

CHAPTER VI

Discussion & Conclusion

In this chapter of the dissertation, the demographic characteristics of the sample will be discussed, followed by a review of the findings of each of the research questions with observations and speculation as to the potential reasons for these findings. After a thorough discussion of the findings, implications for nursing will be discussed, along with limitations and future opportunities for further research. This chapter will end with conclusions based on the results of this study.

One hundred-eighty-five individuals were eligible and subsequently approached to participate in this study over a one year data collection period. One hundred seventeen consented to participate in the study and completed Time 1 of the data collection. One hundred and two participants completed Time 1 and Time 2 data periods and ultimately 81 participants completed all three waves of data collection. This research report has analyzed quantitative data solely on the 81 completed participants. Analysis of data from waves 1 and 2 only, as well as qualitative analysis of the open-ended questions will be completed at a later date.

Fifty-one (63%) of the participants were spouses or partners of the patient having surgery with the remaining participants being children, grand-children or “others.” Fifty-seven percent of the participants were working in addition to dealing with the critical illness of their family member undergoing cardiac surgery and the sample was highly educated, with everyone having a minimum of a high school diploma. Seventy percent of

the participants were female and males accounted for 30% of the sample. The racial background of the participants was 92.5% Caucasian with the remainder being Asian-American, African-American and “other.” These findings are consistent with the local and regional demographics of the southeastern Michigan in which the medical center is located. There is no reason to believe, based on observation of refusals or withdrawals from the study, that there was any particular pattern in those that refused to participate based on age, gender, race or education.

The average of the study participants was 56.48 (S.D. 12.23). One data point that was not collected was whether the subject had any comorbid conditions themselves. Given the oldest subject was 79 years old, one could presume that he/she also has some health concerns that might affect one’s level of psychological distress.

Participants were also asked to identify their anticipated role in the ICU care of their loved one. Thirty of the 81 participants saw themselves as visitor/observers rather than participants or managers of care but none saw themselves as recipients of care. It is interesting to note with the movement toward family-centered care, that health care providers are assuming family members will need care themselves. Prior studies have indicated that family members forego their own needs while the loved one is in the ICU (Williams, 1989).

Family Functioning Prior to Surgery

Research question 1 was “what is the level of family functioning reported by family members prior to surgery?” The Family APGAR instrument was completed at Time1 by all 81 sample participants. The Family APGAR measures family functioning and can vary from 0 to 10 (with 10 indicating the highest level of functioning). For this

sample, the mean score was 9.05 (S.D. 1.756) indicating a high level of family functioning overall for the sample. Only one participant indicated severe family dysfunction was present at Time 1 of data collection with nine participants indicating only moderate family functioning. The remaining 71 participants reported a high level of family functioning.

It was theorized that family functioning would potentially influence how the individual family member appraises the illness and/or caregiving experience and level of uncertainty they were experiencing in the ICU. It was further theorized that if family functioning demonstrated severe family dysfunction, active coping strategies would be used less often. It was further assumed that more avoidant or potentially detrimental coping strategies would be used when greater family dysfunction was reported. Regrettably, there was insufficient variation in family functioning, among the participants in the study, to test these hypotheses.

The participants in this study reported high levels of family functioning and perhaps the influence of dysfunction was negated with such a small subsample reporting moderate to severe dysfunction. It should be noted that family functioning was correlated to appraisal of caregiving ($r = -.04$) and uncertainty in illness ($r = -.12$) in the expected direction. Family functioning contributed very little to psychological distress, the dependent variable in the multiple regression analysis. Additionally, there was no statistically significant difference between males and females on report of family functioning, nor was there by educational level; although again, this was a very highly educated sample. It may also be that at this point in the health crisis of their loved one that families have put aside their level of family angst in order to fully focus on the care

of their loved one. It should be noted that even at the initial data collection time period, family members knew their loved one was undergoing open heart surgery as they were here for the initial clinic workup to assure physiologic stability for surgery.

Selection bias and the highly educated sample may have played a role in the high levels of family functioning reported by the participants in the study. In particular, these subjects may have reported high levels of family functioning because it was the socially desirable answer rather than airing the family's issues at this time. The individuals that chose to participate in the study were also perhaps the best at coping with multiple stressors and did not rely on their family for support. In a study, like this one, where one family member volunteered to be the family informant, one has to wonder if collecting baseline family functioning scores from all family members may provide a more valid measure of actual family functioning.

Social Support Prior to Surgery

Research question 2 asked "what is the level of social support reported by family members prior to surgery?" The MOS-SSS instrument was used to evaluate the respondents perceived level of social support at time 1 data collection. The overall social support index was 4.34 on a 0-5.0 scale indicating moderate to high levels of social support overall. Affectionate and positive social interaction social support was perceived as the most positive sources of social support, followed by tangible support and lastly emotional/information support. There was no significant difference between males and females on their reported levels of social support and the racial diversity was so small, no analysis was possible.

It is interesting to note that emotional/information support was the lowest rated subscale on the MOS-SSS at a time when one could expect that a great deal of emotional and informational support would be needed. One thing to consider regarding the emotional support is while others most probably recognize the need for emotional support, emotional support can be seen as invasive by some and insufficient by others. Some literature on “over-helping” would suggest that some individuals may be overwhelmed and suffer more negative outcomes if too much help is offered (Gilbert & Silvera, 1996).

Emotional/information support may be rated as a low need on the MOS-SSS because of a timing issue. Many of the families had time between being told their loved one needed open heart surgery and the actual day of surgery. It is possible that they felt educationally prepared for the experience, even if not emotionally prepared, because of the preoperative education they received, discussions with knowledgeable friends, as well as the educational information from the internet. It may also be that the participants did not feel that their family or friends could provide reliable information about the experience and therefore did not seek them out as source of education. This is an area that warrants further study.

Participants in the study did mention in verbal comments to the PI after completing the MOS-SSS that two items seemed particularly irrelevant within this context. One item was “is there someone to help you if *you* were confined to bed?” and the other was “someone to help with daily chores if you were sick?” Both of these items seem better suited to someone experiencing a critical or incapacitating illness themselves

versus their loved one. Cronbach's alpha was 0.95 indicating high reliability in the measure.

Appraisal of Illness/Caregiving in the ICU

Research question 3 was "how do family members appraise the illness/caregiving role during the ICU period?" The Appraisal of Caregiving instrument was administered after the family member visited their loved one following adult cardiac surgery but while still in the ICU. This instrument was designed to providing insight into the feelings, beliefs or attitudes someone may have about an illness of a family member and about their role in provide care and support needed by their loved one. The instrument directions were altered by asking participants to indicate how the items most closely represented their feelings over the past three days including the ICU day. The original instrument asked the participants to indicate their perception over the past two weeks. This instrument was originally designed for use in longer term illness of a family member rather than in a critical care unit.

The Appraisal of Caregiving Scale is scored between 27 being the lowest possible score and 108 being the highest possible score. A score of 67.5 is the midpoint of the scale and the higher the reported score the more negative the appraisal of the situation. The 81 participants in this study reported a mean score of 71.26 (S.D. 8.19) with a range from a low of 39 to a high of 89. The sample indicated a slightly higher than negative appraisal from the midpoint of the scale. This would indicate that participants felt their lives were now different based on this critical illness experience of their loved ones.

While the appraisal by the participants indicates a wide range of responses and a mean score indicating more concern about the situation, it was anticipated that a much

higher appraisal scored would be reported. The lower than expected appraisal score may have occurred for several reasons. One such reason could be the family members felt adequately prepared for the experience through their preoperative learning and information gathering. Another plausible reason why the appraisal score was lower than expected may be due to the role in which the caregiver is placed. In the context of longer term and/or home care situations, the location in which the instrument was initially designed for use, participants may not see themselves as responsible for the actual care while their loved one is in the ICU. If the appraisal of caregiving instrument had been administered at the time of hospital discharge, a more negative appraisal may have resulted given the distress of leaving a supportive and protective environment.

Participants were also asked, on the demographics form, to identify the role they perceived themselves assuming during the ICU experience. Did they see themselves as a “visitor/observer,” “participant in care,” “manager of care,” or “recipient of care?” Only 24.7 percent of the respondents saw themselves as “participants in care.” Since the vast majority of the sample did not view themselves as being responsible for the care in the ICU, it is possible that the subjects felt embracing their caregiving role was not necessary until after the hospital discharge of their loved one. It might have been interesting to ask about a perceived role change from the ICU up to the discharge day; although this was not done in this study.

Item 2 on the ACS asked participants to respond by indicate how “not very stressful” the situation was to them with 1 = strongly disagree to 5 = strongly agree. This item mean was 1.86 (S.D. .95), the lowest score of any of the items, indicated indeed these individuals felt this situation was very stressful to them. Indeed family members in

this study, perhaps even those best handling the situation, still felt the situation was very stressful for them. At the same time, participants indicated on item #19 that this situation did not affect their relationship with the person needing their care (Mean = 3.45, S.D. 1.28) further noting their love and commitment to the individual undergoing surgery.

Uncertainty in Illness in the ICU

Research question 4 was “what is the level of uncertainty reported by family members during the ICU period?” As expected family members reported a moderate level of uncertainty (Mean = 94.95, S.D. 7.179) with a possible score of 29 to 145 with the higher scores indicating more uncertainty. There were no statistically significant differences between men and women on reported uncertainty or those with previous ICU experience. It was not expected to detect any differences on uncertainty between men and women therefore this finding was as expected. However, it was expected that perhaps having a previous ICU experience may lessen the perceived uncertainty due to familiarity with the sights and sounds of an ICU. This, however, was not the case. Participants with a previous ICU experience did not report any significant difference in uncertainty than those without that experience. Again, one could speculate that uncertainty was lessened by sufficient preoperative education. It should be noted that this hospital does not provide pre-operative ICU tours to patients and family members to familiarize them with the ICU environment, while other ICUs do. However, verbal reports by study participants were overwhelmingly positive about the preoperative education and support they received prior to surgery.

The influence of relationship status on perceived uncertainty was not significant ($F(68,4) = 2.323, p = .065$) although it did approach significance. The influence of

different educational levels on uncertainty, however, was found to be statistically significant ($F(69,2) = 4.103, p = .021$). The higher the educational level of the individual, the higher the uncertainty score ($r = .297, p = .011$). It was theorized based on previous literature and the uncertainty in illness theory that uncertainty would indeed exist. This sample did report a moderate level of uncertainty. Exactly why a higher level of education was related to a higher uncertainty score is not known. However, it may be that family members with *some* information may have a greater need for more information thereby creating this sense of uncertainty.

Coping in the ICU

Research question 5 was “what are the coping strategies used by family members during the ICU period?” The sample reported they used more active coping strategies overall than avoidant coping strategies. The Brief Cope instrument was used to answer this question. Acceptance was the coping strategy most used by the subjects during the ICU time period. This could be a function of the planned nature of the surgical event. Participants were informed between 2 and 6 weeks prior to surgery of the need for surgery during the preoperative clinic visit. It could be that this time period between when they are told that surgery is necessary and the actual date of surgery plays a part in the acceptance. Family members may ultimately simply accept the current situation as time passes from the clinic appointment to the day of surgery. It is quite possible that anticipatory work needed to prepare for this situation was conducted and family members when confronted with it; simply accepted it. It might be interesting to evaluate coping strategies between the time of being told of the need for surgery and the changes that occur up until the day of surgery.

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 abuse (Mean = 2.370; S.D. .9803). Lazarus points out that denial may be a protective mechanism when threatened but as time passes it may be less beneficial (Lazarus & Folkman, 1984). It is possible that family members used denial after the initial news that surgery was necessary but due to the timing of data collection in the ICU, they had already moved past denial to acceptance. Perhaps more negative and/or avoidant coping strategies are used by individuals after receiving “bad news” situations but with the passage of time, and the reappraisal of the situation that different coping mechanisms are then used. All of the items and all 14 subscales were reported as being used by some of the participants, including substance use. Although men reported lower overall active coping scores (Mean = 28.00, S.D. 7.28) than women (Mean = 32.75, S.D. 7.15) it was not statistically significant. In this study, men did report lower avoidant coping scores (Mean = 11.78, S.D. 1.90) than women (Mean = 13.32, S.D. 3.36) and it was statistically significant ($t(74) = -2.629, p = .01$). What might account for gender differences? Age was not significantly related to coping. Other studies are contradictory on whether coping is influenced by gender and age (Son, Thomas, & Friedmann, 2013) suggesting that further study is needed.

It is also interesting to note that when factor analysis was performed on the Brief Cope instrument to do subsequent regression analyses, self-distraction and humor did not load based on the critical factor loading less than 0.35. Two items on the Brief Cope comprise the humor subscale; item #18 that states “I’ve been making jokes about it,” and item # 28 that states “I’ve been making fun of the situation.” These items had mean

scores respectively of 1.67 (S.D. .94) and 1.38 (S.D. .75), with a score of “1” indicating “I haven’t been doing this at all.” Humor, perhaps, is not a strategy deemed “appropriate” by participants given the grave nature of the situation for their loved one.

The Brief Coping instrument has been used in many studies, but none were reported in the literature with family members in the ICU setting. This scale is a 28-item scale with 14 subscales each comprised of two items. It was conceptualized that each of the 14 subscales is to stand alone for analysis and reporting. The subscale reliability coefficients range from .949 for substance abuse to .275 for behavioral disengagement, yet the overall active coping alpha was .77 and the overall avoidant coping alpha was .54. Other investigators have used the Lazarus’ Ways of Coping Questionnaire and the Family Crisis Oriented Personal Evaluation Scales (FCOPES) to measure coping during critical illness (Son, Thomas, & Friedmann, 2013). The overall Brief Coping alpha coefficient was 0.66 indicating acceptable reliability. It would be interesting to use the Brief Coping and another coping instrument to evaluate the best fit for families in the ICU setting.

Distress in the ICU and Time of Hospital Discharge

Psychological distress was measured at two times within this study. The Distress Thermometer was used as an outcome measure at Time 2 and Time 3 of the study. Seventy-nine participants reported a mean distress score on the DT as 5.791 (S.D. 2.587) and 77 participants reported a mean distress score of 5.220 (S.D. 2.615) at the time of discharge. The pre-established cut-off point of distress is ≥ 4 indicating psychological distress. At both times, participants in this study were distressed. A paired t-test was run and the differences were significant ($t(74) = 2.979, p = .004$) indicating distress was

higher during the ICU at a statistically significant degree. However, the participants continued to have a high level of distress even at the time of discharge.

The Distress Thermometer was designed for use in patients with oncological diseases and undergoing cancer treatment. It was intended to be a valid and reliable, quick measure, to determine clinically if the patient was experiencing psychological distress. It had not been used in the ICU setting for patients or family members prior to this study. The instrument itself is a thermometer that subjects indicate their level of distress on a scale of 0 to 10 with 10 indicating higher levels of distress. The Distress Thermometer also has descriptive items that respondents can further delineate their specific source of distress; this portion of the instrument was completed by not analyzed for this study.

The Distress Thermometer did detect the level of distress family members reported in the ICU and just prior to hospital discharge. In both cases, the mean scores were higher than the cut-off point indicating distress that may require intervention. The mean scores did, however, decrease, as expected, from the ICU until the time of discharge. However, a high level distress score at hospital discharge was not expected and warrants further investigation and possible interventions to assist in reducing distress. In the qualitative comments about their concerns at the time of hospital discharge, participants noted the fear of going home without the safety and security of the nursing staff. They expressed great apprehension about potential complications and their ability to recognize and respond to them after going home. It may also be interesting to measure distress and uncertainty on a weekly basis after hospital discharge until their follow-up clinic appointment to determine when and if their distress drops below the cut-off score.

The Brief Symptom Inventory 18 (BSI-18) was also administered at the time of hospital discharge but not at time 2 in the ICU. The global severity index (GSI), a total distress score indicated that participants, similarly to the Distress Thermometer at Time 3, were psychologically distressed at the time of hospital discharge. The correlation ($r = .585, p < .01$) between the DT at Time 2 and the BSI-18 GSI at Time 3 was significant. The correlation ($r = .568, p < .01$) the DT at Time 3 and the BSI-18 GSI at Time 3 was also significant. The anxiety subscale of the BSI-18 was the highest scoring subscale, followed by depression and finally somatization. This would indicate that anxiety is an overriding symptom of family members, even at the time of hospital discharge. Internal consistency of the GSI and the subscale showed sufficient reliability in the scale with somatization being the lowest at .617. The BSI-18 findings at data collection Time 3 is worrisome, as one would hope that family members are minimally distressed, since they will be the primary caregiver of the patient after discharge. The finding of the BSI-18 and Distress Thermometer suggest that family members may need much more support than perhaps previously understood in order to maximally benefit the family member and ultimately the patient once sent home from the hospital.

In the qualitative comments about “what fears or concerns did you have on the day of surgery,” participants acknowledged many reasons for their distress. The vast majority were simply concerned about their loved one’s survival, despite noting everyone had reassured them “things will be alright.” Many also noted their fear of a complication such as a stroke or major infection that while not killing the loved one could have a major life impact. Several participants while noting the outstanding preoperative instructions

nonetheless noted the fear of the unknown as a concern. One participant did note “zero” concerns or fears as having had absolute faith in the surgeon.

Testing the Model

Research question 7 was “what was the relationship between family functioning, social support, appraisal of illness/caregiving, uncertainty, coping and psychological distress? To test the model guiding this research, multiple regression and path analysis was performed. The results of the regression analysis indicated that the six predictor variables, along with the three demographic variables explained 36.3% of the variance ($R^2=.36$, $F(9,50)=2.984$, $p=.006$). It was found that overall active coping predicted psychological distress (beta = .28, $p < .04$) as did avoidant coping (beta = .30, $p < .05$). In other words, the greater the use of either type (active or avoidant) of coping strategies, the more reported psychological distress. Does coping, therefore, promote psychological distress? More likely, the use of multiple coping strategies is an indicator of the extreme distress an individual is experiencing.

Multiple-step path analysis was used to further understand the relationships between the variables in the model. The path analysis showed that the relationship of the participant to the patient impacted their appraisal of illness/caregiving and their level of uncertainty. Other studies on families in critical care have demonstrated that family needs are different between spouses/partners and children of the patient (Molter, 1979; Williams, 1989). In those studies, it has been suggested that spouses/partners tend to have different concerns than children. The spouse/partner is often the primary caregiver of the patient and their concern may be more focused on the tangible support, care and

resources they will be required to provide to the patient more so than the children respondents in the study.

The appraisal of illness influenced the use of avoidant coping strategies but not active coping strategies. The more negative the appraisal of illness, the greater use of avoidant coping strategies. Avoidant coping strategies included venting, self-blame, substance use, denial and behavioral disengagement. Participants who had a more negative appraisal of illness (more concern for their loved one) may simply be more overwhelmed emotionally and respond using these strategies. While both active and avoidant coping strategies predicted psychological distress, only avoidant coping strategies were influenced by appraisal of illness.

While it is clear that coping is significantly related to psychological distress, the importance of social support and family functioning in the statistical model are questionable. It may be the families with poor functioning opted not to participate in the study as the family dysfunction would add an additional stress of which to cope. Likewise, in light of the critical illness of their loved one and the support they receive from their family and friends, social support may not play a large part in decreasing psychological distress.

Limitations

There are several limitations in this study. First, the actual physiological severity of illness of the individual patients was not measured in this study. It was hypothesized that the families' appraisal of the illness was not related to the actual severity of illness as determined by health care experts. A larger study that incorporates patient severity of illness measures and a comparison to family perception of severity of illness may be able

to shed light on whether families and providers perceive severity of illness, and therefore use different coping strategies, differently. This study is descriptive in nature and only captured one measure at two different times within the study; the Distress Thermometer at Time 2 and Time 3.

Measurement error is a possibility in any study and this is true with this study as well. While most of the instruments are written with low-level English comprehension in mind, a misunderstanding of instrument directions could have occurred. The appropriateness of the Appraisal of Illness/Caregiving measure within the ICU context is another possible limitation in hindsight. The use of a different coping scale should also be considered as further studies on coping of family members are conducted. The Distress Thermometer, another measure in the study, was used in its total form, as mandated by the owners of the instrument required. However, there are 32 items on the instruments that were not necessary for this study and yet participants were burdened to complete that section of the surveys. It is important to note that participants completed the Distress Thermometer at Time 2 and Time 3, and sources of psychological distress were collected, analysis of changes in sources of distress will be completed at a subsequent time.

Internal consistency of instruments is also a limitation of this study. The Family APGAR, MOS-SSS and the BSI-18 had good reliabilities (.867, .951 and .872 respectively). The MUIS-FM instrument had a Cronbach's alpha of .623 and the Appraisal of Caregiving/Illness had an alpha of .627. In reviewing these instruments and attempting to use item-total deletions, it was not possible to improve the reliability score. However, alphas of .623 and .627 are still considered acceptable reliabilities.

The Brief Cope instrument is somewhat more challenging to interpret in this study. The overall internal consistency measure of the BC is .85 indicating a good reliability. The BC is a 28-item instrument that was developed to for each of its 14 scales to be used to examine relationships with other variables. So while the overall reliability is .85, the individual scale reliability coefficient range from .275 for behavioral disengagement to .949 for substance use. However, it is not surprising that these individual scale reliabilities vary so greatly. They are determined based on only two items each. This variability in reliability coefficients is consistent with those reported by the instrument developer (Carver, 1997). The overall active coping subscale reliability was .85 and is considered good while the overall avoidant coping subscale reliability was .66 and is considered acceptable.

Initial refusals to participate in the study were often cited as “too stressed” when in fact this study was designed to better understanding how families cope with this level of stress. Perhaps the most distressed potential subjects opted out of the study—the very subjects from whom we may have learned the most. The participant that chose to be the family informant in the study may have also been inclined to provide the social desirable responses to the family functioning measure thereby negating the theorized effect of family functioning on psychological distress.

Despite limiting the number of measures used, participants were still burdened to complete a total of 9 instruments over the course of the study. The daily monitoring and rounding by the PI or RAs to assure data was collected and not missed was burdensome to the research team and an alternative method, such as a locked box on the unit, for returning surveys might have assisted in improved data collection and a larger sample

size. A locked box on the unit would have definitely eased the study team burden. It is unknown whether a locked box would have been viewed as more helpful to study participants. Security of the locked box, as well as the specific location, would have also been of a concern.

The initial power analysis was conducted and a determination was that 98 participants were needed for the study. Ultimately, only 81 subjects completed all three waves of the study. A larger sample size would potentially have recruited a more diverse sample, allowed more sophisticated data analysis and perhaps detect significance that was not detected in a smaller sample. While this study was conducted in one facility to increase control of processes that might ultimately impact psychological distress, considering another hospital with a more diverse sample to increase racial minorities in these studies is an important consideration for the future.

Implications for Research

This is one step forward in better understanding the coping strategies and predictors of psychological distress in family members in ICUs. Further research using other coping and appraisal of illness measures are warranted. A study solely investigating coping strategies, perhaps using several coping measures, might provide insight into which measure most adequately portrays the coping strategies used by family members. Increasing the representativeness of racial minorities, as well as gay, lesbian and transgendered individuals, in future studies is warranted. In particular, as we continue to have more non-traditional family forms, the type of support and the strategies that promote effective coping may be very different within these groups.

Examining coping and psychological distress over time would also help to better understand the experience of these family members. As noted, determining when to start measuring coping is important. Is the proper time to establish a baseline coping score in the preoperative clinic and at various intervals prior to having surgery? What are the appropriate time intervals to measure coping and psychological distress? And for how long should we measure coping and adjustment in the post-discharge experience; 6 months, 1 year or 2 years? How does family coping and psychological distress relate to the patients' coping and psychological distress? Should key variables be measured for a longer period of time, say monthly for the first 3 months following hospital discharge?

It should also be noted that the health system used for this study has made tremendous strides in preparing patients and families during this critical life period. They have embraced flexible visiting hours and support any family member or friend of the loved one that the patient has indicated is important to them. The health system has also instituted a unit host for the family waiting room that has been a tremendous support system for the families as they wait and wonder. In the qualitative comments collected, participants also indicated a great deal of trust and respect for the surgeons performing the surgeries and the entire health care team. While they were anxious and worried about the outcome of the surgery, they took great assurance that the system was top quality and that allayed many fears. It would be very interesting to compare various experiences of family members in different facilities.

Implications for Practice

This study, along with others, presents a challenge to clinicians. In particular, the importance of assessing coping strategies being used by family members, but also to

acknowledge the psychological distress they are experiencing during this difficult time for them. Determining which coping strategies the person is using may allow the nurse to develop interventions to bolster those strategies helpful to the individual family member. Likewise, observing for use of avoidant coping strategies, like substance abuse, is also important.

Nurses, and other clinicians, should seek to assess, perhaps with a measure as simple as the Distress Thermometer, the level of psychological distress family members are experiencing at varying intervals within the hospital stay and prior to discharge. This could be recorded and conveyed to the home care nurse and/or clinic nurse for follow-up in the outpatient or home setting. It is well recognized that the patient's emotions will change over time; but far too often, we expect the family member's emotional state to be constant.

Nurses should remember that coping and psychological distress change over time and constant assessment and intervention to prevent use of harmful coping strategies can facilitate psychological well-being. We do know from research that family members play a key role in the recovery and coping of patients following major illness.

Nurses must embrace that having a loved one in an ICU will result in distress of the family member. In an environment that is familiar and comfortable, it is easy to not appreciate the level of distress that family members are experiencing. It should also be recognized that family members are "putting on a strong front" for the patient, but may be severely distressed themselves. Nurses must ask and spend the time assisting the family member in coping to minimize psychological distress.

Conclusion

Family members do report high levels of psychological distress during the ICU following adult cardiac surgery and while this distress dissipates, it remains through the hospital discharge and most likely to the home setting. Psychological distress should be assessed and coping strategies that negative distress should be encouraged. No two persons “cope” the same; therefore it is incumbent upon nurses to individually assess and intervene to prevent undue psychological distress by family members. By helping our families, we are ultimately helping our patients.

Appendix A

Quantitative Studies Reviewed

Author	Purpose	Sample	Results
Foster & Chaboyer, 2003	To understand the burden associated with caring for a family member who had been critically ill, 3 months are hospital discharge.	Primary caregivers following 5 day stay in an ICU; English speaking, >18 years of age. 72% females, 28% males with mean age 51.8 years (n=71)	<ul style="list-style-type: none"> • Most caregivers spent ~40 hours week providing care. • Caregiver burden was less than expected. • Moderate self-efficacy and social support were reported. • Differences between men and women existed with men reporting higher time dependence burden and developmental burden. • Filial obligation was correlated to 4 of 5 caregiver burden subscales. • There was no correlation between APACHE score and caregiver burden. <p>Study was conducted in Australia.</p>
	Design Descriptive, correlational	Measures <ul style="list-style-type: none"> • Caregiver Burden Inventory • Filial Obligation Scale • Social Support Scale • Self-Efficacy Scale 	

Author	Purpose	Sample	Results
Sabo, et al., 1989	To identify the relation-ship between attending an ICU family support group and the family's appraisal of stress, social support and hope.	<p>Control group (n=36) had 83% females, 31% were spouses, and 39% were greater than 55 years of age.</p> <p>Study group (n=31) had 64% females, 45% were spouses, and 51% were greater than 55 years of age.</p> <p>All subjects were > 16 years of age, read and spoke English, and was a relative or significant other of a patient in an ICU > 24 hours.</p>	<ul style="list-style-type: none"> • No differences in scores on stress, social support or hope between the control group and study group • The support group was reported as being beneficial by study subjects • Only studied attendance at one support group meeting <p>Study was conducted in the U.S. (Midwest)</p>

	<p>Design Comparative, two group approach</p>	<p>Measures</p> <ul style="list-style-type: none"> • Demographics • Two investigator designed instruments: <ul style="list-style-type: none"> • Perceived benefits of support group • Stress, social support and hope. 	
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Author	Purpose	Sample	Results
Bailey, et al., 2010	To describe family member perception of informational support, anxiety, satisfaction with care and their interrelationships.	A convenience sample of 29 subjects participated in the study. All were ≥ 18 years of age, able to read or speak English or French, in good health and patient was in ICU > 24 hours. Most subjects were children (44.8% then spouses (34.5%).	<ul style="list-style-type: none"> • Subjects reported informational support needs were met frequently (mean score 55.41 out of possible range of 20-80). • Mean anxiety scores were 46.58 for females and 39.80 for males, which were higher than the reference values for working adults. • Satisfaction with care could range from 24 to 96; mean score was 83.90. Least satisfied items were encouraged to participate in care to one's comfort, being able to see the doctor when desired and being encouraged to ask questions. • There was a significant correlation ($r=.741$, $p<.001$) between informational support and satisfaction with care. • No significant relationships were found between information support and anxiety or satisfaction with care and anxiety. <p>This study was conducted in Quebec, Canada.</p>
	<p>Design Cross-sectional descriptive correlational design</p>	<p>Measures</p> <ul style="list-style-type: none"> • Demographics • Modified Critical Care Family Needs Inventory to focus on informational support • State-Trait Anxiety Inventory • Self-report of satisfaction 	

Author	Purpose	Sample	Results
Lemiale, et al., 2010	To evaluate health-related quality of life in relatives of patients 90 days after ICU discharge or death.	284 family members who was the highest in the hierarchy for substitute decision making from 21 ICUs in France were enrolled in the study. 48% were spouses and 67% were females.	<ul style="list-style-type: none"> Physical component of the SF 36 was normal. Mental component score showed substantial impairments in emotional role, social functioning, vitality and mental health. 35.9% were taking anxiolytic or antidepressants and 8.4% were taking psychotropic drugs that were prescribed since discharge or death of the patient. <p>This study was conducted in France.</p>
	Design Multicenter observational study	Measures SF 36 was used to assess health-related quality of life 90 days after ICU discharge or death of the patient.	

Author	Purpose	Sample	Results
Moore, et al., 2012	To examine the effects of a family support coordinator to the ICU care team to improve family satisfaction and quality of care and communication to the family as perceived by the health care providers.	Used spouses, sons, daughters and rarely other relatives of ICU patients. Only one member participated from each family. Little data is presented on the family member; must is on the patient.	<ul style="list-style-type: none"> Family satisfaction improved from baseline with the intervention (using a family support coordinator) Most striking, satisfaction with physician communication, physician care, degree to which the staff helped understand treatments, and the degree to which the ICU team considered the family member needs improved. Nurse and physician perception of satisfaction were similar on satisfaction of interaction with families pre and post intervention. <p>This study was conducted in the U.S. (Northeast).</p>
	Design Quasi-experimental design	Measures Critical Care Family Assistance Program Family Satisfaction Survey (FSS)	

Author	Purpose	Sample	Results
Curtis, et al., 2012.	To test an intervention designed to improve palliative and end-of-life care in the ICU by improving communication among ICU team and family members of critically	Up to 6 family members of patients meeting inclusion criteria were invited to participate in the study. Randomization occurs based on the patient (in ICU > 24 hours, older than 18, mechanically	<ul style="list-style-type: none"> No results today have been presented. This is a status report of a clinical trial. Study started in 2009 and to date (2012) has enrolled 251 family

	ill patients.	ventilated at time of enrollment, having a organ failure assessment with a mortality \geq 50%, family member at the hospital.	members of 143 patients. <ul style="list-style-type: none"> Lessons learned about the study were shared (respondent bias in an unblended study, contamination of the control group, baseline palliative care knowledge and practice in the study hospitals).
	<p>Design</p> <p>Randomized trial of inter-professional, multi-faceted intervention of a communication facilitator.</p>	<p>Measures</p> <ul style="list-style-type: none"> Patient Health Questionnaire Post-Traumatic Stress Disorder Checklist Civilian Version Generalized Anxiety Disorder Length of stay & cost of care 	This study is being conducted in the U.S. (Washington state).

Author	Purpose	Sample	Results
Elizarrara-Rivas, et al., 2010.	To evaluate the psychological response of family primary caregivers of patients hospitalized in ICU with suspected A/H1N1 influenza.	35 family members of patients suspected of having A/H1N1 influenza admitted to the hospital were enrolled. 74.% were females, 43% were spouses and mean age was 32.	<ul style="list-style-type: none"> The majority reported no stress or depression (60% and 57% respectively). High levels of stress and depression occurred in only 3% of the sample. While 'low' scores for depression were reported; 43% of the sample had a score above the cut-off for high risk for clinical depression. The PSS scale had not been used previously with ICU family members. Perceived stress was associated with increasing age and non-spousal relationship. Depression was associated with increasing age, non-spousal relationship and being female. Death anxiety was associated with increasing age and university level education.
	<p>Design</p> <p>Descriptive, correlational</p>	<p>Measures</p> <ul style="list-style-type: none"> Perceived Stress Scale Center for Epidemiological Studies Depression Scale Death Anxiety Questionnaire 	

			This study was completed in Oxaca, Mexico.
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Author	Purpose	Sample	Results
Waters, C., 1999.	To compare African American, Hispanic, and White family members' perceptions of the professional support they expect from critical care nurses during a family member's critical illness.	A convenience sample of 90 subjects (30 from each cultural group) from 4 hospitals from all types of adult ICUs. Most White subjects were spouses, most Hispanic subjects were children and spouses represented the smallest group of African-American participants.	<ul style="list-style-type: none"> • Mean score for the PSQ were 2.99 for the total sample; 3.00 for African-American subjects, 3.01 for Hispanic subjects and 2.97 for White subjects. • The five highest mean scores were calling me at home about major changes, answering questions honestly, assuring me that my family member was receiving the best care, planning nursing procedures that are understandable and giving me information about my family member's condition in terms that I can understand at least once a shift. • There was consistency between cultural groups in terms of high mean scores. There was less consistency in low mean scores between cultural groups.
	Design Comparative study, between group design	Measures <ul style="list-style-type: none"> • Professional Support Questionnaire for Critical Care Nurses Working with Family Members (investigator developed) 	

Author	Purpose	Sample	Results
Garrouste-Orgeas, et al., 2012.	To assess the impact of an ICU diary on the psychological well-being of patients and families 3 and 12 months after ICU discharge.	143 patients participated in the study (48 in the prediary period, 49 in the diary period and 46 in the postdiary period). A single relative was chosen to participate in the study. Must speak French.	<ul style="list-style-type: none"> • The diary did not affect well-being of patients or families at ICU discharge or after 3 months. • At 12 months, the PTS-related symptoms significantly decreased for both the patient and the family. The decrease was larger for the family than the patient. <p>This study was conducted in Paris, France.</p>
	Design Prospective, single-center intervention study Intervention—an	Measures <ul style="list-style-type: none"> • Hospital Anxiety & Depression Scale • Peri-traumatic Dissociative Experiences 	

	elaborate patient, family and provider recorded daily diary for the duration of the ICU stay.	Questionnaire <ul style="list-style-type: none"> • Impact of Events Scale-R 	
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Author	Purpose	Sample	Results
Myhren, Ekegber & Stokland, 2011.	To study ICU patients' and relatives' satisfaction with communication with medical staff, perceived support, environmental strain, and psychological distress.	134 patient/relative dyads participated in the study. All had > 24 hour stay and were ≥ 18 years of age and spoke Norwegian. 129 nurses and 16 physicians participated (84% females)	<ul style="list-style-type: none"> • Patients were very satisfied with communication by the medical staff and environmental stress was less than expected by staff. • Relatives reported a high degree of psychological distress symptoms but less than what staff anticipated. • Relatives reported a higher degree of psychological distress than the patient (p <.0001). • Psychological distress of patients was impacted by unemployment status, more environmental strain and less hope for the situation to get better. • Mean absence from work by relatives was 19.7days and was associated with more psychological distress (p<.001). <p>This study was conducted in Norway.</p>
	Design Cross-sectional, descriptive study.	Measures <ul style="list-style-type: none"> • Satisfaction with ICU Experience (communication, perceived support, environmental strain and psychological distress) (investigator developed) • Hospital Anxiety & Depression Scale • Impact of Events Scale-R 	

Author	Purpose	Sample	Results
Paparrigopoulos, et al, 2006.	To evaluate the short term psychological impact of family members of ICU patients during their stay in the unit.	32 first-degree relatives of ICU patients from two hospitals participated in the study. Mean age of participants was 40.2, 50% (16) were females, 65% were spouses.	<ul style="list-style-type: none"> • 81% of relatives scored above 3 on the PTSDC and were likely to meet the criteria for PTSD. • Females reported more frequent and more intense emotional reactions than males in the first assessment. • Females exhibited significantly higher scores than males on all
	Design Descriptive, correlational	Measures <ul style="list-style-type: none"> • Posttraumatic Stress Disorder Checklist-Civilian (PTSDC) 	

		<ul style="list-style-type: none"> • Center for Epidemiological Studies Depression Scale (CEDDS) • Speilberger's State-Trait Anxiety Inventory • Impact of Event Scale 	<p>measures of psychopathology at time 2.</p> <ul style="list-style-type: none"> • Spouses exhibited higher levels of state anxiety than children ($p < .026$). • Trait anxiety was the most significant predictor of depressive reactions at both assessments and the single predictor of PTSD. <p>This study was conducted in Athens, Greece.</p>
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Author	Purpose	Sample	Results
Myhren, et al., 2004	To determine satisfaction in regard to information concerning and support and facilities for relatives in the ICU as compared to the staff's expectations on these issues.	68 subjects participated in the study (50 relatives of patients who survived and 18 relatives of patients who died in the ICU). Had to be ≥ 18 years, ≥ 24 hour ICU stay and all mechanically ventilated patients.	<ul style="list-style-type: none"> • Relatives were generally very satisfied with the information in the ICU. • Staff expected a lower degree of satisfaction than relatives ($p < .001$). • Relatives of non-survivors were most satisfied with accommodating nurses and physicians. • Support from nurses was significantly higher than support from physicians ($p < .001$) for survivors, as expected by nurses and physicians. • Relatives of non-survivors reported the same level of support from both nurses and physicians. • Average distress scores did not differ significantly between survivors and non-survivors but was lower than expected from staff. <p>This study was conducted in Oslo, Norway.</p>
	Design Prospective, descriptive	Measures <ul style="list-style-type: none"> • 78 investigator developed instrument to measure satisfaction with the ICU experience 	

Appendix B

Qualitative Studies Reviewed

Author	Purpose	Themes/Findings
Johansson, Hildingh & Fridlund, 2002.	To generate a theoretical model of how relatives/close friends cope when faced with having an adult next-of-kin/close friend admitted to critical care.	<ul style="list-style-type: none"> • Two main categories emerged from the data—“external resources and internal resources”—those who used social support from others and those that avoid social support from others • Four coping strategies emerged: including alleviating feelings, mastering feelings, recycling feelings and excluding feelings and used external support • Those “alleviating feelings” were individuals who either denied their feelings in order to cope initially or very slowly opened up and talked about their feelings • Those “mastering feelings” used their intellect to balance their feelings and cope. These persons also used external support. • Those “recycling feelings” were individuals who had to go over their feelings multiple times; they often reject social support as they felt it drained them. • Those “excluding feelings” were individuals that simply didn’t allow their feelings to interfere with their normal daily lives despite their loved one being in an ICU. They simply didn’t allow themselves to “feel.” They did not think they needed social support. <p>This study was conducted in Sweden.</p>
	<p style="text-align: center;">Design & Method</p> Grounded theory; using audiotaped interviews then open coding, axial coding and selective coding	
	<p style="text-align: center;">Sample</p> 18 adult relatives or friends (11 women & 7 men) of patients with life threatening but no imminent death were used	

Author	Purpose	Themes/Findings
Jamerson, et al., 1996	To describe the experiences of families with a relative in an ICU to elicit ways to better meet families’ needs.	<ul style="list-style-type: none"> • Four themes emerged from the data and participants were noted to go through these four phases: hovering, information seeking, tracking and garnering of resources. • Hovering is the initial sense of confusion where the individual is trying to determine the diagnosis or prognosis. • Information seeking is the active process of gathering information. Information seeking assists them from moving from hovering if the information is made available. • Tracking is the process of monitoring the loved one’s care and the participant’s satisfaction with the care • Garnering resources is the final process experienced by participants; such as getting a pillow or blanket for themselves or having a friend listen to their stories. <p>This study was conducted in the United States.</p>
	<p style="text-align: center;">Design & Method</p> Retrospective, descriptive and qualitative. Focus group and individual unstructured interviews were used.	
	<p style="text-align: center;">Sample</p> 18 women and 2 men with relatives in a surgical trauma ICU. Participants were either related or significant others.	

Author	Purpose	Themes/Findings
Patel, C.T.C., 1996	To explore how to inspire hope in families of the critically ill.	<ul style="list-style-type: none"> • Eight hope-inspiring strategies emerged from the data; these were: spiritual/religious activities, support from significant others, positive relationships with caregivers, devotion, optimistic attitude, physical presence at the bedside, talking to others and distraction mechanisms. • Three serendipitous findings also emerged including spousal appraisal of the ICU experience, hope objects of spouses of critically ill patients, and preconceived ideas affecting the spouse's hope states. • How the spouse appraises the entire situation impacted what they hoped for. Hope objects, or what they hoped for, varied between participants and how one appraised the patient's prognosis impacted the spouse's hope.
	Design & Method Qualitative exploratory design using modified open-ended questions	
	Sample 20 spouses (9 males & 11 females) of first-time critically ill adults in a medical cardiac ICU after 24 hours of admission.	
		This study was conducted in the United States.

Author	Purpose	Themes/Findings
Plowfield, L.A., 1999	To examine the waiting experiences of families following a sudden, unexpected neurological ICU hospitalization.	<ul style="list-style-type: none"> • Two broad themes emerged from the data of this sample while waiting following a neurological crisis—uncertainty and searching for meaning. • Uncertainty was reported as a perceptual condition of “not knowing” and led to altered perceptions of time, confusion regarding treatment details, an inability to envision the future without the patient, and a loss of situational control. • Two subthemes of loss of situation control were an absence of power and a dependence upon strangers. • Searching for Meaning was identified as trying to find a reason for the crisis, make sense of the situation and to find a purpose in their experience while waiting. Families had to search for meaning in the hospital rules, hospital politics, and attempt to master their environment. • Families did refer to the concept of hope as one way of coping with the situation. • Waiting is hard on families; they need to visit the patient and they need information.
	Design & Method Phenomenological approach using in depth interviewing, participant observation and field notes.	
	Sample 12 families participated in the study with an average of 3 individuals per family with one person serving as informant for the study. All patients had never been in an ICU and had no chronic neurological conditions	
		This study was conducted in the United States.

Author	Purpose	Themes/Findings
Agard, A.S. & Harder, I., 2006.	To explore and describe the experiences of relatives of critically ill patients in an adult ICU.	<ul style="list-style-type: none"> • Three dominant coping strategies emerged from the data and included: enduring uncertainty, putting self-aside and forming personal cues. • All participants noted that enduring the uncertainty

	Design & Method Grounded theory; using audiotaped interviews	<p>was stressful and they need information; however, information did not always alleviate the anxiety. The ups and downs of the patient in the ICU, along with the environment, created a prolonged sense of enduring uncertainty.</p> <ul style="list-style-type: none"> • Putting self aside was another major coping strategy that emerged. They didn't always know or understand their role in the ICU and they tried to keep their own spirits up as to not worry the patient. Many focused on the present and avoided future thinking. • Picking up their own personal cues was also found to be important—even if the healthcare team gave them information, they need to verify it within themselves. • Participants were noted to “may not always allow themselves to show their anxiety, sorrow, or pain.” <p>This study was conducted in Denmark.</p>
	Sample 4 spouses and 3 parents of critically ill patients were interviewed.	

Author	Purpose	Themes/Findings
Chiang, V.C.L., 2011.	To conduct a theoretical analysis of the critical ill patients' perception of the impact of information support and care from their main family carer in the ICU and afterwards.	<ul style="list-style-type: none"> • Three themes emerged from the dyadic interviews and were being there with, coping and self-relying. • Being there with was reported by patients as important that family carers be present to provide a sense of support, calming influence and encouragement. It was likewise important to family carers to be there with the patient. • Coping was viewed as a day-to-day event and multiple coping strategies were used by participants; as well as learning to adjust at the same time. • During the ICU stay, the emotional and physical dependence of the patient on the health care providers existed, but it also existed on the family carers. This was noted to slowly decline with more self-relying over time. Patients and spouses so themselves as “being there for each other” as an important dimension of the ICU stay and discharge. <p>This study was completed in Hong Kong, China.</p>
	Design & Method Grounded theory; using audiotaped interviews in the ICU and then 3 months after hospital discharge	
	Sample 16 interviews of patient-carer dyads were completed.	

Author	Purpose	Themes/Findings
Engstrom, A., & Soderberg, S. 2004.	To describe partners' experiences when their spouses received care in the ICU.	<ul style="list-style-type: none"> • Three major themes emerged from the data; being present, putting oneself in second place and living in uncertainty • Three categories emerged from “being present” and included seeing the critically ill person, wishing to be near them, and showing respect to them. • Two categories emerged from “putting oneself in second place” and included having someone near and living a changed everyday life.
	Design & Method Phenomenological using semi-structured interviews	

	<p>Sample 7 partners (1 man and 6 woman) with a family member in an ICU for > 24 hours.</p>	<ul style="list-style-type: none"> • Three categories emerged from “living in uncertainty” and included being sad and afraid, knowing and not knowing, and alternating between hope and despair. • Lastly, the authors remind us that the whole family is influenced when a family member is in an ICU; not just the ICU patient. <p>This study was conducted in Sweden.</p>
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Author	Purpose	Themes/Findings
Cypress, B.S., 211.	<p>To describe and understand the lived intensive care unit experience of nurses, patients, and family members during critical illness.</p> <p>Design & Method Phenomenological approach using Merleau-Pontian perspective and in-depth interviews.</p> <p>Sample 5 nurses, 5 patients and 5 family member participants were included in the study.</p>	<ul style="list-style-type: none"> • Five common themes among the sub-samples were found to be important; physical care and comfort, physiological care, the family as a unit, psychosocial support and transformation. The nurses, the patients and the family members all found these themes to be important. Nurses were reported as “becoming a part of the family” by the patient and family member. Additionally, all subgroups found the ICU experience to be transformative to them. • A nurse specific theme was that of advocacy. Nurses felt a duty to advocate for the patient and family member. • A patient specific theme was that of uncertainty. Patients reported a feeling of not knowing their outcomes. • A family member specific theme was the importance of confidence in the nurse and health care team. <p>This study was conducted in the United State (New York).</p>

Author	Purpose	Themes/Findings
Rose, P.A., 1995.	<p>To explore and describe the meanings that families ascribe to the ICU experience.</p> <p>Design & Method Phenomenological study using unstructured interviews</p> <p>Sample 18 family members from 8 families were in the study</p>	<ul style="list-style-type: none"> • Five categories of meaning emerged from the data and included it could either way, everything is good, going upstairs, like living on a roller-coast or there is no hope. • All 5 meanings changed over time based on the cue the family member received from the patient, the staff or the setting. • All families started on with “it could go either way” but based on cues; two different trajectories emerged—going either the way of “everything is good” and the patient is “going upstairs” or “living on a roller-coaster” to finally “there is no hope.” <p>This study was conducted in Canada.</p>

Author	Purpose	Themes/Findings
Olsen, K.D., Dysvik, E., & Hansen, B.S., 2009.	To investigate what the presence of family members meant to patients in ICUs.	<ul style="list-style-type: none"> • Many participants had little or no immediate memory of the ICU and over half had nightmares or hallucinations. Data were collected after transfer out of the ICU (a range of 3-14 days following ICU discharge). • Participants describe the presence of families as important support (even though they couldn't always remember them). • When participants were conscious they found it relaxing to have a family member nearby. • While intubated, patients wanted family members to be present but not communicate due to frustrations with not being able to talk. • Participants expressed concern about family members seeing them in such dire situations. • Some participants were ambivalent about visiting while they were unconscious; particularly an ex-wife visitor. • Duration of visitation was not deemed important, but flexibility was important to participants.
	Design & Method Qualitative approach with semi-structured interviews	
	Sample 11 ICU patients (4 women and 7 men) were interviewed to determine the meaning of family members' presence during their ICU stay.	

Author	Purpose	Themes/Findings
Johansson, I., Frielund, B. & Hildingh, C., 2005	To generate a theoretical understanding of what relatives experience as supportive when faced with an adult next-of-kin admitted to critical care.	<ul style="list-style-type: none"> • Three themes emerged as strategies that were supportive to the family member in this study and included "to trust oneself," "to encounter charity—to be supported by others as a person," and "to encounter professionalism—to be supported by others as a relative." • Authors noted that what the relatives perceived as supportive was based on the situation in the ICU. If they were given grim news, what was supportive was different than if the news was more positive. • To trust oneself was shown to be important to participants as supportive in their experience. • To be supported by others as a person, a unique person, was also shown to be an important supportive strategy • To be viewed as a relative and given support by health care providers was also deemed important. <p>This study was conducted in Sweden.</p>
	Design & Method Grounded theory; using interviews	
	Sample 29 adult relatives or close friends with a loved one in an ICU; relatives of dying or deceased patients were excluded.	

Author	Purpose	Themes/Findings
Kean, S., 2010.	To explore families' experiences with critical illness in ICU and nurses' perceptions of families.	<ul style="list-style-type: none"> • In all cases, these families experienced a loved one's brain injury with uncertain outcomes. • Two major themes emerged and included ambiguous loss and mapping the future.

	<p>Design & Method Ground theory using focus group methods</p>	<ul style="list-style-type: none"> • Ambiguous loss was evident in all families as the extent of the brain injury and the final functional/cognitive outcomes was unknown. One family expressed that their family was physically present, but not psychosocially and therefore loss was evident. • Mapping the future is also challenging based on the varying degree of recovery of the brain injured patient. Each family member had a different map to the future as individuals but also a collective map of the family for the future.
	<p>Sample 9 family interviews (12 adults and 12 children/young people) with a relative suffering a brain injury</p>	
		<p>This study was conducted in the U.K.</p>

Author	Purpose	Themes/Findings
Sodersrom, I.M.K, et al., 2009.	To describe and interpret the family adaptation during ICU hospitalization and up to 18 months after discharge.	<ul style="list-style-type: none"> • Three themes emerged from the data including “striving for endurance,” “striving for consolation,” and “striving to rebuild life under new conditions.” • Striving for the endurance to cope with chaos, uncertainty, perception of reality and time distortions requires a great deal of energy on the part of the family members. This was a recurring theme. • Striving for consolation was an important theme for others—to be acknowledged that what they are experiencing is real and scary and troubling was reported. Some participants were silent and yet suffered immensely. • After the patient returns home, new conditions exist and families must strive to rebuild life with these new circumstances particularly if the disabled family member cannot resume their former activities and position in the family.
	<p>Design & Method Qualitative design with hermeneutical analysis and paradigm cases constructed.</p>	
	<p>Sample 31 family members of 8 families were included in the study.</p>	
		<p>This study was conducted in Sweden.</p>

Appendix C

Verbal Script for Subject Recruitment

My name is _____ (researcher or assistant). We are conducting a study to better understand how family members cope with a loved one undergoing cardiac surgery. Additionally, we would like to find out what contributes to your coping and how coping changes over time. The title of the study is "Coping and Coping Outcomes of Family Members of Adult Cardiac Surgery Patients in the ICU and Prior to Discharge." It is being conducted by Michael Williams, who is a Registered Nurse and doctoral candidate at the University of Michigan School of Nursing.

If you agree to participate in this study, you will be asked to complete a set of questionnaires at three times; today, the day of surgery sometime after the surgery, and the day before or day of discharge from the hospital. All of your information will remain confidential and anonymous. You may choose not to participate in this study or withdraw at any time without any repercussions. Please be assured that your loved one's care will not be affected in any way whatsoever if you choose not to participate.

Would you be potentially interested? (If potential subjects request not to participate further, than them for their time and wish them well. If the potential subject agrees to continue, continue with verbal script).

Please read over the informed consent form. The consent form explains the research protocol in detail. If you have any questions as you review the consent form, I will be available to answer them. As a family member, you will be asked to complete a series of questionnaires at three separate times. As a patient, your consent is needed to retrieve information from your medical record on any untoward event and/or complication you experienced in the operating room or before you leave the hospital. If after reading the consent form, you choose not to participate in this study, simply turn in the form without completing it. Otherwise, please sign the consent form and return it to me. You will be given a copy of the consent form for your records. After you return the consent form, you will be given the time #1 questionnaires to complete. Please complete the questionnaires and I will remain nearby and available by telephone to retrieve the completed forms. Thank you so much for your time and willingness to participate in the study.

Appendix D

Family Member Demographic Data Tool

Family Member Demographic Data Form

What is your relationship to patient?

- Spouse Partner Son Daughter Grandson Granddaughter
 Other (please specify): _____

How many years have you known the patient? _____ (years)

What is your age? _____ (years) **What is your gender?** Male Female

What is your ethnic/racial background?

- African-American/Black Asian/Pacific Islander Hispanic
 White/Caucasian Other (please specify): _____

Are you currently working? Yes No Retired

If yes, do you work? Full-time Part-time

What is (or was) your occupation? _____

What is the highest level of education you have completed?

- Less than high school
- High school
- College
- Graduate school

Have you ever had a family member in an ICU previously? Yes No

Please indicate which one of the following best describes how you view yourself at this time: *During the ICU time period*, I view my primary role as:

- a visitor observing to assure my loved one is recovering as expected. I don't expect to do physical care but rather to provide encouragement and emotional support.
- a participant in the care of my loved one in the ICU. I foresee myself assisting the nurses with the physical care of my loved one to the extent of my skills.
- a recipient of care, along with my loved one. I expect that I will need significant emotional support from the ICU nurses to cope with this stress.
- a manager of care since my loved one will be unable to do so. I anticipate being the primary caregiver at home and expect to begin this role in the ICU.

Appendix E

Family APGAR

Family APGAR

The following questions have been developed to help us better understand you and your family. You should feel free to ask questions about any item in the questionnaire. Answer each question as “almost always,” “some of the time,” or “hardly ever.” Add any additional comments you want. Family is defined as the individual(s) with whom you usually live.

For each question, check only one box.

	Almost always 2	Some of the time 1	Hardly ever 0
I am satisfied with the help that I receive from members of my family when something is troubling me. Comment: _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am satisfied with the way members of my family discuss items of common interest and share problem-solving with me. Comment: _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I find that members of my family accept my wishes to take on new activities or make changes. Comment: _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am satisfied with the way members of my family express affection and respond to my feelings, such as anger, sorrow, and love. Comment: _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am satisfied with the way members of my family and I share time together. Comment: _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Appendix F

MOS-Social Support Survey

MOS SOCIAL SUPPORT SURVEY

People sometimes look to others for companionship, assistance, or other types of support. How often is each of the following kinds of support available to you if you need it. Circle one number on each line.

	<u>None of the time</u>	<u>A little of the time</u>	<u>Some of the time</u>	<u>Most of the time</u>	<u>All of the time</u>
1. <u>Someone you can count on to listen to you when you need to talk.</u>	<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>	<u>5</u>
2. <u>Someone to give you information to help you understand a situation.</u>	<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>	<u>5</u>
3. <u>Someone to confide in or talk to about yourself or your problems.</u>	<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>	<u>5</u>
4. <u>Someone whose advice you really want.</u>	<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>	<u>5</u>
5. <u>Someone to share your most private worries and fears with.</u>	<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>	<u>5</u>
6. <u>Someone to turn to for suggestions about how to deal with a personal problem.</u>	<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>	<u>5</u>
7. <u>Someone to help you if you were confined to bed.</u>	<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>	<u>5</u>
8. <u>Someone to take you to the doctor if you need it.</u>	<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>	<u>5</u>
9. <u>Someone to prepare your meals if you were unable to do it yourself</u>	<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>	<u>5</u>
10. <u>Someone to help with daily chores if you were sick.</u>	<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>	<u>5</u>
11. <u>Someone who shows you love and affection.</u>	<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>	<u>5</u>
12. <u>Someone to love and make you feel wanted.</u>	<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>	<u>5</u>

	<u>None of the time</u>	<u>A little of the time</u>	<u>Some of the time</u>	<u>Most of the time</u>	<u>All of the time</u>
13. <u>Someone who hugs you.</u>	<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>	<u>5</u>
14. <u>Someone to have a good time with.</u>	<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>	<u>5</u>
15. <u>Someone to get together with for relaxation.</u>	<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>	<u>5</u>
16. <u>Someone to do something enjoyable with.</u>	<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>	<u>5</u>
17. <u>Someone to do things with to help you get your mind off things.</u>	<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>	<u>5</u>

Appendix G

APPRAISAL OF CAREGIVING

Directions: Each of the statements below represents a feeling, belief, or attitude that someone like yourself might have about the illness of a family member and about your role of providing the care and support needed by your family member. We refer to this care and support as “caregiving.” We are aware that your feelings, as a caregiver, about the illness and treatment may fluctuate and change from day to day and week to week.

Please read the following statements. We would like to know how true each statement is of **your** own thoughts and feelings about caregiving. There are no right or wrong answers. Circle the answer that is closest to how you have been feeling over the past three days including today.

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
1. This situation has made me feel more appreciated by others.	1	2	3	4	5
2. This situation is not very stressful for me.	1	2	3	4	5
3. I feel things are going to get worse for me.	1	2	3	4	5
4. I haven't been doing very well since this most recent situation started	1	2	3	4	5
5. This situation does not affect my independence.	1	2	3	4	5
6. I feel a sense of loss at not being able to meet all my responsibilities.	1	2	3	4	5
7. I worry that I'll have to give up a lot of things in the future	1	2	3	4	5
8. My relationships with friends and family are not affected by this situation.	1	2	3	4	5
9. This situation does not affect how I feel about myself.	1	2	3	4	5
10. I'm afraid that in the future I won't have the energy and endurance I have now.	1	2	3	4	5
11. I've grown a lot since this most recent situation began.	1	2	3	4	5

	Strongly disagree	Disagree	Neutral	Agree	Strongly Disagree
12. It seems like there is nothing more I can do that makes a difference in how the person needing my care feels.	1	2	3	4	5
13. My responsibilities will continue to be what they've always been.	1	2	3	4	5
14. This situation does not affect my lifestyle.	1	2	3	4	5
15. This situation threatens to overwhelm me.	1	2	3	4	5
16. My relationships with others have become more meaningful since this situation began.	1	2	3	4	5
17. I'm afraid my own physical health will begin to suffer.	1	2	3	4	5
18. I worry that in the future I will be less able to do the things I like to do.	1	2	3	4	5
19. This situation does not affect my relationship with the person needing my care.	1	2	3	4	5
20. I believe good things will come my way because of how I am handling this difficult situation.	1	2	3	4	5
21. I worry that in the future I will not be able to help the person needing my care.	1	2	3	4	5
22. I worry that my emotional health will suffer.	1	2	3	4	5
23. Each day has become more meaningful since this most recent situation started.	1	2	3	4	5
24. I'm concerned that this situation will cause financial hardship for me in the future	1	2	3	4	5

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
25. I've discovered resources I never knew I had.	1	2	3	4	5
26. I'm not sure I will be able to handle this situation in the future.	1	2	3	4	5
27. This situation does not affect my emotional state.	1	2	3	4	5

Appendix H

Permission to use ACR Instrument

Permission to use the ACR Instrument developed by M. Oberst was granted by Dr. Laurel Northouse, dissertation committee member on Dr. Oerst's behalf.

Appendix I

UNCERTAINTY IN ILLNESS--FAMILY

Directions: Please read each statement. Take your time and think about what each statement says. Then circle under the column that most closely measures how you are feeling about your family member **TODAY**. If you agree with a statement, then you would circle either “strongly agree” or “agree.” If you disagree with a statement, then you would circle either “strongly disagree” or “disagree.” If you are undecided about how you feel about your family member, then circle “undecided” for that statement. Please respond to every statement.

	Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
1. I don't know what is wrong with him/her.	1	2	3	4	5
2. I have a lot of questions without answers.	1	2	3	4	5
3. I am unsure if his/her illness is getting better or worse.	1	2	3	4	5
4. It is unclear how bad his/her symptoms will be.	1	2	3	4	5
5. The explanations they give about him/her seem hazy to me.	1	2	3	4	5
6. The purpose of his/her care is clear to me.	1	2	3	4	5
7. When he/she has symptoms, I know what this means about his/her condition.	1	2	3	4	5
8. His/her symptoms continue to change unpredictably.	1	2	3	4	5
9. I understand everything explained to me.	1	2	3	4	5
10. The doctors say things to me that could have many meanings.	1	2	3	4	5
11. I can predict how long his/her illness will last.	1	2	3	4	5
12. His/her care is too complex to figure out.	1	2	3	4	5
13. It is difficult to know if the care or medications he/she is getting are helping.	1	2	3	4	5

	Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
14. Because of the unpredictability of his/her illness, I cannot plan for the future.	1	2	3	4	5
15. The course of his/her condition keeps changing. He/she has good and bad days.	1	2	3	4	5
16. I have been given many differing opinions about what is wrong with him/her.	1	2	3	4	5
17. It is not clear what is going to happen to him/her.	1	2	3	4	5
18. I usually know if he/she is going to have a good or bad day.	1	2	3	4	5
19. The results of his/her tests are inconsistent.	1	2	3	4	5
20. The effectiveness of the care is undetermined.	1	2	3	4	5
21. I can generally predict the course of his/her condition.	1	2	3	4	5
22. Because of the condition, what he/she can do and cannot do keeps changing.	1	2	3	4	5
23. I'm certain they will not find anything else wrong with him/her.	1	2	3	4	5
24. The treatment he/she is receiving has a known likelihood of success.	1	2	3	4	5
25. They have not given him/her a specific diagnosis.	1	2	3	4	5
26. His/her physical distress is predictable. I know when it is going to get better or worse.	1	2	3	4	5
27. His/her diagnosis is definite and will not change.	1	2	3	4	5
28. The seriousness of his/her condition has been determined.	1	2	3	4	5
29. The doctors and nurses use everyday language so I can understand what they are saying.	1	2	3	4	5

Appendix J

Permission to Use the MUIS-Family

Permission to use the MUIS-Family was granted from the office of Dr. Merle Mishel, PhD, RN, FAAN, University of North Carolina.

Appendix K

Brief Cope Instrument

BRIEF COPE

These items deal with ways you've been coping with the stress in your life since you found out your loved one was going to have to have this operation. There are many ways to try to deal with problems. These items ask what you've been doing to cope with this one. Obviously, different people deal with things in different ways, but I'm interested in how you've tried to deal with it. Each item says something about a particular way of coping. I want to know to how much or how frequently you've been doing what the item says. Don't answer on the basis of whether it seems to be working or not—just whether or not you're doing it. Use these response choices. Try to rate each item separately in your mind from the others. Make your answers as true FOR YOU as you can.

	I haven't been doing this at all	I have been doing a little bit	I've been doing this a medium amount	I've been doing this a lot
1. I've been turning to work or other activities to take my mind off things.	1	2	3	4
2. I've been concentrating my efforts on doing something about the situation I'm in.	1	2	3	4
3. I've been saying to myself "this isn't real."	1	2	3	4
4. I've been using alcohol or other drugs to make myself feel better	1	2	3	4
5. I've been getting emotional support from others	1	2	3	4
7. I've been giving up trying to deal with it.	1	2	3	4
7. I've been taking action to try and make the situation better	1	2	3	4
9. I've been refusing to believe that it has happened.	1	2	3	4
9. I've been saying things to let my unpleasant feelings escape.	1	2	3	4
10. I've been getting help and advice from other people.	1	2	3	4

	I haven't been doing this at all	I have been doing a little bit	I've been doing this a medium amount	I've been doing this a lot
11. I've been using alcohol or other drugs to help me get through it.	1	2	3	4
12. I've been trying to see it in a different light, to make it seem more positive.	1	2	3	4
13. I've been criticizing myself.	1	2	3	4
14. I've been trying to come up with a strategy about what to do.	1	2	3	4
15. I've been getting comfort and understanding from someone.	1	2	3	4
16. I've been giving up the attempt to cope.	1	2	3	4
17. I've been looking for something good in what is happening.	1	2	3	4
18. I've been making jokes about it.	1	2	3	4
19. I've been doing something to think about it less, such as going to the movies, watching TV, reading, daydreaming, sleeping or shopping.	1	2	3	4
20. I've been accepting the reality of the fact that it has happened.	1	2	3	4
21. I've been expressing my negative feelings.	1	2	3	4
22. I've been trying to find comfort in my religion or spiritual beliefs.	1	2	3	4
23. I've been trying to get advice or help from other people about what to do.	1	2	3	4

	I haven't been doing this at all	I have been doing a little bit	I've been doing this a medium amount	I've been doing this a lot
24. I've been learning to live with it	1	2	3	4
25. I've been thinking hard about what steps to take.	1	2	3	4
26. I've been blaming myself for things that happened.	1	2	3	4
27. I've been praying or meditating.	1	2	3	4
28. I've been making fun of the situation.	1	2	3	4

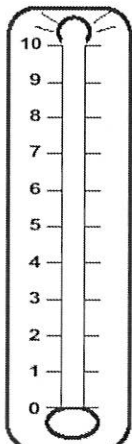
Appendix L

Permission to Use BSI-18

150 BSI-18 instruments were purchased from Pearson, Inc. for this study.

Appendix M

The Distress Thermometer

<p>NCCN[®] Practice Guidelines in Oncology – v.1.2010</p>	<p>Distress Management</p>	<p>Guidelines Index Distress Management TOC Discussion References</p>			
<p>SCREENING TOOLS FOR MEASURING DISTRESS</p>					
<p>Instructions: First please circle the number (0-10) that best describes how much distress you have been experiencing in the past week including today.</p>					
<p>Extreme distress</p>		<p>No distress</p>			
<p>Second, please indicate if any of the following has been a problem for you in the past week including today. Be sure to check YES or NO for each.</p>					
<table style="width: 100%; border: none;"> <tr> <td style="width: 33%; vertical-align: top;"> <p>YES NO <u>Practical Problems</u></p> <p><input type="checkbox"/> <input type="checkbox"/> Child care</p> <p><input type="checkbox"/> <input type="checkbox"/> Housing</p> <p><input type="checkbox"/> <input type="checkbox"/> Insurance/financial</p> <p><input type="checkbox"/> <input type="checkbox"/> Transportation</p> <p><input type="checkbox"/> <input type="checkbox"/> Work/school</p> <p style="text-align: center;"><u>Family Problems</u></p> <p><input type="checkbox"/> <input type="checkbox"/> Dealing with children</p> <p><input type="checkbox"/> <input type="checkbox"/> Dealing with partner</p> <p><input type="checkbox"/> <input type="checkbox"/> Ability to have children</p> <p style="text-align: center;"><u>Emotional Problems</u></p> <p><input type="checkbox"/> <input type="checkbox"/> Depression</p> <p><input type="checkbox"/> <input type="checkbox"/> Fears</p> <p><input type="checkbox"/> <input type="checkbox"/> Nervousness</p> <p><input type="checkbox"/> <input type="checkbox"/> Sadness</p> <p><input type="checkbox"/> <input type="checkbox"/> Worry</p> <p><input type="checkbox"/> <input type="checkbox"/> Loss of interest in usual activities</p> <p><input type="checkbox"/> <input type="checkbox"/> <u>Spiritual/religious concerns</u></p> </td> <td style="width: 33%; vertical-align: top;"> <p>YES NO <u>Physical Problems</u></p> <p><input type="checkbox"/> <input type="checkbox"/> Appearance</p> <p><input type="checkbox"/> <input type="checkbox"/> Bathing/dressing</p> <p><input type="checkbox"/> <input type="checkbox"/> Breathing</p> <p><input type="checkbox"/> <input type="checkbox"/> Changes in urination</p> <p><input type="checkbox"/> <input type="checkbox"/> Constipation</p> <p><input type="checkbox"/> <input type="checkbox"/> Diarrhea</p> <p><input type="checkbox"/> <input type="checkbox"/> Eating</p> <p><input type="checkbox"/> <input type="checkbox"/> Fatigue</p> <p><input type="checkbox"/> <input type="checkbox"/> Feeling Swollen</p> <p><input type="checkbox"/> <input type="checkbox"/> Fevers</p> <p><input type="checkbox"/> <input type="checkbox"/> Getting around</p> <p><input type="checkbox"/> <input type="checkbox"/> Indigestion</p> <p><input type="checkbox"/> <input type="checkbox"/> Memory/concentration</p> <p><input type="checkbox"/> <input type="checkbox"/> Mouth sores</p> <p><input type="checkbox"/> <input type="checkbox"/> Nausea</p> <p><input type="checkbox"/> <input type="checkbox"/> Nose dry/congested</p> <p><input type="checkbox"/> <input type="checkbox"/> Pain</p> <p><input type="checkbox"/> <input type="checkbox"/> Sexual</p> <p><input type="checkbox"/> <input type="checkbox"/> Skin dry/itchy</p> <p><input type="checkbox"/> <input type="checkbox"/> Sleep</p> <p><input type="checkbox"/> <input type="checkbox"/> Tingling in hands/feet</p> </td> <td style="width: 33%;"></td> </tr> </table>			<p>YES NO <u>Practical Problems</u></p> <p><input type="checkbox"/> <input type="checkbox"/> Child care</p> <p><input type="checkbox"/> <input type="checkbox"/> Housing</p> <p><input type="checkbox"/> <input type="checkbox"/> Insurance/financial</p> <p><input type="checkbox"/> <input type="checkbox"/> Transportation</p> <p><input type="checkbox"/> <input type="checkbox"/> Work/school</p> <p style="text-align: center;"><u>Family Problems</u></p> <p><input type="checkbox"/> <input type="checkbox"/> Dealing with children</p> <p><input type="checkbox"/> <input type="checkbox"/> Dealing with partner</p> <p><input type="checkbox"/> <input type="checkbox"/> Ability to have children</p> <p style="text-align: center;"><u>Emotional Problems</u></p> <p><input type="checkbox"/> <input type="checkbox"/> Depression</p> <p><input type="checkbox"/> <input type="checkbox"/> Fears</p> <p><input type="checkbox"/> <input type="checkbox"/> Nervousness</p> <p><input type="checkbox"/> <input type="checkbox"/> Sadness</p> <p><input type="checkbox"/> <input type="checkbox"/> Worry</p> <p><input type="checkbox"/> <input type="checkbox"/> Loss of interest in usual activities</p> <p><input type="checkbox"/> <input type="checkbox"/> <u>Spiritual/religious concerns</u></p>	<p>YES NO <u>Physical Problems</u></p> <p><input type="checkbox"/> <input type="checkbox"/> Appearance</p> <p><input type="checkbox"/> <input type="checkbox"/> Bathing/dressing</p> <p><input type="checkbox"/> <input type="checkbox"/> Breathing</p> <p><input type="checkbox"/> <input type="checkbox"/> Changes in urination</p> <p><input type="checkbox"/> <input type="checkbox"/> Constipation</p> <p><input type="checkbox"/> <input type="checkbox"/> Diarrhea</p> <p><input type="checkbox"/> <input type="checkbox"/> Eating</p> <p><input type="checkbox"/> <input type="checkbox"/> Fatigue</p> <p><input type="checkbox"/> <input type="checkbox"/> Feeling Swollen</p> <p><input type="checkbox"/> <input type="checkbox"/> Fevers</p> <p><input type="checkbox"/> <input type="checkbox"/> Getting around</p> <p><input type="checkbox"/> <input type="checkbox"/> Indigestion</p> <p><input type="checkbox"/> <input type="checkbox"/> Memory/concentration</p> <p><input type="checkbox"/> <input type="checkbox"/> Mouth sores</p> <p><input type="checkbox"/> <input type="checkbox"/> Nausea</p> <p><input type="checkbox"/> <input type="checkbox"/> Nose dry/congested</p> <p><input type="checkbox"/> <input type="checkbox"/> Pain</p> <p><input type="checkbox"/> <input type="checkbox"/> Sexual</p> <p><input type="checkbox"/> <input type="checkbox"/> Skin dry/itchy</p> <p><input type="checkbox"/> <input type="checkbox"/> Sleep</p> <p><input type="checkbox"/> <input type="checkbox"/> Tingling in hands/feet</p>	
<p>YES NO <u>Practical Problems</u></p> <p><input type="checkbox"/> <input type="checkbox"/> Child care</p> <p><input type="checkbox"/> <input type="checkbox"/> Housing</p> <p><input type="checkbox"/> <input type="checkbox"/> Insurance/financial</p> <p><input type="checkbox"/> <input type="checkbox"/> Transportation</p> <p><input type="checkbox"/> <input type="checkbox"/> Work/school</p> <p style="text-align: center;"><u>Family Problems</u></p> <p><input type="checkbox"/> <input type="checkbox"/> Dealing with children</p> <p><input type="checkbox"/> <input type="checkbox"/> Dealing with partner</p> <p><input type="checkbox"/> <input type="checkbox"/> Ability to have children</p> <p style="text-align: center;"><u>Emotional Problems</u></p> <p><input type="checkbox"/> <input type="checkbox"/> Depression</p> <p><input type="checkbox"/> <input type="checkbox"/> Fears</p> <p><input type="checkbox"/> <input type="checkbox"/> Nervousness</p> <p><input type="checkbox"/> <input type="checkbox"/> Sadness</p> <p><input type="checkbox"/> <input type="checkbox"/> Worry</p> <p><input type="checkbox"/> <input type="checkbox"/> Loss of interest in usual activities</p> <p><input type="checkbox"/> <input type="checkbox"/> <u>Spiritual/religious concerns</u></p>	<p>YES NO <u>Physical Problems</u></p> <p><input type="checkbox"/> <input type="checkbox"/> Appearance</p> <p><input type="checkbox"/> <input type="checkbox"/> Bathing/dressing</p> <p><input type="checkbox"/> <input type="checkbox"/> Breathing</p> <p><input type="checkbox"/> <input type="checkbox"/> Changes in urination</p> <p><input type="checkbox"/> <input type="checkbox"/> Constipation</p> <p><input type="checkbox"/> <input type="checkbox"/> Diarrhea</p> <p><input type="checkbox"/> <input type="checkbox"/> Eating</p> <p><input type="checkbox"/> <input type="checkbox"/> Fatigue</p> <p><input type="checkbox"/> <input type="checkbox"/> Feeling Swollen</p> <p><input type="checkbox"/> <input type="checkbox"/> Fevers</p> <p><input type="checkbox"/> <input type="checkbox"/> Getting around</p> <p><input type="checkbox"/> <input type="checkbox"/> Indigestion</p> <p><input type="checkbox"/> <input type="checkbox"/> Memory/concentration</p> <p><input type="checkbox"/> <input type="checkbox"/> Mouth sores</p> <p><input type="checkbox"/> <input type="checkbox"/> Nausea</p> <p><input type="checkbox"/> <input type="checkbox"/> Nose dry/congested</p> <p><input type="checkbox"/> <input type="checkbox"/> Pain</p> <p><input type="checkbox"/> <input type="checkbox"/> Sexual</p> <p><input type="checkbox"/> <input type="checkbox"/> Skin dry/itchy</p> <p><input type="checkbox"/> <input type="checkbox"/> Sleep</p> <p><input type="checkbox"/> <input type="checkbox"/> Tingling in hands/feet</p>				
<p>Other Problems: _____</p>					
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Appendix N

Patient Data Form

FROM PATIENT RECORD:

Type of Surgery: _____

Length of Surgery: _____

Complications During Surgery:

Arrhythmia Hemorrhage Intraoperative MI Severe electrolyte imbalance
 Other: _____

Immediate Postoperative Complications:

Acute renal failure Arrhythmia Hemorrhage Postoperative MI
 Severe electrolyte imbalance Other: _____

Extraordinary Measures:

Cardiopulmonary Arrest Hemorrhage Insertion of IABP Insertion of VAD
 Lethal arrhythmia treatment Other: _____

Did the patient have any of the following postoperative complications (including in the ICU)?

<input type="checkbox"/> Atrial fibrillation	<input type="checkbox"/> Cardiac arrest	<input type="checkbox"/> CVA
<input type="checkbox"/> Infection-sternum	<input type="checkbox"/> Infection—septicemia	<input type="checkbox"/> Multi-system failure
<input type="checkbox"/> Perioperative MI	<input type="checkbox"/> Pneumonia	<input type="checkbox"/> Prolonged ventilation
<input type="checkbox"/> Pulmonary embolism	<input type="checkbox"/> Renal failure	<input type="checkbox"/> Cardiac tamponade
<input type="checkbox"/> Other: _____		

Planned Discharge Date: _____

Actual Discharge Date: _____

Hospital LOS: _____

Appendix O

Permission to Use Distress Thermometer



National
Comprehensive
Cancer
Network*

275 Commerce Drive
Suite 300
Fort Washington, PA 19034
215.690.0300
Fax: 215.690.0280
www.nccn.org

May 27, 2010

Michael Williams, MSN, RN, CCRN, CNE
University of Michigan School of Nursing
2139 Ascot Road
Ann Arbor, MI 48103

Dear Mr. Williams:

On behalf of the National Comprehensive Cancer Network ("NCCN") I am writing to grant you limited one time permission to reproduce the **Distress Thermometer Screening Tool FIGURE (DIS-A)** from the **NCCN 1.2010 Distress Management Guidelines** for use in your PhD dissertation work at the University of Michigan School of Nursing, where you will be using the Distress Thermometer to determine distress among family members with a relative having open heart surgery. Permission is granted solely for the purposes described herein which you represent and warrant to be for non-promotional educational use only. The following qualifications also apply to the permission granted by this letter:

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Massachusetts General Hospital
Cancer Center

Duke Comprehensive
Cancer Center

Fox Chase Cancer Center

Huntsman Cancer Institute
at the University of Utah

Fred Hutchinson Cancer
Research Center/
Seattle Cancer Care Alliance

Arthur G. James Cancer
Hospital and Richard J. Solove
Research Institute at
The Ohio State University

The Sidney Kimmel
Comprehensive Cancer Center
at Johns Hopkins

Robert H. Lurie Comprehensive
Cancer Center of Northwestern
University

Memorial Sloan-Kettering
Cancer Center

H. Lee Moffitt Cancer Center
& Research Institute at the
University of South Florida

Roswell Park Cancer Institute

Siteman Cancer Center at
Barnes-Jewish Hospital and
Washington University
School of Medicine

St. Jude Children's
Research Hospital/
University of Tennessee
Cancer Institute

Stanford Comprehensive
Cancer Center

University of Alabama
at Birmingham Comprehensive
Cancer Center

UCSF Helen Diller Family
Comprehensive Cancer Center

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Comprehensive
Cancer Center

UNMC Eppley Cancer
Center at The Nebraska
Medical Center

The University of Texas
M. D. Anderson Cancer Center

Vanderbilt-Ingram
Cancer Center

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"The NCCN Guidelines are a statement of consensus of its authors regarding their views of currently accepted approaches to treatment. Any clinician seeking to apply or consult any NCCN guideline is expected to use independent medical judgment in the context of individual clinical circumstances to determine any patient's care or treatment. The National Comprehensive Cancer Network makes no warranties of any kind whatsoever regarding their content, use or application and disclaims any responsibility for their application or use in any way."

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8. You acknowledge that the NCCN is sole owner of the Guidelines, and any derivative works created from the Guidelines. You further acknowledge that the NCCN is the owner of the name "National Comprehensive Cancer Network, Inc.®," and "the NCCN®" and any derivatives thereof (the "Marks"). You agree that you shall not use the Marks in any manner or for any purpose other than to acknowledge ownership of the Guidelines by the NCCN as described in this letter. Your use of the Marks and/or Guidelines for the purposes described herein in no way constitutes an endorsement of your works or opinions by the NCCN. You acknowledge that use of the Marks and reprinting of the Guidelines pursuant to the permission granted hereunder shall not create in your favor any right, title, or interest in or to the Marks and/or the Guidelines. The permission granted hereunder is for a one-time use of the Marks and/or Guidelines. You agree that each use of the Marks and/or the Guidelines by you, beyond or in addition to that described herein, shall require written approval by the NCCN.
9. Your use of the Marks and/or Guidelines as described herein shall signify your acceptance of the terms and conditions of this letter. The NCCN reserves the right to at any time revoke the permission granted hereunder if, in its discretion, the NCCN determines that you have violated or are in violation of the terms of this letter of permission.

Thank you for your interest in the work of the NCCN.

Sincerely,



Nicole Fair
CME Specialist
NCCN

Appendix P

Open Ended Questions

Your Thoughts & Feelings Now & At the Time of Surgery

Your insight into your feelings and thoughts are important to this research. Please answer the last two questions from your perspective.

What are you feeling and thinking right now?

What fears or concerns did you have the day of surgery?

Appendix Q

Patient Data Form

FROM PATIENT RECORD:

Type of Surgery: _____

Length of Surgery: _____

Complications During Surgery:

- Arrhythmia Hemorrhage Intraoperative MI Severe electrolyte imbalance
 Other: _____

Immediate Postoperative Complications:

- Acute renal failure Arrhythmia Hemorrhage Postoperative MI
 Severe electrolyte imbalance Other: _____

Extraordinary Measures:

- Cardiopulmonary Arrest Hemorrhage Insertion of IABP Insertion of VAD
 Lethal arrhythmia treatment Other: _____

Did the patient have any of the following postoperative complications (including in the ICU)?

- | | | |
|--|---|--|
| <input type="checkbox"/> Atrial fibrillation | <input type="checkbox"/> Cardiac arrest | <input type="checkbox"/> CVA |
| <input type="checkbox"/> Infection-sternum | <input type="checkbox"/> Infection—septicemia | <input type="checkbox"/> Multi-system failure |
| <input type="checkbox"/> Perioperative MI | <input type="checkbox"/> Pneumonia | <input type="checkbox"/> Prolonged ventilation |
| <input type="checkbox"/> Pulmonary embolism | <input type="checkbox"/> Renal failure | <input type="checkbox"/> Cardiac tamponade |
| <input type="checkbox"/> Other: _____ | | |

Actual Discharge Date: _____

Loved One Having Open Heart Surgery?

If so, your participation in a research study on Coping and Coping Outcomes of Family Members in the ICU and Prior to Discharge is desired.

You will be asked to complete a series of questionnaires at three separate times (in the clinic, in the ICU and at time of discharge). You will be given a \$10 meal card for the hospital cafeteria after completing the ICU data collection.

Please ask the nurse or doctor about participating in the study or contact the Principal Investigator,

Michael L. Williams, MSN, RN, CCRN, CNE
Doctoral Candidate, University of Michigan
School of Nursing
734- 845 - 7465 or
mwms@umich.edu



Appendix S

Family Consent Form

UNIVERSITY OF MICHIGAN CONSENT TO BE PART OF A RESEARCH STUDY

INFORMATION ABOUT THIS FORM

You may be eligible to take part in a research study. This form gives you important information about the study. It describes the purpose of the study, and the risks and possible benefits of participating in the study.

Please take time to review this information carefully. After you have finished, you should talk to the researchers about the study and ask them any questions you have. You may also wish to talk to others (for example, your friends, family, or other doctors) about your participation in this study. If you decide to take part in the study, you will be asked to sign this form. *Before you sign this form, be sure you understand what the study is about, including the risks and possible benefits to you.*

1. GENERAL INFORMATION ABOUT THIS STUDY AND THE RESEARCHERS

1.1 Study title: Coping & Psychological Distress of Family Members of Adult Cardiac Surgery Patients in the ICU and Prior to Discharge

1.2 Company or agency sponsoring the study: This study is a doctoral dissertation from the University of Michigan School of Nursing for the Principal Investigator and is not sponsored by a company or agency.

1.3 Names, degrees, and affiliations of the researchers conducting the study:

Principal Investigator: Michael L. Williams, MSN, RN, CCRN, CNE
Doctoral Candidate, University of Michigan School of Nursing

Co-Principal Investigator: Carol Loveland-Cherry, PhD, RN, FAAN.
Professor, University of Michigan School of Nursing

2. PURPOSE OF THIS STUDY

2.1 Study purpose: This research is being conducted to determine what coping strategies family members of adult cardiac surgery patients use, how uncertainty effects family coping, the significance of the experience from the family member's perspective and ultimately the psychological distress family members experience based on their coping strategies used. By better understanding family coping, nursing interventions may be tailored to assist in coping and minimize psychological distress.

3. INFORMATION ABOUT STUDY PARTICIPANTS (SUBJECTS)

Taking part in this study is completely **voluntary**. You do not have to participate if you don't want to. You may also leave the study at any time. If you leave the study before it is finished, there will be no penalty to you, and you will not lose any benefits to which you are otherwise entitled.

- 3.1 **Who can take part in this study?** Family members of patients undergoing first time heart surgery may participate in this study. Potential subjects must be an adult family member or significant other older than 18 years of age (as identified by the patient), able to read and write the English language, willing and able to participate in three data collection points in the study
- 3.2 **How many people (subjects) are expected to take part in this study?** 120 subjects at the University of Michigan Hospitals are expected to take part in this study.

4. INFORMATION ABOUT STUDY PARTICIPATION

- 4.1 **What will happen to me in this study?** You will be asked to complete a series of paper and pencil questionnaires at three different time periods. The first time for completing the questionnaires will be in the CVC OR waiting room, secondly in the ICU waiting room the day of surgery and lastly on the day of discharge from the hospital.
- 4.2 **How much of my time will be needed to take part in this study?** ? For each data collection period, completion of the questionnaires should take between 30 and 60 minutes.
- 4.3 **When will my participation in the study be over?** After the completion of the third data collection or any time in which you choose to drop out of the study.

5. INFORMATION ABOUT RISKS AND BENEFITS

- 5.1 **What risks will I face by taking part in the study? What will the researchers do to protect me against these risks?**

The known or expected risks are minimal but during completion of the questionnaires you may experience some emotional discomfort or anxiety. The researchers will try to minimize these risks by providing you with a private space to complete the questionnaires and be available in the event emotional discomfort or anxiety is experienced. If undue anxiety is experienced, you may be referred to hospital resources, such as the CVICU Clinical Nurse Specialist or Emergency Psychiatric Services are also available. There may be additional risks that are unknown or unexpected as with any research study.

5.2 What happens if I get hurt, become sick, or have other problems as a result of this research?

The researchers have taken steps to minimize the risks of this study. Even so, you may still have problems or side effects, even when the researchers are careful to avoid them. Please tell the researchers listed in Section 10 about any injuries, side effects, or other problems that you have during this study. You should also tell your regular doctors.

5.3 If I take part in this study, can I also participate in other studies?

Being in more than one research study at the same time, or even at different times, may increase the risks to you. It may also affect the results of the studies. You should not take part in more than one study without approval from the researchers involved in each study.

5.4 How could I benefit if I take part in this study? How could others benefit?

You may not receive any personal benefits from being in this study. However, by collecting information from you and others, doctors and nurses will have a better understanding of the experience of being a family member of a patient undergoing cardiac surgery. Your experience and willingness to share it may benefit others facing the same experience. You will be given \$10 after completing the surveys in the ICU.

5.5 Will the researchers tell me if they learn of new information that could change my willingness to stay in this study?

Yes, the researchers will tell you if they learn of important new information that may change your willingness to stay in this study. If new information is provided to you after you have joined the study, it is possible that you may be asked to sign a new consent form that includes the new information.

6. OTHER OPTIONS

6.1 If I decide not to take part in this study, what other options do I have?

Your participation in this study is completely voluntary. You may opt not to participate. You and your loved one will experience no repercussions or penalty.

7. ENDING THE STUDY

7.1 If I want to stop participating in the study, what should I do?

You are free to leave the study at any time. If you leave the study before it is finished, there will be no penalty to you. You will not lose any benefits to which you may otherwise be entitled. If you choose to tell the researchers why you are leaving the study, your reasons for leaving may be kept as part of the study record. If you decide to leave the study before it is finished, please tell one of the persons listed in Section 10 "Contact Information" (below).

7.2 Could there be any harm to me if I decide to leave the study before it is finished?

You will experience no harm if you decide to leave the study before it is finished. Informing the investigator as to why you are leaving the study would be helpful to improve procedures for subsequent studies and is appreciated but is not required.

7.3 Could the researchers take me out of the study even if I want to continue to participate?

Yes. There are many reasons why the researchers may need to end your participation in the study. Some examples are:

- ✓ The researcher believes that it is not in your best interest to stay in the study.
- ✓ You become ineligible to participate—for instance, your loved one dies between time 1 and time 3 time periods.
- ✓ Your condition changes and you need treatment that is not allowed while you are taking part in the study.
- ✓ You do not follow instructions from the researchers.
- ✓ The study is suspended or canceled.

8. FINANCIAL INFORMATION

8.1 Who will pay for the costs of the study? Will I or my health plan be billed for any costs of the study?

There are no costs or billing for this study. By signing this form, you do not give up your right to seek payment if you are harmed as a result of being in this study.

8.2 Will I be paid or given anything for taking part in this study?

Yes. You will be paid \$20 for your participation in this study.

8.3 Who could profit or financially benefit from the study results?

No individual or organization will benefit financially from the study results.

9. CONFIDENTIALITY OF SUBJECT RECORDS AND AUTHORIZATION TO RELEASE YOUR PROTECTED HEALTH INFORMATION

The information below describes how your privacy and the confidentiality of your research records will be protected in this study.

9.1 How will the researchers protect my privacy?

In order to protect the privacy of subjects, the following actions will be taken: 1) You will be approached in OR waiting room and/or consultation room to provide privacy in explaining the study and obtaining informed consent., 2) you will be assigned a 'subject identification code' upon entrance into the study and 3) a private consultation room or family conference room will be used to provide privacy during data collection. Your name and your subject identification code will be maintained on a list kept by the principal investigator in a locked cabinet in his office. This information is necessary to correctly identify you and others in the study at subsequent data

collection periods. This information sheet will be secured on a daily basis and all paper records will be shredded after publication of data.

**9.2 What information about me could be seen by the researchers or by other people?
Why? Who might see it?**

There are many reasons why information about you may be used or seen by the researchers or others during or after this study. Examples include:

- The researchers may need the information to make sure you can take part in the study.
- University, Food and Drug Administration (FDA), and/or other government officials may need the information to make sure that the study is done in a safe and proper manner.
- Study sponsors or funders, or safety monitors or committees, may need the information to:
 - Make sure the study is done safely and properly
 - Learn more about side effects
 - Analyze the results of the study
- The researchers may need to use the information to create a databank of information about your condition or its treatment.
- If you receive any payments for taking part in this study, the University of Michigan accounting department may need your name, address, social security number, payment amount, and related information for tax reporting purposes.
- Federal or State law may require the study team to give information to government agencies. For example, to prevent harm to you or others, or for public health reasons.

The results of this study could be published in an article, but would not include any information that would let others know who you are.

9.3 What happens to information about me after the study is over or if I leave the study before it is finished?

As a rule, the researchers will not continue to use or disclose information about you, but will keep it secure until it is destroyed. Sometimes, it may be necessary for information about you to continue to be used or disclosed, even after you have left the study or the study is over. Examples of reasons for this include:

- To avoid losing study results that have already included your information
- To provide limited information for research, education, or other activities (This information would not include your name, social security number, or anything else that could let others know who you are.)
- To help University and government officials make sure that the study was conducted properly

As long as your information is kept within the University of Michigan Health System, it is protected by the Health System's privacy policies. For more information about these policies, ask for a copy of the University of Michigan Notice of Privacy Practices. This information is also available on the web at <http://www.med.umich.edu/hipaa/npp.htm>. Note that once your information has been

shared with others as described under Question 9.2, it may no longer be protected by the privacy regulations of the federal Health Insurance Portability and Accountability Act of 1996 (HIPAA).

9.4 When does my permission expire?

Your permission expires at the end of the study, unless you cancel it sooner. You may cancel your permission at any time by writing to the researchers listed in Section 10 "Contact Information" (below).

10. CONTACT INFORMATION

10.1 Who can I contact about this study?

Please contact the researchers listed below to:

- Obtain more information about the study
- Ask a question about the study procedures or treatments
- Talk about study-related costs to you or your health plan
- Report an illness, injury, or other problem (you may also need to tell your regular doctors)
- Leave the study before it is finished
- Express a concern about the study

Principal Investigator: Michael L. Williams
Mailing Address: 326 Marshall Building, Ypsilanti, MI 48197
Telephone: 734- 845-7465

You may also express a concern about a study by contacting the Institutional Review Board listed below, or by calling the University of Michigan Compliance Help Line at 1-866-990-0111.

University of Michigan Medical School Institutional Review Board (IRBMED)
2800 Plymouth Road
Building 200, Room 2086
Ann Arbor, MI 48109-2800
Telephone: 734-763-4768 (For International Studies: US Country Code: 001)
Fax: 734-763-1234
e-mail: irbmed@umich.edu

If you are concerned about a possible violation of your privacy, contact the University of Michigan Health System Privacy Officer at 1-866-990-0111.

When you call or write about a concern, please provide as much information as possible, including the name of the researcher, the IRBMED number (at the top of this form), and details about the problem. This will help University officials to look into your concern. When reporting a concern, you do not have to give your name unless you want to.

11. RECORD OF INFORMATION PROVIDED

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Page 6 of 8

Consent Subtitle: _____
Consent Version: _____

11.1 What documents will be given to me?

Your signature in the next section means that you have received copies of all of the following documents:

- This "Consent to be Part of a Research Study" document. *(Note: In addition to the copy you receive, copies of this document will be stored in a separate confidential research file and may be entered into your regular University of Michigan medical record.)*

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Page 7 of 8

Consent Subtitle: _____
Consent Version: _____

12. SIGNATURES

Research Subject:

I understand the information printed on this form. I have discussed this study, its risks and potential benefits, and my other choices with _____. My questions so far have been answered. I understand that if I have more questions or concerns about the study or my participation as a research subject, I may contact one of the people listed in Section 10 (above). I understand that I will receive a copy of this form at the time I sign it and later upon request. I understand that if my ability to consent for myself changes, either I or my legal representative may be asked to re-consent prior to my continued participation in this study.

Signature of Subject: _____ Date: _____

Name (Print legal name): _____

Legal Representative (if applicable):

Signature of Person Legally Authorized to Give Consent _____ Date: _____

Name (Print legal name): _____ Phone: _____

Address: _____

Check Relationship to Subject:

Parent Spouse Child Sibling Legal Guardian Other: _____

If this consent is for a child who is a ward of the state (for example a foster child), please tell the study team immediately. The researchers may need to contact the IRBMED.

Reason subject is unable to sign for self: _____

Principal Investigator (or Designee):

I have given this research subject (or his/her legally authorized representative, if applicable) information about this study that I believe is accurate and complete. The subject has indicated that he or she understands the nature of the study and the risks and benefits of participating.

Name: _____ Title: _____

Signature: _____ Date of Signature: _____

Witness (optional):

I observed the above subject (or his/her legally authorized representative, if applicable) sign this consent document.

Name: _____

Signature: _____ Date of Signature: _____

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Consent Subtitle: _____
Consent Version: _____

Appendix T

Patient Consent Form

PATIENT

UNIVERSITY OF MICHIGAN CONSENT TO BE PART OF A RESEARCH STUDY

INFORMATION ABOUT THIS FORM

You may be eligible to take part in a research study. This form gives you important information about the study. It describes the purpose of the study, and the risks and possible benefits of participating in the study.

Please take time to review this information carefully. After you have finished, you should talk to the researchers about the study and ask them any questions you have. You may also wish to talk to others (for example, your friends, family, or other doctors) about your participation in this study. If you decide to take part in the study, you will be asked to sign this form. *Before you sign this form, be sure you understand what the study is about, including the risks and possible benefits to you.*

1. GENERAL INFORMATION ABOUT THIS STUDY AND THE RESEARCHERS

1.1 Study title: Coping & Psychological Distress of Family Members of Adult Cardiac Surgery Patients in the ICU and Prior to Discharge

1.2 Company or agency sponsoring the study: This study is a doctoral dissertation from the University of Michigan School of Nursing for the Principal Investigator and is not sponsored by a company or agency.

1.3 Names, degrees, and affiliations of the researchers conducting the study:

Principal Investigator: Michael L. Williams, MSN, RN, CCRN, CNE
Doctoral Candidate, University of Michigan School of Nursing

Co-Principal Investigators: Carol Loveland-Cherry, PhD, RN, FAAN.
Professor, University of Michigan School of Nursing

2. PURPOSE OF THIS STUDY

2.1 Study purpose: This research is being conducted to determine what coping strategies family members of adult cardiac surgery patients use, how uncertainty effects family coping, the significance of the experience from the family member's perspective and ultimately the psychological distress family members experience based on their coping strategies used. By better understanding family coping, nursing interventions may be tailored to assist in coping and minimize psychological distress.

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Page 1 of 7

Consent Subtitle: _____
Consent Version: _____

3. INFORMATION ABOUT STUDY PARTICIPANTS (SUBJECTS)

Taking part in this study is completely **voluntary**. You do not have to participate if you don't want to. You may also leave the study at any time. If you leave the study before it is finished, there will be no penalty to you, and you will not lose any benefits to which you are otherwise entitled.

3.1 Who can take part in this study? Family members of patients undergoing first time heart surgery may participate in this study. Potential subjects must be an adult family member or significant other older than 18 years of age (as identified by the patient), able to read and write the English language, willing and able to participate in three data collection points in the study

3.2 How many people (subjects) are expected to take part in this study? 120 subjects from the University of Michigan Hospitals are expected to take part in this study.

4. INFORMATION ABOUT STUDY PARTICIPATION

4.1 What will happen to me in this study? As a patient participant, your consent allows the investigator to access your medical record, to determine whether you experienced an untoward event in the operating room or any time after surgery. You will not need to complete any questionnaires yourself.

4.2 How much of my time will be needed to take part in this study? None.

4.3 When will my participation in the study be over? After the collection from your medical record or any time in which you choose to drop out of the study.

5. INFORMATION ABOUT RISKS AND BENEFITS

5.1 What risks will I face by taking part in the study? What will the researchers do to protect me against these risks?

There are no known or expected risks from your participation in this study. The researcher will collect data on the surgical procedure, complications you experienced and any untoward events from your medical record. There may be additional risks that are unknown or unexpected as with any research study.

5.2 What happens if I get hurt, become sick, or have other problems as a result of this research?

There are no anticipated risks for you as only your medical record will be used to collect data

5.3 If I take part in this study, can I also participate in other studies?

Being in more than one research study at the same time, or even at different times, may increase the risks to you. It may also affect the results of the studies. You should not take part in more than one study without approval from the researchers involved in each study.

5.4 How could I benefit if I take part in this study? How could others benefit?

You may not receive any personal benefits from being in this study. However, by collecting information from you and others, doctors and nurses will have a better understanding of the experience of being a family member of a patient undergoing cardiac surgery. Your experience and willingness to share it may benefit others facing the same experience.

6. OTHER OPTIONS

6.1 If I decide not to take part in this study, what other options do I have?

Your participation in this study is completely voluntary. You may opt not to participate. You and your loved one will experience no repercussions or penalty.

7. ENDING THE STUDY

7.1 If I want to stop participating in the study, what should I do?

You are free to leave the study at any time. If you leave the study before it is finished, there will be no penalty to you. You will not lose any benefits to which you may otherwise be entitled. If you choose to tell the researchers why you are leaving the study, your reasons for leaving may be kept as part of the study record. If you decide to leave the study before it is finished, please tell one of the persons listed in Section 10 "Contact Information" (below).

7.2 Could there be any harm to me if I decide to leave the study before it is finished?

You will experience no harm if you decide to leave the study before it is finished. Informing the investigator as to why you are leaving the study would be helpful to improve procedures for subsequent studies and is appreciated but is not required.

7.3 Could the researchers take me out of the study even if I want to continue to participate?

Yes. There are many reasons why the researchers may need to end your participation in the study. Some examples are:

- ✓ The researcher believes that it is not in your best interest to stay in the study.
- ✓ You become ineligible to participate.
- ✓ Your condition changes and you need treatment that is not allowed while you are taking part in the study.
- ✓ You do not follow instructions from the researchers.
- ✓ The study is suspended or canceled.

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8. FINANCIAL INFORMATION

8.1 Who will pay for the costs of the study? Will I or my health plan be billed for any costs of the study?

There are no costs or billing for this study. By signing this form, you do not give up your right to seek payment if you are harmed as a result of being in this study.

8.2 Will I be paid or given anything for taking part in this study?

No. You will not be paid for participating in this study.

8.3 Who could profit or financially benefit from the study results?

No individual or organization will benefit financially from the study results.

9. CONFIDENTIALITY OF SUBJECT RECORDS AND AUTHORIZATION TO RELEASE YOUR PROTECTED HEALTH INFORMATION

The information below describes how your privacy and the confidentiality of your research records will be protected in this study.

9.1 How will the researchers protect my privacy?

The data form used to collect information from your medical chart will be coded with a study identification number that is a partner code for your family member participating in this study. No personal identifying information will be collected from you. By assigning a study identification number to you, your confidentiality will be ensured.

9.2 What information about me could be seen by the researchers or by other people? Why? Who might see it?

There are many reasons why information about you may be used or seen by the researchers or others during or after this study. Examples include:

- The researchers may need the information to make sure you can take part in the study.
- University, Food and Drug Administration (FDA), and/or other government officials may need the information to make sure that the study is done in a safe and proper manner.
- Study sponsors or funders, or safety monitors or committees, may need the information to:
 - Make sure the study is done safely and properly
 - Learn more about side effects
 - Analyze the results of the study
- The researchers may need to use the information to create a databank of information about your condition or its treatment.
- Federal or State law may require the study team to give information to government agencies. For example, to prevent harm to you or others, or for public health reasons.

The results of this study could be published in an article, but would not include any information that would let others know who you are.

9.3 What happens to information about me after the study is over or if I leave the study before it is finished?

As a rule, the researchers will not continue to use or disclose information about you, but will keep it secure until it is destroyed. Sometimes, it may be necessary for information about you to continue to be used or disclosed, even after you have left the study or the study is over. Examples of reasons for this include:

- To avoid losing study results that have already included your information
- To provide limited information for research, education, or other activities (This information would not include your name, social security number, or anything else that could let others know who you are.)
- To help University and government officials make sure that the study was conducted properly

As long as your information is kept within the University of Michigan Health System, it is protected by the Health System's privacy policies. For more information about these policies, ask for a copy of the University of Michigan Notice of Privacy Practices. This information is also available on the web at <http://www.med.umich.edu/hipaa/npp.htm>. Note that once your information has been shared with others as described under Question 9.2, it may no longer be protected by the privacy regulations of the federal Health Insurance Portability and Accountability Act of 1996 (HIPAA).

9.4 When does my permission expire?

Your permission expires at the end of the study, unless you cancel it sooner. You may cancel your permission at any time by writing to the researchers listed in Section 10 "Contact Information" (below).

10. CONTACT INFORMATION

10.1 Who can I contact about this study?

Please contact the researchers listed below to:

- Obtain more information about the study
- Ask a question about the study procedures or treatments
- Talk about study-related costs to you or your health plan
- Report an illness, injury, or other problem (you may also need to tell your regular doctors)
- Leave the study before it is finished
- Express a concern about the study

Principal Investigator: Michael L. Williams
Mailing Address: 326 Marshall Building, Ypsilanti, MI 48197
Telephone: 734- 845-7465

You may also express a concern about a study by contacting the Institutional Review Board listed below, or by calling the University of Michigan Compliance Help Line at 1-866-990-0111.

University of Michigan Medical School Institutional Review Board (IRBMED)
2800 Plymouth Road
Building 200, Room 2086
Ann Arbor, MI 48109-2800
Telephone: 734-763-4768 (For International Studies: US Country Code: 001)
Fax: 734-763-1234
e-mail: irbmed@umich.edu

If you are concerned about a possible violation of your privacy, contact the University of Michigan Health System Privacy Officer at 1-866-990-0111.

When you call or write about a concern, please provide as much information as possible, including the name of the researcher, the IRBMED number (at the top of this form), and details about the problem. This will help University officials to look into your concern. When reporting a concern, you do not have to give your name unless you want to.

11. RECORD OF INFORMATION PROVIDED

11.1 What documents will be given to me?

Your signature in the next section means that you have received copies of all of the following documents:

- This "Consent to be Part of a Research Study" document. *(Note: In addition to the copy you receive, copies of this document will be stored in a separate confidential research file and may be entered into your regular University of Michigan medical record.)*

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Consent Subtitle: _____
Consent Version: _____

12. SIGNATURES

Research Subject:

I understand the information printed on this form. I have discussed this study, its risks and potential benefits, and my other choices with _____. My questions so far have been answered. I understand that if I have more questions or concerns about the study or my participation as a research subject, I may contact one of the people listed in Section 10 (above). I understand that I will receive a copy of this form at the time I sign it and later upon request. I understand that if my ability to consent for myself changes, either I or my legal representative may be asked to re-consent prior to my continued participation in this study.

Signature of Subject: _____ Date: _____

Name (Print legal name): _____

Legal Representative (if applicable):

Signature of Person Legally Authorized to Give Consent _____ Date: _____

Name (Print legal name): _____ Phone: _____

Address: _____

Check Relationship to Subject:

Parent Spouse Child Sibling Legal Guardian Other: _____

If this consent is for a child who is a ward of the state (for example a foster child), please tell the study team immediately. The researchers may need to contact the IRBMED.

Reason subject is unable to sign for self: _____

Principal Investigator (or Designee):

I have given this research subject (or his/her legally authorized representative, if applicable) information about this study that I believe is accurate and complete. The subject has indicated that he or she understands the nature of the study and the risks and benefits of participating.

Name: _____ Title: _____

Signature: _____ Date of Signature: _____

Witness (optional):

I observed the above subject (or his/her legally authorized representative, if applicable) sign this consent document.

Name: _____

Signature: _____ Date of Signature: _____

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