where little qualitative information is available. As well, this study was designed to bring together two very important areas: ICU syndrome and responses of family members to this syndrome. The purpose of this chapter is to discuss the findings of this study in relation to the available literature, exploring similarities and differences between the research findings, and existing knowledge of ICU syndrome and its impact. New information, which goes beyond that currently reflected in the literature, will be highlighted.

The literature reviewed for this study indicated that patients’ experience with confusion or delirium could be fearful. It is clear that there is still a limited amount of knowledge available about ICU syndrome from either the patient’s or family members’ perspectives. However, it is possible to make some comparisons between this study findings and those discussed in the literature. It can be argued that it is difficult to draw any comparison or parallels with the literature reviewed as these findings come from only this current study. However, the participants in this study spoke freely and readily about their experience with this syndrome and the impact it had on them.
Commonalities were found across the respondents, and these findings went beyond the current literature. At the end of the interviews, many respondents reported that while it may have been difficult to talk about their experiences with the syndrome, just talking about the syndrome felt good, and they were glad they had participated. In this study three of the respondents were nurses and verbalized some knowledge of the illness or the syndrome. This knowledge did not prove to have any bearing on their ability to provide the researcher with the information needed nor did it necessarily change the kind of information obtained. These respondents had similar themes and responses to the other participants.

Discussion

Impact of Critical Illness on the Family

This research study was guided by a theoretical framework that promotes the inclusion of family in the nurse's perspective. The critical illness is disturbing to the patient, but represents a "disruptive event" for the family as well (Reider, 1994, p.272). This author also noted high levels of anxiety in family members following the admission of a family member to a critical care unit. The notion used to support this study advocates using a systems perspective; if a change affects one member of a unit, then there will be an effect on all other members of the family unit (Wright & Leahey, 1984). Thus, it is assumed that ICU syndrome will affect not only the patient, but the family members as well. The interviews with the family members clearly demonstrated that they suffered from high levels of anxiety during the hospitalization. This anxiety was
noticeably reduced by the time of the second interviews which was confirmed by the participants. These findings are consistent with the literature that indicates increased levels of anxiety soon after the admission to critical care and a decrease over time. In this study the source of the anxiety was twofold, resulting from the critical illness and further complicated by the ICU syndrome.

Leahey and Wright (1987) propose some basic assumptions about families with a life-threatening illness. Among these assumptions is the proposal that family functioning is often altered by a life-threatening illness. Indeed the life-threatening illness complicated by the ICU syndrome was stressful and anxiety-producing for these respondents. Specifically, several respondents talked about not being able to do what they wanted to do and feeling a need to get on with their lives. All of the respondents had put most of their lives on hold while the patient was ill, and some of the respondents had abandoned work. The trajectory of a family's life can be changed by a life-threatening diagnosis (Leahey & Wright, 1987), confirmed by some participants in this study. The planning that was done by the respondents during the hospitalization ranged from immediate plans for that day, to the need to change jobs or move closer to family members, to the need to make major changes to their lives. The respondents were aware that some of these changes could result in financial hardships for them and could result in changes to employment to accommodate family needs. Clearly, for these respondents, the potential trajectory change caused them to make plans to accommodate the potential long-term effects of either the illness or the syndrome.
Several of the studies reviewed indicated that families are affected to a greater degree than the patient by the serious illness and that the illness has a reciprocal effect on family members (Cohen et al., 1988; Kleeman, 1989; Kleiber et al., 1994; Koller, 1991; Reider, 1994). The studies on the impact of myocardial infarction on spouses further support this point of view (Nyamathi, 1987; Mayou et al., 1978). While it is not possible to determine the degree of impact on the family members, this study clearly confirms that there is a great impact on the respondents. The themes of the respondents’ need to deal with the loss, maintaining strength, the respondents’ emotional responses of guilt, anger, and blaming all confirmed this impact. During the hospitalization and the ICU syndrome event, it was the family members who planned for the future and stood by the patient until they improved, despite any unusual behaviours.

Family needs during a critical illness.

Families’ needs during a critical illness have been well documented with the use of some quantitative tools, for instance the Critical Care Family Needs Inventory (CCFNI), the Jaloweic Coping Scale (JCS), and Family Member Structured Interview Guide (FMSIG). The identified needs include having a waiting room nearby, having a washroom near the unit, calling family at home with changes in the patient’s condition, knowing the course of treatment, being assured the best care is being given, feeling hopeful, talking to the physician daily, knowing the staff, having a hospital contact person, and finally having questions answered honestly (Hickey, 1990). The need to
have hope and a feeling of optimism was a predominant theme throughout this study, and this need was noted in both interviews.

The need for information has also been identified as an important family need in critical care (Bouman, 1984; Kleinpell, 1991; Kleinpell & Powers, 1992). Respondents in this study had a great need for information about the cause and effect of the syndrome, the duration, and its potential consequences. These informational needs were only being partially met by the health care team in this study. This lack of information caused increased stress for the family members interviewed. Respondents viewed this informational role as a collaborative one between nurses and physicians. The majority of the information they did obtain was from the nursing staff, but they still felt a lack of information. These respondents felt that the presence of the medical staff in the critical care unit or even in the patient’s room did not always guarantee that their informational needs would be met. In the case of one patient who continued to suffer ill health even though he was discharged, at the time of the follow-up interview, his wife expressed the most concern and frustration about not being able to obtain information from physicians and the lack of communication between the specialists. Nurses can take a key role in providing the much needed information to family members, thus reducing this frustration and a great deal of anxiety experienced by the family members.

This study served to further identify this need for information, partly in relation to the syndrome and in relation to the illness. Additionally, two daughters who happened to be nurses, took on clearly defined roles as an intermediary or contact person between the
team and the other family members. These daughters served to pass on information from the medical staff to the others and to try to support, reassure, and calm other family members. In fact, the wife of one patient agreed to meet with the researcher only after her daughter had spoken with the researcher and encouraged her to do so impressing upon her mother that it would be helpful to do so. This intermediary role has not been previously explored. It is clear from this study that while information is at times being provided, it may not be provided in such a manner that family members can understand, nor do they have the chance to clarify it.

Family responses to crisis situation.

Family responses to a crisis situation identified by Kleeman (1989) include fright, anger, denial, hostility, distrust, remorse, guilt, grief, and hope. Due to the impact of the critical illness and the lack of previous exposure to such an event, many of the respondents in this study had responses such as anxiety, shock, and fright at seeing the patient behave in such a manner, followed by anger, guilt, and hope. In this study, these responses listed were directly related to the ICU syndrome. However, they may be considered as part of the overall situation, which included a critical illness. The family members expressed shock and fright when they saw these unusual behaviours, particularly if the patient did not respond to family members in the usual manner. Even the daughter who had previous experience with ICU syndrome had many of these emotional reactions. She was still very concerned about her father even though she had some previous exposure to the syndrome.
The respondents in this study often felt a great deal of guilt, particularly in situations where they had encouraged the patient to go ahead with some procedure and then things had gone wrong. For most of the family members, hope remained a strong component of the whole situation. They believed that the syndrome would resolve and often believed that if the patient could get a good night’s sleep, things would be better the next day. They still felt hope upon discharge, evident in the follow-up interviews. In one follow-up interview, it became clear that a patient had never completely recovered from his surgery and was just now beginning to feel a little better. His wife expressed hope that now finally things were going to be “okay.” Another respondent whose wife was still recovering from cardiac surgery and a subsequent stroke, expressed similar sentiments in the follow-up interview and firmly believed that his wife would return to her previous active state. He remained hopeful that they could continue to do many of the things they enjoyed doing together. This need to have hope is one that is consistent with the needs identified by Kleeman (1989) and through the CCFNI.

**Patient’s Experience With Confusion.**

The literature review indicated that the patient’s experience with confusion could be a fearful, terrifying experience during which they suffered loss of all markers and normal cues, often having visual or auditory hallucinations (Easton & MacKenzie, 1988; Williams et al., 1979). Although this study focused on family members, it is still possible to deduce a limited amount of information about the patient’s experience from these interviews with the family members. The patients in this study shared some
information with family members regarding their hallucinations. As well, some family members were able to determine subtle behavioural changes in the patient prior to the staff determining the onset of the syndrome. Visual hallucinations were reported by Andersson et al., (1993) and Neelon (1990). Indeed some of the patients in this study experienced some form of hallucinations, either visual or olfactory. This was most notable in the case of one patient who thought his oxygen was a poisonous gas. He sought validation of this idea from his daughter and looked to her as the one individual he could trust to help him out of this terrible situation.

A notable finding in the literature indicates the vast majority of individuals who suffer from a confused episode “suffer in silence” (Easton & MacKenzie, 1988, p. 234) and are reluctant to share this experience with the staff (Andersson et al., 1993; Edmands, 1995; Neelon, 1990; Owens & Hutelmyer, 1982). At the time of the initial interviews, the majority of the patients were still affected by the ICU syndrome. Family members expressed concern at that time and were unsure how they would begin to tell the patient about their behaviours during that time period, or that they had had the syndrome. They did anticipate a gap in the patient’s memory for that time period. Many respondents had thought about this issue and felt that it was their duty to tell the patient about the syndrome. They believed that they would be able to provide the information in a more sensitive, caring manner than the health care team. In the follow-up interviews, most family members had not shared their version of the events with the patient. One daughter felt that her father would flatly deny being confused. At the time, of the follow
up interview, the patients had not yet referred to that time period nor had they directly questioned the family members about those days. Perhaps this indicates that patients had no recall of the events, or that they were indeed reluctant to share their experiences with the confusion and were “suffering in silence” as proposed in the literature review. The question then arises about what the long-term consequences if any are, of this silence and reluctance to openly talk about the confusion.

Effect of Myocardial Infarction on Spouses

The literature that examined the impact of myocardial infarction on spouses, primarily wives, discussed the potential loss of a mate or the actual loss of a healthy mate (Bedsworth & Molen, 1982). In the same way, the present study found that respondents made plans and considered the “what if’s.” Family members in this study began to make plans and deal with the “what if’s” when they thought that the patient would not be able to return to a previous level of functioning, or that he or she might die. Many respondents had been worried about or made plans already to modify or change their own lives in order to support the remaining family members. In the follow-up interview, one daughter spoke of her plans to buy a new home in order to provide her parents with a self-contained apartment. Dhooper (1983) conducted interviews until three months post discharge and showed a significant negative impact on the emotional health of family members, due to the seriousness and suddenness of the event indicating an effect over time.
The studies reviewed indicate that many spouses had some effects on their personal health related to the impact of the myocardial infarction. In this study, these findings were not corroborated, and indeed the tremendous strength exhibited by the family members interviewed would contradict these previous findings. The strength that these respondents exhibited was primarily of a psychological nature; none of the respondents indicated that they had any physical illnesses during this time. At the time of the follow-up interviews, they had not encountered any unusual illnesses. Family members felt that it was crucial for them to be strong and maintain a “stiff upper lip” in order to remain at the bedside and help the patient. They identified a time and a place that they thought was acceptable to break down and cry, and this was the only time that their strength was let down.

**Impact Over Time**

Although the findings of this study did not go beyond 12 weeks post ICU syndrome, the potential long-term impact of this experience on family members should be considered. The literature on PTSD indicated that any event out of the normal range of coping could be seen as a potential for development of the syndrome (Allen & Bloom, 1994; Dicks, 1990). Respondents in this study were not followed for a long enough time period to ascertain if this was an actual problem that could be identified. However, in interviewing these family members, it is clear that this syndrome (viewed by the respondents in such a manner as a stressor “out of range of usual human experiences”) (Dicks, 1990, p. 2) could have long-term effects on family members. Only one
respondent had previous experience with a confusional episode with that same patient; the remainder had not encountered this syndrome. The insight and information gained from this study are important additions to this literature on family members and PTSD. The implication of this study is that some level of intervention is necessary to help deal with the stressor. Viewing ICU syndrome as a stressor indicates that this is a potential problem and provides the health care team with a mandate for intervention with family members.

**Findings of This Study Beyond the Current Literature**

While this study confirms some of the findings about similar situations, the findings and scope of this study provide specific information about an area not yet researched. The findings of this study are in relation to ICU syndrome and its impact on family members. It was suspected by this researcher that to encounter a family member not only in a critical care unit but also suffering ICU syndrome would serve as an additional stressor. These respondents felt that many of the factors associated with the syndrome such as the role they took on, the need for strength, the trust of the patient in the family members, the need to seek information about the unknown, the attempt to find cause and effect, the anger, the guilt and associated responsibility, and, finally, the search for the person they knew all served as stressors. These findings support the position of Hickey and Leske (1992) who suggest that the patient is not the only victim of the critical illness, but that family members are an important component of the nursing assessment in critical care, and that family members may be affected to a greater degree than the
patient. These findings certainly support and extend the research that exists on family members’ needs for physical comfort during critical care.

Roles.

The family members’ roles to care and to be present during the hospitalization were shown to be significant ones, adopted perhaps as a result of some previous role held in the family unit or a newly developed one resulting from the crisis situation. This great need to remain in the hospital and be supportive of the patient’s needs was deemed to be beneficial to the patient by the respondents. These respondents felt that it was a normal part of caring for their family members to take on this role. None of the literature to date has explored this active role taken on by family members, yet this study has demonstrated importance of this response. Some family members speculated as to what would happen if they were not present in the hospital, or if a patient did not have family at all.

These respondents clearly indicated strong roles for them specifically related to ICU syndrome. They were seen as helpful, caring, or supportive roles, sometimes congruent with an existing role they held in the family. This role could be new in the family unit and one for which a child takes on a stronger, parenting role for others during this time period. The need for two daughters to act as some form of intermediary between the health care professionals and the family members indicates the complexity of the family/health care provider interactions. It is hoped that through this type of research, the health care team might have a better indication of the need for consistent
and caring interactions with family members. Support, either in a physical or in an emotional form, was necessary for these respondents and helped them to continue assisting the patient or other family members. None of the studies reviewed evaluated the kind of support that family members needed or felt was useful to them. Indeed, this focus is a new area for nurses to move towards. Throughout the hospitalization and into the follow-up interviews, family members remained optimistic and looked for hopeful messages from health care professionals. Again, this was deemed as a form of support. Family members viewed such support as enabling them to provide what was needed for the patient.

Maintaining strength.

One aspect noted in this study not seen in the literature review was the tremendous strength of the respondents, and how important it was to maintain this strength. These family members were present at the bedside for long periods and demonstrated great emotional and physical strength in spite of stressful and often difficult circumstances. This strength was maintained throughout the hospitalization. When they were unable to maintain strength, family members took time away from the patient’s bedside. These respondents indicated a need to let this strength abate for a short time and for someone to acknowledge their fears, guilt, grief, and fatigue.

Importance of information.

The finding in relation to strength ties in with another aspect of the study, that of the implied need for strong communication skills on the part of the health care team.
These respondents needed not only information about the critical illness, but also about the syndrome as well as support and acknowledgment of what they were going through. The time provided by the researcher was enough for some family members, most agreed at the end of the first interview that just to talk about it and have validation of their feelings was helpful. This effect and type of intervention has not yet been assessed by other authors, and it is not known what is needed and what is beneficial. Perhaps the lack of intervention until now stems from either an assumption on the part of the health care team that it is not needed, or is simply due to a lack of understanding. These findings should provide a basis for planning interventions.

The occurrence of ICU syndrome meant to these respondents that they would have to reassess their plans for the future. This planning came about as a direct result of the syndrome and the effects noted during the hospitalization. As well, family members planned for the future in case the patient could not return to a previous level of functioning or died. Children planned to care for a remaining parent or made plans to help both parents, if needed. Planning included the need to make lifestyle changes, noted during a follow-up interview. None of these aspects were noted in the literature review by this researcher. The literature review revealed an element of fear related to the "unknown, unexpected, and uncontrollable" situation of a critical illness (Kleiber et al., 1994, p. 72). These respondents were planning for the future, but more in relation to the "what if's." This might be suggestive of a connection between the fear of the unknown in relation to the syndrome itself. These plans were made in case the syndrome
did not resolve, or the patient could not return to the previous level of functioning. The role that health care professionals have taken on in the past has been directly related to discharge planning. Most likely, this planning conducted by the respondents is a new role initiated only by family members and could be better supported by the health care team.

Trust.

The respondents indicated they held a great deal of trust and remained hopeful that the patient would improve. They indicated that this trust was extended to the staff and that learning to trust the staff was important. Yet, if that trust was violated or not present, there were serious consequences. Trust is a component of the need for excellent communication skills by the staff. The nurses provided most of the information to the family members in this study, and most felt that the nurse knew enough about the patient to tell them what they needed to know. The notion of trust has been put forth in the past by the studies reviewed (Bozett, 1987; Hickey, 1990; Reider, 1994). These studies propose this concept as a component of the assessment of family needs, but have not sought to ascertain the meaning of trust for family members. This current research serves to demonstrate to the health care team what trust means to the respondents and how this trusting relationship can be formed in family interactions. The patient’s trust in the family members, as in this study, is a crucial part of the family’s reason for being at the hospital, and of what family members can contribute to the overall recovery of that
patient such as the history of the patient, information about the patient’s likes and dislikes, and even help in understanding what the patient is saying.

The patients trusted the family member’s ability to help with or take over treatment decisions on their behalf while in the hospital. Some patients sought family members’ confirmation or validation of their feelings or ideas when they suffered from paranoia.

**Attaching meaning to the patients behaviour.**

Another aspect noted in this study is the family members’ attempt to make meaning of the behaviours that they witnessed during the ICU syndrome. This category or theme has not been identified as a component in any of the studies reviewed. This study demonstrated, however, that this could be one of the unique aspects that family can bring to the patient and health care team. The connection to some past or known behaviours of the patient aided the family members to potentially make meaning of the syndrome behaviours. The importance of family interaction during this time was thought by the family members to be helpful to the patient to bring the past and present closer together, another attempt to make meaning from these behaviours.

**Family members’ emotional responses.**

The stronger emotional responses such as anger, blaming, guilt, and feelings of responsibility were specifically related to the syndrome in this study. These responses were unforeseen and not clearly identified in the literature review, as there is limited research to date on this aspect. What is known is that there are a myriad of emotional
responses to a critical illness, and the ICU syndrome serves to intensify the critical illness (Halm et al., 1993; Kleiber et al., 1994; Koller, 1991; Reider, 1994). Emotional responses such as anxiety, shock, fear, and anger clearly had a significant impact on the respondents and served to increase their stress. An interesting finding of this study was that this anger at times was directed towards the patient who had developed the syndrome, not solely at the situation or the staff. It is thought that this was a component of this questioning phase, when the respondents began to ask why the syndrome didn’t happen to them. The syndrome and subsequent need to spend time at the hospital often led the respondents to feel some frustration and anger at having to put their lives on hold for an indefinite time period.

In addition, it was not possible to predict the depth of the responses obtained and the significant impact the syndrome had on the respondents. The experience with a critical illness was heightened and emphasized by the onset of ICU syndrome. Despite the purpose of this study seeking to determine the effects of this syndrome on family members, it could be argued by this author that this depth of these responses has not been known until now, and that these responses may not be only attributed to the syndrome, but could be potentially noted in all critical illnesses. What became clear to the researcher in this study is what the nurses’ role can be in this situation. Family members depend on the staff to provide them with a great deal of information and to do so in a caring and professional manner. It was heart-rending for this researcher to be privy to some situations in which health care professionals took for granted their impact on
family members and how either their support or lack of support could affect these respondents.

Summary

In summary, this chapter discusses many similarities noted in these findings with the literature reviewed for this study. Yet it also points out several areas in which the findings of this study are either specific to ICU syndrome or not yet corroborated. Many of the findings highlight the lack of information about the combined effects of these two specific phenomena -- ICU syndrome and family needs. There still remains a limited amount of research in this area. Using systems theory as a guiding principle for this study, it becomes clear that the effect of ICU syndrome on one family member, the patient, will cause an effect on the remaining family members. The experience with ICU syndrome of these family members produces anxiety and fear and forces them to deal with actual or potential losses. The need for information about the syndrome is a predominant theme; even if information is provided by the health care team, it may not be adequately meeting the family members' needs. This study accentuates the vital role that the health care team can play in meeting these informational needs.

A large number of emotional responses were noted in this study, being anger, blame, guilt, and feelings of responsibility. These were associated with the appearance of the syndrome. Family members clearly verbalized and outlined the impact that this syndrome had played on their lives at present. There is a potential for a long-term effects, most notably if the patient is thought not to be able to recover to a previous level
of functioning. These respondents found the stressor of coping with ICU syndrome out of their usual range of experiences, and much like the literature on PTSD, this could precipitate some kind of delayed response.

Several aspects of this study were the strength exhibited by respondents, the trust in the health care team, the trust the patients had for the family members, and the need to make plans for the future. Hope and optimism were the predominant outlooks held by these respondents. Yet, in some cases, this trust was not present, and this could have detrimental effects. Clearly, the experience with a critical illness was emphasized and intensified by the onset of ICU syndrome.
CHAPTER SIX

SUMMARY AND RECOMMENDATIONS

Summary

This study was qualitative, designed to provide information regarding the impact on family members when a patient undergoes ICU syndrome. ICU syndrome is an acute, transient state with accompanying changes to mentation and an impairment to intellectual functioning. This syndrome stems either from environmental factors within the critical care units or from patient factors such as metabolic or drug related causes. ICU syndrome is reported to lead to an increase in mortality and morbidity.

Historically, nurses in critical care have failed to include the family members as a component of their practice. Yet, a critical illness is reported to greatly affect the family members, not just the patient (Reider, 1994). For many family members, the admission to a critical care unit can represent a crisis (Artinian, 1991). Current health care standards reflect an increased interest in viewing the health care consumer as not only the patient but also the family and significant others (Whall, 1980). This study brings together two important aspects -- ICU syndrome and the family members' descriptions of their encounter with this syndrome. A guiding principle for this study is derived from a systems perspective, which indicates as changes occur in one individual, a similar, or reactive, process will occur in the family members. Presently, there is no research that combines these two aspects.
The literature reviewed for this study included several related bodies of literature, as there was no single body of literature specifically related to this study. The literature relating to the patients' experience with an acute confusional episode indicates that this is a terrifying experience. Most patients reported some form of hallucinations and were reluctant to talk about their experience with the confusion, possibly for fear of being labelled as crazy. However, the events do appear to have a significant impact for that individual.

A family's needs during the critical illness of a family member have been determined previously. Historically, studies have sought to determine such needs as having a telephone and waiting rooms near the critical care unit, and informational needs. It is known that anxiety levels in family members are high during a critical illness. A wide range of emotional responses are possible following a critical illness and include anger, fear, anxiety, shock, denial, hostility, distrust, remorse, guilt, grief, depression, and hope (Kleeman, 1989). All the studies reviewed indicate that family members of critically ill patients do undergo many stressors and have more than the previously determined physical needs. In addition to general studies examining critical illness, research has shown that the effects of a myocardial infarction (MI) on spouses and family members have significant impact on the emotional health of family members themselves (Dhooper, 1983). Some studies have implied that there are many losses associated with an MI, related to the actual or potential loss of a mate (Bedsworth & Molen, 1982). Spouses of myocardial infarction patients are reported to live through a
parallel stressful experience of their own (Mardsen & Dracup, 1991). A further area of the literature that is concerned with post-traumatic stress disorder (PTSD) may offer some insight into a longer impact of critical illness and ICU syndrome in particular.

This study used a qualitative descriptive method to understand the phenomena of interest. Interviews were conducted with the family members during the hospitalization phase of the patient, and follow-up interviews were conducted several weeks later. All guidelines provided by the university research services were adhered to during the study. Data were obtained from the interviews and transcribed verbatim. The findings of this study revealed that the participants moved through or expressed several different types of responses, or categories related to the syndrome. These categories were as follows: support—knowing who to turn to, the respondents' reason for being there, the respondents' need to maintain strength, the trust, the cause and effect or a questioning, the need to deal with the loss of the patient and to plan for the “what if’s”, to make meaning of the patients' behaviours, the anger, the guilt and feelings of responsibility, the need to seek information, the blaming, and, finally looking for [that person]. There were many similarities of the findings of this study with the literature reviewed, and many new findings emerged. Several of the findings relate directly to the ICU syndrome, a specific focus of the study. Family members interviewed still had some similar needs and feelings of anxiety as noted in the literature. The experience with ICU syndrome is indeed fear and anxiety producing and forces many respondents to deal with the actual or potential loss of the patient. There remains a great need for information
from the family members in relation to the syndrome. This study also noted a large number of emotional responses such as anger, blame, guilt, and feelings of responsibility. Family members clearly verbalized the impact this syndrome had on them. There appears to be a potential for long-term effects, and this remains to be studied. The stress of a critical illness was significantly increased by the addition of the syndrome.

Recommendations

This study clearly indicates that family members of a patient who experiences ICU syndrome do indeed have many different emotional responses and a great deal to tell us as health care professionals. The following section contains recommendations for nursing practice and research.

Nursing Research

Nurses can assume a leadership role in guiding further research into this syndrome and the impact on family members, and the implementation of an interventional program for family members. The findings of this study provide the impetus for a future research study, perhaps based on some planned intervention program with family members. Study subjects could be randomized into either the intervention group or a control group who receive standardized care. The effects of these interventions could then be evaluated. The act of listening by this researcher was neither time-consuming nor extenuating, yet the respondents verbalized that having their concerns and feelings validated was beneficial. If an intervention is planned and carried out, the effects of that intervention should be evaluated as outcomes, similar to those
carried out in a program evaluation model which measures outcomes. It is important that nurses continue to determine which programs are useful and effective.

Additionally, this research study could be replicated with participants followed over a longer time period. This would provide information on the effects of the syndrome over time. In the follow-up interviews for this study, at least one of the patients, no longer suffering from ICU syndrome, had developed some type of chronic illness. This finding could be further explored to determine if a relationship exists between the development of a chronic illness following ICU syndrome and family members’ stress levels. Again, the information gained in a long-term study would be useful to determine any relationship to the development of Post Traumatic Stress Disorder as conceptualized in the literature review. Many of these respondents when interviewed approximately 8 to 12 weeks later still discussed issues that had surfaced in the first interview.

The type of data obtained from this study indicate that previous studies using quantitative tools such as the CCFNI focused on the immediate physical needs of family members and, therefore, missed a crucial and important body of knowledge. The goal of nursing to move towards interventions with family members is reflected in an interview with Nancy Molter, conducted by Leske (1991). Molter felt that it was time “to move from descriptive studies of family needs to investigating the value of specific interventions” (Leske, 1991, p. 186). With the application of a qualitative research methodology, we can learn more about the depth and meaning of the needs of family
members. Nurses can play a key role in this discovery phase and in providing relevant interventions for family members.

**Nursing Practice**

The findings of this study suggest implications for nursing practice. First, nurses do play a significant role in caring for an individual and the family members who undergo ICU syndrome. They are present 24 hours a day not only to provide direct care to the patient, but to support, inform, and care for family members. The family members interviewed not only clearly articulated their needs during this time but also demonstrated the depth of these needs. It appears that at the very least, nurses need to understand the impact of this syndrome on family members and to acknowledge their distress. Their actions towards family members, whether intentional or unintentional, can mean more to family members than the nurses realize. As demonstrated in this study, a critical illness to these respondents coupled with a greater stressor such as ICU syndrome requires a caring, professional, and supportive nurse, regardless of the source of the syndrome. Nurses need to be more aware of the impact of their care and the support they are capable of providing family members during this time.

Secondly, nurses could assume a greater role in providing support and counselling to family members during the period of ICU syndrome. Based on the findings of this study, it would be beneficial to develop a role for an advanced practice nurse to provide interventions. Collaboration with other disciplines such as social work, pastoral care, or psychology could be elicited in this program planning. This intervention
role would serve dual purposes. First, it would serve to highlight the problem among these other disciplines. Second, it would help to create the opportunity for interdisciplinary team work. Ownership of this problem rests not solely on the shoulders of the nursing profession and can be dealt with by a larger group to provide a greater awareness and more effective solution. Furthermore, developing some kind of intervention can not come about without the support of administration in each facility. However, knowledge is the first step in understanding the need for intervention. Without this knowledge it will be difficult to convince administrators of the need for this program. Dissemination of the findings of this study could be the first step in meeting this educational goal.

The findings of this study highlighting the need for information regarding ICU syndrome clearly indicates that nurses could play a primary role in providing this information to family members. Several family members interviewed thought that this information should be provided as a component of pre-operative teaching for cardiac surgery patients. This information could, therefore, be added to the teaching material as a potential complication to minimize the disruption to the family should this occur. In addition, family members clearly indicated to the researcher that a greater effort should be made to facilitate family/physician interactions. Since the nurse plays such a vital role constantly monitoring a critically ill patient, the nurse could serve to co-ordinate these interactions. In doing so, the nurse would further demonstrate the ability to provide care not only to the patient but also to the family.
In addition to dissemination of the findings of this study, education of the nurses is also necessary. The findings of this study could be included in in-service educational programs for critical care staff nurses. This information could also be incorporated into family nursing programs currently offered in undergraduate programs. Additionally, these findings could be a component of any specialty courses or introductions to critical care and could emphasize the need for nursing interventions with family members. Moreover, the ability to provide this much needed intervention may require further education for some individuals than for others, which could have implications for resource allocation. The addition of an advanced practice nurse could have a financial impact on an institution.

Education and information regarding this syndrome would also be useful to nurses who work in home care. The articles reviewed for this study, indicate that perhaps there is some potential for long-term effects of the syndrome in addition to the critical illness. As these nurses could be providing care to those individuals who have suffered from the syndrome, this knowledge would enable them to make appropriate referrals and initiate interventions. Home care nurses are in a position to evaluate not only the client of care, but the family members as they visit the home. Long-term effects on the family members subsequent to the syndrome may not be evident until after the discharge from the hospital. The knowledge of the syndrome would be essential for these nurses to evaluate the family members' coping abilities and effects of the syndrome.
Summary

In summary, this study was developed to ascertain and explore the needs of family members during a time when a patient undergoes ICU syndrome. This report presents the major themes and common categories of the respondents. The findings of this study will contribute to nurses' understanding of family members of patients who have ICU syndrome, enabling critical care nurses to provide sensitive care to family members during a stressful and emotional time. Several implications for nursing practice, nursing research, and nursing education have been suggested based on the results of this study.
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Appendix A

The Impact of ICU Syndrome on Family Members

My name is Lucy Shorthouse. I am a Registered Nurse enrolled in the Master of Science in Nursing program at the University of British Columbia. I am interested in learning about the experiences and impact of a patient’s acute confusion in a critical care setting on the other family members. I believe that there are many effects on the family members as a patient undergoes acute confusion. Despite that belief, there is no other study like this which has been conducted. It is important for nurses to know and understand what it is like for family members of a confused person.

My study will involve from you:

1. two interviews, each lasting from thirty to sixty minutes, conducted in a location of your choice, at your convenience;

2. a discussion of what it was like for you to see your family member confused;

3. audiotaping of the interviews.

All the information that you share with me will be kept confidential. Your name will not appear on the audiotapes, any transcripts, or the completed study. Access to the audiotapes and typed transcripts will be limited to my thesis committee, my typist, and myself. The audiotapes and transcripts will be destroyed when all the scholarly reports have been completed.

Your participation in this study is strictly voluntary and your participation or refusal to participate will not affect any care that your family member receives. If you agree to participate in the study, at any time you may refuse to answer any question, request the information be removed from the audiotape, or withdraw from the study. This will in no way affect the care your family member receives.

If you have any question about the study or the interviews, please feel free to contact me or my faculty advisor at the telephone numbers listed below.

Thank you,

Lucy Shorthouse, R.N., BScN
Dr. Carol Jillings, Faculty Advisor (xxx) xxx xxxx
PARTICIPANT CONSENT FORM

The Impact of Intensive Care Unit Syndrome From A Family’s Perspective

INVESTIGATOR: Lucy Shorthouse, RN BScN MSN Student

SUPERVISOR: Dr. C. Jillings Telephone xxx-xxxx

This study is designed to explore and discover the experiences of family members of a patient who has confusion in an intensive care unit. I will be asked in an interview about my experiences and thoughts during the time my family member was confused. The interview will take approximately one to two hours. A second interview may be required to clarify or verify information provided during the first interview.

The information gained from this study will help to understand the experiences of the family members. It will not benefit me directly, but the participation in this study will provide important information to help other families in the future.

There is no monetary compensation for participation in this study. Participation is entirely voluntary, and if you initially wish to participate, and then change your mind, you are under no obligation; and are free to withdraw at any time. Refusal to participate in this study will have no effect on the services provided to either yourself or your family member by the health care providers.

All information will be kept confidential; a code number will be used to identify participants, and I will be the only one to know both the names and corresponding numbers of subjects.
This study is being conducted as a component of a graduate thesis. If you have any questions you may contact me at xxx-xxxx for further explanation.

I, ____________________________, consent to participate in the above described study. I acknowledge a copy of this consent form.

Signature: _______________________

Date: ___________________________
Appendix C

Demographic Information

PATIENT:

NAME: _______________ CODE # __________
DOB: _______________ AGE: __________
SEX: _______________

ADMITTING DIAGNOSIS: ____________________________
SECONDARY DIAGNOSIS: __________________________
DATE ADMITTED TO HOSPITAL: ___________________
DATE ADMITTED TO CRITICAL CARE UNIT: __________
DATE ICU SYNDROME NOTED: ______________________
DATE RESOLVED: __________________________________

ICU: _______ CSICU: _______ CCU: _______

FEATURES OF THE SYNDROME:

clouding of consciousness __________ difficulty with orientation ______
unusual affect ____________________ confusion __________
hallucinations ____________________ incoherent speech __________
paranoid ideas ____________________ agitation __________
ventilated ________________________ loss day/night routine __________
restlessness ______________________ immobility __________
↓attention ________________________
Appendix D

Demographic Information

FAMILY

NAME(S): ___________________________  CODE ______________

NAME OF PATIENT: ___________________________

RELATIONSHIP: ___________________________

DOB: ___________________________  AGE: ______________

SEX: ___________________________

EDUCATIONAL LEVEL: ELEMENTARY SCHOOL ______________
HIGH SCHOOL ______________
COLLEGE ______________
UNIVERSITY ______________
GRADUATE DEGREE ______________

OCCUPATION ___________________________
Appendix E

Interview Guide

I am interested in finding out what the experience was like for you while

________________________ was in the ICU/CSICU/CCU, during the
time they were confused.

Please describe for me what this was like for you.

Please tell me or describe for me what it was like for you to go through this.

What do you think the effects are on you?

Can you describe for me the feelings you had during this time?
CONFIDENTIALITY CONSENT

I understand that the tapes I listen to and transcribe are confidential. The nature of these tapes and the contents are highly personal.

I agree that I will not share any information that I hear on these tapes with any other person besides the researcher.

I understand that I can not keep a computer disc of these transcriptions and will return the disc to the researcher.

Signed ____________________    Date ____________________