THE RESILIENCY MODEL OF FAMILY STRESS,
ADJUSTMENT, AND ADAPTATION
A CASE STUDY

THESIS

Presented in Partial Fulfillment of the Requirements for
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The resiliency Model of Family Stress, Adjustment, and Adaptation by McCubbin and McCubbin is based on Hill's Family Stress Theory. It provides a method to assess family functioning and the coping techniques utilized to facilitate adjustment and adaptation to a medically stressful hospitalizations and diagnosis. It provides a method to assess stressors, family coping, and how the crisis has disrupted the family functioning. The main emphasis of this model is on resiliency of families and their ability to recover from adverse events. It defines the family strengths and the family's response to health stressors. It assists the health care team in defining areas that interventions may be developed to better assist families in achieving positive adjustment to illness. This theory is utilized to assess a family that has just given birth to an infant diagnosed with short gut syndrome, which has a poor long-term prognosis and is being discharged home with hospice involvement and palliative care. This stressful event impacts the whole family and their ability to find positive avenues to cope is paramount to how they adjust and adapt to this event.
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CHAPTER 1

INTRODUCTION TO THE FAMILY

The family that will be discussed in this paper is the family of a thirty-four week premature baby that was a patient in the Neonatal Intensive Care Unit (NICU) and later transitioned into the neonatal step-down unit. R.P. is the thirty-three year old mother of baby, and J.P. is the thirty-eight year old father. R.P. and J.P. have been married for ten years and have two other healthy children, living in a traditional nuclear family. J.P. is a stay-at-home mom who is involved in volunteering at her children’s elementary school and helping in the office of their church. R.P. works as a regional manager of a major food distributing company and usually spends about sixty hours a week at his job, and travels out of town one to two times every two weeks requiring an overnight away from home. H.P. is the eight-year-old son of R.P. and J.P. and B.P. is the five-year-old daughter. This pregnancy was planned and the family was looking forward to the birth of their third child. They live in a small town approximately eighty miles from large tertiary care center. They have a large extended family that lives within their community that is actively involved in their lives. They are involved in their church and attend church as a family weekly. J.P.’s brother is a physician who works as a Gastroenterologist in another state.
J.P. received prenatal care in her first trimester. It was noted that her fundal measurements were inconsistent with her expected date of confinement, therefore an ultrasound was done during the fourth month of the pregnancy, which showed polyhydramnios and a dilated proximal intestine in the fetus. Multiple ultrasounds were done and the pregnancy was followed closely. J.P.’s Obstetrician counseled the family and the decision to deliver at a large tertiary center, close to a Children’s Hospital was made because it was able to care for high-risk pregnancies and critically-ill infants. Follow-up antenatal ultrasonography showed evidence of some sort of bowel atresia, and due to the significant increase in polyhydramnios, R.P. was admitted to the hospital for induction of labor at thirty-four weeks gestation.

A.P. was born by spontaneous vaginal delivery with apgars of 9 at 1 minute and 9 at 5 minutes. She required brief continuous positive airway pressure (CPAP) in the delivery room immediately after delivery and weaned quickly to room air. The family verbalized great relief at seeing their daughter appear so healthy. After a short time of bonding with the parents and visiting with the siblings, A.P. was transferred to a Children’s Hospital for further evaluation of her suspected bowel obstruction. An abdominal x-ray showed findings consistent with a proximal atresia. An upper GI was done to rule out the possibility of malrotation, but this did not definitively prove this. It was felt that A.P. needed exploratory surgery, potential bowel resection and a potential ostomy in order to bypass the area of obstruction. She was taken to the operating room at approximately twenty hours of age.

J.P. was discharged early from the delivering hospital so that she could be with her daughter and husband at the time of surgery for A.P. A large extended family was
present at the time of surgery and seemed to offer a great deal of support to the family. The family's local pastor was also there and provided prayer and support to the family. They were optimistic that after surgery, things would get "back to normal" quickly and verbalized that they were anxious to take A.P. home.

Upon surgical exploration of the abdomen, A.P. was found to have a very dilated duodenum with essentially no bowel remaining after the duodenum with only a small-unused micro colon. There was a small area that was suspected to be an area that once represented her small intestines that was only two-three centimeters in length with the appearance of a shoestring. A biopsy was sent to ensure the findings did not represent total bowel Hirschsprung's disease, which was positive for ganglion cells ruling out this theory. It is suspected that an antenatal midgut volvulus was the cause of the absence of the small intestines. The small bowel remnants, along with the mesentery were removed and an anastomosis of the distal duodenum and proximal colon was done. Because of the short bowel scenario and the high risk of total parental nutrition (TPN) cholestasis, the gallbladder was removed. A gastrostomy tube (G-tube) was placed for future feeding needs and a broviac was placed for anticipated long term TPN.

A.P. returned to the NICU and was extubated quickly and her surgical condition stabilized. The family was informed of the critical nature of A.P.'s short gut and a poor long-term prognosis was given. A care conference was held with the family four days after surgery to discuss long-term care issues. Participants included representatives from the nursing staff, pastoral care, case management, gastroenterology, surgeons, and parents. The parents came to the conference with an extensive outline of questions regarding A.P.'s surgical and medical condition, issues about liver/small bowel.
transplantation and questions about her quality of life. The current surgical condition was explained and the need for TPN was discussed. The risk of liver damage from prolonged TPN was discussed at great length. Parents asked questions about supportive/hospice care which they verbalized they thought would be the best for their baby if she was going to have a life of suffering. It was emphasized that the treatment plans are based upon the current clinical status and changes in A.P.'s condition could lead to modifications of treatment and prognosis. At this point in A.P.'s hospitalization, she had stabilized and was receiving TPN and continuous feeds at 1 ml per hour per her G-tube.

A.P. remained in the NICU for ten-days, visitations were limited to parents and grandparents only. She was transferred to the step-down unit at ten-days of age for ongoing care. The family visited daily while A.P. was in the NICU and initially showed profound grief with crying and talking with staff of the loss of their “perfect” daughter. The siblings did not visit while in the NICU but were brought into the step-down unit soon after her transfer. During H.P.’s first visit, he was very quiet at his sister’s bedside, intently looking at her every detail. He remained quiet in his affect while his younger sister B.P. playfully approached the “new” baby and excitedly expressed her happiness to being a “big” sister. It was a short-time later after a few visits with their new baby that H.P. showed his profound emotions for his new baby sister and the loss that his family was experiencing. The family was gathered around J.P. who was holding A.P. and the family was at her side. A.P. was very bright eyed and focusing on her family, when H.P. went to touch his sister he began to cry loudly, unable to control his sobs as he buried his head into his mom’s lap. J.P. immediately began crying too and the dad knelt down to provide comfort to his family. B.P. looked upon her crying family with grave concern,
unsure how to interpret their sadness. The family stayed a while longer and returned daily for sometime. At approximately a month of age, family visits became more sporadic. Usually the mother would visit alone while the father was “home watching the other kids”. J.P. verbalized that R.P. had been working a lot and is really busy at work, making it difficult to visit. She discussed with the nursing staff that H.P. is really taking this hard and is waking up at night and coming into his parent’s room saying, “he’s scared”. His school is also being affected with frequent visits to the school nurse complaining of a stomachache and requesting to go home. J.P. has spoken with the principal and guidance counselor about their family situation. The guidance counselor has spoken with H.P. and will meet with him weekly to see how he is coping. J.P. frequently comments that A.P. “only has a short-time with us”. The nursing staff and medical staff offer support and encourage bonding through holding and involvement in A.P.’s cares. The staff has recognized that J.P. looks more unkept, tired and seems withdrawn at times, they are concerned she is experiencing some depression. The crib is decorated with pictures from the older siblings depicting their family that includes their “new” baby. B.P. has decorated the crib with her pictures that show A.P. as a baby crawling, waving out a car window, and playing on swings with her and her brother. It has been noted that the parents have become more distant and visit less frequently. There is concern that the parents are not bonding and are detaching themselves from their daughter due to the uncertainty of her prognosis.
CHAPTER 2

SHORT BOWEL SYNDROME

Short-Bowel Syndrome (SBS) occurs when there is inadequate length of functional intestine to maintain normal enteral nutrition. Because infants and children require increased caloric needs to maintain normal growth and development, SBS can have devastating effects in these patients. Short-bowel syndrome typically is the result of a catastrophic event involving the small intestine and possibly the colon. Necrotizing enterocolitis, multi-level small bowel atresia and midgut volvulus from malrotation with ischemic bowel infarction are the most common causes of SBS in the neonate (O’Neill, Grosfeld, Fonkalsrud, Coran & Caldamone, 2004). It is estimated that approximately 10,000-20,000 people in the United States have the diagnosis of SBS and require TPN (Cuffari, 2003).

The normal intestinal development occurs early in fetal development. The small intestine is derived from the midgut and is anatomically complete by 20 weeks’ gestation. Most of its intrauterine growth occurs in the third trimester. The small intestine of the neonate is approximately 250 cm in length. By adulthood, the small intestine grows to approximately 750 cm (Cuffari, 2003). The mucosal surface area changes significantly with age. Subsequently, the infant and young child has a favorable long-term prognosis
compared to an adult in regards to potential intestinal growth and adaptation after intestinal resection.

The intestine has an enormous capacity to absorb secretions and ingested fluids. The majority of digestion and absorption is completed within the first 100-150 cm of the jejunum in a healthy individual. Patients who have less than 100 cm of jejunum exhibit significant malabsorption (Cuffari, 2003). According to O’Neil and colleagues, the extent of problems associated with SBS usually depends on which sections of the small bowel are affected. The normal small bowel varies in length between 10 and 28 feet and is divided into three sections. The first section is the duodenum. The duodenum is a relatively short part of the small bowel that immediately follows the stomach and measures approximately 10-12 inches. The duodenum is responsible for absorption of Iron, Calcium, Magnesium, and Chloride. However, the jejunum is able to adapt to assume the function of the duodenum if it is resected. The jejunum accounts for approximately two-fifths of the small intestines. It is considered the largest section because it has many folds that create a larger surface area for absorption. The jejunum is the site of absorption of most macronutrients and minerals. It also has an important role in carbohydrate absorption and nonfat vitamin absorption. With removal of the jejunum, there is loss of carbohydrate enzymes and decreased carbohydrate digestion and absorption, causing higher concentration of luminal sugars that provide a medium for bacterial growth. The interaction of bacteria and carbohydrates fermentation produces lactic acid. Cholecystokinin and secretin production are decreased and pancreaticobiliary secretions are altered causing malabsorption of fats and protein digestion (O’Neil et al., 2003). The last section of small intestine is the ileum. It makes up the remaining three-
fifths of the small bowels. Usually, about one half of the small bowel can be removed without causing significant problems. The entire jejunal can usually be removed without significant malabsorption. The ileum can usually compensate for the losses that occur without the jejunum except for the lactase deficiency. Removal of the ileum accounts for most of the problems seen in short bowel syndrome because it is responsible for the absorption of carbohydrates, protein, fats, fat-soluble vitamins, bile salts, B12, and other electrolytes. Removal of the ileum causes vitamin B12 deficiencies, fat-soluble vitamin deficiencies and diarrhea. The diarrhea is due to the increase in transit time through the gut and the loss of absorptive surface area. According to Cuffari, “bile salts are markedly reduced, and excess bile salts pass into the colon, resulting in impaired electrolyte absorption and increased colonic secretory activity. Due to the interruption of the enterohepatic cycle of bile, the liver cannot synthesize enough bile to replace the loss and fat cannot be absorbed” (2003, p. 11).

During the early post-operative phase after significant intestinal loss, attention is directed toward maintenance of fluid and electrolyte balance. TPN is begun and replacement of fluids started. According to O’Neil and colleagues, “enteral feeds should be introduced gradually, to stimulate adaptive mechanisms of the bowel, nutritional needs can be met by TPN” (2003, p. 521). Elemental formulas have a theoretical advantage of being better absorbed because they are already in an elemental form. Parenteral nutrition is an important therapy in the care of the patient with SBS. TPN provides adequate protein, calories, other macronutrients, and micronutrients until the bowel has had time to adapt. Despite bowel adaptation and nutritional therapy, some patients are unable to be weaned from TPN. These patients usually are those with less than sixty cm of small
bowel remaining, loss of the ileum and ileocecal valve, and loss of the colon. The most frequent manifestation of hepatobiliary disease in patients with SBS on long-term TPN is cholestasis. Biliary sludge or gallstones are found in approximately 50% of patients receiving TPN with no oral intake for 3 months (Cavicchi, 2000). Progressive liver dysfunction and hepatic cirrhosis can occur with long-term usage of TPN. These patients are candidates for liver-intestinal transplantation. Transplant surgery is usually reserved for patients who are dependent on TPN and are showing signs of liver failure.

Specific drug therapies in SBS are mainly aimed at decreasing gastric hypersecretion or decreasing diarrhea. Sawyer and colleagues recommend treatment with proton pump inhibitors or histamin-2 (H2) blockers in the early postoperative period. They also advocate for Imodium for patients that have retractable diarrhea from the loss of their colon and ileum (Sawyer & Sawyer, 2004). The current medical management strives to promote an acceptable quality and quantity of life. TPN provides appropriate caloric needs for growth and improved enteral formulas can facilitate the absorptive capacity of the remaining small intestines.

There is no reliable cure that currently exists for SBS. Patients who are maintained on TPN at home have reasonably good short-term outcomes. Data from Howard and colleagues reveal that the 4-year survival rate in patients who depend on TPN is about 70% (1995). However, many patients that need long-term TPN have severe septic complications that increase the morbidity of this disease. The most common cause of death in these patients is liver failure (Sawyer & Sawyer, 2004). Organ transplantation is a promising therapeutic option but continues to have a high morbidity rate. Early postoperative mortality rates can be as high as 30%. The literature supports
offering palliative care in many different circumstances. In the case of neonatal conditions where the newborn is likely to die even with all available treatments, palliative care should be offered. Severe short gut syndrome with the inability to survive without TPN has been discussed in the literature as a syndrome that meets the criteria for palliative care (Carter, 2004). Providing an environment in the NICU where palliative care can be integrated into patient and family care plans will be instrumental in helping the family cope and adjust to the hospitalization and transition home regardless of whether the treatment goal is obtaining a cure, prolonging life, or exclusively palliative and comfort care until an expected death.
CHAPTER 3

THE RESILIENCY MODEL OF FAMILY STRESS, ADJUSTMENT, AND ADAPTATION

The theory used to assess A.P.'s family is The Resiliency Model of Family Stress, Adjustment, and Adaptation by McCubbin and McCubbin. The Resiliency Model is based on Hill's Family Stress Theory. Friedman, Bowden and Jones (2003) describe The Resiliency Model as a way to assess the stressors, family coping, and how the crisis has disrupted the family functioning. The main emphasis of this model is on resiliency of families and their ability to recover from adverse events (Friedman et al.). Hanson (2001) describes this model as a way for nurses “to facilitate family adjustment and adaptation by looking at family strengths and capacities for responding to stress. Based on the family’ response to health stressors, the nurse and the family, working together, create interventions that are most likely to result in positive family adjustment” (p.54).

This theory is chosen because J.P. and R.P are experiencing a very difficult situation with the birth of their new daughter and her diagnosis of short gut syndrome, which has a poor long-term prognosis. This stressful event impacts the whole family and their ability to find positive avenues to cope with this difficult situation is paramount to how they adjust and adapt to this event.
There are ten concepts that are the foundation for all family stress models. Friedman (2003) defines these basic stress and coping concepts that occur as a family moves from the initial stress phase, coping phase, and eventual adaptation to include: stress as the state of tension within a person or social system that occurs when actual or perceived demands remain unmanaged, the stressors which precipitate the stress process and bring about change in the family system, family perceptions that define the nature and gravity of the family stressor, family coping that utilizes family resources that will strengthen the family unit, the family crisis phases in which families are in a continuous disruptive state, the adaptation phase which restores functional stability to the family, family coherence which fosters family bonds, and family resilience which allows families to build on the strengths of each other and adapt to a stressful event in a manageable and positive way.

The Resiliency Model of Family Stress, Adjustment, and Adaptation emphasizes family adjustment and adaptation to a stressful event, the family’s ability to recover from the event, and what strengths influence this process. Friedman and colleagues define the four fundamental assumptions about family life to include: families face hardships and changes as a natural and predictable aspect of family life over the life cycle, families develop basic strengths and capabilities designed to foster the growth and development of family members and the family unit and to protect the family from major disruptions in the face of family transitions and changes, families develop basic and unique strengths and capabilities designed to protect the family from unexpected or normative stressors and stains and to foster the family’s adaptation following a family crisis or major transition and change, and families benefit from and contribute to the network or
relationships and resources in the community, particularly during periods of family stress, and crisis (Friedman, Bowden & Jones, 2003, p.470). This model emphasizes the variables involved in family adaptation over time to chronic stress, such as the stress of a family member's illness. It consists of the Adjustment Phases and the Adaptation Phase.
CHAPTER 4

ADJUSTMENT PHASE

The premise of the Adjustment Phase focuses on the onset of the stressor that occurs at the outset of a family illness. It is the phase in which families attempt to maintain patterns of interaction, roles, and rules that have been established to guide day-to-day activity. According to McCubbin and colleagues the most prominent family protective factors that sustain families through stressful periods are “family celebrations and traditions, family hardiness, family time and routine, supportive communication, financial management, and strong social support” (McCubbin, McCubbin, Thompson, Han, & Allen, 1997, p.5). If there is a major illness such as a prolonged hospitalization the family may not adapt as well as if it is a minor illness, such as a case of the flu. In this phase, the pile-up of demands the family is experiencing interacts with family resources and capabilities to shape the outcome of the Adjustment Phase. The pile-up of demands may include the sequelae of a newborn that is born with a chronic life-threatening condition, the family’s strains, marriage conflicts, and needs of other family members. Families will be more vulnerable to these stressors if more than one stressor is present at the time of the illness or event. The illness may include life-threatening or nonlife-threatening physical problems for a family member. The family’s level of vulnerability to stress may be influenced by prior strains in the family and the life-cycle
stage the family is in at the time of the stressor. Poor family functioning patterns may include ineffective coping responses to stress, ineffective communication, or a lack of cohesiveness and organizational structure. Hanson (2001) states, “the event or demand can influence many aspects of family life including health, roles and responsibilities, and boundaries” (p.333). Family types and established patterns of functioning are important in the Adjustment Phase. Family attributes such as cohesion and flexibility are important in helping families manage the stress of a chronic illness. Hanson concludes that “economic stability, cohesiveness, flexibility, hardiness, shared spiritual beliefs, open communication, traditions, celebrations, routines, and community organization are critical family resources that enable families to manage the stressor and prevent major upheaval in their functioning” (p.334). Outcomes of the Adjustment Phase vary along a continuum from effective adjustment, in which the family maintains established functioning patterns and experiences a sense of control over their environment, to ineffective adjustment, in which individual family member experience a deterioration in personal development and become unable to accomplish life tasks. Any significant event or change in one family member will affect all family members in varying degrees (Wright & Leakey, 2000).
CHAPTER 5

ADAPTATION PHASE

If family functioning is not adequate to manage the stressful events such as a family illness, the family moves into a crisis situation and the Adaptation Phase of the Resiliency Model of Family Stress (Friedman et al., 2003). Family crisis is defined as, “the families susceptibility to continued instability, disorganization and dysfunction from normative and non-normative life events that disrupt the family system and precipitate changes in, or the necessity for changes in, the family’s patterns of functioning” (McCubbin et al., 1997, p.4). The Adaptation Phased involves the family’s ability to bounce back and adapt in a family crisis situation. Their resiliency deals with whether the family views the illness as a challenge and can work together as a unit to manage the illness and to meet everyone’s needs. In the adaptation phase of the model, response to a crisis situation is determined by the pile-up of demands, stressors, strains, as well as the strengths and capabilities of the family unit. The family’s resiliency deals with whether the family views the illness as a challenge and can work together as a unit to manage the illness and to meet everyone’s needs. The family develops and practices new coping strategies in order to achieve a new balance and fit at multiple levels including the individual to family and the family to community level. The Adaptation Phase of the Resiliency Model occurs over a period of time, and often has long-term consequences.
The stressful event may foster new capabilities and strengths within the family unit. The formation of newly developed problem-solving and coping techniques that assist in making the crisis manageable. Pile-up stressors and demands of the illness and the aftermath of the medical treatments may include financial strains, role ambiguity and loss, and increased emotional hardship for individual family members, increased strain in family relationships, and normal life transitions. Adaptation techniques such as role flexibility, maintaining normalcy to daily life, gaining information and knowledge, being open and honest, using humor and laughter, maintaining active linkages with the community such as participating in clubs or church activities, the use of social support systems, and spiritual support helps families effectively cope. McCubbin and colleagues identified four critical family recovery factors that assist families through the Adaptation Phase when they have a sick child, they include: “family integration that occurs when the family maintains an optimistic outlook to promote the child’s health, family support and esteem building in which parents of ill children look to get support from the community and friends, family recreation orientation, control, and organization where the families emphasizes family organization, rules, and leisure time together and lastly, family optimism and mastery to maintain a sense of order and optimism. Also through mastery of the medical regimen that carries into the home environment an increase in the family’s understanding of the medical situation, helps with the adaptation process” (p.7). Families are often overwhelmed and severely challenged in the face of adversity. They may experience disharmony and imbalance, and sometimes even deteriorate in the face of a family trauma. Through the use of family protective factors and recovery factors families are able to adapt and recover from a crisis situation.
The resiliency Model of Family Stress, Adjustment, and Adaptation will be used to assess and intervene with the family that is dealing with a new diagnosis of short gut in their infant daughter because they are dealing with an event that has detrimental effects to their family. Their family unit has changed and their hopes and dreams of adding another family member to share their lives had drastically been altered. Their daughter has a condition that has a high likelihood of being fatal at an early age, with much uncertainty to her future health. This condition has altered the functioning of the family as previously known. The parents are focused on their “sick” new baby, while juggling the demands of raising other children, needing to return to work, the need to travel to a hospital an hour away from their home causing disruption in their roles as parents to their other children and added stress to their desire to be with their new baby. This model will assist with the assessment of the family and provide methods of intervention that will help them successfully adapt and develop effective problem solving and coping techniques. The Resiliency Model of Family Stress, Adjustment, and Adaptation provide a comprehensive framework for assessing this family’s strengths and areas of vulnerability in this stressful period of their lives. This model will assist in identifying methods to promote positive adaptation and changes in their lives to care for their newborn with chronic health problems and an uncertain prognosis while maintaining family balance.
CHAPTER 6

FAMILY ASSESSMENT

Hanson (2001) states, “the practice of family nursing requires that nurses use a systematic approach to assessment of the family as client” (p. 170). Family assessment begins upon admission of the patient and continues throughout the hospitalization until discharge. Wright and Leahey stress the importance of family assessment when the family is experiencing emotional, physical, and/or spiritual suffering or disruption caused by a family crisis such as acute illness, injury, or death (2000). The initial assessment is usually in a question/answer format to obtain basic data, but is then conducted in greater detail as the hospitalization continues. “The amount of detail is determined by the client, the clinician, the time available, and the instrument or guidelines used” (Hanson 2001, p. 172).

Many different models or combination of models are available for family assessment, providing a systematic method of assessing families. The Resiliency Model of Family Stress as described by McCubbin and McCubbin selected variables that resulted from a stressor, such as an unexpected acute illness that contributed to increased family demands. There are various tools available to assist in the assessment of these families. The literature discusses various instruments that were developed specifically to measure components of the Resiliency Model of Family Stress (Leske & Jiricha, 1998). Family demands such as prior stressors, strains, and transitions can be measured with the Family Inventory of Life Events and Changes tool (FILE). This is a 70-item instrument
designed to assess both normative and situation family life events, stressors, hardships, and strains a family might experience (McCubbin et al. 1980 cited in Tak & McCubbin, 2002 & Doucette & Pinelli, 2004). Family strengths and capabilities are frequently measured using the Family Hardiness Index. This is a 20-item questionnaire that measures four components that families use to respond to stressful life events: confidence, challenge, commitment, and control. Families are asked to indicate the degree to which statements applied to their family situation on a 3-point scale (McCubbin, McCubbin, Thompson, Han, & Allen, 1997). The family Inventory of Resources for Management is a tool used to assess family resources. It assesses social, psychological, and community resources that the family uses to help them cope with a current stressful event. Another instrument that is mentioned in the literature that assesses family resources is the Olson’s Family Adaptability and Cohesion Evaluation Scale (FACES III). It measures family adaptability, cohesion, and social resources (Board & Ryan-Wenger, 2000). Coping can be measured with the Family Crisis Oriented Personal Evaluation Scale (F-COPES). This instrument measures coping strategies used by families in difficult situations. It is designed to focus on coping strategies within the family and on the family’s interaction with the community. Another tool seen in the literature that assesses parental coping with an ill child is the Coping Health Inventory for Parents (CHIP) (McCubbin et al. 1979 as cited in Tak & McCubbin, 2002). Problem-solving communication is often measured using the Family Problem Solving Communication Index. This is a 10-item measure designed to assess the specific communication style that families use to manage and solve problems and conflicts in various types of stressful situations (Leske & Jiricha, 1998 & Doucette & Pinelli, 2004). Lastly, family adaptation and outcomes can be measured using the Family Adaptation Scale. This is an 8-item inventory measuring the family’s feelings about health, tension, depression, energy, fear, and anger (Leske & Jiricha, 1998). There are many well-
established, valid instruments that are available to the healthcare provider to assess the needs of families during an acute/chronic illness of a family member that will assist them in identifying areas of need within the family.

The Friedman Family Assessment Model consists of six categories that assist the healthcare provider in assessing family’s under stress, they include: identifying data, developmental stage and history, environmental data, family structure, family functions, and family stress, coping, and adaptation (Friedman, Bowden, & Jones, 2003). Each category contains many sub-categories that may or may not be relevant to a specific family. After a basic screening of the family, the healthcare provider will identify areas that need further assessment. Friedman et al. states, “the depth and breadth of assessment is dependent on the family’s goals, problems, and resources, as well as the nurses role in working with the family (p.583).

The Friedman Family Assessment Model is used to assess the family that has a daughter hospitalized who was born with the absence of her small intestines and has a poor long-term prognosis. The baby described in this case study was a patient in the Neonatal Intensive Care Unit (NICU) for eight weeks. A.P. had a relatively smooth hospitalization after she stabilized from her initial surgery. She progressed quickly and stabilized from a surgical standpoint. She was started on feeds at 1 ml/hour per her G-tube and was advanced to 4 ml/hour over the initial six weeks of her hospitalization. She suddenly developed increased stool output and showed evidence of poor absorption of her nutrients at this rate. Feeds needed to be reduced to 2 ml/hour and subsequently advanced to 3 ml/hour at the time of discharge. Her total enteral intake was minimal, receiving the remainder of her nutrition from total parental nutrition (TPN). She had an indwelling broviac that would be continued indefinitely for homegoing use and TPN needs. Multiple health care providers were involved in caring for this family, including the Neonatologists, the Neonatal Nurse Practitioners (NNP’s), several staff nurses who
were primarily assigned to care for this baby, dietitians, hospital pastoral care, social work and case management/discharge planners.

J.P. had a high-risk pregnancy caused by a potential bowel obstruction of her unborn baby with subsequent polyhydramnios. A premature delivery was electively done at 34 weeks gestation due to antenatal ultrasonography showing worsening polyhydramnios. These are all stressors that the family was dealing with prior to the birth of A.P. After her birth it quickly became evident to the family that they were dealing with a much worse diagnosis of short gut syndrome, that has life long issues for their new daughter. A grave prognosis was given, with a high likelihood of A.P. dying at an early age from this problem. The family was discharged with hospice involvement and twelve hours of nursing care in their home daily to provide palliative care for A.P. This family is dealing with a very difficult situation that started with the prenatal diagnosis, actual diagnosis after surgery, the transitions occurring within their family and the realization of the long term health problems that will impact their daily lives in caring for A.P. The family was assessed in terms of the Adaptation and Adjustment Phase of the Resiliency Model of Family Stress.

The advance Practice nurse (APN) can utilize multiple assessment tools to generate data regarding this family. The techniques should focus on the family’s coping skills, the presence/absence of support systems, identifying other stressors the family may be dealing with, determining family typology, determining how the family views the hospitalization of the baby, and identifying the family’s problem solving skills.

According to Wright and Leahey (2000) “the genogram and the ecomap are two tools that are particularly helpful for the nurse to utilize in outlining the family’s internal and external structures” (p. 86 & 87). The genogram should include at least three generations to allow for identifying possible support systems in the extended family in addition to identifying any additional stressors that may be present. The genogram can
also help the nurse ascertain information regarding genetic issues, past or present illnesses the family may be coping with, and family structures.

"The ecomap is a visual representation of the family unit in relation to the community; it shows the nature of the relationships among family members and the world around them" (Hanson, 2001, p. 181). The ecomap can provide insight into strengths the family can utilize, identify possible weaknesses regarding access to potential support systems, identify stressful relationships between individuals, identify possible medical/behavioral/emotional problems of family members, and show what resources are going into and coming out of the family unit. Wright and Leahey state, "the genogram and the ecomap increase the nurse's awareness of the whole family and the family's interactions with larger systems and their extended family" (p.96).

Another assessment tool that the APN can use with this family is a focused interview. The practitioner should ask questions such as: Who comprises the family? How long has the family been together? Does anyone else live with you? Is there anyone else you think of as family that does not live with you? Describe the roles of each family member. How are you feeling about A.P.? Share with me what you know about the baby's condition and long-term prognosis? What other concerns do you have taking care of A.P. at home? How are both parents dealing with this diagnosis? Who will help at home when A.P. comes home from the hospital? Will any extended family be helping with A.P. and the other children? How is their marriage? How are they communicating through this stressful time? How are the other children coping? Are there any behavior problems they are seeing with A.P.'s prolonged hospitalization and change in family functioning? Are they involved in a church? Do they find comfort and support in their church community? Have they had A.P. baptized? What are their feelings having nursing care in their home for 12 hours a day? What interruptions in their daily lives do they foresee with this intrusion? Tell me how your family typically deals with problems.
Tell me what you do to relieve stress when you are feeling overwhelmed. What are your main concerns at the present time? Tell me what we can do to help relieve some of the stress you are feeling right now. What would you like assistance with at the present time? Which family member makes the most important decisions for the family? Are there financial issues? Will you be returning to work? Will dad be able to take time off work? Are there community services your family uses? Are there community services you would like to learn about but do not know how to contact? (Friedman et al., 2003).

Through assessment, areas of maladjustment can be identified that allow the APN to develop nursing diagnoses relevant to the family and it’s adaptation and adjustment to the family member’s illness. The case study that was described above has many applicable nursing diagnoses that would be relevant for the healthcare team. The priority issues for this family would include: anticipatory grieving d/t the loss of a healthy newborn and the uncertain future for A.P., a deficit in knowledge r/t the complexity of understanding the care needed by A.P. such as continuous feeds, TPN, risk for infection, and increase in stool output r/t poor absorption of feeds, potential for feeling powerlessness r/t the inevitable progression of the disease process, interrupted family process r/t disruption of roles within daily family life related to caring for a chronically ill child and a prolonged hospitalization, risk of chronic sorrow r/t the chronic nature of A.P.’s illness, and risk of social isolation r/t ongoing health care needs of AP and the family being consumed by the care. One study indicated families are at risk for experiencing role ambiguity, disruption, and loss. The primary caregiver of a chronically ill/injured family member often becomes consumed with the role of “dependable one” in the family resulting in social isolation from other social supports (Renz, 1997). Another study explored family coping after discharge from the NICU which indicated that stress from life events since the child’s birth significantly reduced mothers’ marital satisfaction, whereas stress related to the child’s perinatal status significantly decreased the fathers’
sense of family cohesion (Doucette & Pinelli, 2004). These studies explore the significant changes that occur within a family when confronted with chronic illness/injury within the family unit. Other diagnoses may be added or deleted as the assessment and interventions are explored in collaboration with the healthcare team and the family. Friedman explains that “after family and individual health problems have been identified, they should be listed in order of priority, according to their importance to the family. Then the nurse and family may co-determine the direction for nursing care” (p. 183). This process enhanced collaboration and provides an optimal setting for family interventions to be successful.

These questions will help the practitioner identify the strengths/weaknesses within the family, will identify possible areas of intervention that the family identified as wanting assistance with, will identify possible support systems, and will help the APN formulate goals and plan intervention strategies. The literature supports that in most illness situations, the hardships are severe and major changes must take place in the family system, otherwise the family will experience maladjustment, resulting in a state of crisis. Crisis may cause deterioration of the family members’ health, deterioration of the family unit’s integrity and ability to function (Board & Ryan-Wenger, 2000). Therefore, through family assessment and identification of appropriate family nursing diagnosis, the APN is able to assist the family in identifying areas that will facilitate movement through the Adjustment Phase and Adaptation Phase of the Resiliency Model of Family Stress.
CHAPTER 7

INTERVENTIONS

The Calgary Family Intervention Model will be used to define needed interventions for this family. This model aims to promote, improve, and sustain effective family functioning in three domains: cognitive, affective, and behavioral. Wright and Leahey (2000) state, “a change in one domain will affect another domain” (p.157). Based on this family’s assessment and the fact that their baby was in the NICU and will have ongoing medical concerns, this family was in need of intervention. Through the focused interview, the genogram, and the ecomap, areas of needed intervention were established. This family had many strengths, had some weaknesses, and could benefit from outside support. Strengths identified include role flexibility, strong ties to their church, and significant extended family that was willing to help.

J.P. and R.P. were able to shuffle their normal roles and help each other with various tasks. According to Friedman (2003) “because of the rapid and pervasive changes in our society and hence in family life, role flexibility, especially among mates, constitutes a powerful type of coping strategy” (p. 479). J.P. originally identified that she was responsible for all the household chores since she did not work outside the home. During A.P.’s hospitalization, both J.P. and R.P. shared the responsibilities of meal preparation, laundry, and helping the other siblings with homework. Hamilton McCubbin indicates that families who are able to manage stress, work hard at keeping the family functioning. He states, “when under stress, it is very easy for family members to
withdraw from each other, doing things together is a coping skill utilized by families” (Thames & Thomason, 2002, p. 3). J.P. verbalized concern about how things would be when R.P. needed to return to work full-time and they got back to their routine once A.P. was discharged.

This family’s support from their church congregation was also a strong support system they utilized throughout A.P.’s hospital stay. Research validates that family’s spirituality, assists the family in placing the disease process into perspective. Callaban defines spirituality as, “the manner by which individuals make sense and establish meaning in the face of potentially life-threatening chronic illness” (Callaban, 2003, p. 236). Friedman discusses the importance of spiritual and religious beliefs as “the most fundamentally held beliefs of individuals and families, as the core of all family coping and adaptation (Walsh, 1998; Wright et al., 1996 as cited in Friedman, 2003). According to Friedman (2003), “These sustaining beliefs help families to endure acute life-threatening experiences, tolerate chronic, long-term strains, and ultimately to maintain the family unit” (p. 486).

An additional strength that was identified through the focused interview was that the family found the interaction with their extended family as an instrumental part of their family coping. The grandparents, aunts and uncles were helping with household chores, childcare and keeping the church community updated on their family’s needs. The importance of social supports and resources has been demonstrated consistently for families of both sick and health newborns, with respect to adjustment and to stress (Pinelli, 2004). Friedman discusses the importance of including as many family members as possible in planned educational and counseling sessions. He states that, “it allows family members to express themselves and support each other. It also stimulates much-needed group discussion and feedback and assures that all attending members obtain the needed information” (Friedman, 2003, p. 187).
A major weakness that was identified during the focused interview included the family’s understanding of the diagnosis and the course of events that would occur in the months to come for A.P. They did not know what to expect with hospice involvement and how soon after going home things could “turn for the worse”. They had concerns regarding staying at home when things got bad for A.P. and verbalized, “they have never seen someone die”. They also expressed concern for their other children and how they would be impacted by these events. They discussed their fear of bonding with their infant when they knew she was going to die from this disease. They also talked about R.P.’s brother who is a Gastroenterologist and his recommendations that “they should make A.P. comfortable and let the inevitable death come sooner than later”. He recommended that they do only what is needed to keep A.P. comfortable and that they should limit other interventions that may prolong her life. R.P. felt torn between his trust and loyalty to his brother and his desire to follow what the medical team was advising for A.P. and his desire to keep her alive as long as she was not suffering.

Family interventions will focus on the identified family strengths and weaknesses that were identified through the focused interview. Vosburgh and Simpson (1993) maintain “a focus for intervention becomes searching for strengths, welcoming differences in families and being respectfully curious about their uniqueness” (as cited in Friedman, 2003, p. 187).

The first family strength identified was the role flexibility that was occurring during A.P.’s hospitalization. Both R.P. and J.P. felt it was necessary to look at effective ways to ensure that they could meet each other’s needs after A.P. went home. R.P. acknowledged that he was required to work long hours and travel weekly. He also felt that it was important to continue his exercise routine, not only for his physical health but also for his emotional well-being. He verbalizes that his martial arts and his workouts are a way to “unwind” from the day and he looks forward to them. J.P. verbalizes that in
normal circumstances she is okay with his commitments outside of the house, but when
A.P. comes home, she could not see them being able to juggle home-life with R.P. being
away as often. J.P verbalized, “that she cannot do this by herself”. R.P. communicated
that he could incorporate his workout into his martial arts training and limit it to two
nights a week. He also felt it would be possible to limit his business travel over the next
few months as they adjusted to having A.P. home. Wright and Leahey (2000) indicate,
“the first useful intervention, within the stage of creating the circumstances for change,
was bringing the family together to engage in new and different conversations” (p. 27).
Families may need help to coordinate responsibilities for particular caregiver activities
(Gilliss et al., 1989 as cited in Hanson, 2001). Through renegotiation, R.P and J.P. can
make changes to reorganize themselves around A.P.’s chronic illness and meet ongoing
family needs. Communication is listed as one of the ten most important tools that
promotes family resiliency (McCubbin, et al. 1997). The APN can promote the
importance of effective communication as a tool to effective negotiation of roles and
responsibilities. McCubbin and colleagues emphasize that “family hardiness is inclusive
of a shared commitment to work together to attack and solve the presenting problem; the
family reframes and defines the hardships it experiences as challenges” (p. 9).

The second area of strength this family identified was their strong belief in God
and their support from their church family. Friedman (2003) discusses the
importance of maintaining family involvement in family rituals that have meaning and
value to the family. Attending church and seeking an ongoing relationship with the
church community can help the family’s coping response. He states, “these beliefs are
powerful forces in enhancing family resilience” (p. 486). The family was encouraged to
continue their relationship with their church and keep them involved during this transition
in their lives. They verbalized a desire to have A.P. baptized before being discharged and
having their pastor come and visit with them while still in the hospital. A.P. was baptized
in the hospital chapel by their church pastor a week before being discharged. A large extended family and church family was invited and attended the baptism, along with friends and caregivers of A.P. The pastoral care department stayed involved throughout the hospitalization. The church had arranged to provide meals for the family three to four times a week for the next few months while they were adjusting to having A.P. home. According to Thames and colleagues (2002), “families are better able to endure hardships if they reach out to the community instead of becoming isolated from it” (p.3). Wright and Leahey (2000) discuss the implications of interventions that “invite meaningful conversation, noticing and distinguishing family and individual strengths and resources, and careful exploration of concerns” as methods to make a positive difference for families facing a family member’s chronic-illness (p. 27).

Through the use of the genogram, and the focused interview, family support from the extended family was identified as another strength to this family unit. Watts and Shrader (1998) describe the genogram “as a tool to better understand the dynamics that occur within different households, and how these influence household decision-making and patterns of behaviors” (p.462). The genogram identified a large extended family that lives within close proximity to this family. They are involved with them on a daily basis and have been helping with the family demands during A.P.’s hospitalization. The ecomap showed the strong relationships and connections they have with their extended family. J.P. communicated that her mother and sisters have expressed a desire to help with A.P.’s cares once she is discharged from the hospital. R.P. and J.P. both felt their extended family would be willing to help in any way possible. Renz (1997) discusses effective family coping, as directly related to the balance that is achieved between the pile-up of demands the family is experiencing and the family resources and capabilities. She states, “the family’s resources and capabilities to buffer the stress over time may consist of the family’s appraisal of the injury/illness, cohesion, family time together, and
a strong family schema” (p.5). The APN may be instrumental in involving extended family in learning the cares that A.P. will require after discharge. During the hospitalization the parents and extended family should be encouraged to visit on a regular basis so that they will become comfortable caring for A.P. The parents, grandparents and other extended family that will be involved with A.P. can begin with holding, diaper changes, baths, and consoling through nesting and therapeutic touch. The nurse and the APN can facilitate this learning process through reassurance of how they are doing and by demonstrating correct methods that are beneficial to babies like A.P. Simple parenting tasks such as bathing can increase the confidence level of the parents, and other family members. This will help them feel they are contributing to the care of the baby. They are encouraged to bring clothes from home for her to wear, another way to make the parents feel like they have some input into the day-to-day activities of the baby. As they become more comfortable handling A.P., the APN and nurse can assist the family in learning how to provide G-tube feeds and broviac care.

Other interventions that the APN can utilize with this family include: To commend family or individual strengths, to validate emotional responses related to A.P’s hospitalization, to help the family utilize outside support systems to deal with the stress of A.P’s hospitalization, to encourage respite from prolonged visits by encouraging families to go home and get sleep, taking a break, or even dividing the time at the bedside with other family members so that J.P. and R.P. feel comfortable leaving A.P., and lastly by commending the family on individual strengths, the APN can foster a mutual caring and respectful relationship. Wright and Leahey (2000) state, “by commending families’ competence and strengths and offering them a new opinion of themselves, a context for change is created that allows families to then discover their own solutions to problems” (p. 166). It is important for healthcare team members to encourage parents to give themselves permission to step away from the bedside and take time off from visiting.
According to Wright and Leahey (2000), “caregiving, coping, and caring for one’s own health need to be balanced” (p. 171). If A.P. was having a good day, the practitioner could suggest to the family that they “take the night off” from visiting the hospital. Perhaps they could have a family dinner with the other two children, go to the movies, or even rent a video and have popcorn at home.

An area of weakness that was identified is the family’s uneasiness regarding what to expect as A.P. transitions home and how soon thereafter to expect her to “take a turn for the worse”. They expressed concern with the death and dying process and methods to help their children cope with A.P.’s illness as it advances. An APN can be instrumental in assisting in educating the family about the physiology of the disease process and the pathology occurring. Friedman (2003) states, “families often respond to stress by seeking knowledge and information concerning the stressor, this is particularly true in the case of serious or life-threatening health problems” (p.481). The APN can facilitate an open forum to allow the family to ask specific questions of the various specialty services involved with A.P. through a care conference. A care conference was arranged at two different times during A.P.’s hospitalization, once initially after surgery and again a few weeks prior to discharge. This conference brought together providers of care that included neonatologists, surgeons, aurse practitioners, social work, case management, hospice, and pastoral care. It gave the family the opportunity to openly discuss any questions they had regarding A.P. and her current plan of care. This meeting lasted approximately two hours, and through this meeting it was identified that they needed further information from hospice. The APN facilitated a meeting between hospice and the family at A.P.’s bedside. They met the primary nurse that would be following them at home and discussed in depth their desires. The hospice nurse was able to alleviate some of their concerns regarding suffering and pain that A.P. may experience by talking about hospice’s philosophy of treatment and the use of medications to ensure comfort through
the dying process. They provided a palliative care plan for A.P. that reinforced to the family that their wishes would be honored as they transitioned home. The hospice nurse was able to provide a referral to a support program for the siblings that would assist the children in their grieving process in a developmentally appropriate way. She also encouraged the family to seek counseling on a regular basis with either a professional counselor or a church pastor to keep the line of communication open and ensure that the family’s needs were openly explored. The family agreed that they would set up a weekly appointment with their pastor to ensure that openness and sharing of ideas and feelings continued during this stressful time. Friedman (2003) states, “good communication is vital to family functioning, it becomes even more crucial during periods of family stress and crisis” (p. 481). The anticipated outcome of the external strategies is that the family will tolerate and ultimately endure the life-threatening events to one of its members as well as the chronic strains of the ongoing illness (Callaban, 2003). The social worker was also able to provide the family with information about a support group that met at Children’s Hospital that involved families that were also going through similar circumstances as they were. J.P. expressed interest in being involved in this group and thought she would call them and find out more information. R.P was hesitant to participate in support groups but thought that it was something that might help J.P. by having other people in similar circumstances to talk to. The APN was able to provide the family with websites that were accessible from the Internet that provided further evidence-based information on short-gut syndrome. Friedman (2003) concludes, “assisting families to use the Internet effectively to gain accurate and current information is an increasingly important role for family nurses to play in helping families cope” (p. 481). The family verbalized that the care conference was very helpful and felt more comfortable as they approached discharge. By validating emotional responses the practitioner can open a floodgate of emotions. “Validation of intense affect can alleviate
feelings of isolation and loneliness and help family members to make the connection between a family member’s illness and their emotional response” (Wright & Leahey, 2000, p. 168).

As discharge approached, A.P. was relatively stable without any acute issues. Formal infant CPR teaching was arranged, medication administration was taught, along with broviac care and TPN usage, feeding pump usage and feeding through a G-tube. The family decided it would be best if they stayed for a 24-48 hour period prior to discharge to ensure they were comfortable with all cares. They also had the grandparents and aunts of A.P. come two at a time to also learn the cares and have an opportunity to ask questions. The APN provided support, reassurance, and ongoing teaching during that time. The case manager arranged home nursing care for the family, which was able to provide 12 hours of daily nursing care in their home. The APN counseled the family on the long-term care plan and follow-up appointments that would be needed for A.P. A.P. would need to have regular pediatrician visits, in addition to close follow-up with the Surgery Clinic at Children’s Hospital. Hospice would visit weekly initially, until A.P.’s condition worsened or further family concerns were identified. Hospice planned on adjusting their visits as needed as A.P.’s condition deteriorates.

In addition, the APN can revisit some of the other questions from the original focused interview to determine whether the family is moving through the Adaptation Phase of the Resiliency Model, and to ascertain whether further interventions/referrals need to be done to enable the family to function at their optimal capacity. Research indicates that infants with chronic, on-going health problems were associated with increased risk for poor family adjustment (Doucette, & Pinelli, 2004). Therefore, a theoretical foundation such as The Resiliency Model of Family Stress, Adjustment and Adaptation can guide the practitioner in evaluating the family for risk factors that could lead to maladjustment. Through the Calgary Family Intervention Model the healthcare
team can focus on promoting, improving, and sustaining effective family functioning (Wright & Leahey, 2000).
CHAPTER 8

PALLIATIVE CARE OF THE NEWBORN

Palliative care of the newborn is holistic and extensive care for an infant who is not going to "get better". Palliative care focuses on both the infant and the family. Its purpose is to relieve infant suffering and improve the conditions of the infant’s living and dying. It focuses on the infant’s physical needs as well as the psychological, social, emotional, and spiritual needs of the family (Catlin & Carter, 2002). It is important to address palliative care of the newborn because each year in the United States 15,000 children are born who have conditions that are incompatible with prolonged life beyond the first year or die soon after birth. Infant mortality in the United States is approximately 7 per 1,000 live births with the majority occurring within the first month of life (March of Dimes, 2005).

The American Academy of Pediatrics supports the development of clinical policies and standards that promote the welfare of infants and children living with life-threatening or terminal conditions. They advocate for providing equitable and effective support for curative, life-prolonging, and palliative care of the newborn (AAP, 2000). Dying with dignity and without pain or distress is the primary goal of palliative care. Principles for palliative care have been outlined in the literature to address the child and
family’s needs as they go through their illness. They include: respect for the dignity of patients and families, access to competent and compassionate palliative care that may include therapies that are likely to improve the family’s quality of life through education, grief and family counseling, peer support, spiritual support, respite care, and hospice involvement (AAP, 2000).

The Resiliency Model of Family Stress, Adjustment, and Adaptation can guide the practitioner in evaluating the family and identifying their strengths and areas of weaknesses. Through a thorough assessment, appropriate interventions may be outlined to help the family who has chosen palliative care for their newborn. The healthcare team can continue to focus on promoting, improving, and sustaining effective family functioning through a time in a family’s life when they are faced with the likelihood of losing a family member. When parents lose an infant, they are losing more than a child. They are losing their hopes and dreams for the future. Caregivers must help the family focus on the positive aspects of the infant’s life, no matter how short the life may be (Maginnes, 2002). It is vital that the healthcare team recognizes the range of emotions that parents and the family unit experience. While palliative care will not change the outcome, it can make the outcome a more positive experience for families.
LIST OF REFERENCES


