

**COPING AND PSYCHOLOGICAL DISTRESS OF FAMILY MEMBERS OF
ADULT CARDIAC SURGERY PATIENTS IN THE ICU AND PRIOR TO
DISCHARGE**

by

Michael L. Williams

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Doctoral Committee:

Emeritus Professor Carol Loveland-Cherry, Chair
Associate Professor Cynthia Arslanian-Engoren
Professor Berit Ingersoll-Dayton
Professor Laurel Northouse

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DEDICATION

This dissertation is dedicated to families everywhere. To my extended family -- aunts, uncles, cousins, second-cousins, great-grandparents, and siblings--who taught me the value and meaning of family. To my grandparents, who taught me to value the wisdom and gentleness of the elderly. To my parents who taught me to love and to believe in myself. To my children, who taught me that the struggles in life are worth every minute and for whom I would sacrifice my life in a heartbeat. And to my partner, William A. Pollard, who taught me the true meaning of love. You are all a part of me, and I love each and every one of you!

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Abstract

The purpose of this research was to explore the relationships of family functioning, social support, appraisal of illness/caregiving, uncertainty, and coping on psychological distress among family members of loved ones undergoing adult cardiac surgery. A descriptive correlational design with instruments to measure the six variables of interest and demographics was used to collect data at three points in a planned adult cardiac surgery experience. A convenience sample of 81 family members was recruited and completed all three data collection points. The sample was primarily Caucasian (92.8%), female (70%), spouses (63%) and highly educated (100% had completed high school or more). There were no statistically significant differences in any of the predictor variables by age, gender or race. Psychological distress, as measured on the Distress Thermometer, during the ICU stay was 5.791 (S.D. 2.587) and 5.220 (S.D. 2.615) prior to discharge. While both psychological distress scores indicate significant effect on the family members, the decrease was statistically significant. The results of the regression analysis showed that the model, along with three demographic variables (age, relationship, and gender) accounted for 36.3% of the variance; both overall active coping and avoidant coping predicted psychological distress. Path analysis showed that the only significant predictors of psychological distress were overall active coping and overall avoidant coping at similar levels of influence. The most frequently used coping strategies reported by the sample were active coping strategies of acceptance, use of emotional support, positive reframing, active coping and planning. Avoidant coping

strategies, such as venting, self-blame, and substance use, were reported less frequently, although some subjects did report using these strategies. Nurses should be mindful of the psychological distress these family members experience throughout the hospital stay and further research should determine what interventions may assist with decreasing it.

CHAPTER I

Introduction

Statement of the Problem

A number of studies have shown that patients in an intensive care unit (ICU) experience a great deal of stress and anxiety (Artinian, 1991; Bedsworth & Molen, 1982; Boumann, 1984; Curry, 1995; Gilliss, 1984; King & Gregor, 1985). However, most of these studies have focused solely on the patient's experience while in the ICU and not the experience from the family's perspective. With the advent of ICUs in the early 1960s, family members were rarely permitted to visit in the ICU, let alone assume an active role in the care of their loved one. In 1979, Molter published the first paper on family needs in the ICU. However, there is limited research focusing on the coping strategies used by family members in the ICU (Molter, 1979).

Since 1979, researchers have examined the family needs of critically ill patients and have found five general needs (Bouman, 1984; Coulter, 1989; Daley, 1984; Dracup & Breu, 1978; Engli & Kirsivali-Farmer, 1993; Forrester, Murphy, Price & Monaghan, 1990; Freichels, 1991; Hampe, 1975; Kasper & Nyamathi, 1988; Kirschbaum, 1990; Koller, 1991; Krumberger, 1985; Leske, 1986; Leske, 1991; Lynn-McHale & Bellinger, 1998; Macey & Bouman, 1991; Molter, 1979; Murphy, Forrester, Price & Monaghan, 1992; Noyes, 1998; O'Neill-Norris & Grove, 1986; Pelletier, 1992; Price, Forrester, Murphy & Monaghan, 1991; Rawlins, Rawlins & Horner, 1990; Rodgers, 1983; Silva,

1987; Simpson, 1989; Stahler, 1984; Stillwell, 1984; Wilkinson, 1995; Williams, 1989). These general needs are the necessity for proximity, information, support, resources, and participation in care (Leske, 1991). While studies have examined family needs in a variety of populations, including various ICU types and age ranges, they lack a comprehensive theoretical foundation. The needs model is insufficient to completely explain the dynamic nature of the phenomenon these families are experiencing during an acute episode of care. A broader understanding of the dynamic nature of this experience may be more fruitful to develop and test interventions to assist family members during this stressful life experience.

Stress, coping, and anxiety in family members are three concepts, rather than family member needs, that have been explored by some researchers during critical illnesses (Aldridge, 2005; Artinian, 1991; Board & Ryan-Wegner, 2000; Foxall, Kollasch & McDermott, 1989; Halm, et al., 1993; Jay & Youngblut, 1991; King & Gregor, 1985; LaMontagne, Hepworth, Johnson & Deshpande, 1994; LaMontagne & Pawlak, 1990; LaMontagne, Johnson & Hepworth, 1995; Leske, 2003; Mellins & Ehrhardt, 1994; Nolan, Cupples, Brown, Pierce, Lepley & Ohler, 1992; Pryzby, 2005; Uzark & Crowley, 1989). These studies on the concepts of stress, coping, and anxiety have provided some guidance in working with families but a broader, more conceptually integrated understanding may assist clinicians to work more effectively with families in the ICU.

Some studies examined individual and family-member anxiety within the context of the ICU (Garvin, Moser, Riegel, McKinley, & Doering, 2003; Halm, 1993; Reider, 1994). In fact, several studies evaluated interventions aimed at decreasing family anxiety in the ICU, most of which were psycho-educational in design (Halm, 1990; Pryzby, 2005). Each of these

studies, however, found that no intervention was sufficient in significantly decreasing anxiety in this environment. It is most probable that the uncertainty and stress experienced during this time period results in such significant anxiety that, regardless of the intervention, anxiety is likely to be present to some degree.

In order to alleviate some of the psychological distress, including anxiety, which is experienced by these family members, a better understanding of their coping strategies is needed. The coping strategies that family members use during stressful situations, like an ICU admission of a loved one, have not been systematically studied. In fact, some studies with coping in the title only refer to coping but do not measure it (Jaloweic, 1993). Therefore, only anecdotal and theoretical knowledge of adaptive coping strategies is known (Cox, 1992; Crumlish, 1998; Dhooper, 1983; Frank, Haut, Smick & Chaney, 1990; Johansson, Fridlund, & Hildingh, 2005; Johansson, Hildingh & Fridland, 2004; King & Gregor, 1985; LaMontagne & Pawlak, 1990; LaMontagne, Johnson, & Hepworth, 1995; Mellins & Ehrhardt, 1994; Norbeck, 1985; Nyamathi, Jacoby, Constancia, & Ruvevich, 1992; Nyamathi, 1987; Nyamathi, Dracup & Jacoby, 1988; Schweer, Hart, Glick, & Mobily, 1999; Twibell, 1998). Uncertainty, stress and coping have been shown to be conceptually and empirically linked in many studies using cancer and post-surgical populations for both patients and families, but few have examined family experiences in the ICU (Brock, 1990; Davis, 1990; Galloway & Graydon, 1996; Germino, Mishel, Belyea, Harris, et al, 1998; Mishel, 1981; Mishel, 1983a; Mishel, 1983b; Mishel, 1984; Mishel, 1990; Mishel & Braden, 1987; Mishel & Braden, 1988; Mishel & Murdaugh, 1987; Santacrocce, 2001; Wunderlich, Perry, Lavin & Katz, 1999). Since uncertainty is clearly a factor during the ICU time period, further investigation as to its role in family stress and coping is warranted.

The Changing Context of Healthcare

Another reason for interest in studying family stress and coping during critical illness is that significant changes have occurred in healthcare during the past two decades. Technological advances, rising health care costs, shifting of healthcare burden to families, publicity related to nosocomial infections and many other changes have occurred (Iglehart, 2009; Ginsburg & Lesser, 2006). One major change in recent years is the mistrust of the healthcare system due to medical errors. These dangers have been highlighted repeatedly by the media and have further frightened patients and family members undergoing hospital procedures. The news of thousands of patient deaths per year has attracted the attention of anyone who is hospitalized or has a loved one in the hospital (Blank, 2012; Institute of Medicine, 1999).

The cost of healthcare and the resulting burden to patients and family members are other significant healthcare trends that have had a great impact on patients and families. In 1980, health care expenses in the U.S. was \$1,106 per person (\$255 billion overall) and in 2008 the cost rose to \$7,681 per person (over \$2 trillion overall) (AMA, 2013; Stanton, 2006). Along with the increased cost of healthcare, there has been a shift in more payment being required of patients (Blank, 2012). In the 1980s, patients undergoing coronary artery bypass graft surgery had a 13-day length of stay (Center for Disease Control, 2007; Steinbrook, 2006). The length of stay for these patients in 2001 was 4.7 days and in 2006 was targeted at 4 days (Center for Disease Control, 2007). The types and complexity of adult cardiac surgery have changed and reporting length of stay data has become controversial. However, hospital websites report the hospital stay “may be as short as 3-4 days,” “around 3-7 days,” or an “average of 5 days” (Glendale Adventist Hospital, 2013; University of Toledo

Hospital, 2013; Einstein Medical Center, 2013). While some of the decreased length of stay is attributable to increased efficacy in surgical techniques, advances in anesthesia, and the development of home care services, much of this change has been driven by health care insurers, The Joint Commission, and the federal government to save money. The resultant burden on the patient and family when going home so early after major surgical procedures has greatly increased (Lazar, Fitzgerald, Ahmad, Bao, Colton, Shapira & Shemin, 2001; Weintraub, Jones, Craver, Guyton, & Cohen, 1988).

These changes have also significantly affected healthcare practitioners, including nurses. In previous years when resources were not as restricted and length of stay was greater, healthcare providers had sufficient time to provide emotional support, education, and caring services to clients and their families (Jakob & Rothen, 1997). It simply is not possible to provide the same level of emotional support, patient and family education, and caring services to patients when the length of stay has changed so drastically. These demands on healthcare workers due to patient acuity, along with the current nursing shortage, have healthcare practitioners very concerned about the quality of care they provide to their clients (Reed, Blegen & Goode, 1998). In addition, the increased consumerism and scrutiny by patients and families has increased the demand on healthcare providers making the environment even more stressful in which to work. This additional stress that nurses must contend with as they work may also influence the ability of the nurse to work with these families.

The Family in this New Context

While families have always been a focus of nursing care (Whall, 1986), much of this focus was in home care, long-term care or public- health settings. These settings, one could argue, are more attuned to incorporating families into care (Lewandowski & Tesler, 2003). Indeed, in home-care situations, families are the primary caregivers and healthcare providers are consultants and supporters of this care (Buhler-Wilkerson, 2012). Similarly, public-health nursing, from its inception, viewed groups and families as their clients (Whall, 1986). Long-term care situations also (particularly as nursing-home expenses increased) included family members in the provision of care. In the late 1960s, families (mostly mothers) were seen as important to the care of the hospitalized child (Lewandowski & Tesler, 2003). Family-centered care was born and expanded through the 1960s and 1970s in pediatric settings.

According to Grenvik and Pinsky (2009), Florence Nightingale created the very first ICU in the Crimean War. ICUs were subsequently created out of the need for extended post-operative recovery and later expanded with the technology explosion and our ability to keep people alive under dire circumstances. From its inception, an ICU was seen as an extension of the operating room where families were simply not allowed to participate and the role of the family was reduced or limited to mostly that of a visitor (Lewandowski & Tesler, 2003). In 1968, Drs. Max Harry Weil, Peter Safar and William Shoemaker established the Society of Critical Care Medicine thus supporting further development of ICUs and in 1971 the American Association of Cardiovascular Nurses was established to provide nurses with the education needed to work in ICUs (Grenvik & Pinsky, 2009). It was not until the 1970s and 1980s that discussions of family-centered care was begun in adult

acute-care settings (AACN, 2012). In the early 1980s, Molter (1979) and Leske (1986) proposed that families in the ICU have specific needs and must receive care themselves; thus began the interest in family care in ICU settings. Unfortunately, despite the early adoption of family-centered care in pediatric settings, many challenges to implementing family-centered care in adult ICUs still exist (AACN, 2012; Ramsey, Cathelyn, Gugliotta & Glenn, 2000).

Furthermore, whether families should be incorporated into care in the ICU setting is very controversial to this day (Berwick & Kotagal, 2004; Brilli, 2004; Cleveland, 1994; Kirchhoff, 1982; Kirchhoff, Hansen, Evans & Fullmer, 1985; Stockdale & Hughes, 1988). The potential benefits of family care in the ICU include increased family satisfaction, decreased family member anxiety, improved communication, and allows for patient/family teaching. The perceived barriers to family care in the ICU include the potential for increased physiologic stress on the patient, interference with the provision of care, mentally exhausting to patients and families, and increased infection rates (AACN, 2012). With the shortened lengths of stay, however, the increased consumerism and concern for patient safety, families are participating in ways that differ from previous years (Beardwood, Walters, Eyeles & French, 1999; Kelner & Wellman, 1997; Kizer, 2001). Since patients belong and live within a family system, one responsibility of the family is to provide care of their loved ones and they expect to be informed, educated, and incorporated into the healthcare plans of the client (Craft & Willadsen, 1992). It is interesting to note that the changing family role in this new healthcare context has not been made explicit to families (Lewandowski & Tesler, 2003). While some families readily accept their new role, other families would prefer to wait in the family waiting room (or at home) until their loved one has “returned to normal.”

Purpose

Family members who have a loved one undergoing cardiac surgery are understandably stressed. The degree of stress, the understanding of the stressful experiences and strategies that assist in coping with this distress are not well understood. By developing a better understanding of this experience by family members, nurses can hopefully develop interventions to minimize the psychological distress experienced by these family members. Ultimately, both family and patient will benefit.

The purpose of this research was to (1) describe the level of family functioning and social support reported by family members prior to surgery, (2) describe their appraisal of illness/caregiving, uncertainty and coping strategies while in the ICU, (3) determine the relationship among family functioning, social support, appraisal of illness/caregiving, uncertainty, coping and psychological distress while in the ICU, and (4) describe changes in distress from the ICU to hospital discharge time.

Significance

This research was conducted to better understand coping and its impact on psychological distress of family members during critical illness of a loved one. Without a broader understanding of the coping strategies and experience these family members undergo, it is difficult to tailor interventions to assist them during this uncertain time. As nurses, and other healthcare workers, are stressed for time and resources, they too must utilize their resources wisely. Creating, implementing, and evaluating interventions targeted at common sources of psychological distress and methods to bolster active coping strategies are needed.

Organization of the Dissertation

This research report is arranged such that Chapter 2 of this study will highlight the relevant literature related to family members in ICUs. Chapter 3 provides the theoretical underpinnings of this research, while chapter 4 provides detailed methodological strategies to complete this study. In chapter 5, the results are presented and finally in chapter 6, a discussion of the implications, limitations, and conclusions of the study are presented.

CHAPTER II

Review of Literature

Using the Cumulative Index to Nursing and Allied Health Literature (CINAHL) and PubMed, a comprehensive literature search was undertaken to determine the level of knowledge regarding the concepts of interest experienced by family members in the adult ICU setting. Both CINAHL and PubMed were searched using standard Boolean phrases with the following delimiters: English language only, peer-reviewed articles and human subjects. There was no publication date limit or other delimiters when completing the searches. The criteria of interest for inclusion in this literature search were any empirical articles pertaining to *adult* family members and focused on the general experience in the ICU. Those articles that did not meet inclusion criteria were those focusing on the experience of only the patient or healthcare provider, occurred in a pediatric or neonatal ICU, or focused on a narrow area of the experience such as end-of-life care or ventilator support.

The first search of both databases combining the key words of “family,” “ICU,” “coping,” and “psychological distress” yielded only one article from each of the databases. A secondary strategy was undertaken where the key words of “family” and “ICU” were systematically paired with one additional key word from the concepts of interest to elicit “hits” from the electronic databases. The CINAHL database was searched first with this method followed by a search of the PubMed database. One hundred and sixteen hits resulted from the CINAHL search with 287 hits from the

PubMed search. As the titles of articles were reviewed it was discovered that many did not meet the inclusion criteria, as they often focused on the critically ill patient (not the family member), were conducted in a pediatric ICU or were specifically focused on end-of-life care in the ICU. Results from the two database searches resulted in 61 potential articles; 24 from CINAHL and 37 from PubMed, for inclusion in in the review (Table 1).

Table 1

Literature Search Results

CINAHL Search			PubMed Search		
Keywords: Family ICU plus:			Keywords: Family ICU plus:		
	Hits	Potential n		Hits	Potential n
--Family functioning	6	1	--Family functioning	13	1
--Social support	18	6	--Social support	129	6
--Appraisal of illness/ caregiving	0	0	--Appraisal of illness/ caregiving	0	0
--Uncertainty	34	9	--Uncertainty	32	6
--Coping	51	6	--Coping	88	17
--Psychological distress	7	2	--Psychological distress	25	7
Total		24	Total		37

After comparing the research found in CINAHL and PubMed, duplicates between the databases were discovered. After elimination of duplicate articles, the number of potentials articles for review was 36. Thirty-six articles were then targeted for retrieval. Of the 36 articles, seven were subsequently determined to be not applicable as they

focused on family member needs or psychosocial response of the patient, not the family. Two articles were not retrievable through multiple sources and two had an English language abstract, but the text of the article was in Spanish. The final number of articles for review was 25.

The 25 studies used in this literature were sorted into quantitative studies and qualitative studies. An evidence table for the quantitative studies was created and included the author and date of publication, along with the purpose, design, method, sample and findings (Appendix A). A separate evidence table for the qualitative studies was created and included the author and date of publication, along with the purpose, design, method, sample and themes/findings (Appendix B). Salient concepts and findings from all of the studies were gleaned from the research to serve as the basis of this research.

Thirteen of the 25 studies in this literature review used a qualitative design to study the experience of family members in the ICU. Four of the qualitative studies used grounded theory methodology to examine coping strategies, to determine supportive interventions for family members, to determine the impact of brain injury on the family, and determine the impact of family caring on the ICU patient respectively (Chiang, 2011; Johansson, Hildingh, & Fridlund, 2002, 2005; Kean, 2010). A phenomenological approach was used in the nine other qualitative studies. Six of the studies, using the phenomenological approach, were seeking to better understand the family member experience (Agard & Harder, 2006; Cypress, 2011; Engstrom & Soderberg, 2004; Jamerson, et al., 1996; Olsen, Dysvik & Hansen, 2009; Soderstrom, Saveman, Hagberg, & Benzein, 2009). The three remaining qualitative studies had varied foci of interest; one

examined hope-inspiring strategies, one examined the impact of neurological crisis and the other sought to understand the meaning of critical illness to families (Patel, 1996; Plowfield, 1999; Rose, 1995).

Twelve of the retrieved studies used quantitative approaches to examine various aspects of family members' experiences in the ICU. One study (Foster & Chaboyer, 2003) focused on the burden families experience one year following the ICU stay. Three studies focused on supporting the family during critical illness (Bailey, Sabbagh, Loiselle, Boileau & McVey, 2010; Moore, et al., 2012; Sabo, et al., 1989). Three of the studies focused on communication, both inter-professional and provider-family member communication, along with satisfaction (Curtis, et al., 2012; Myhren, Ekeberg, & Stokland, 2011; Myhren, Ekeberg, Langen, & Stokland, 2004). The focus of one study was not as much on the family member responses to critical illness, but rather whether there were differences perceived between racial groups on their treatment by nurses and other healthcare providers (Waters, 1999). Lastly, one qualitative study focused on psychological responses of family members during the influenza A/H1N1 pandemic in Oaxaca, Mexico.

Three quantitative studies were deemed to be most relevant to this study. One study examined the short-term psychological impact on family members (Paparrigopoulos, 2006). This study showed that high rates of anxiety, depression and posttraumatic stress symptoms were present in family members in the ICU and declined over time. Lemiale, et al. (2010), examined the health-related quality of life in family members of ICU patients 90 days following the ICU discharge or death of the loved one. This study demonstrated that impaired mental health is present even 90 days following

the ICU discharge or death. The last quantitative study of interest examined the impact of a unit diary on the psychological distress among patients and families members (Garrouste-Orgeas, et al., 2012). In this study, a structured diary and diary protocol were implemented and subsequently evaluated 12 months following the ICU stay. The study showed that the diary had a significant impact on decreasing posttraumatic stress disorder symptoms at 12 months for both the patient and the family member.

It should be noted that these studies dated back to 1997 but most have been conducted since the year 2000. It is also interesting to note that most of these studies have been conducted in countries other than the United States; in fact, only five of the 25 studies were conducted in the United States. Furthermore, only one study focused on family coping (Johanson, Hilding, & Fridlund, 2002) in the ICU.

While developing this research study, it was noted that none of the research studies reviewed provided a conceptual framework that adequately explained the phenomenon. In order to build a framework for this study, research examining family coping and psychological distress in critical care and *acute care* settings were also reviewed.

Psychological Distress

In examining the literature on coping and psychological distress among family members in the ICU, the limited number of relevant studies was noted. While much research has been conducted to examine family needs, research on the coping strategies used by family members and the psychological impact on family members is lacking (Johansson, Hilding, & Fridlund, 2002). In the ICU context, most of the emphasis of research studies was on the patient and less on the family.

Anxiety, depressive symptoms and posttraumatic stress symptoms have been documented in family members of critically ill patients (Garrouste-Orgeas, et al., 2012; Paparrigopoulos, 2006; Rukholm, Bailey, Coutu-Wakulczyk, & Bailey, 1991). In 1984, Gilliss conducted a study that found that both the patient and families experienced great “stress” during and following coronary artery bypass surgery and proposed interventions that may decrease stress. Others have documented that “most families, however, regardless of their level of functioning, are likely to display, or at least feel, some negative reactions to stressful events” (McClowry, 1992, p. 560). As far back as 1982, researchers noted that psychological stress occurs in spouses of patients with myocardial infarction and that coping strategies were being employed to manage the stress (Bedsworth & Molen, 1982).

Family Functioning

Family functioning is altered when a loved one undergoes a crisis, such as a myocardial infarction, or other critical illness (Dhooper, 1983). When a family member is critically ill, the entire family is impacted such that the emotional health of the family members, financial management, household management and dealing with children may be negatively affected (Dhooper, 1983; McClowry, 1992; Reider, 1994).

As family structures have changed and the family has evolved, how families function has also changed (Huang, 1991). With the critical illness of a family member, family communication patterns, just one aspect of family functioning, are likely to be altered (McClowry, 1992). Financial strain and lack of intra-family support have also been reported as a concern during adult cardiac surgery experience (Artinian, 1982). Furthermore, variation in emotional reactions between family members is not uncommon

(McClowry, 1992, Rukholm, Bailey, Coutu-Wakulczyk, & Bailey, 1991). Ultimately, many aspects of family life are impacted by a critical care hospitalization (Titler, Cohen, & Craft, 1991).

Social Support

Social support is conceptually defined as the physical and emotional comfort given to an individual through family, friends, co-workers, or any other individual. Social support and social networks have been shown to assist family members during critical illness of their loved one (Artinian, 1991; Nyamathi, Jacoby, Constanica & Ruvevich, 1992). Social support has also been shown to assist with the coping process that family members use during critical illness (King & Gregor, 1985; Johansson, Fridlund & Hildingh, 2005; Patel, 1996). Little research on the impact of social support on the family of critically ill patients exists. The value of social support in the context of family care exists in literature on other patient populations, particularly those with more chronic health conditions (Given, Collins & Given, 1988).

Appraisal of Illness/Caregiving

According to Lazarus & Folkman (1984), appraisal is the constant cognitive evaluation of the environment with respect to one's personal well-being. Appraisal of illness is about the beliefs and viewpoints an individual has about the illness or illness experience. In essence, in the context of the ICU environment, appraisal is how one sees the situation; whether it is threatening or non-threatening to that individual. Many studies have shown that family members perceive admission to an ICU as a threat to them (Artinian, 1989, 1991; Dhooper, 1983; Gillis, 1984; Halm, et al., 1993; King & Gregor, 1985; Nyamathi, 1987; Reider, 1994; Titler, Cohen & Craft, 1991). Some studies have

shown the appraisal of the illness severity, perceived psychological distress and satisfaction with care differs between the family member and healthcare provider (Jacono, Hicks, Antonioni, O'Brien, & Rasi, 1990; Myhren, Ekeberg, Stokland, 2010; Myhren, Ekeberg, Langen, & Stokland, 2004).

Uncertainty

According to Mishel (1984, 1988), uncertainty is the inability to determine the meaning of illness-related events and occurs when insufficient conscious or unconscious cues, or stimuli, prevent the person from adequately structuring, categorizing, or predicting outcomes. Uncertainty is reported as occurring among family members of ICU patients (Agard & Harder, 2006; Jamerson, et al., 1996; Johansson, Hildingh, & Fridlund, 2002; King & Gregor, 1985). Most of the populations, where uncertainty in illness has been examined, have been in acute care or chronic care situations; very few have measured uncertainty during the ICU phase. Yet, many of the studies cited above reported uncertainty is experienced by family members in this setting and is generally accepted to result in psychological distress.

Coping

Only a handful of studies in acute care settings actually investigated coping (Kreamer, 1989; Manne, et.al, 1994; Manne, et.al, 1999; Starr, 1989; Voepel-Lewis, 1990) with even fewer examining coping in critical care settings (Johansson, Hildingh, & Fridlund, 2002; Nyamathi, 1987; Reeder, 1990). A number of investigators (Gilliss, 1984; Jacobs, et al., 1998; Kreamer, 1989) assumed coping occurred because the person had experienced stress, but they did not specifically measure coping. Jalowiec identified that "one of the most serious problems [I] encountered in this review of literature on

coping from 1980-1990 had to do with inferring coping from other variables, rather than measuring it directly” (1993, p. 76). Other researchers (Pelletier, 1992; Starr, 1989) used adaptation or adjustment to a stressor as a measure but did not include coping as a variable in the study. Clearly, a broader understanding of coping during critical illness and over time is still needed.

Additional Observations of the Literature

In reviewing the literature related to families with a family member experiencing an acute or critical hospitalization, Lazarus’ transactional stress and coping framework is by far the theoretical framework that is most frequently used to study family stress and coping during *acute* illness but has been occasionally used only occasionally as a framework in studies in ICUs. Also, the vast majority of study subjects have been Caucasian and many have been female. Most studies examining family stress and coping have been those with a family member undergoing cancer diagnoses or treatment or major cardiovascular disease. Most subjects used to determine “family” responses were spouses, but children, siblings, parents, and significant others were included in some studies. With the exception of qualitative studies, the family member has been the unit of analysis rather than the family as a system. In general, females report a higher level of stress than men in these studies, and in general, younger family members report more distress than older family members. Lastly, there has been little consistency in instrumentation noted across studies, and many instruments were self-developed.

Studies have also noted a temporal pattern to the experience of acute and life-threatening events for family members (Bouman, 1997; Bull, Maruyama & Luo, 1997; Buse’ & Pieper, 1990; Cozac, 1988; Derdirian, 1989; Halm, 1993; Mayou, Foster &

Williamson, 1978; Pelletier, 1992; Sigsbee & Geden, 1990). Bouman's dissertation study (1997) examined family uncertainty, social support, and adaptation during the ICU stay, prior to discharge, one week after discharge, and four weeks after hospital discharge. Her study found uncertainty is the highest during the ICU experience and decreases over time and that the higher the level of uncertainty the higher the level of danger appraisal (Bouman, 1997).

The temporal nature of acute and critical crises must be acknowledged. In order to best understand the phenomenon of interest from a family member or family perspective, inclusion of uncertainty, stress, coping, and adjustment over time is important. It is also important that nurses understand how the experience varies over time in order to best match nursing interventions to assist the family members. Conducting studies with a longitudinal approach is important to advance our understanding of the impact of the acute or critical illness on the family.

Some studies have also reported that females, in general, report a higher level of stress than males (Mayou, Foster & Williamson, 1993; Oberst & Scott, 1988; Rukholm, et al., 1991; Sales, 1992), while one study (Voepel-Lewis, et al., 1990) found no statistically significant difference in stress by gender. Others reported differences in stress and coping abilities based on family-member age; in other words, the younger the family member the more distress they reported (Jacobs, 1998; Reider, 1994; Rukholm, et al., 1991). While not absolutely consistent, findings in the reviewed studies indicated that women in general are more willing to report higher levels of distress. Perhaps, also due to life experiences and development of greater coping skills, family members of younger ages report greater distress.

The consistent finding that women generally report higher levels of distress than men is also interesting (Huang, 1991; Paparrigopoulos, et al., 2006). Perhaps, women are simply more willing to report distress, particularly emotional distress, than men or the social norms permit women to more freely express emotion than men. This may not truly mean that men do not experience the same levels of distress, but rather it may reflect a social expectation and thus measurement issue. In fact, in one study, male caregivers experienced more burden of caregiving at one year following an ICU stay than females (Foster & Chaboyer, 2003).

Summary

Since 1979, when Molter published the first study of families in ICUs, research on the effects of hospitalization in both acute care and ICUs demonstrated the experience is stressful to both the patient *and* the family. A few studies have also indicated that the experience of the patient (who may be comatose or greatly sedated) may differ greatly from that of a family member (Bedsworth & Molen, 1982; Davison, Goldenberg, Gleave, & Degner, 2003; Halm, 1993; Nyamathi, 1987; Starr, 1989; Wochna, 1997).

Most studies, investigating families in acute and critical care, have studied subjects who are Caucasian and female (Artinian, 1991; Gilliss, 1984; Leske, 1991). Additionally, most studies did not utilize the entire family system, rather they used a single informant to study this family phenomenon (Artinian, 1991; Bedsworth & Molen, 1982; Gilliss, 1984; Jacono, Hicks, Antonioni, O'Brien, & Rasi, 1990; Nyamathi, Jacoby, Constanica & Ruvevich, 1992). Most studies had marriage required as an inclusion criterion thus eliminating single individuals and/or couples in same-sex relationships.

One study did identify that one same-sex couple participated in the study but the sample was so small, analysis was not possible (Davison, Goldberg, Gleave & Degner, 2003).

Lastly, it is important to note, that despite 30 years of studying families in ICUs, our understanding of how families cope and what interventions make a difference in mitigating physical and psychological distress is still limited. This study was designed to explore a broader theoretical model as it applies to families having a loved one in an ICU.

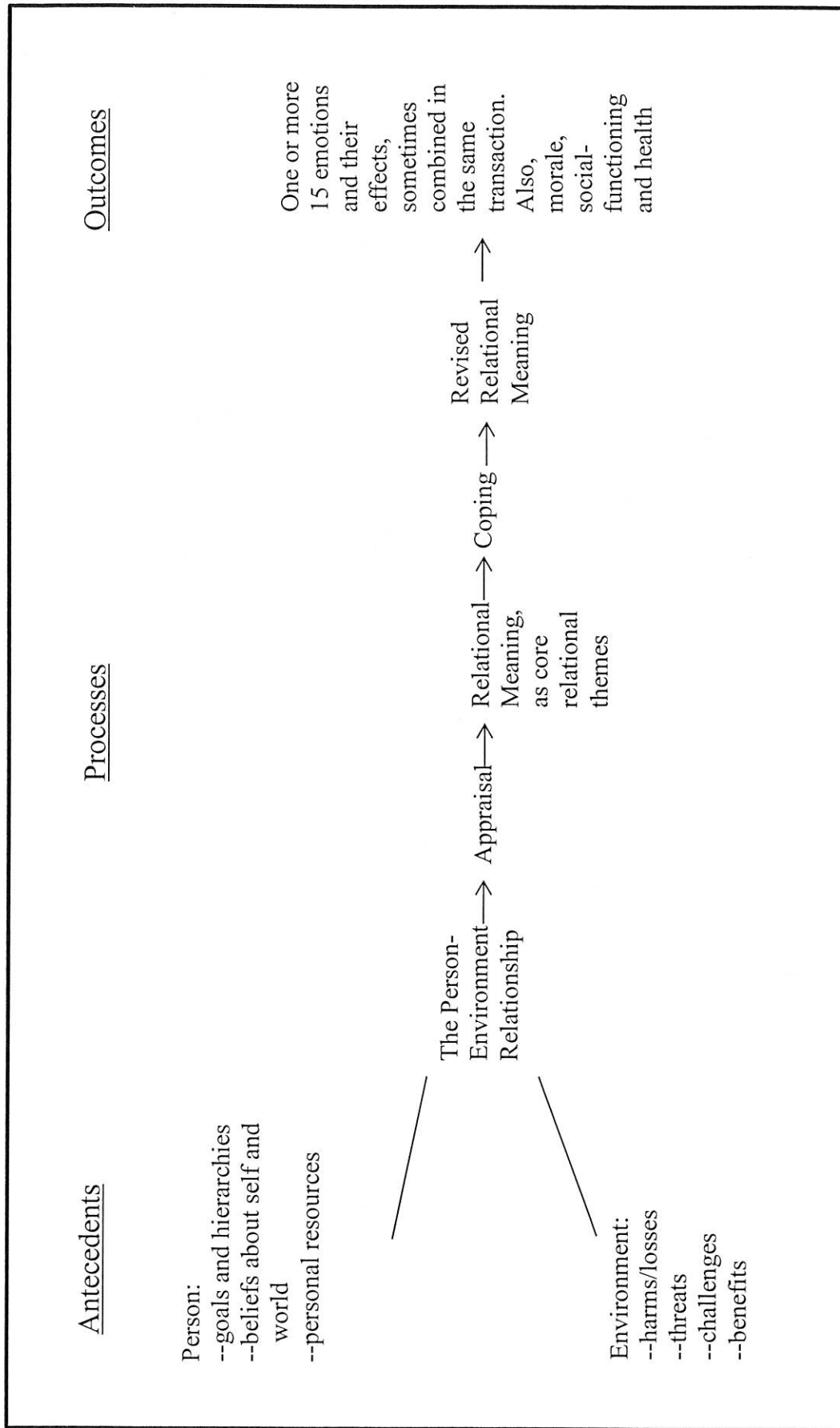
CHAPTER III

Conceptual Framework

Few clinicians would dispute the notion that families experience “stress” when a loved one has an acute hospitalization or critical illness. In fact, a number of studies have documented stress among patients and families in acute and critical care (Bedsworth & Molen, 1982; Gilliss, 1984; Jamerson, et al., 1996; Johansson, Fridlun, & Hildingh, 2005; Nyamathi, 1987; Paparrigopoulos, et al., 2006; Plowfield, 1999; Reider, 1994; Rose, 1995; Titler, Cohen & Craft, 1991). Clarity of what causes stress, however, and its impact on health and well-being have not always been evident in the literature. Indeed, common language use of the word “stress” has also distorted its empirical use (Merriam-Webster, 2008). Stress-coping theory, along with the theory of uncertainty in illness, provides the conceptual basis for this research.

Stress, as a concept, was introduced into the scientific literature in the 1930s and the nursing literature in the 1970s. Generally, three theoretical approaches to stress have been outlined: stress as a response, stress as a stimulus, and stress as a transaction (Lyon, 2000; Perry & Potter, 2004). Lazarus (2000) developed a transactional model of stress whereby stress was not measured directly, but rather as the result of the transaction between a person and his or her environment. Lazarus’ transactional model of stress contends that the interaction of the person in his/her environment, along with how the individual appraises the situation results in the meaning and stress the individual perceives.

Figure 1. Revised Model of Stress and Coping, Lazarus, 1991



As shown in the model in Figure 1, antecedents include the person's beliefs and resources, as well as the environmental harms, losses, and challenges. Lazarus believes that individuals quickly appraise the situation as threatening or non-threatening, and this meaning as ascribed to the transaction determines the extent to which coping strategies are utilized and result in emotional and physical outcomes.

Lazarus' transactional model of stress is well-suited for studying the experiences of family members of patients with acute or critical illness since the person-environment transaction is constantly changing, often seen as threatening, and quite often uncertain. His model also helps to better explain the multiple types of outcomes (or reactions) of individuals experiencing what appear to be the exact same stress demands. The model has been used extensively and has been useful in explaining the transaction of stress (DeLongis, Coyne, Dakof, Folkman & Lazarus, 1982; Fanciullaci, Alessandri & Fanciullacci, 1998; Kobasa, 1979; Ornish, et al., 1983; Werner, 1993). Lastly, multiple studies (Bedsworth & Molen, 1982; Bull, Maruyama & Luo, 1997; Davison, Goldenberg, Gleave & Degner 2003; Derdarian, 1989; Mah & Johnson, 1993; Manne, et al., 1994; Manne, Pape, Taylor & Dougherty, 1999; O'Keefe & Gilliss, 1988; Pelletier, 1992; Rukolm, Coutu-Wakulczyk, & Bailey, 1991; Starr, 1989) conducted by nurses in acute and critical-care environments have used Lazarus' transactional model of stress for research purposes and expanded our knowledge.

While a transactional model of stress holds potential for evaluating families in an ICU environment, there are some dimensions of stress as a stimulus that may also have applicability. In particular, the dimensions of stress, such as, locus, duration, temporality, forecasting, tone, and impact are used in the stress-as-stimulus model (Werner, 1993), but

it is possible these dimensions may also occur within the stress-as-transaction model. These dimensions, if used within the context of the transactional-stress model, would fit best in the person-environment interaction. Locus, whether the stressor is internal or external, in this case is stable—the stressor is external to the person (the ICU situation). Duration and frequency, however, may be very different from one patient to another. A patient-family may experience repeated ICU stays thereby gaining knowledge and coping resources from exposure, or they may have a very prolonged ICU stay versus a shorter one. Temporality will affect the person-environment construct as over time a new reality (and new opportunity for reappraisal) for family members within the ICU will exist. Furthermore, the ICU admission is often seen as a major life event and overshadows (but does not completely replace) the daily stressors, role stressors, and other ambient stressors, such as a child with an injury or an ill parent while the spouse is recovering from surgery, that a family member may simultaneously experience in the ICU (Molter, 1979; Leske, 2003).

The Concept of Appraisal

Lazarus (1964) introduced the concept of appraisal. Lazarus proposes that a person constantly evaluates his/her relationship to the environment. This constant evaluative process is called appraising, and the evaluative outcome is appraisal. According to Lazarus, individuals are constantly evaluating their relationships with the environment and how it impacts their personal well-being. This is the basic premise of appraisal theory (Lazarus & Folkman, 1984; Lazarus & Launier, 1978). If an individual appraises a situation as non-threatening, he/she will respond accordingly; however, if the situation is appraised as threatening, his/her response will change. This concept of

appraisal is at the heart of why individuals respond to seemingly identical stressors in quite different ways.

Lazarus (2000a) contends that there are three components to appraisal. They are primary appraisal, secondary appraisal, and reappraisal. Primary appraising is the process of determining the relevance of the situation to one's value, goals commitments, and beliefs about self and the world. Essentially, primary appraisal is the judgment of whether the situation (person-environment transaction) is relevant and what might be the expected outcome (Lazarus, 2000a). In other words, one person may appraise the death of their debilitated elderly grandmother as a dignified event, while another may appraise it as a major threat to the family. The variation in appraisal will, therefore, result in very different coping strategies being used.

Secondary appraising, according to Lazarus, is the evaluative process where the individual determines the extent of threat to him- or herself. In other words, if primary appraisal is that the situation is very threatening, secondary appraising occurs when the individual determines what person-environment constraints exist, as well as coping options available in order to respond to the situation. Secondary appraising in a stressful transaction is where the individual evaluates coping options, decides which ones to choose, and determines how to set them in motion (Lazarus & Launier, 1978). If a family member is critically ill and one's primary appraisal is that this is a threat to the family, secondary appraisal would occur whereby one would determine what coping resources are available, what one can do about the situation, and what constraints exist to respond to the stressor.

Reappraisal, according to Lazarus, occurs when an individual re-evaluates the situation (person-environment transaction) and determines that it is no longer a threat or that the extent of the threat is lessened. Since transactions between the person and his/her environment are constantly changing and various coping strategies are used, re-evaluation (reappraisal) of the situation may be very different from originally appraised. According to Lazarus (2000), “reappraisal is an extremely effective way to cope with a stressful situation.” Reappraisal itself can act as a form of coping. Reappraisal is essentially reframing one’s mental model of the situation and as Lazarus points out it is sometimes difficult to distinguish one’s changing mental beliefs of a situation from ego defense. When, however, the personal meaning of the situation fits the evidence, it is reappraisal. In other words, if one reappraises the situation of the dying grandmother as simply “she is sleeping soundly rather than dying,” this is not reappraisal, rather it is a maladaptive coping mechanism, since the evidence is quite the contrary.

The Concept of Uncertainty

Budner (1962) defined uncertainty as “a cognitive state created when an event cannot be adequately structured or categorized because sufficient cues are lacking” (p. 30). Yoshida (1997) noted that uncertainty occurs “when persons lack an adequate explanatory framework for understanding their situations and predicting outcomes” (p. 12). Both Budner and Yoshida concur that uncertainty occurs when the situation is such that the individual has no frame of reference in which to appraise it. Mishel (1981) proposed a conceptualization of uncertainty in the context of illness. Her theory, and the consensus of most theoreticians, is that illness and uncertainty often co-exist. According to Mishel (1984, 1988), uncertainty is the inability to determine the meaning of illness-

related events and occurs when insufficient conscious or unconscious cues, or stimuli, prevents the person from adequately structuring, categorizing, or predicting outcomes.

Mishel was influenced by Lazarus' cognitive appraisal model, but focused on uncertainty experienced during acute illness then was later expanded to include chronic-illness situations (Mishel, 1988, 1997 & 1999). According to Mishel (1988), when stimuli are perceived as uncertain, the person is unable to subjectively evaluate the illness and treatments. Lack of cognitive structure of the illness and related events prevents the person from adequately appraising the situation; therefore, if events are perceived as uncertain, they are automatically appraised as threatening. The person must then first address the uncertainty for adequate reappraisal of the situation. Mishel introduced her model of Uncertainty in Illness in 1981. It subsequently has undergone further development and empirical testing. In 1988, Mishel introduced her revised model. While Mishel's model was originally introduced in acute care settings and expanded to chronic conditions, studies have been completed using her theoretical framework in ICUs as well (Mishel & Murdaugh, 1987).

Antecedents to Uncertainty. In Mishel's model, uncertainty is determined by those characteristics in the person-environment context that affect one's perception of uncertainty. In other words, if symptom patterns are consistent (easily diagnosed), the environment is familiar (repeat situations), or the event is congruent between expectations and experiences (what the individual expects to occur), little uncertainty results. Cognitive capacity refers to the ability to understand information. If a person lacks the cognitive ability to process information, then uncertainty may result. Lastly, structure providers are considered available resources to assist in interpretation of the

stimuli frame. Resources, such as a healthcare provider, another family member, a family friend, or written/spoken information, may act as a “structure provider” to offer sufficient information to create a frame of reference and thus modulate uncertainty.

Appraisal in the context of uncertainty involves the processes of inference and illusion. Inferences involve the general beliefs about one’s self and his/her interaction with the environment. Inferences can also incorporate prior and/or similar experiences one has undergone. Illusion refers to beliefs arising from uncertainty. In other words, illusions are beliefs that generally things will turn out for the better and reflect a positive outlook despite uncertainty. Some individuals have more positive illusions than others resulting in a more hopeful outlook than another person’s. Other individuals such as health care providers, other family members, and friends can bolster a person’s hope by fostering illusions.

Appraisal of Uncertainty. When an individual appraises uncertainty as danger, coping is initiated to reduce the uncertainty and manage emotions. When uncertainty is appraised as an opportunity, coping is initiated to maintain uncertainty and to sustain the belief in a positive outcome. In Mishel’s model, coping can involve either mobilizing or buffering strategies where an individual uses methods to block input of new stimuli that could alter the person’s appraisal of uncertainty as an opportunity.

In Mishel’s model of uncertainty in illness, her conceptualization indicates that uncertainty is not a component or subset of appraisal, but is one potential outcome of the appraisal process. In other words, the antecedents in her model (stimuli frame, cognitive capacities and structure providers) may result in an appraisal of uncertainty.

Coping

Coping is often viewed as an outcome of stress rather than a transactional concept (Lazarus, 2000). Lazarus and Folkman (1984, p. 141) define “coping as a constantly changing cognitive and behavioral effort to manage specific external and/or internal demands that are appraised as exceeding the resources of the person.” In a transactional stress model, coping is an individual, internal process to manage psychological stress. It is not seen as a trait of the individual or as an outcome of the stress process. Coping is something that varies from individual to individual. Lazarus proposes three main principles to coping:

- There is no universally effective or ineffective coping strategy;
- To study the coping process requires that we describe in detail what the person is thinking and doing at each stage with each specific threat; and
- There are two major functions of coping: either problem-solving or altering our emotions (2000, p.204).

Lazarus notes that denial, frequently seen as harmful, can be helpful in some circumstances and research on the benefits of denial as a helpful coping strategy in ICU settings has been reported (Gentry, Foster, & Haney, 1972; Levine, et al, 1987; Livneh, Antonak, & Gerhardt, 1999; Malan, 1992). Denial may be helpful in some situations and harmful in others. Denial may be helpful in the initial stages of a disease, to assist with emotional coping of overwhelming information, but harmful in later stages, when the individual must adjust to living with a health issue. Therefore, Lazarus is explicit that the process of coping is in itself neutral. Meaning must be applied in order to determine whether the coping strategies are either helpful or harmful. In a transactional stress

model, temporal effects will occur, therefore, the specific coping strategies used by an individual will vary over time. Denial may be used as an initial coping function during initial ICU admission but may not be beneficial at a later time in hospitalization. Lazarus (2000) does note that coping is either focused on solving problems (problem-focused) or managing one's emotions (emotion-focused). He further notes, however, that the specific categorization of the coping strategy (problem-focused versus emotion-focused) is less important than knowing which specific strategy is being used.

In essence, coping is highly individualized, varies over time and in different situations, and, ultimately, serves a problem-focused or emotion-focused function (Lazarus, 2000). Coping strategies are neither universally helpful nor harmful, but neutral, until meaning is ascribed to them. All individuals use both types of coping (problem-focused and emotion-focused) (Lazarus, 2000; Mishel, 1988). Furthermore, an individual must tell you about his/her methods of coping since they may not be readily observable (Lazarus, 2000).

Outcomes—Psychological & Physical Distress

The outcomes of the transactional stress model are identified as psychological well-being and physical well-being. Lazarus notes that the immediate effects of stress, appraisal, and coping are physiological changes, positive or negative feelings, quality of the encounter, and such longer term effects as somatic health/illness, morale (well-being), and social functioning (Lazarus & Folkman, 1984). In his later revised model of stress and coping, Lazarus (1991) indicates that the outcomes of his model are emotions, morale, social functioning, and health. While physical well-being was not of interest in

this study it is presented to explain the complexity and comprehensiveness of the transactional stress theory.

Psychological Well-Being

Psychological well-being has its origins in psychology and has multiple definitions and meanings. Maslow (1968), Rogers (1961), Jung (1933), and Allport (1961) all conceptualized psychological well-being somewhat differently. Maslow (1968) viewed psychological well-being as striving toward self-actualization, while Rogers viewed it as being a fully functioning being. Jung conceptualized psychological well-being as a process of individuation, and Allport viewed it as a process of maturation. Bradburn (1969) conceptualized psychological well-being as happiness. More recently, Ryff (1989) conceptualized psychological well-being as a concept with six dimensions, those being 1) self-acceptance, 2) positive relationship with others, 3) autonomy, 4) environmental mastery, 5) purpose in life, and 6) personal growth. According to Ryff, her re-conceptualization has a stronger theoretical grounding than previous uses of psychological well-being. During the literature review process any concept that implied a generalized satisfaction in life or emotional eustress was considered “psychological well-being” and was therefore included.

Physical Well-Being

In all models of stress (stress as response, stress as a stimuli, and stress as a transaction), there is the belief that stress can influence human physiological functions in both a positive and negative manner. Stress experiences have been investigated with somatic symptoms, neuro-psychoimmunological derangements, and other acute and chronic health conditions, particularly in individual patients (Cohen, Tyrrell & Smith,

1991; Hardy & Smith, 1988; Levenson & Bemis, 1991; Manuck, Olsson, & Hjendahl, 1992; McEwen, Albeck & Camerson, 1995; Mitchell & Drossman, 1997; Potempa, 1994; Smith & Allred, 1989, Yehuda, Giller & Southwick, 1991). More recently, researchers have examined stress and its consequential physiological effects on family members or the effect of families on physiological changes on patients (Davidson, Jones, & Bienvenu, 2012; Fumis & Deheinzelin, 2009; Leske, 1992; McAdam & Puntillo, 2009; McAdam, Dracup, White, Fontaine & Puntillo, 2010; Simpson & Shaver, 1990). In Lazarus' transactional model of stress, health outcomes are clearly identified as intermediate and long-term effects of stress, appraisal, and coping. Physiological alterations due to stress vary significantly between individuals and across various body systems. Cardiovascular responsiveness, hypothalamus-pituitary axis alterations, and depression of the neuroendocrine and immune systems are the systems most affected by stress (White & Porth, 2000). Physical well-being may be viewed as a focused or global concept (i.e., a specific physical alteration such as blood pressure, oxygen saturation, heart rate, laboratory tests, or a more global concept such as general sense of feeling physically well). Any concept that implies a generalized sense of physical well-being or a specific physiological measurement was considered "physical well-being" and was included in the while reviewing this literature.

Conceptual Framework Summary

Lazarus' stress-coping model and Mishel's uncertainty-in-illness model, along with other literature, provided the framework for developing the model guiding this research (Figure 2). This model is a synthesis of these theories and literature on families in both acute and critical care settings. Each of the concepts within the model was

determined to be important to the better understanding this complex phenomenon.

While physical well-being is a potential outcome variable of the framework, a decision was made to focus on psychological well-being for family members that would hopefully be more amenable to nursing interventions.

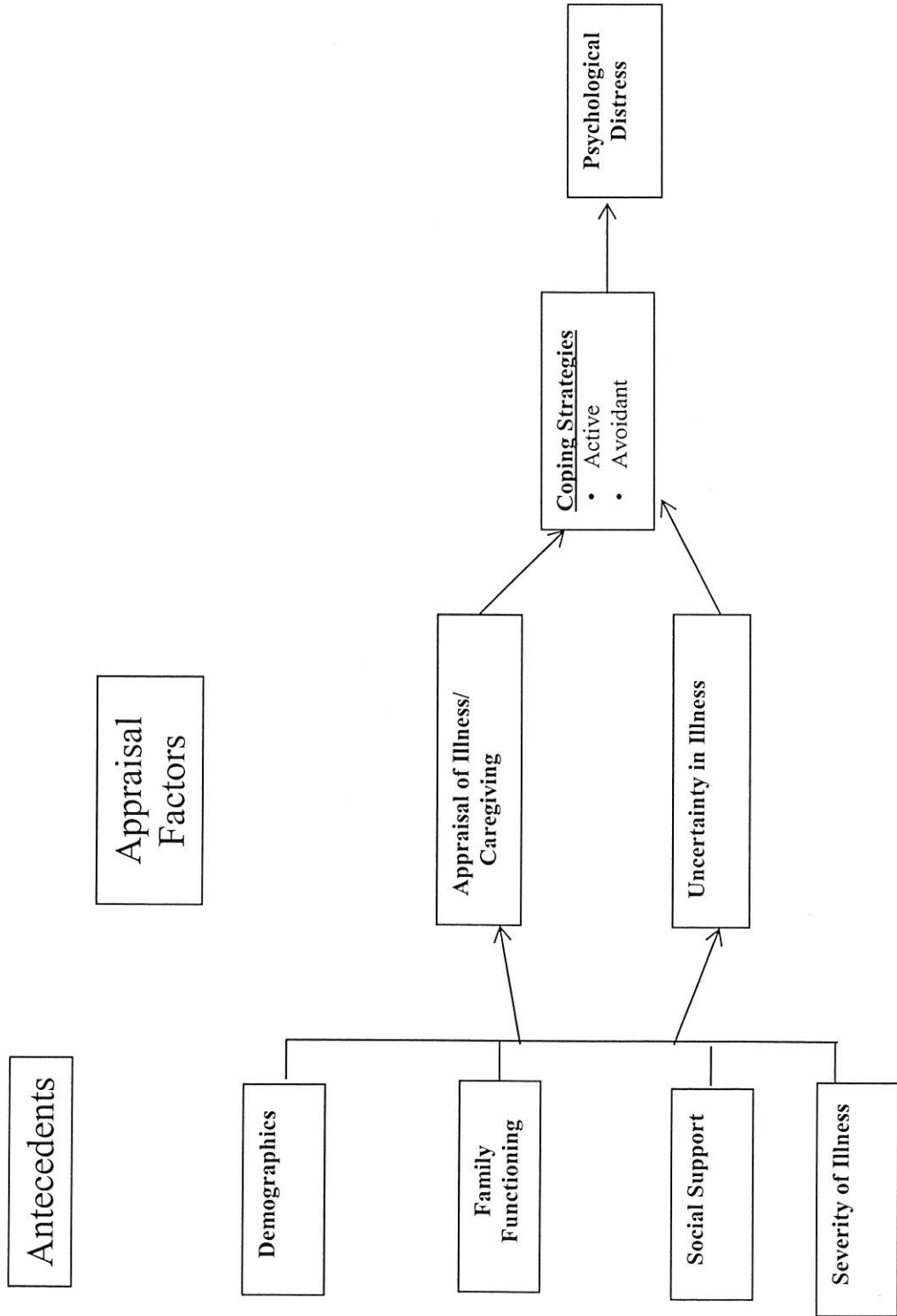
Conceptual and Operational Definitions

Antecedents:

No standard conceptual definition of family functioning is evident in the literature. Indeed, controversy over what defines family and how family functioning is defined exist. For the purpose of this research, family functioning refers to the family processes as they change over time to meet the needs of the individual family member and the family as a unit. Family functioning is operationally being defined through use of the Family Adaptability-Partnership-Growth-Affection-Resolve (APGAR) instrument (Smilkstein, 1978; Smilkstein, et al., 1982).

Social support is conceptually defined as the physical and emotional comfort given to an individual through family, friends, co-workers, or any other individual. Social support is operationalized by use of the 17-item Medical Outcomes Study Social Support Survey (MOS-SSS) (Sherbourne & Stewart, 1991). Severity of illness is conceptualized as the extent of organ-system-derangement or physiologic status of a patient. In simpler terms, severity of illness is simply how sick the family member perceives the patient to be. In this study, severity of illness was conceptualized as a predictor variable in this research and it was held constant by using similar patient types: those undergoing first-time, non-emergent, adult cardiac surgery.

Figure 2. Model Guiding this Study



Appraisal Factors:

Appraisal of illness refers to the beliefs and viewpoints an individual has about the illness or illness experience. For this study, the focus was on the family members' appraisal of the illness and the patient's situation. Appraisal of illness was measured operationally by use of the 27-item Appraisal of Caregiving instrument (Oberst, Thomas & Gass, 1989). According to Mishel, uncertainty is one potential outcome of illness appraisal. Conceptually Mishel, defines uncertainty as the inability to determine the meaning of illness-related events, occurring when the decision maker is unable to assign definite value to objects or events, or is unable to predict outcomes accurately. For this study, uncertainty in illness was measured using the 29-item family version of the Uncertainty in Illness Scale (MUIS-FM) (Mishel, 1981; 1984).

The conceptual definition of coping, for this study, is the process of managing taxing circumstances, expending effort to solve personal and interpersonal problems, and seeking to master, minimize, reduce, or tolerate stress. Coping was operationally defined through use of the 28-item Brief Coping survey (Carver, 1997).

Outcome Factor:

Psychological distress, the outcome variable of this study, was conceptually defined as a perceived inability to cope effectively, a change in emotional status, discomfort, and communication of discomfort or harm (Ridner, 2004). Operationally, psychological distress was defined and measured using the 18-item Brief Symptom Inventory-18 tool and the single-item Distress Thermometer (Derogatis; 2011, NCCN, 2012).

Specific Aims and Research Questions

This research was conducted to determine what coping strategies family members of adult cardiac-surgery patients use throughout the ICU experience and up to the time of hospital discharge. The degree to which family member demographics, level of family functioning and degree of social support impacted appraisal of caregiving/illness and uncertainty was also examined. Lastly, how coping changes from the ICU to hospital discharge, how uncertainty affects family coping, the significance of the experience from the family member's perspective, and ultimately the distress family members experience based on their coping strategies were examined.

The specific aims and research questions of this study were to:

1. Describe the level of family functioning and social support reported by family members prior to surgery.

Research Question #1: What is the level of family functioning reported by family members prior to surgery?

Research Question #2: What is the level of social support reported by family members prior to surgery?

2. Describe the family members' appraisal of illness/caregiving, uncertainty, and coping strategies immediately after surgery.

Research Question #3: How do family members appraise the illness/caregiving role during the ICU period?

Research Question #4: What is the level of uncertainty reported by family members during the ICU period?

Research Question #5: What are the coping strategies used by family members during the ICU period?

3. Describe changes of psychological distress among family members from the ICU period to the hospital discharge period.

Research Question #6: What is the change in psychological distress reported by family members from the ICU time period to the day of hospital discharge following adult cardiac surgery?

4. Determine the relationship among family functioning, social support, appraisal of illness/caregiving, coping, and psychological distress during the ICU period.

Research Question #7: What is the relationship between family functioning, social support, appraisal of illness/caregiving, uncertainty, coping, and psychological distress during the ICU period?

CHAPTER IV

Methodology

Research Design

A descriptive correlational design was used for this study to investigate the relationships between the antecedent variables (demographics, social support, and family functioning), uncertainty, appraisal of caregiving, coping, and psychological distress at the time of discharge. This design is appropriate for this study, as little is known about the relationships among the concepts being studied but a theoretical correlation is proposed. It is also non-intrusive, measures natural behaviors, examines variables over time, and strengthens our understanding of a phenomenon. Limitations of this design are the inability to assess causality and low degree of control. For this study, the three data-collection points were during the clinic visit for the preoperative history and physical (Time 1), within 12 hours after ICU admission (Time 2), and within 24 hours prior to time of discharge from the hospital (Time 3).

Setting

The site for this study was a large academic medical center located in the midwestern United States. The clinic nurse identified potential participants using the Adult Cardiac Surgery Clinic schedule and provided a written list of patient names, planned surgical procedure and appointment dates and times to the principal investigator (PI) the week prior to the patient's clinic visit for his/her preoperative history and physical examination. After check-in at the reception desk, patients and families were

approached about this study by the PI or research assistant (RA). The Cardiovascular Center (CVC) clinical waiting room was the site of initial contact between the potential participant and the PI or RA. A verbal script (Appendix C) was used to describe the study, informed consent was obtained, and collection of family demographic data, as well as family functioning (FAPGAR) and social support (MOS-SSS), occurred (Time 1). Time 2 occurred within the 12 hours in the CVC ICU after their family member had cardiac surgery. During time 2, the appraisal of caregiving, uncertainty in illness, coping and distress thermometer were completed. Time 3 data collection occurred on the cardiothoracic step-down unit within 24 hours prior to discharge from the hospital. Two instruments were used to measure distress at time 3. Administrative permission to conduct the study was granted by the nurse managers of the Adult Cardiac Surgery clinic, the CVC ICU, the cardiothoracic step-down unit and the Medical Director of the Adult Cardiac Surgery Service. Institutional review board (IRB) approval was obtained from the University of Michigan Health System prior to starting data collection.

Sample

A family member of an adult cardiac-surgery patient was the participant of this research. Throughout this proposal, when the term “participant” is used, it refers to a family member of the patient. When the person having surgery is being described, the term “patient” will be used. *The patient is not a research subject for this study.* It is important to note, however, that patient consent was obtained to access the medical record for extraordinary measures and/or complications that might affect coping or psychological distress of a family member.

The target population was family members of adult clients undergoing a planned, first-time cardiac revascularization or first-time valve surgery. Family member, for this study, was defined as anyone reported as a family member by the patient and might include any of the following: wife, husband, domestic partner, son, daughter, mother, father, brother, brother-in-law, sister, sister-in-law, son-in-law, daughter-in-law, mother-in-law, father-in-law, aunt, uncle, niece, nephew, stepparent, stepchild, or grandparent, and includes “in loco parentis” (in place of parents) relationships.

Participant inclusion criteria for this study were: (a) self-identified as a family member or significant other of the patient undergoing surgery, (b) 18 years of age or older, (c) willing and able to participate in the three data collection points of the study, (d) ability to read and write English, and (e) completion of a signed consent form.

Participants were excluded from the study if the patient’s surgery was unplanned, or the patient came directly from the catheterization lab or emergency room to the operating room.

Patient criteria for inclusion in the study included: (a) must be 18 years or older and (2) undergoing a planned first-time cardiac revascularization or first-time valve surgery. Those patients who had had a heart transplant, unplanned cardiac surgery or were admitted to the operating room directly from the cardiac catheterization lab or emergency room were excluded.

An a priori power analysis was completed and a sample size of 90 was determined to be needed for this study. A convenience sample, using non-probability sampling technique, was used as it was deemed feasible and practical for this study. The proposed sample size (n=120) was determined by conducting a power analysis using the G power

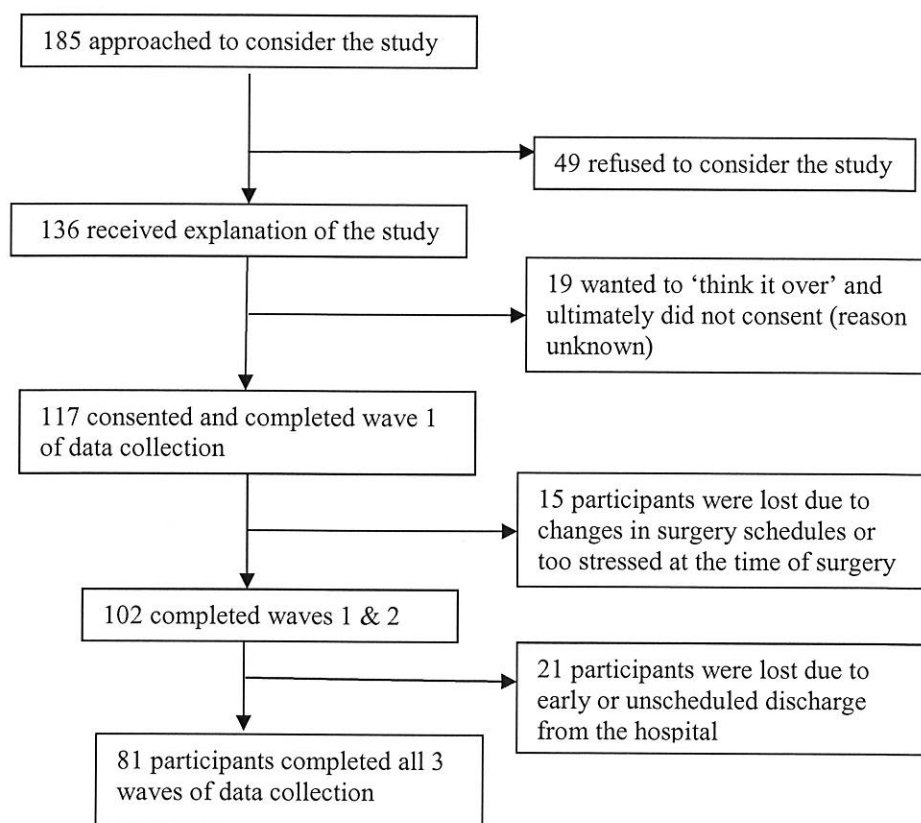
program and adjusting for attrition (Faul, Erdeflter, Buchner, & Lang, 2009). With an effect size of 0.30 and power of 0.80, 90 subjects are needed to conduct the planned data analysis (using a two-group F test). The 0.80 power is a common convention in behavioral research and was used to calculate sample size. According to Cohen (1988), when using multiple regression analyses, 0.15 is a medium-effect size and 0.35 is a large-effect size. Using a conservative estimate of 25% attrition, 120 subjects were needed.

One hundred eighty-five eligible individuals were approached to participate in the study. Forty-nine subjects declined on initial approach for a variety of reasons (Table 1). Individuals who were approached and refused were asked to identify a reason for declining to participate in the study. One hundred thirty-six individuals were provided information on the study and informed of the study purpose and asked to sign the consent form. Nineteen of the 136 wanted to “think it over” and ultimately did not consent and participate without reason resulting in an enrollment rate of 63.2%. One hundred-seventeen subjects ultimately consented and completed Time 1 data collection. Time 2 data collection was completed by 102 participants for a Time 2 retention rate of 87.2%. Eight-one subjects completed all three waves of the study for a retention rate of 87.2%.

Table 2. Reasons for Refusals (n=68)

n	Reason Given for Refusing to Participate in Study
22	Too stressed
19	Wanted to “think it over” but ultimately did not consent
12	No family or friends available to participate
6	No interest
3	Participating in another study
3	No reason given
2	“Very private person”
1	Don’t believe in research
68	Total

Figure 3. Flowchart of Participant Involvement in Study



Instruments

In order to operationalize the concepts of interest, nine instruments were used to measure the variables under study. The MOS-Social Support Survey and the Family APGAR were collected only at Time 1, along with a Family Demographic Data Form. At Time 2, Appraisal of Caregiving, Uncertainty in Illness, Brief Cope, and the Distress Thermometer were completed by each participant in the study. At Time 3, the BSI-18, Distress Thermometer, and two open-ended questions were collected from study participants. Below are the instruments and related data collection periods (Table 2).

Table 3

Instruments & Administration Points

Time 1—Preoperative Clinic Visit for History & Physical Exam	Time 2—Within 12 hours of ICU admission	Time 3—Within 24 hours prior to hospital discharge
Verbal explanation	Uncertainty in Illness	BSI-18
Family Informed Consent	Appraisal of Caregiving	Distress Thermometer
Patient Informed Consent	Brief Cope	Two Open-Ended
Family Member Demographic	Distress Thermometer	Questions
Data Questionnaire		Patient Data Form
Family APGAR		
MOS-Social Support Survey		

Antecedent Factors

Family Member Demographic Data Tool: A family member demographic data tool (FMDDT) was developed by the PI and was used in Time 1 data collection only. Information included on the FMDDT included relationship to the patient, gender, age, race, level of education, and occupation (Appendix D).

Family APGAR: The FAPGAR is a 5-item scale used to measure family functioning in five basic components of family life: adaptation (family problem solving), partnership (sharing responsibility and decision making), growth (physical and emotional maturation), affection (caring relationships within the family), and resolve (commitment to share time, space, and resources with other family members). Item scores range from 0-2 with 0 = “hardly ever,” 1 = “sometimes,” and 2 = “almost always.” A summarized

score for the Family APGAR is calculated by totaling the individual item scores and can range from 0-10. Total FAPGAR scores less than 3 suggest severe family dysfunction, those between 4 and 6 are moderate family functioning, and those between 7 and 10 represent a well-functioning family unit (Smilkstein, 1978). Cronbach's alpha of 0.86 was reported in one study and it varied from 0.89 to 0.92 in another study (Knafl, Knafl, Gallo, & Angst, 2007; Northouse, Mood, Templin, Mellon & George, 2000). The Family APGAR is a public domain instrument and therefore permission was not necessary for use in this study,

MOS--Social Support Survey (MOS-SSS): The MOS-SSS is a 19-item self-report measure of the multidimensional aspects of social support. The MOS-SSS contains four subscales and an overall functional social support scale. The MOS-SSS is scored on a 5-point scale ranging from 1 (none of the time) to 5 (all of the time) for each item. The four subscales are emotional/informational support (8 items), tangible support (4 items), affectionate support (3 items), positive social interaction (3 items), and one additional overall item. Reliability for the MOS-SSS in published studies has been high with a Cronbach's alpha > .91 (Sherbourne & Stewart, 1991). A mean score is calculated for each of the four subscales, and an overall support score is determined by calculating a mean of all 19 items. A conversion from the mean score to a standardized score of 0-100% is provided to compare to other published results (Appendix E).

Appraisal Factors

The Appraisal of Caregiving instrument and the Uncertainty in Illness Family instrument were used to operationalize appraisal.

Appraisal of Caregiving: Appraisal of caregiving was measured using the Appraisal of Caregiving Scale (ACS-R). The ACS-R is a 27-item self-report measure designed to determine the intensity of four possible appraisals of caregiving: harm/loss, threat, challenge, or benign. The original ACS was developed by Oberst, Thomas, Gass and Ward (1989) and included 53-items designed to measure the meaning of illness-caregiving in terms of the intensity of each of the four appraisal dimensions. The directions on the ACS-R for the participants ask that they reflect over the past two weeks to indicate their level of caregiving (Appendix F). The PI adapted the directions to indicate how family members perceive caregiving during the ICU time period. Responses to individual items on the ACS-R range from 1 (strongly disagree) to 5 (strongly agree). Total scores range from 27 to 108 with the higher scores indicating a more negative appraisal of caregiving. Permission to use the ACS-R for this study was obtained from Dr. Laurel Northouse via email (Appendix G).

Uncertainty in Illness: Uncertainty was measured using the 31-item family version of the Mishel Uncertainty in Illness Scale (MUIS-Family). Items of the MUIS-Family are scored on a 5-point scale with 1 = “strongly agree,” 2 = “agree,” 3 = “undecided,” 4 = “disagree,” and 5 = “strongly disagree.” The scale has shown adequate construct validity, and reliability has been reported as 0.81 to 0.92 (Mishel & Epstein, 1997). Lower scores indicate less uncertainty while higher scores indicate greater uncertainty. Individual item scores are summed to determine overall uncertainty score.

The MUIS-Family scores range from 31 to 150 indicating low uncertainty to high uncertainty, respectively (Appendix H). Permission to use the MUIS-Family in this study was obtained from Dr. Merle Mishel (Appendix I).

Coping Variable

The Brief Cope Inventory was used to operationalize coping. Brief Cope (BC): The Brief Cope is a 28-item self-report measure of coping with stressful life events. Each item is scored on a 1 to 4 scale with 1 = "I haven't been doing this a lot," 2 = "I have been doing a little bit," 3 = "I've been doing this a medium amount," and 4 = "I've been doing this a lot." There are 14 identified subscales within the tool, each with two items. The 14 subscales are self-distraction, active coping, denial, substance abuse, use of emotional support, use of instrumental support, behavioral disengagement, venting, positive reframing, planning, humor, acceptance, religion, and self-blame. Each subscale is individually scored and can range from 2 to 8; a score of 2 indicated little use of that particular coping strategy and 8 indicated a high use. The author reports that he does not compute a composite score for this measure but does offer that researchers may create second order factors if desired. The author of the BC suggests that each scale be used to examine patterns of use between subjects and over time (Carver, 1997). Cronbach's alpha reliabilities for each scale vary from 0.50 (venting) to 0.90 (substance abuse) with only three scales below 0.60 indicating at least minimal reliability. The BC instrument is a public-domain instrument, and no permission for use was needed (Appendix J).

Psychological Distress Variable: The Brief Symptom Inventory-18 and the Distress Thermometer were used to measure psychological distress.

Brief Symptom Inventory-18: The BSI-18 is an adaptation of the 53-item Brief Symptom Inventory (BSI). The BSI-18 consists of 18 items with each item scored on a 0 to 4 scale with 0 = “not at all,” 1 = “a little bit,” 2 = “moderately,” 3 = “quite a bit,” to 4 = “extremely.” The BSI-18 has three subscales, anxiety, depression and somatization, each consisting of 6 items. A global severity index is computed by totaling the scores of all 18 items. The BSI-18 has reported coefficient alphas of 0.74 for somatization, 0.84 for depression, 0.79 for anxiety, and a total global severity index of 0.89 (Derogatis, 2011). The BSI-18 is available for purchase through Pearson Canada Assessment, Inc., for use in research studies. Permission to use the BSI-18 and a sufficient number of forms for the study were purchased (Appendix K).

Distress Thermometer: Recently, a single-item measure of distress using a visual analog scale from 0 (no distress) to 10 (extreme distress) was developed at Memorial Sloan Kettering to determine the level of distress cancer patients feel as a result of their disease (NCCN, 2012). The Distress Thermometer (DT) was validated for use in patients with all types of cancer (Baken & Woolley, 2011; Keir, Calhoun-Eagan, Swartz, Saleh & Friedman, 2008). No studies, however, had used the DT with non-cancer patients. The DT is a visual analog scale on which participants rate their level of distress from “0” (none) to “10” (extreme). A cut-off point of ≥ 4 indicates psychological distress. In addition to the visual analog, the DT has 34 items to indicate the source of the distress. According to the National Comprehensive Cancer Network, the DT must be administered in total, including the 34 potential distress-source items (Appendix L). These 34 distress source items were also completed by the participants in the study. Information on

reliability of the DT was not found. Permission to use the Distress Thermometer for this study was obtained from the National Comprehensive Cancer Network (Appendix M).

Illness/Injury Variable: In order to control for variations that may exist in coping with specific illnesses or injuries, patient type was narrowly constrained to include only first-time coronary revascularization and/or valve surgery patients for this study. Additionally, the phase of illness was controlled in this study by collecting data at particular points in the patient's trajectory of care, during the ICU and at the time of hospital discharge. While the actual severity of illness of individual patients may vary, patient data on comorbidities, degree of valvular stenosis or incompetence, or degree of coronary artery stenosis was not collected in this study. It was hypothesized that physiologic severity of illness, as defined by healthcare providers, has some, but not total influence on how family members perceive severity of illness, therefore physiologic severity of illness measures were not used in this study.

Patient ICU Data Form: An ICU patient data form was used at Time 3 data collection to determine if any complications and/or extraordinary measures were used either in the ICU or throughout the patient's hospitalization (Appendix N). The PI or RA collected the data from the electronic medical record if patient consent had been given. Key postoperative complications abstracted from the Society of Thoracic Surgeon data form (STS) were collected, such as use of assistive devices (ventricular assist devices, intra-aortic balloon pumps, continuous renal replacement therapies) or use of extraordinary measures such as cardiopulmonary resuscitation, defibrillation, open-chest management, or resuscitation. These items were collected as extraordinary measures or

severe complications as they may affect coping or psychological distress experienced by the family member.

Open-Ended Questions: In order to develop a deeper understanding of the concepts of interest, two open-ended questions were added at time 3 to allow participants to add other information not captured by the other instruments. The two open-ended questions were 1) what are you feeling and thinking right now? and 2) what fears or concerns did you have on the day of surgery? These questions provided additional insight into the experience family members have undergone since the day of surgery until the day of hospital discharge (Appendix O).

Reliability and Validity of Instruments

Each of the instruments used for this study was known to be valid and reliable.

The following table indicates the instruments in a succinct format (Table 3):

Table 4

Validity and Reliability of Study Instruments

Instrument	# of Items	Validity	Reliability
Family APGAR	5	Face validity (Smilkstein, 1978)	Cronbach's alpha of 0.86 (Knafl, Knafl, Gallo, & Angst, 2007)
		Construct & criterion-related validity with Pless-Satterwhite Family Functioning Index (Good, Smilkstein, Good, Shaffer & Arons, 1979)	Cronbach's alpha 0.89 to 0.92 (Northouse, Mood, Templin, Mellon & George, 2000)
MOS-SSS	17	Discriminant and construct validity (Sherbourne & Stewart, 1991)	Cronbach's alpha >0.91 (Sherbourne & Stewart, 1991)
Appraisal of Caregiving	27	Oberst, Thomas, Gass & Ward (1989)	Cronbach's alpha varies from 0.91 (threat) to 0.72 (challenge). (Oberst, Thomas, Gass & Ward, 1989)
MUIS-FM	27	Concurrent validity with Hospital Stress Events Scale (Mishel, 1981)	Cronbach's alpha 0.81-0.92 (Mishel & Epstein, 1997)
Brief Cope	28	Concurrent validity with COPE Inventory (Carver, 1997)	Cronbach's alpha reliabilities vary from 0.50 (venting) to 0.90 (substance abuse) (Carver, 1997)
BSI-18	18	Convergence with SCL-90-R and GSI (Derogatis, 2011).	Cronbach's alpha 0.89 for global severity index (Derogatis, 2011)
Distress Thermometer	1	Baken & Woolley, 2011 Keir, et.al., 2008	No information on the reliability of the DT was found.

Human Subjects Protection

Prior to starting data collection, approval from the institutional review board at the medical center was obtained from the University of Michigan Health System's Institutional Review Board. This research was conducted at a time that participants were psychologically vulnerable thus every attempt to assure a true desire to participate without coercion was made by the PI or RAs. Participants were fully informed of the nature of the study, their participation and time commitment, and were given every opportunity to withdraw from the study at all three time periods. All participants in the study signed an informed consent form that was maintained in a locked file cabinet in the home office of the PI and were given a copy of the consent form for their records.

The participants in this study had a very low, although real, potential to experience undue psychological distress due to the study itself. Participants were informed of this potential and were informed of resources for support such as clinical nurse specialist counseling, mental health services at the facility and referrals to mental health services if needed. Participants were also informed that they could withdraw at any time throughout the study without repercussions and should feel comfortable doing so if they experience undue psychological distress. Lastly, if undue distress was noted and referral to the clinical nurse specialist and/or psychiatric emergency room was warranted, the participants were allowed to withdraw from the study.

The researcher protected the confidentiality of responses by assuring private space to complete the questionnaires and maintaining the completed forms in a locked file cabinet in the home office of the PI. The subject identification list with subject name and

subject identification code numbers was maintained by the PI separate from the coded questionnaires.

The research assistants (RA) for this study were undergraduate nursing students who had expressed interest in collecting data and underwent data collection training by the PI. The PI and the RAs involved in this study completed the PEERRS training at the University of Michigan. The PI provided a 4 hour training session to the RAs in participant recruitment, data collection, protection of confidentiality, obtaining participant and patient consent, recognition of undue anxiety or psychological distress, and the overall goals of the study. The PI provided monthly email announcements to remind RAs of the study procedures and when a project director was hired and trained, he made weekly audits of the written materials and random observations of RAs during the study.

Once potential participants were identified, a verbal script of the study was used to introduce the study. If potential participants expressed interest in participating, pre-screening questions were used to verify eligibility for the study. Pre-screening questions included age of the family member, ability to read, write, and understand English, agreement to participate in two data-collection points, and willingness to sign an informed-consent form. Participants were then asked to sign a comprehensive informed-consent form indicating consent to participate in the study at Times 1, 2, and 3.

Privacy: In order to protect their privacy, participants were approached in the CVC clinic waiting room, consultation room, and/or exam room to provide privacy to explain the purpose of the study, the level of involvement and to obtain informed consent. Participants were assigned a “subject identification code” upon entrance into the study.

An identification code list of participant names was maintained by the PI in a locked cabinet in his office. This information was necessary to identify participants (family members) for data collection at times 2 and 3. A password secured email account was used to maintain the patient name and subject ID number. The PI and RAs were each allowed access to maintain the list and the password was changed at random intervals during the study. During Time 3 data collection, a private consultation room or family conference room on the cardiothoracic step down unit was offered to provide privacy during data collection. Most participants chose to complete the Time 3 instruments in a corner of the patient's room which provided sufficient privacy as reported by participants.

Names, addresses, telephone numbers, and email addresses were obtained of family-member participants on a separate 3x5 index card and used for mailing research results to participants upon their request. These information cards were stored in a locked file cabinet in the home office of the PI. The 3x5 index identification cards were maintained separately from subject identification codes to protect confidentiality. These index cards will be maintained for a period of 2 years following the completion of this study in the event a participant has a question about the study or if the PI chooses to do a 6-month, 1 and 2 year follow-up study.

Withdrawing from the Study If the patient died during the study period, the participant's participation ended. Fortunately, no patients died during this study. Participants could also choose, at any time, to withdraw from the study. No undue distress or need for referral occurred during this study. If a participant withdrew from the study at any point, data were maintained (stored in locked cabinet) until the completion

of the study. Only one participant withdrew from the study after his/her initial consent and who was reported as “too anxious” to complete the study.

Risks and Benefits

No direct risks to the participants, the public, or community were anticipated in this study. Undue psychological distress during this stressful experience and upon completion of study instruments was possible, but only one subject withdrew from the study. Each family member was evaluated by the PI or RA for signs and symptoms of severe anxiety or undue stress during data collection periods, but none were evident. The PI or RA was available via direct-line cell phone and in physical proximity to assist family members in working through the distress as needed. Mental-health support services were available at the clinical agency, at a cost to the study participants, in the event a referral was necessary.

Procedure

Initial Recruitment of Subjects: First, the Adult Cardiac Surgery clinic nurse provided a list of potential patients meeting the inclusion criteria a week prior to the clinic visit. By having the clinic schedule in advance, the PI knew the days and times family members would be available in the clinic waiting room for recruitment. Daily, the PI and/or RAs would provide a list of potential study participants to the receptionists in the clinic. The receptionist would notify the PI or RA when the patient checked into the clinic, and the patient and family were then approached.

The physicians and nurses in the clinic were each given a letter of introduction as to the nature of the study as well as contact information of the PI and RA. Additional handouts were available in the clinic for the surgeons and nurses to hand to families if

they so desired. Flyers were also posted in the clinic with information about the study so potential participants were not surprised when approached in the CVC clinic waiting room to participate in the study (Appendix P). Initially, the study was designed so that the clinic nurse would provide the initial introduction of the study. This proved to be too burdensome for the clinic staff, however, so after patient check-in, the PI or RA approached the potential participants to introduce the study. The IRB was notified of this change but an amendment to the proposal was not necessary according to IRB staff.

The PI or RA made daily visits to the CVC Adult Cardiac Surgery Clinical waiting room, based on the clinic schedule, to approach potential participants. After initial identification by the PI or RA in the CVC clinic waiting room, each family was screened to ensure that they met the inclusion/exclusion criteria of the study. Each patient was also screened to ensure meeting the inclusion/exclusion criteria. Occasionally, patients screened by the clinic nurse did not ultimately meet the inclusion criteria but were approached by the PI or RA. These potential participants were thanked for their interest but were not included in the study. After ascertaining the family member met the criteria, the PI or RA explained the study in further detail and asked them to consider participating in the study. If the participants expressed a willingness to participate, the PI or RA explained the study in depth, along with the consent process for the patient and the subject. The explanation of the study and consenting occurred in either the CVC clinic room or private consultation room in the CVC clinic. One individual from each family was asked to be the informant for this study, starting with the patient's spouse or partner, and then the children. The family, as a whole, however, ultimately chose among themselves who the individual would be to participate in the

study. Potential participants were given an informed consent form to sign indicating their agreement to participate in the study. A copy of the consent form was provided to the participants if they chose, and each was given a business card with the PI's contact information on it. Each survey was coded and matched to a list of participants maintained by the PI. This ensured that participant data from times 1, 2, and 3 could be matched. Surveys were maintained in a locked file cabinet in a secure room in the hospital. As surveys were completed, the PI would remove those surveys and make note to the RAs that the survey had been picked up. All surveys were maintained in a locked file cabinet in the PI's home office.

Time 1 Data Collection: If the family-member participant completed the informed consent tool, three questionnaires (FMDDT, FAPGAR, MOS-SSS) were given to the family-member participant to complete in the CVC clinic waiting room. Participants were asked to complete these questionnaires at that time in the waiting room or private consultation room of the CVC clinic waiting room while the patient was waiting for his/her clinic appointment. No data, just the informed consent, were collected from the patient at this time. Participants were informed of where the research team member would be available or to contact the PI or RA by a phone number to hand in their questionnaires when completed.

Time 2 Data Collection: The Time 2 questionnaires (ACS, MUIS-FM, Brief Cope, BSI-18, Distress Thermometer) were distributed to participants in ICU waiting room. Participants were asked to complete these forms after visiting their loved one in the ICU and to notify the research team member via telephone when completed. The team member would then obtain the completed questionnaires. Participants were given

the Time 2 data-collection instruments with the research-team member's name and telephone number for any questions during the completion of the instruments and also to return the forms. When all Time 2 instruments were completed and turned in to the PI or RA, subjects were given a thank you card containing \$10. Subjects were also given a second business card with contact information of the PI so they were reminded of the Time 3 data collection phase.

Time 3 Data Collection: The PI or RA made daily rounds on the cardiothoracic step down unit to determine the discharge dates of patients. Participants were approached either the day of discharge or the day prior to discharge to verify their willingness to complete the study. Completion of the questionnaires reaffirmed their consent to participate in the study. Participants were asked to complete the Time 3 questionnaires (BSI-18, Distress Thermometer, and open-ended questions) at that time. The PI or RA would provide contact information to be notified to return and pick up the completed time 3 instruments. Data collection, in general, occurred in a corner of the patient's room which provided sufficient privacy according to participants, but occasionally was completed in the family waiting room or consultation room based on participant preference.

Anticipating a discharge date for Time 3 data collection was challenging, as some patients progress faster and/or slower than other patients. The targeted length of stay, however, for uncomplicated cardiac-surgery patients at this facility is four days postoperatively (A. Wenk, UMHS Cardiac Surgery Data Manager, personal communication, July 14, 2010). Three strategies were used to avoid missing participants at the Time 3 data collection period. First, a daily visit (Sunday through Saturday) to the

step-down nursing unit was conducted to consult with the charge nurse about potential discharges. Secondly, a daily discharge planning list was electronically generated and shared with the PI in order to plan for the day of discharge. And third, the participants themselves were given business cards in the CVC ICU reminding them of the of Time 3 data collection and to contact the PI or RA via telephone if they were going home. It was not anticipated that the participants would contact the PI or RA given the stressful experience they were undergoing but this option was provided, and a small number of participants, perhaps 5, did use this approach. A cell phone with an exclusive phone number of this study was purchased, so participants, nurses, doctors, or others could call this direct line for inquiries. The primary method to assure completion of time 3 data collection was daily rounds by a research-team member.

At each of the data-collection points, the PI or RA remained nearby and was available by phone if any questions occurred while the family member completed the questionnaire. Because the surveys were lengthy and could take 30 minutes to 45 minutes to complete at Time 2, participants were encouraged to take rest breaks to complete the instruments if needed. Participants recorded their responses to the questionnaires directly onto the forms distributed at each data-collection point. Family-member participants were also directed to complete the questionnaires without the assistance of other family members. The PI or RA returned to collect the instruments at the mutually agreed upon time and location or when contacted via telephone. At the completion of the Time 3 instruments, participants were thanked for their time and given an additional \$10 for their participation.

Patient Consent: Patient information was needed from the chart; therefore, informed consent from patients was also needed. Patients were approached during the CVC clinic preoperative visit along with their family member. Their participation in the study, allowing access to their medical record, was explained, and written informed consent was obtained. If the patient did not consent to participate in the study, the family-member data were still used for data analysis, but the patient data were not obtained. A consent form signed by patients was obtained so that data from the medical record could be collected. Very limited data (patient age, type of surgery, length of surgery, extraordinary measures used, as well as intra-operative and postoperative complications) were required from the patient's medical record. This information, however, was necessary to account for any confounding effects that extraordinary measures or postoperative complications may have had on family coping or psychological distress.

CHAPTER V

Results

Data Analysis

IBM Statistical Package for Social Sciences (SPSS) version 19 was used to analyze the quantitative data from the demographic and survey instruments. Descriptive statistics were used to analyze characteristics of the sample and study variables. The significance level for this study was set at $p \leq 0.05$.

Demographic Data

Eighty-one participants completed all three waves of the study. All questionnaires were deemed usable as minimal data was missing from the questionnaires. Of the 81 participants in the study, 23 (29.9%) were male and 54 (70.1%) were female. Four participants did not indicate their gender. The racial background of the participants was overwhelmingly Caucasian with 74 (92.5%) being white, 3 (3.8%) being Asian-American, 2 (2.5%) being African-American, and 1 (1.2%) indicating 'other' as the race. The mean age of participants in the study was 56.48 (S.D. 12.23) while the median was 56.00. The youngest participant in the study was 24 years of age and the oldest was 79 years of age.

Fifty-one (63%) of the participants reported being the spouse or partner to the patient having surgery. Nine (11%) of the participants were sons of the patient, 10 (12.3%) were daughters, 1 (1.2%) was a grand-daughter and 10 (12.3%) indicated their relationship as 'other.' The vast majority of the others were friends or neighbors of the

patient. In general, the participants had known the patient for a relatively long period of time. The average length of relationship between the participant and the patient was 38.65 years (S.D. 15.13) with a median of 40.5 years. However, the range of length of relationship varied from three years to as many as 71 years.

Forty-six (57.5%) of the participants reported that they were working, while 14 (17.5%) were not working and 20 (25%) were retired. For those participants who were working 29 (74.3%) indicated they worked full time while 10 (25.7%) were working part time. The sample was relatively highly educated. All of the participants had at minimal graduated high school. Thirty-four (42.5%) had completed high school, 28 (35%) had complete college and 18 (22.5) had completed graduate school.

In order to understand whether the participants had prior ICU experience and how they perceived their role in the ICU, two demographic questions were asked. Fifty-one (64.6%) reported having prior ICU experience while 28 (35.4%) reported this as their first ICU experience. Participants were also asked to identify for themselves whether they anticipated their role in the ICU to be that of a visitor/observer, participant in care, recipient of care or manager of care. Thirty (37.5%) participants indicated they foresaw themselves as a visitor/observer, 20 (25%) indicated themselves to be participants in care, 20 (25%) indicated they expected to be managers of care, while 9 (11.2%) indicated they expected to assume more than one role while in the ICU (despite being asked to pick only one role). Interesting to note, no participant in the study identified themselves as a potential recipient of care while in the ICU.

Table 5*Demographic Data from Sample (N=81)*

Variables	Frequency (<i>n</i>)	Percentage (%)
Gender		
Male	23	29.9
Female	54	70.1
Missing	1	
Total	77	100
Race		
Caucasian	74	92.5
Asian-American	3	3.8
African-American	2	2.5
Other	1	1.2
Missing	1	
Total	80	100
Relationship		
Spouse/Partner	51	63
Son	9	11
Daughter	10	12.3
Granddaughter	1	1.2
Other (friends, neighbors)	10	12.3
Total	81	100

Table 5 continued*Demographic Data from Sample continued (N=81)*

Variables	Frequency (<i>n</i>)	Percentage (%)
Education		
High School	34	42.5
College	28	35.0
Graduate School	18	22.5
Missing	1	
Total	80	100
Prior ICU Experience		
Yes	51	64.6
No	28	35.4
Missing	1	
Total	79	100
Anticipated Role in ICU		
Visitor/Observer	30	37.5
Participant in Care	20	25
Manager of Care	20	25
Recipient of Care	0	0
More than one role	9	11.2
None	1	1.3
Missing	1	
Total	80	100

Research Question 1

Research question 1 was “what is the level of family functioning reported by family members prior to surgery?” In order to answer this question, 81 participants completed the Family APGAR instrument. Scores ranged from 3 to the maximum of 10. The mean score on the Family AGPAR for the sample was 9.05 (S.D. 1.756) with a median score of 10. One participant indicated a score of 3 on the Family APGAR indicating severe family dysfunction and nine participants had Family APGAR scores between 4 and 6 indicating moderate family functioning. Seventy of the participants reported scores between 7 and 10 on the Family APGAR indicating a well-functioning family unit. Alpha reliability coefficient for the Family APGAR was .867.

A t-test was run to determine if any significant differences existed between males and females on family functioning. The results revealed there was no significant difference ($t(74) = 1.550, p=.125$). Using the analysis of variance (ANOVA) test, differences on family functioning by educational level were also analyzed. Results of the ANOVA demonstrated that no statistically significant differences existed by level of education ($F(76,4) = 1.254; p=.291$ respectively). The sample was too homogeneous to analyze the impact of race on family functioning.

Table 6***Family APGAR Scores (N=80)***

Variables	Frequency (<i>n</i>)	Percentage (%)
Family APGAR		
3	1	1.3
4	2	2.5
5	4	5.0
6	3	3.8
7	2	2.5
8	5	6.3
9	9	11.3
10	54	67.5
Missing	1	
Total	80	100

Note: 0-3 scores indicate severe family dysfunction
4-6 scores indicate moderately family functioning
7-10 scores indicate well-functioning family

Research Question 2

Research question 2 was “what is the level of social support reported by family members prior to surgery?” In order to answer this research question, the MOS-SSS instrument was administered to 81 participants. The MOS-SSS is scored on a 5-point scale ranging from 1 (none of the time) to 5 (all of the time) for each item. The mean scores for the four subscales and the overall support index showed, in general, moderate

to high levels of reported support in all areas (see Table 7). The emotional/informational subscale was the lowest reported mean score (Mean = 4.2119, S.D. 0.7473) with both the affectionate and social interaction subscales showing the same higher mean scores (4.2614, S.D. 0.5676). The mean scores can also transformed to a 0 – 100 scale to compare to other published means (Sherbourne & Stewart, 1991). An internal consistency test was run for this study, and Cronbach’s alpha was .951.

Table 7

Medical Outcomes Study: Social Support Survey Scores

Subscales	Mean Score:	S.D.	Transformed Score
Emotional/Information Support	4.2119	.74739	80.3
Tangible Support	4.2438	.83289	81.0
Affectionate Support	4.6214	.57676	90.5
Positive Social Interaction	4.6214	.57676	90.5
Overall Social Support Index	4.3405	.62365	83.5

T-tests were run between the four subscales and the global support index and gender to determine if any significant differences existed between males and females on any dimension of social support. The results revealed there was no significant difference between males and females on any dimension of social support (Table 8). Since the

racial diversity of the sample was so small, it was not possible to analyze if differences existed among racial groups in their reports of social support.

Table 8
Differences in Social Support Sub-Scales by Gender

Subscales	<i>t</i> score	<i>p</i> value
Emotional/Information Support	-1.589	.120
Tangible Support	.007	.995
Affectionate Support	-1.349	.182
Positive Social Interaction	-1.349	.182
Overall Social Support Index	-1.459	.149

Research Question 3

Research Question 3 was “how do family members appraise the illness/caregiving role during the ICU period?” In order to answer this question, the Appraisal of Caregiving instrument was administered to 81 participants. Responses to individual items on the ACS-R range from 1 (strongly disagree) to 5 (strongly agree). The mean score of the sample on ACS-R was 71.26 (S.D. 8.19) with the lowest score being 50.00 and the highest score 89.00. Total scores ranged from 27 to 108 with the higher scores indicating a more negative appraisal of caregiving. A score of 67.5 is the midpoint of the scale. This sample’s score of 71.26 fell very close to the midpoint of the scale indicating a more neutral perception of caregiving. Cronbach’s alpha was computed for this study

on the ACS-R and was .627. Item-total statistics were examined to determine if any item deletions would improve coefficient alpha. No item deletions would improve the internal consistency reported.

A t-test was run to determine if differences between men and women existed on their appraisal of caregiving. Results of the t-test showed that no significant differences existed between men and women as to their appraisal of caregiving ($t(71) = -1.225, p = .213$). An ANOVA was run to determine if differences existed among different educational groups on appraisal of caregiving; no difference was found ($F(73,7) = .137; p = .873$). An independent samples Mann Whitney U test was performed and determined no differences between those with previous ICU experience and those without were significant for their appraisal of caregiving ($p = .848$). Since the diversity of the sample was so small, it was not possible to analyze if differences existed among racial groups in their report of appraisal of caregiving.

Research Question 4

Research Question 4 was “what is the level of uncertainty reported by family members during the ICU period?” The Uncertainty in Illness Scale Family version was administered to participants to answer this question. Two of the items on the MUIS-Family were eliminated from this study as they were deemed irrelevant for family members in ICU. Items of the MUIS-Family are scored on a 5-point scale with 1 = “strongly agree,” 2 = “agree,” 3 = “undecided,” 4 = “disagree,” and 5 = “strongly disagree.” With the 31-item instrument, the MUIS-Family scores ranged from 31 to 150 indicating low uncertainty to high uncertainty, respectively. For this study, scores ranged

from 29 to 145 with higher scores indicating higher uncertainty. The mean uncertainty score for the sample was 94.95 (S.D. 7.719) with a range from 70.00 to 110.00. Overall, the mean score indicates a moderate level of uncertainty for this sample. For this study, Cronbach's alpha of the MUIS-Family instrument was .623. Item-total statistics were examined to determine if any item deletions would improve coefficient alpha. No item deletions would improve the internal consistency reported.

The mean uncertainty score for men in the sample was 95.14 and 94.79 for women. A t-test was run to determine whether a statistically significant difference between men and women existed and the results were that no difference existed ($t(68) = .168, p = .867$). A t-test was also performed to determine whether a difference in uncertainty existed for those with previous ICU experience and those without that exposure. The results showed there was no statistically significant difference between those with or without previous ICU experience ($t(69) = .659, p = .512$). An ANOVA was performed to determine if differences in mean scores of uncertainty existed among different relationship to the patient or different educational levels. The results showed that no differences existed for relationship status (spouse, son, daughter, son, other) or educational level with reported uncertainty ($F(68,4) = 2.323, p = .065$; $F(69,2) = .435, p = .512$ respectively).

Research Question 5

Research question 5 was “what are the coping strategies used by family members during the ICU period?” Study participants completed the Brief Cope instrument to answer this question. Each item is scored on a 1 to 4 scale with 1 = “I haven’t been doing this a lot,” 2 = “I have been doing a little bit,” 3 = “I’ve been doing this a medium amount,” and 4 = “I’ve been doing this a lot.” Acceptance was the coping strategy most used by the subjects in this study. The mean score for acceptance was 6.3704 (S.D. 1.528) followed by use of emotional support (Mean = 5.728; S.D. 1.620) and positive reframing (Mean = 5.432; S.D. 1.850). The coping strategies least used by study participants were behavioral disengagement (Mean = 2.300; S.D. .7696), denial (Mean = 2.370; S.D. .7490) and substance use (Mean = 2.370; S.D. .9803) (see Table 9). All 14 subscales of the Brief Cope were reported as being used by some participants in the study.

In order to calculate scale scores of the Brief Cope, the following items are combined and added (Carver, 1977):

- Self-distraction, items 1 and 19
- Active coping, items 2 and 7
- Denial, items 3 and 8
- Substance use, items 4 and 11
- Use of emotional support, items 5 and 15
- Use of instrumental support, items 10 and 23
- Behavioral disengagement, items 6 and 16
- Venting, items 9 and 21
- Positive reframing, items 12 and 17
- Planning, items 14 and 25
- Humor, items 18 and 28
- Acceptance, items 20 and 24
- Religion, items 22 and 27
- and Self-blame, items 13 and 26.

Table 9*Means and Standard Deviations of Coping Strategies*

	<i>n</i>	Mean	S.D.	Alpha	Possible Scale Range
<i>Active Coping Strategies</i>					
Acceptance	81	6.3704	1.528	.714	2-8
Use of emotional support	81	5.7284	1.620	.720	2-8
Positive reframing	81	5.4321	1.850	.734	2-8
Active coping	80	5.3000	1.513	.473	2-8
Planning	81	5.0741	1.759	.711	2-8
Religion	81	4.9630	2.395	.904	2-8
Use of instrumental support	81	4.8148	1.768	.773	2-8
<i>Avoidant Coping Strategies</i>					
Venting	81	3.2593	1.104	.323	2-8
Self-blame	81	2.6420	1.132	.471	2-8
Substance use	81	2.3704	.9803	.949	2-8
Denial	81	2.3704	.7409	.527	2-8
Behavioral Disengagement	80	2.3000	.7696	.275	2-8
<i>Non-Loading Subscales</i>					
Self-distraction	81	4.4568	1.500	.408	2-8
Humor	81	3.0617	1.560	.800	2-8

Table 9 (continued)

Means and Standard Deviations of Coping Strategies

	n	Mean	S.D.	Alpha	Possible Scale Range
Overall Coping Strategies					
Overall Active Coping	80	37.65	8.203	.85	14-56
Overall Avoidant Coping	80	12.97	2.925	.66	10-40

Males and females did differ on their use of various coping subscales. To determine if the differences were significant, an independent t-test was performed between the 14 subscales and gender (Table 10). There was no statistically significant difference between males and females on any of the subscale scores and the limited racial diversity of the sample prohibited examining differences between races on coping strategies. Only one subscale was affected by the relationship of the participant to the patient. Humor as a coping strategy was significantly different by relationship to the patient ($F(76, 4) = 4.004, p = .005$).

The Cronbach's alpha coefficient for the Brief Cope instrument for this study was .85, which is considered good. Alpha reliability coefficient for the overall active coping scale was 0.85, also good. The coefficient alpha of the overall avoidant coping scale was .66, which is acceptable. Alpha reliability coefficients for the subscales ranged from 0.28 (behavioral disengagement) to 0.95 (substance use). The low alpha coefficient of 0.28 for behavioral disengagement is unacceptable, but that subscale is based on only two items.

Table 10***Means Scores of Coping Strategies by Gender***

	Males	Females	Possible Scale Range
<i>Active Coping Strategies</i>			
Acceptance	6.130	6.444	2-8
Use of emotional support	5.087	6.092	2-8
Positive reframing	5.127	5.537	2-8
Active coping	4.956	5.434	2-8
Planning	4.347	5.333	2-8
Religion	4.434	5.148	2-8
Use of instrumental support	3.956	5.240	2-8
<i>Avoidant Coping Strategies</i>			
Venting	3.127	3.333	2-8
Self-blame	2.391	2.777	2-8
Substance use	2.173	2.481	2-8
Denial	2.260	2.444	2-8
Behavioral Disengagement	2.043	2.415	2-8
<i>Non-Loading Subscales</i>			
Self-distraction	4.217	4.518	2-8
Humor	2.913	3.148	2-8

Higher order exploratory factor analysis was conducted on the Brief Cope instrument to determine the underlying factor structure of the 14 coping strategies. In a previous study, a two-factor solution, active and avoidant coping was reported (Kershaw, Northouse, Kritpracha, Schafenacker & Mood, 2004). The results of this factor analysis supported the two-factor solution of active and avoidant coping. Self-distraction and venting did not load on either factor, using a critical factor loading less than 0.35. Seven subscales loaded on the *active* coping factor, including: active coping, emotional support, instrumental support, positive reframing, planning, acceptance and religion. Five subscales loaded on the *avoidant* coping factor, including: denial, substance use, behavioral disengagement, humor, and self-blame.

After creation of the overall active coping score and the overall avoidant coping score, additional analysis to determine if there were differences by gender on these overall scores was analyzed. Men reported a lower active coping mean scores (Mean = 28.00, S.D. 7.28) than women (Mean = 32.75, S.D. 7.15) which was marginally statistically significant ($t = -1.915$, $df = 74$, $p = .06$). However, men also reported lower avoidant coping mean scores (Mean = 11.78, S.D. 1.90) than women (Mean = 13.32, S.D. 3.63) which was statistically significant ($t = -2.629$, $df = 74$, $p = .01$). Age was not correlated to overall active coping mean ($r = -.114$, $p = .314$) but was statistically significantly correlated to the overall avoidant coping score ($r = -.237$, $p = .03$).

Research Question 6

Research question 6 was “what is the reported change in psychological distress by family members from the ICU time period to the day of hospital discharge following adult cardiac surgery?” Psychological distress was measured at two times within this study. The Distress Thermometer (DT) was used at Time 2 and Time 3 while the BSI-18 was only used at Time 3 data collection to lessen the potential burden of participants having to complete so many instruments. This question was answered by examining differences in DT changes over time.

The Distress Thermometer is a single-item measure of distress using a visual analog scale from 0 (no distress) to 10 (extreme distress). During the ICU experience, 79 participants reported a mean distress score on the DT as 5.791 (S.D. 2.587) with scores ranging from the minimum score possible, 0, to the highest possible score of 10. At the time of discharge, 77 participants reported a mean distress score of 5.220 (S.D. 2.615). A cut-off point of ≥ 4 indicates psychological distress; therefore, psychological distress at the time of surgery and at time of discharge existed in this sample.

A paired t-test was run to determine if differences in means between the ICU and discharge timeframes existed. Seventy-five valid cases existed for analysis to determine if the change in distress scores was significant. The ICU mean score of distress was 5.940 (S.D. 2.524) and the mean score of distress at hospital discharge was 5.240. This difference in mean scores was significant using a paired t-test ($t(74) = 2.979; p = .004$) indicating that distress scores were higher during the ICU period and declined toward hospital discharge.

The BSI-18 was administered to family members at the time of hospital discharge only. Mean scores of each of the subscales and the global severity index were calculated (Table 11). In addition, the author of the instrument (Derogatis, 2011) recommends that the scores be converted to standardized scores ranging from 0 to 100 for comparisons with other groups, therefore means were then calculated for the standardized scores of the sample (Table 12). Furthermore, Derogatis recommends that investigators calculate scores that are gender-specific for comparison to group norms (Table 13).

Table 11

Raw Score Means of the BSI-18 Subscales

Subscales	Minimum Score	Maximum Score	Mean Score	S.D.
Somatization	0	9	1.362	2.094
Depression	0	14	2.062	2.739
Anxiety	0	18	4.400	4.300
Global Severity Index	0	32	7.825	7.722

Table 12*Mean Scores of the Standardized BSI-18 Subscales*

Subscales	Minimum Score	Maximum Score	Mean Score	S.D.
Somatization	38	79	53.05	9.759
Depression	40	70	47.31	7.777
Anxiety	38	79	53.05	9.759
Global Severity Index	33	70	49.38	8.819

Table 13*Mean Scores of the Standardized BSI-18 Subscales by Gender*

Subscales	Mean Score	S.D.
Somatization		
Males	45.00	5.072
Females	47.77	1.112
Depression		
Males	46.73	7.758
Females	47.56	7.845
Anxiety		
Males	49.78	10.617
Females	54.47	9.105
Global Severity Index (GSI)		
Males	46.78	9.395
Females	50.50	8.400

Pearson's correlation between the BSI-18 GSI and the Distress Thermometer were analyzed to determine if psychological distress scores on the instruments were significantly related. The BSI-18, administered only at time 3 was correlated with the Distress Thermometer at Time 2 and Time 3. The correlation ($r = .585, p < .01$) between the BSI-18 GSI and the DT at Time 2 was significant. The correlation between the BSI-18 GSI and the DT at Time 3, when both instruments were administered, was significant as well ($r = .568, p < .01$).

Internal consistency was analyzed for each of the subscale dimensions using six items each, as well as the global severity index using all 18 items of the BSI. The Cronbach's alphas were calculated for each subscale and the global severity index (Table 14). Item 17, an item within the depression dimension was excluded from reliability analysis, as it had a zero variance.

Table 14

Internal Consistency of the BSI-18 and Its Subscales

Dimension	Cronbach's Alpha
Somatization	.617
Depression	.732
Anxiety	.845
Global Severity Index	.872

Research Question 7

Research Question 7 was “what is the relationship between family functioning, social support, appraisal of illness/caregiving, uncertainty, coping, and psychological distress?” In order to answer this research question, a multiple regression was used. The dependent variable in this equation was psychological distress in the ICU as measured by the Distress Thermometer at Time 1. The independent variables were selected demographics (age, gender, and relationship status), family functioning, social support, appraisal of illness/caregiving, uncertainty in illness, the overall active coping factor and the overall avoidant coping factor. The assumed casual model is outlined in Figure 4.

The results of the regression analysis indicated that the six predictor variables, along with the three demographic variables explained 36.3% of the variance ($R^2=.35$, $F(9,50)=2.984$, $p=.006$). It was found that overall active coping predicted psychological distress (beta = .28, $p < .04$) as did avoidant coping (beta = .30, $p < .04$). Multiple-step path analysis was used to further understand the relationships between the variables in the model. First appraisal of illness/caregiving was regressed on the selected demographics of age, gender and relationships. Correlation coefficients for these demographics were .03, .15 and .18 respectively for appraisal of illness/caregiving. Uncertainty in illness was regressed on the same selected demographics and resulted in coefficients of -.16, .20 and -.12 respectively. Sequentially, the following regressions were completed: 1) appraisal of illness/caregiving was regressed on the family functioning and then social support, 2) uncertainty in illness was regressed on family functioning and then social support, 3) active coping strategies were regressed on appraisal of illness and then uncertainty in illness, 4) avoidant coping strategies were regressed on appraisal of

illness/caregiving and then uncertainty in illness, and 5) psychological distress was regressed on active coping strategies and then avoidant coping strategies. Each of the sequential regressions performed are documented in Tables 15-18.

Figure 4: Assumed Casual Model

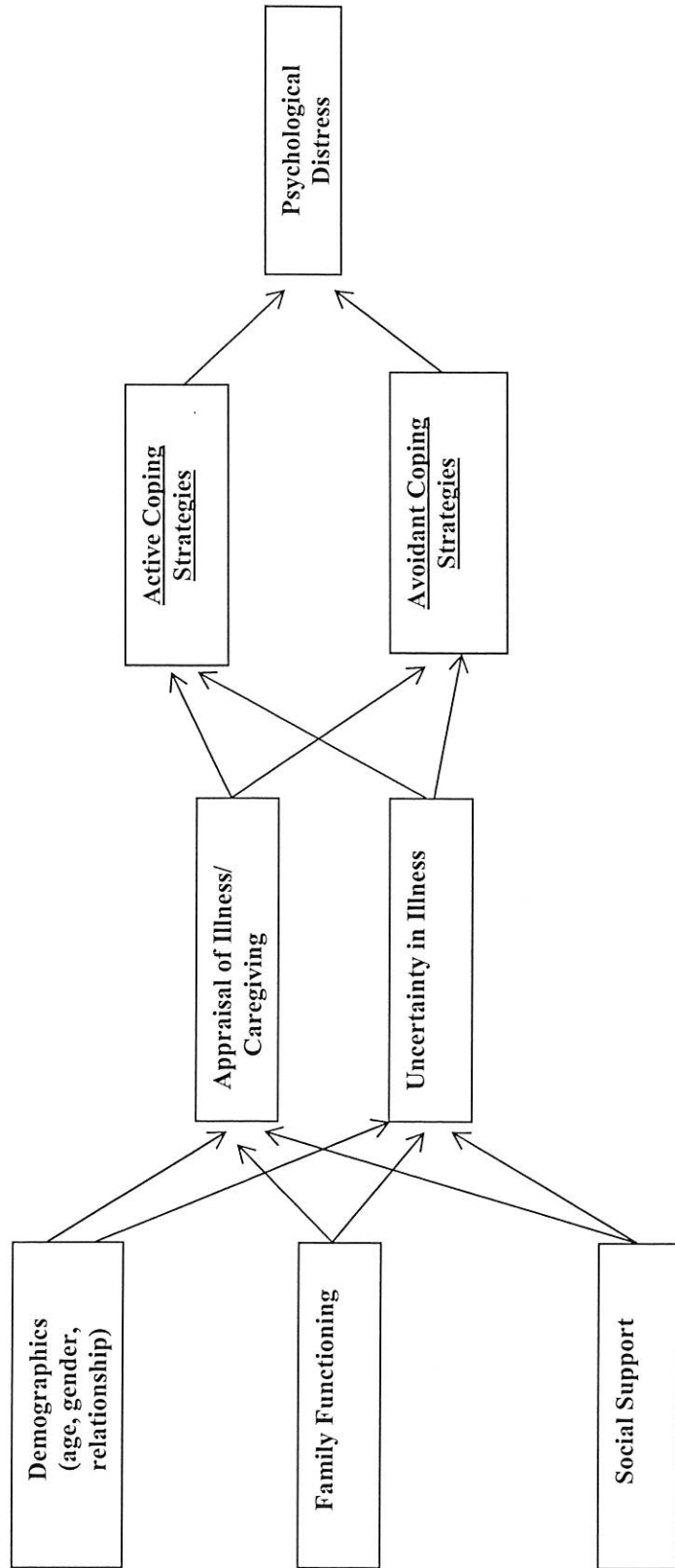


Table 15***Regression of Variables on Appraisal of Caregiving***

Variable	Regression Coefficient	Standard Errors	Standardized Coefficients	<i>t</i> statistic	<i>p</i> value
Age	.027	8.238	.027	.237	.813
Gender	.147	8.284	.147	1.255	.213
Relationship	.241	7.998	.241	2.154	.034
Family	.040	8.253	-.040	-.342	.734
Functioning					
Social	.174	8.066	-.174	-1.482	.143
Support					

Table 16***Regression of Variables on Uncertainty in Illness***

Variable	Regression Coefficient	Standard Errors	Standardized Coefficients	<i>t</i> statistic	<i>p</i> value
Age	.160	7.672	-.160	-1.336	.176
Gender	.020	7.913	-.020	-.168	.867
Relationship	.289	7.440	-.289	-2.547	.013
Family	.129	7.762	-.129	-1.089	.280
Functioning					
Social	.011	6.866	.011	.089	.929
Support					

Table 17***Regression of Variables on Active Coping Strategies***

Variable	Regression Coefficient	Standard Errors	Standardized Coefficients	<i>t</i> statistic	<i>p</i> value
Appraisal of Caregiving	.153	7.110	.153	1.330	.187
Uncertainty	.225	7.046	-.225	-1.932	.057

Table 18***Regression of Variables on Avoidant Coping Strategies***

Variable	Regression Coefficient	Standard Errors	Standardized Coefficients	<i>t</i> statistic	<i>p</i> value
Appraisal of Caregiving	.304	3.140	.304	2.743	.008
Uncertainty	.015	3.319	.015	.127	.899

Table 19***Regression of Variables on Psychological Distress***

Variable	Regression Coefficient	Standard Errors	Standardized Coefficients	<i>t</i> statistic	<i>p</i> value
Active Coping Strategies	.407	2.352	.407	3.888	.000
Avoidant Coping Strategies	.383	2.355	.383	3.613	.001

The resultant model with significant paths is shown in Figure 5.

Figure 5: Final Casual Path

