

ABSTRACT

Effective Familial Coping with a Chronically or Terminally Ill Child

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Due to a personal experience with chronic illness as a child and a passion for these children and their families, this thesis deals with effective and ineffective coping mechanisms of parents and siblings of a child with a chronic or terminal illness. A review of the literature is proposed and themes are identified for these families such as uncertainty about the child's illness and its prognosis and increased psychological and financial stressors on the family throughout the child's illness. Many of the resources utilized for the research on this topic discussed the increased stress on the entire family during a child's illness, promoting the use of the family systems approach when applying the nursing process. When using the nursing process with this approach, the nurse, along with the family, assesses the health history and dynamics of the family, diagnoses the important issues at hand, plans ways to alleviate these issues, implements appropriate interventions, and evaluates whether the interventions worked to improve the family's issues noted in the nursing diagnosis. Finally, nursing implications regarding effective and ineffective methods of coping for mothers, fathers, and siblings are outlined. This thesis provides nurses with a knowledge base for implementing a family nursing technique and promoting positive coping mechanisms for the families of children with chronic or terminal illnesses.

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EFFECTIVE FAMILIAL COPING WITH A CHRONICALLY
OR TERMINALLY ILL CHILD

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CHAPTER ONE

Introduction and Background

Background

Though terminally and chronically ill children are defined differently, it is assumed that all patients and their families will employ ways to cope with the diagnosis of a child's illness. Nurses and other healthcare providers should be aware of appropriate nursing interventions to implement for these families. According to the World Health Organization (2013), a chronic disease is defined as one "of long duration and generally slow progression." Another way to help describe chronic illness is referenced by Larsen and Lubkin (2009), in that it "continues indefinitely...[and] can appear suddenly or through an insidious process, have episodic flare-ups or exacerbations, or remain in remission with an absence of symptoms for long periods of time" (pp. 4-5). A terminal illnesses, however, is described by the Department for Work and Pensions in the United Kingdom as "any illness which ends in death...[and] there is no possibility for recovery" (Crown, 2009). For the purposes of this paper, terminal illnesses encompass aspects relating to parents of children living with a terminal illness and parents of those children who have died due to a terminal illness.

Prevalence and Incidence

Upon researching the prevalence and incidence of chronic and terminal illnesses in children, limited information is available. However, according to the University of Michigan Health System, authors Boyse, Boujaoude, and Laundry (2012) determined that,

according to their description of a chronic illness as one that “lasts over three months...about 15-18% of children in the United States live with a chronic condition” of which they include asthma, diabetes, cerebral palsy, sickle cell anemia, cystic fibrosis, cancer, AIDS, epilepsy, spina bifida, and congenital heart problems. In regards to terminal illnesses, it is noted by the Centers for Disease Control and Prevention (CDC) (2014) in the United States that the second leading cause of death in children ages one to four are “congenital malformations, deformations, and chromosomal abnormalities” and in children ages five to fourteen, the second leading cause of death was “cancer” (“Child health”). Because cancer is such a large cause of child mortality in the United States, it is generally one of the first illnesses one thinks of when discussing terminal illnesses.

According to the CDC document “Cancer Among Children” (2013), the leading causes of cancer related deaths in children in the United States in 2010 were leukemias and brain and central nervous system cancers. CureSearch (2012) provides data suggesting that survival rates have drastically improved over the years, however, still “12% of children who are diagnosed with cancer do not survive.”

Implications

As limited as these statistics and data are for general conditions, they imply that healthcare providers, nurses, and researchers need not only to continue studying cures for both chronic and terminal illnesses, but also provide effective ways for child patients and families to cope during the duration of the child’s illness. Though acute illnesses and infectious diseases are important as well, chronic and terminal illnesses usually need long-term or lifelong treatment that permits nurses to engage in close relationships with these patients and their families. Because illnesses require the utilizations of coping

mechanisms by the patient and family, whether healthy or unhealthy, it is important for the nurse to implement interventions to promote healthy coping mechanisms. Lazarus and Folkman (1984), authors of *Stress, Appraisal, and Coping* define coping as “constantly changing cognitive and behavioral efforts to manage specific external and internal demands that are appraised as taxing or exceeding the resources of a person,” such as childhood illnesses. Unfortunately, there is limited research on this subject, as evidenced by Burke, Handley-Derry, Costello, Kauffmann, and Dillon (1997) who suggest that more research needs to be conducted in regards to the effect these illnesses have on children and their families. Furthermore, Melnyk, Alpert-Gillis, Hensel, Cable-Beiling, and Rubenstein (1997) found in their literature review that providing interventions to help these families cope is necessary and should occur promptly, which lead to the topic of their research. This paper is written in hopes to outline some of the interventions that could be helpful for parents and siblings of these children.

Many coping interventions deal with the psychological aspects that an illness may have on the family and child. Koplewicz and Gurian (2001) determined that chronic illnesses affect nearly 20% of children physically—close to the estimate made by Boyse et al. (2012) of 15% to 18%—and that having this kind of illness can also pose psychosocial problems for the child that need to be addressed. In order to do that, the nurse needs to understand the implications of a disease, its prognosis, and establish a trusting relationship with the patient and family to assess their needs holistically and be sure to include the physical, emotional, psychological, and spiritual aspects of the patient and family when planning and implementing care.

Throughout this paper, the reader will find a review of literature, a description of the family health systems approach described by Anderson (2000), as evidenced in articles by authors including Broger and Zeni (2011), Dodgson, Garwick, Blozis, Patterson, Bennett, & Blum (2000) and Hovey (2005), which describes that the suffering of one family member has an effect on the entire family, and a concluding chapter discussing the interventions that nurses need to put in place such as providing families with as much information and knowledge as possible, helping families find support groups, determine what aspects of support they may be lacking, determine what types of coping may be beneficial and healthy, such as religion and spirituality, and determining coping differences in fathers, mothers, and siblings of the child.

CHAPTER TWO

Literature Review

Introduction

The literature reviewed consisted of documents discussing chronic and terminal illnesses, with a focus on children, and how the families of these children utilize effective or ineffective coping mechanisms during times of illness. Because of the focus on enhancing the utilization of positive coping mechanisms to manage the threats and emotions of a child's diagnosis, it is important for nurses to intervene for both the patients and the families of the patient. This is supported by Kathryn Hoehn Anderson's (2000) statement that "without consideration of family needs, patient care is incomplete" (p. 111). Additionally, Burke, Handley-Derry, Costello, Kauffmann, and Dillon (1997) determined that parental coping could effect how the child reacts to being in the hospital, justifying that both the child and family should be assessed and provided with interventions for positive coping enhancement.

Many of the articles discussed stress in the family when a child is diagnosed with an illness (Broger & Zeni, 2011; Burke et al., 1997; Dodgson et al., 2000; Gage, 2013; Hexem, Mollen, Carroll, Lanctot, & Feudtner, 2011; Hovey, 2005; Kloosterhouse & Ames, 2002; Knafl & Zoeller, 2000; Melnyk et al., 1997; Rempel, Ravindran, Rogers, & Magill-Evans, 2013; Ritchie, Stewart, Ellerton, Thompson, Meade, & Viscount, 2000; Williams, Ridder, Setter, Liebergen, Curry, Piamjariyakul, & Williams, 2009). Within the theme of stress, many subthemes emerged throughout the literature including the

physical (Ritchie et al., 2000), psychological (Koplewicz & Gurian, 2001), and financial (Bona, Dussel, Orellana, Kang, Geyer, Feudtner, & Wolfe, 2014; Kuhlthau, Hill, Yucel, & Perrin, 2005) stress that the ill children and their families face. In addition, other themes that emerged from the literature included differences between fathers and mothers in coping, sibling coping, and uncertainty regarding the child's illness. Though "Chapter 4: Implications for Practice" details and reviews much of the literature, the remaining literature will be described in more detail in this chapter.

Family Health Systems Approach

Many studies were reviewed regarding chronic and terminal illnesses in children and coping in their families. As Dodgson et al. (2000) notes from Patterson and Garwick (1994), the entire family is affected when a child is diagnosed with an illness, suggesting the pertinence of providing care for both the child and other family members. This is outlined in Anderson's (2000) article discussing her family health systems framework for providing nursing care for the entire family. In Anderson's (2000) framework, the goal of the family health systems approach is to provide families with a way to return to an acceptable or even higher level of functioning during the health crisis of a family member. This suggests that utilizing the nursing process, in collaboration with the family, of continually assessing, diagnosing, planning, implementing, and evaluating the care of the family provides families with ways to increase their family functioning through the help of effective nursing care (Anderson, 2000). Anderson (2000) determined that by utilizing this theoretical approach, which is explained in more detail in Chapter Three, the family will move "toward improved health and well-being," and learn

to effectively handle sickness in the family “while promoting family strengths and overall health” (p. 117).

Stress

Burke, Handley-Derry, Costello, Kauffmann, and Dillon (1997) conducted a study with the stated purpose of determining an intervention’s value on a chronically ill child’s behavioral and developmental levels after being in the hospital, “parental stress and coping, and on family functioning” (p. 476). According to Burke et al. (1997), parental coping affects the positive or negative reactions that these ill children have on being hospitalized. Therefore, it can be assumed, as suggested in the family projection process by Bowen (Bowen Center, n.d.), that parental coping and stress has an effect on the outcome of the child’s illness. Burke et al. (1997) found that the implementation of the “stress-point intervention” did indeed help parents cope with the child’s illness throughout the hospitalization process (p. 484). Additionally, Burke et al. (1997) found that, with this intervention, family functioning also increased, which implies that the family effectively coped with the stressor.

Another source of stress for families with a chronically or terminally ill child is finances. In an article by Bona et al. (2014), the authors express the need for more focus on financial issues that families are facing during their child’s illness. Additionally, Kuhlthau et al. (2005) found that in families of children with special healthcare needs, “18% needed additional income, over a quarter have cut back work hours, and 13% had a family member stop work,” adding up to “just over 40% or 3,746,000 families nationwide with finance-related family problems related to their child’s health condition” (pp. 209-210). Because of this increase in financial burden for these families, there is an

implication that the need to keep parents and guardians working is high, however, if someone must quit his or her job to take care of the child, the financial burden increases even more due to a decrease in income. This could lead to an even higher increase in stress on the family, especially for the parents or caregivers providing the source of income for the family.

According to Koplewicz and Gurian (2001), a chronic illness can have psychological effects on children and they assert that the familial reaction to the illness will influence the ill child. Therefore, it is important for parents to be able to cope effectively, so that the ill child will have decreased anxiety and implement effective coping mechanisms as well (Koplewicz & Gurian, 2001). Because the aim is improving outcomes for families of these children, it is vital for nurses to utilize a family approach when providing care for the patient (Anderson, 2000). Koplewicz and Gurian (2001) suggest family therapy, stating that “it can...be helpful for ventilation of feelings and clarification of misinformation by children and their siblings” (p. 4). Correcting this misinformation can aid in reducing the amount of uncertainty the children and family may be facing regarding the child’s illness.

Uncertainty

Dodgson et al. (2000) conducted their study on uncertainty due to the family’s lack of knowledge regarding the child’s prognosis and how it effects stress in the family. The researchers “hypothesized that children with chronic conditions that are more uncertain will be associated with more distress in the family” (Dodgson et al., 2000, p. 255). Dodgson et al. (2000) found that unpredictability of symptoms for mothers had a positive correlation to family/social disruption, emotional strain, and financial burden.

For fathers, Dodgson et al. (2000) also found a positive correlation between unpredictability of symptoms and family/social disruption. These findings suggest the probability of an increase in the child's likelihood of having a negative outcome (Dodgson et al., 2000). However, in regards to the child's prognosis, there was not a positive correlation between uncertainty in the prognosis and family distress (Dodgson et al., 2000). Dodgson et al. (2000) suggests that a continual assessment be performed to decrease familial uncertainty regarding a child's illness, and therefore, decreasing familial distress and enhancing coping mechanisms utilized in dealing with the stresses of a chronically or terminally ill child.

Paternal and Maternal Differences and Coping

Some of the articles reviewed specifically discussed the differences in mothers and fathers and how they cope with the illness of their child, while others focused on mothers or fathers only. Hovey (2005) and Broger and Zeni (2011) suggest that ill children with fathers who are more involved in the child's care have more positive outcomes. Further, Broger and Zeni (2011) state that not only will the ill child be affected positively, but also the entire family unit.

Melnyk et al. (1997) focused on the coping process of mothers with children who are critically ill. In Melnyk et al.'s (1997) pilot study, the researchers created an intervention entitled Creating Opportunities for Parent Empowerment, or COPE, that aimed to help "enhance coping outcomes in critically ill young children and their mothers" (p. 4). The first phase of the COPE intervention gave mothers the knowledge of how their ill child would behave and the role of the parent in the situation of a critically ill child (Melnyk et al., 1997). The second phase gave mothers more

information about how a child will react to being in the hospital and how the mothers can help the children cope effectively and also provided the mother and child with an activity book to complete together to help encourage positive coping (Melnyk et al. 1997).

Melnyk et al. (1997) found that the mothers receiving the COPE intervention were more supportive physically and emotionally, were not as negative, and “reported significantly fewer PTSD symptoms for themselves” in comparison to the group that did not receive the COPE intervention (p. 9). These findings suggest the importance of providing families with ways to positively and effectively cope with stressful situations regarding their child’s health.

On the contrary, Hovey (2005) studied fathers with the purpose of gaining insight on the fathers’ coping mechanisms utilized and what mechanisms the fathers felt their wives utilized during the chronic illness of a child. Hovey (2005) found that the child’s health and limits on time, such as “extra demands on time” and “enough time alone” for the parents were of most concern to the father for himself and the child’s mother (p. 91). Hovey (2005) found that the fathers’ focus was providing activities and an environment where the family would be able to feel normal and still maintain positivity considering the circumstances. Hovey (2005) also found that “trying to figure out what to do, looking at options, getting information, and weighing choices” were the main mechanisms that fathers used to cope (p. 92). The fathers in Hovey’s (2005) study felt that their wives used the same sort of mechanisms as themselves with the addition of “reading about the problem” (p. 92). By employing these strategies, the parents provided themselves with a knowledge base about the illness, thus reducing uncertainty regarding diagnosis, treatment, and prognosis. Additionally, it was found that a small number of

fathers ineffectively utilized drugs and alcohol to cope with their child's illness (Hovey, 2005). Broger and Zeni (2011) assert that "effective management by fathers of stressors brought on by their child's chronic illness can lead to greater involvement by fathers...thereby positively affecting the individual child as well as the family's overall well-being" (p. 97). This suggests that the use of ineffective coping mechanisms, especially by the father, may mean that the ill child and family may suffer.

Broger and Zeni (2011) assert that fathers are more involved in their children's lives now than in the past, therefore, it is important to involve fathers in the care of a chronically or terminally ill child. In their study, Broger and Zeni (2011) were trying to gain information on coping mechanisms of fathers with chronically ill children. The problem that Broger and Zeni (2011) faced when conducting their literature review was the lack of research focusing in on fathers. Darbyshire et al. (2012) supports this problem when interviews with fathers about a telephone support program revealed that fathers wished more support was available to them. What Broger and Zeni (2011) found when studying fathers' coping mechanisms was the use of positive reappraisal, planful problem solving, seeking social support, self-controlling, distancing, confrontive coping, accepting responsibility, and escape-avoidance in that order. There was an inverse correlation between the fathers' age and distancing, self-controlling, and escape-avoidance and an inverse correlation between the fathers were marital status and confrontive coping, accepting responsibility, and escape-avoidance. All in all, Broger and Zeni (2011) noted the importance of coping by stating that the "effective use of coping mechanisms can be a successful tool in improving the overall outcome of a child's well-being," which is the ultimate goal (p. 102).

According to Alam, Barrera, D'Agostino, Nicholas, and Schneiderman (2012), differences exist between mothers' and fathers' grief reactions following the death of a child due to cancer. The purpose of this study was to identify these differences for parents of children both six and 18 months following the child's death. Alam et al. (2012) found differences in mothers and fathers in the themes of employment attitudes and practices, grief expression, coping with grief, and relationships with surviving children. Additionally, Alam et al. (2012) noticed that over the 12-month period, parents' attitudes changed regarding employment, grief expressions, coping with grief, and relationships with extended family members.

In the study conducted by Knafl and Zoeller (2000), the goal was to determine both mothers' and fathers' views of the impact of a child's illness on their personal life and on the entire family. The researchers found that both mothers and fathers "develop[ed] a shared view of the illness, its management, and its impact on family life" (Knafl & Zoeller, 2000, p. 298). They determined that when both the mother and father share a positive outlook on the illness, their ability to return to a prior, stable level of functioning was plausible within months (Knafl & Zoeller, 2000). However, some parents did not have a shared experience, but rather an individual one. Knafl and Zoeller (2000) found that "for these couples it usually was the mother who emphasized the negative impact of the illness" (p. 298). Knafl and Zoeller (2000) agree with Dodgson et al. (2000) and Anderson (2000) that ongoing assessments of families with ill children are important and should be performed. Further, Knafl and Zoeller (2000) assert that the effect of the illness should also be assessed for each individual family member.

Siblings

Williams et al. (2009) determined that the negative symptoms siblings could be expressing when their sibling is ill are those of “loneliness and isolation, anxiety, depression, vulnerability, anger...worry...somatic complaints...and...behavior problems” (p. 97). Further, Williams et al. (2009) found that a minimal amount of studies did cite positive effects on these siblings, including “increased family closeness, increased sensitivity or empathy, and personal maturation in siblings” (p. 97). Williams et al.’s (2009) study provides information regarding how parents feel their children who are not ill act in relation to the child that is ill. Unfortunately, it was found that only about one-third of parents felt that siblings of children with cystic fibrosis and one-fourth of parents felt that siblings of cancer patients had positive outcomes, suggesting that, siblings of chronically or terminally ill children have more negative outcomes and experiences than positive ones (Williams et al., 2009).

Conclusion

This review represents the literature found during the research of effective familial coping mechanisms of chronically or terminally ill children. The remaining literature is discussed in Chapter Four, entitled “Implications for Practice.” Chapter Four goes into more depth about the remaining studies and how nurses can utilize the findings to improve care of the family living with a chronically or terminally ill child.

CHAPTER THREE

Family Health Systems Framework and Childhood Illness

Introduction

As Dodgson et al. (2000) cites Patterson and Garwick (1994), according to the “Family Systems Theory, the whole family is affected when a young child is diagnosed with a chronic condition” (p. 254). A number of descriptions of the family unit could be taken into account such as a child who has both parents and multiple siblings, a child with a single parent, or a child who is an only child with both parents, one parent, or any form of legal guardian(s) or caregiver, and many more. Ultimately, no matter what the family dynamic is, the caregivers, guardians, siblings, and loved ones of the child will be affected by the child’s illness (Dodgson et al., 2000 citing Patterson and Garwick, 1994).

It can be assumed that stressors vary from family-to-family and person-to-person; however, the family of a child with an illness has an even greater amount of stress placed on it (Friedman, Bowden, & Jones, 2003). Friedman et al. (2003) state that “stressors that are perceived as losses and are ambiguous (unclear)” —such as families grieving the loss of their child or their child’s health and the family that feels uncertainty about their child’s illness (Dodgson et al. 2000)—“have greater negative effects on families” (p. 465). This added stress comes in the form of physical stress and illness (Ritchie et al., 2000), mental stress and illness (Koplewicz & Gurian, 2001), and even financial stress as discussed specifically by Bona et al. (2014) and Kuhlthau et al. (2005). Friedman et al. (2003) determines that “a family’s perceptions and handling of its problems,” such as a

child newly diagnosed with an illness, “through the use of various resources and coping strategies are crucial to the family’s success in dealing with the demands placed on it” (p. 464).

As mentioned, each family member suffers when one child is diagnosed with an illness (Dodgson et al., 2000 citing Patterson and Garwick, 1994). Thus, it is necessary for the nurse to provide care both in terms of the child as an individual and the family unit as the patient as well. The family health system theoretical framework outlined by Anderson (2000) provides nurses with a nursing-process based method of providing care for the family as a whole. The aim of this chapter is to discuss Anderson’s (2000) family health system framework and the importance of providing awareness and prevention of triangulation and the family projection process as described in Murray Bowen’s family systems theory (Anderson, 2000; Bowen Center, n.d.; Miller & Winstead-Fry, 1982).

Family Health Systems Approach

Anderson (2000) describes the family health system framework as one that assesses “family dynamics, family strengths, and family concerns in health and illness across the life span” (p. 104). The objectives of this framework “aim at strengthening, maintaining, or restoring the family’s ability to deal with health-related interactions that affect family functioning” (Anderson, 2000, p. 104). The optimal outcome for the family during a crisis is to return to either the same level or a higher level of family functioning than they were prior to the stressor, which in this case is the chronic or terminal illness of a child (Friedman et al., 2003 citing Mederer & Hill, 1983). In order to return to this optimal level of functioning, it is necessary for the nurse to focus on the five aspects of family health outlined by Anderson (2000). These aspects include interactive,

developmental, coping, integrity, and health processes. The interactive aspect of the family health system framework deals with how the family interacts with each other through communication and the level of support each family member receives through the others (Anderson, 2000). When assessing and providing care for the developmental aspect of the framework, the nurse not only assesses the development of each family member, but also the family as a whole (Anderson, 2000). Coping focuses on how families have dealt with stress and dire situations in the past and their ability to utilize “resources” and “problem solve” when these issues arise (Anderson, 2000, p. 105). Integrity of the family emphasizes those things such as “family identity, family history, family values, and family rituals” (Anderson, 2000, p. 105). The last part of the family health system framework concerns health processes, including the health of the family, their “health beliefs, . . . health responses and practices, lifestyle practices, and health care provision during illness and wellness” (Anderson, 2000, p. 105). Because each of these parts of Anderson’s (2000) theoretical framework can affect the family of a chronically or terminally ill child, the model for the family health system approach to family nursing and the process outlined in Anderson’s (2000) article, “The Family Health System Approach to Family Systems Nursing,” can be effectively utilized to improve family functioning.

Assessment

The nursing process, as used by nurses everywhere and taught throughout nursing education, consists of five steps, including assessment of the patient, nursing diagnosis of the problem, creating a plan to address the problem, intervening in order to help fix the problem, and finally, evaluating the patient outcomes to see if the interventions did, in

fact, help alleviate the problem. The Texas Board of Nursing (2013) follows this process with the omission of the diagnosis step. Anderson's (2000) family health system framework is consistent with the nursing process in that it provides an outline for nurses on how to provide family care by describing what should be done in each step of the nursing process.

The first step in both the nursing process and providing family health system nursing care in Anderson's (2000) model is to conduct an assessment on the family. During the assessment, the family nurse "focuses on the dynamics of family interaction, including patterns of communication, conflict resolution, roles, instrumental and relationship functioning, nurturance, expressions of intimacy, and support" (p. 108). In doing this, the nurse is gaining insight into the family's interactions, which is one of the five categories to include when taking the family health system approach to provide care for the family. When assessing the family using this framework, the family nurse uses the techniques of interventive questioning, genograms, ecomaps, listening and verifying family needs, and providing the family with "respect and integration of [their] strengths and desires" (Anderson, 2000, p. 107). Interventive questioning consists of questions that are asked deliberately to obtain information from the patient (Tomm, 1988). A genogram is a picture or map of the family that gives "the details of family membership, the family-of-origin histories, health histories and conditions, and significant family events and their relationships to health happenings or vice versa" (Anderson, 2000, p. 107). Finally, an ecomap is a tool that determines the family's relationship to the surrounding environment (Anderson, 2000). Each of these assessment techniques are helpful, however, Anderson

(2000) asserts that interventive questioning (Tomm, 1988) is of primary importance during the assessment and intervention aspects of the nursing process.

In regards to family nursing relating to a child with an illness, the nurse will discuss with the family to see what they know about the illness, such as when the child was diagnosed, the expected duration and prognosis of the illness, the pathological and physiological processes of the illness, and how to care for the illness. Additionally, the nurse will ask questions regarding the five topics of interaction, development, coping, integrity, and health as outlined in Anderson's (2000) framework. It is essential to assess the family's coping strategies and what their "past experience with stress and crises" has been in order to give the nurse a solid foundation to plan for the care of this family during their child's illness (Anderson, 2000, p. 108). Furthermore, not only is it necessary to assess the family's coping ability, but to holistically assess the physical, psychological, spiritual, and emotional aspects of the family and its individual members because each part of the patient are interrelated and can affect the family's ability to cope with a child's illness. A good, thorough assessment by the nurse allows him or her to gain insight into what issues the family is truly and potentially facing. This type of assessment helps the nurse effectively care for the child and family and provide interventions that lead to the best patient outcomes as possible.

Diagnosis

Once the nurse has collected data from the family assessment, it is important to create a nursing diagnosis by "hypothesizing the concern, problem, or strength, and the etiology of the issue" (Anderson, 2000, p. 109). When focusing on the important problems affecting the family of a child with a chronic or terminal illness, stress

management and coping skills required to effectively manage both the child's illness and the needs of the family in relation to the child's illness are important to consider (Anderson, 2000). For the family with increased stress related to the child's illness, an important nursing diagnosis to focus on would be a risk for employing ineffective coping mechanisms related to a lack of knowledge regarding positive coping strategies during times of crisis (Dodgson et al., 2000). When the diagnosis is formulated, the nurse can then create a plan and provide interventions for the family. When creating the diagnosis, it is important for the nurse to collaborate with the family in order to implement a plan that will be most effective according to what the family believes will be most helpful during this time (Anderson, 2000). It is also necessary for the nurse to refer back to the original assessment in order to address each problem correctly, help correct as many problems as possible during his or her time with the patient and the patient's family, and maximize on the "strength[s] or concern[s]" of the family (Anderson, 2000, p. 109).

Planning

Once the diagnosis is formed, it is explained to the family for clarification, and an agreement is reached (Anderson, 2000). Upon agreement of the diagnosis, it is necessary to come up with a plan for how to fix the etiology of the problem. Anderson (2000) poses the assumption in her family health system framework that the nurse "will be involved in promoting and assisting the family to maintain current family strengths" (p. 109). Without the involvement and direction of the nurse in the planning process, the family could lose sight of the goal and the patient and family outcomes would suffer. If the nurse promotes the family strengths, there is an increased likelihood for better patient and family outcomes. For the family with a chronically or terminally ill child, involving

the family in the plan of how and what interventions are to be carried out can help put them at ease. It has been shown that one main source of stress for the family of an ill child is uncertainty regarding the child's diagnosis (Dodgson et al., 2000). The uncertainty Dodgson et al. (2000) refers to relates to the disease process and prognosis, however, it can be assumed that uncertainty regarding any part of the child's care, including the plan of care and any other aspect of the nursing process will cause negative stress on the child and the family. It is of utmost importance to include the child and family in every part of the nursing care provided to help improve patient and family outcomes and encourage the patient and family to comply with the nursing plan and interventions.

Intervention

Just as in the nursing process, in the family health system framework, the nurse is responsible for implementing evidence-based nursing interventions for the patient and family based on their needs, the nurse's skills, and the family's awareness of what needs to occur to improve patient and family outcomes (Anderson, 2000). With Anderson's (2000) framework, the two ways that nurses intervene with families are through "interventive questioning," as described in the assessment section, "and concrete family or nurse activity interventions" (p. 110). Interventions to help the family cope with a chronically or terminally ill child are discussed further in "Chapter Four: Implications for Practice." Throughout the intervention process, it is necessary to follow-up with the family and determine how the patient's and family's needs are changing over time (Anderson, 2000). This requires continual assessment of the patient and family in order

to change the intervention process as time goes on and determine if patient and family outcomes are improving or worsening (Anderson, 2000).

Bowen's Family Systems Theory

It is important to note the two aspects of triangulation and the family projection process of Bowen's family systems theory that could be prevented by the nurse to help promote positive outcomes for the patient and family. The understanding of triangulation and the family projection process from Bowen's family systems theory could be helpful in preventing the loss or regression of a healthy family system during times of crisis (Miller & Winstead-Fry, 1982). According to *Family Systems Theory in Nursing Practice* by Miller and Winstead-Fry (1982), triangulation is the process of one person, or point, of the triangle that holds the other two people, or points, together. For example, a child may hold the parents' relationship together, rather than the parents having something in common with one another to hold their own relationship together (Miller & Winstead-Fry, 1982). Miller and Winstead-Fry (1982) assert that if the triangulation process between father, mother, and child increases, so the child with an illness will have increased symptoms. This can be accredited to the level of differentiation, or "emotional maturity," of the family system (Miller & Winstead-Fry, 1982, p. 7). If a family is less differentiated, it is assumed that during times of health crisis, the family will be unable to handle the stress of a child's illness, therefore leading to physical, psychological, and emotional instability and illness (Miller & Winstead-Fry, 1982).

When a child is chronically or terminally ill, this poses a threat to the family system. A triangle between the parents and the ill child may be formed. When the child is diagnosed, the parents' stress increases, and according to Miller and Winstead-Fry

(1982), the symptoms of the child will also increase. This could then cause more stress on the parents, resulting in a cycle of stress and illness in both the child and the family. This is comparable to Miller and Winstead-Fry's (1982) example of a couple that has a new baby. The husband-wife relationship may suffer due to a new mother-father-child triangle. When this occurs, the husband-wife relationship is in jeopardy for those who are not well differentiated. The couple may then put all their focus and energy into the child and lose their own relationship. In times of increased stress, such as if the child becomes ill, the husband-wife relationship in less differentiated couples cannot withstand the stress and the husband and wife may then look to other people or things to help alleviate the stress. For example, the father may consume himself in his work, while the mother consumes herself in the care of the ill child, providing minimal growth in the relationship between the parents, which could, therefore, increase the stress even more within the family system. As mentioned previously, when the stress in the family system increases, the signs and symptoms of illness can worsen in the ill child, and further, the parents may begin to experience illness as well (Miller & Winstead-Fry, 1982). The nurse should be adamant about providing intervention in order to prevent the risk of increased triangulation and stress in the family system, exacerbation of the child's illness, and possible illness in the parents. The nurse should teach the family positive and effective coping strategies on how to overcome the obstacles and handle the child's illness in a way that promotes health for the child and his or her family holistically. For example, the parents should participate in respite care to allow some time with each other while someone else is tending to their ill child, allowing for optimal husband-wife relationship growth.

In order to prevent the triangulation process, the nurse should make the family aware of how triangulation works and determine the family's coping mechanisms during previous family crises (Anderson, 2000). This part of the assessment allows the nurse to diagnose, plan, and intervene for the family based on the parents' ability to cope and find common ground within their own relationship rather than rely on their child or other outside sources to keep them together. If the family is well balanced with parents who are working together effectively, this suggests a higher level of differentiation and allows the family, and more importantly, the ill child, to work together on providing optimal care and heading towards recovery, remission, or a well-managed illness (Miller & Winstead-Fry, 1982).

The second component of Bowen's family systems theory that is necessary for the nurse to prevent is the family projection process. In short, the family projection process occurs when the parents project their anxieties on the child (Bowen Center, n.d.). When a child has a physical illness, the stress levels increase in the family, as Dodgson et al. (2000) noted. If the family is not well differentiated, increased anxiety levels will not be tolerated well (Miller & Winstead-Fry, 1982). This, in turn, causes high levels of anxiety in the parents, which can be projected to the ill child, increasing the parents' risk of psychological illness and the child's risk of increasing physical or psychological symptoms of illness, and thus, a deteriorating condition (Bowen Center, n.d.).

In order to prevent this cycle of projection, it is important for the nurse to make the family aware of the anxieties they are facing and how the family has coped with stressful events in the past (Anderson, 2000). Once determined, the nurse should provide care for the family by teaching effective coping strategies and providing support. By

making the family aware of effective and ineffective coping strategies to use during times of increased stress and informing the family of triangulation and the family projection process described in Bowen's family systems theory, exacerbation of the child's disease and formation of physical or psychological illness in the parents or siblings of the ill child could be prevented (Burke et al., 1997).

Evaluation

The final step in the nursing process is evaluating how well the plan and nursing interventions for the family have worked in regards to whether the family's problems are resolving or worsening (Anderson, 2000). Anderson (2000) notes that the process of evaluating, planning, intervening, and revising is "ongoing" and, over time, family "outcomes change as the family changes" (p. 110). Because of the possibility that patient and family problems can resolve or intensify, the family's needs change (Anderson, 2000). For this reason, it is critical to reassess the family at each visit, evaluate the plan thus far, and modify as necessary in collaboration with the family (Anderson, 2000).

Conclusion

In conclusion, taking the family health system approach outlined by Anderson (2000) is an important step when caring for the child and family of the child with a chronic or terminal illness. This approach is simple to maintain while performing the nursing duties of assessing, diagnosing, planning, intervening, and evaluating (Texas Board of Nursing, 2013). By using this approach, Anderson (2000) provides "a means for nurses to approach family care and to include health restoration, maintenance, and promotion strategies" in the hopes of providing better patient and family outcomes throughout the nursing care of an ill child (p. 111)

CHAPTER FOUR

Implications for Practice

Introduction

After a review of literature, it is of great importance to provide information on implications for nursing practice to enhance the effective coping mechanisms of families of children with chronic and terminal illnesses. Though there is little quantity of research on this subject, there is a quite a variety, including coping skills of different family members, such as parents versus siblings or what types of support programs are useful. This displays that the nurse is responsible for knowing what interventions are helpful to whom.

Grief and bereavement are natural in the lifetime of humans. Family members and friends get sick and may pass away, suggesting that most people experience death or sadness in their lifetimes. Many of the research articles described in this review correlate a child's chronic or terminal illness, hospitalization, life, and death as a significant source of stress for the child and family (Broger & Zeni, 2011; Burke et al., 1997; Dodgson et al., 2000; Gage, 2013; Hexem, Mollen, Carroll, Lanctot, & Feudtner, 2011; Hovey, 2005; Kloosterhouse & Ames, 2002; Knafl & Zoeller, 2000; Melnyk, et al., 1997; Rempel, Ravindran, Rogers, & Magill-Evans, 2013; Ritchie, Stewart, Ellerton, Thompson, Meade, & Viscount, 2000; Williams, Ridder, Setter, Liebergen, Curry, Piamjariyakul, & Williams, 2009). Hovey (2005) asserts in her study that "when [an] illness becomes a chronic condition, the impact on the family and each of its members is immense," therefore, it can be assumed that the entire family will require nursing care (p. 84).

Supporting this, Burke et al. (1997) state that when the parents, or family, are stressed, it could place further stress on the ill child, and in turn could “exacerbate children’s reactions to hospitalization” or illness (p. 476). Therefore, this suggests that if a family is able to cope well, the child has a better chance of coping and reduced chance of disease exacerbations (Burke et al., 1997). This poses the challenge to healthcare providers to help intervene and reduce this stress on the family, and more importantly, prevent complications in the ill child. The simplest intervention that most studies suggested is to provide support groups for these families—whether they are in person, telephone-based, within the church, with families who have children each with different illnesses or parents with children each with the same illness—to enhance the psychological health of a family living with a child suffering from a chronic or terminal illness (Alam et al., 2012; Ballard, 2004; Broger & Zeni, 2011; Darbyshire, Cleghorn, Downes, Elford, Gannoni, McCullagh, & Shute, 2013; Gage, 2013; Hexem et al., 2011; Hovey, 2005; Kloosterhouse & Ames, 2002; Ritchie et al., 2000; Williams et al., 2009).

First, it is necessary to realize the common emotions that parents feel upon diagnosis and throughout the course of their child’s illness, such as fear, sadness, anger, and guilt (Alam et al., 2012; Ballard, 2004; Broger & Zeni, 2011; Gage, 2013; Hexem et al., 2011; Kloosterhouse & Ames, 2002; Knafl & Zoeller, 2000; Menezes, 2010; Rempel et al., 2013; Ritchie et al., 2000; Williams et al., 2009). Once the nurse is aware of typical reactions to a diagnosis, the nurse should implement the first stage of the nursing process and assess what discrepancies there are between how each parent is coping with the illness (Knafl & Zoeller, 2000). Furthermore, in the parents who do not have similar reactions to a child’s illness, it is noted that mothers typically have a more negative

outlook than the fathers (Knafl & Zoeller, 2000). Once these differences and parents' ability to express their emotions are identified, it is important for the nurse to implement interventions and enhance coping of these parents, but the question is how to do so.

Support Programs

Support groups are a prominent theme in enhancing coping in families. Support groups can provide the family with an outlet to discuss and communicate with others about their experiences and their feelings about their child's illness (Alam et al., 2012; Ballard, 2004; Broger & Zeni, 2011; Darbyshire et al., 2013; Gage, 2013; Hexem et al., 2011; Hovey, 2005; Kloosterhouse & Ames, 2002; Menezes, 2010; Ritchie et al., 2000; Williams et al., 2009). Two different studies, conducted by Darbyshire et al. (2013) and Ritchie et al. (2000) described the impact of a telephone support program for the families of a child experiencing a chronic or terminal illness. Darbyshire et al. (2013) implemented a program in which nurses kept in contact with families of deceased children over the course of about one year post-death. Ritchie et al. (2000), on the other hand, implemented a telephone program in which multiple parents were involved in a group together, rather than only the parent and healthcare professional, and were able to talk about their feelings with one another. Not only should these and other support groups be implemented, Brazil, Ozer, Coutier, Levine, and Stryer (2005) encourage the importance of evaluating whether interventions implemented have created the expected outcome for the patient, and in this case, the family as well. Darbyshire et al. (2013) found that their aim of providing a helpful telephone support program after the death of a child "was being achieved" (p. 545). Ritchie et al. (2000) found that there were many positive outcomes of the telephone support program, including "increased confidence,

changed perspectives, decreased isolation, and changed family activities and health care encounters” and these positive outcomes were “attributed...to the opportunity to share and compare feelings,” once again, expressing that communication is key to coping and psychological health (p. 33).

Reducing Uncertainty

Another important intervention for healthcare professionals to implement is that of reducing the amount of uncertainty related to a child’s diagnosis, treatment, and prognosis as this adds extra stress to the parents (Broger & Zeni, 2011; Dodgson et al., 2000; Hovey, 2005; Menezes, 2010; Rempel et al., 2013). Dodgson et al. (2000) argues that uncertainty is a “major stressor that influences family functioning” in children who are diagnosed with a chronic illness (p. 253). Menezes (2010) supported Dodgson et al. (2000) with the finding that uncertainty was a major theme for families dealing with ill children. Though this may be true, Rempel et al. (2013) observed that parents “were effective in watching for and accommodating the unexpected” (p. 625). This kind of accommodation is necessary to the health of the family and the child. The implication of the risk of uncertainty, according to the family systems theory Dodgson et al. (2000) mentioned in their study, is that uncertainty in regards to unpredictability of the disease and its prognosis can cause more familial distress.

According to Rempel et al. (2013) and Menezes (2010), though families have learned to adapt and use this uncertainty for the better, nurses have a responsibility to provide parents with as much information as possible about their child’s diagnosis. The unknown can cause anxiety or fear and nurses need to have discussions with the parents explaining all of the implications for the diagnosis, including what the illness actually is,

how it happened, the medical care, differentiation between healthcare professional responsibilities and parental responsibilities, and treatment for this particular disease (Dodgson et al., 2000; Burke et al., 1997). After giving the family the basic, initial details, the nurse should be sure to answer all parents' questions to the best of his or her knowledge whenever a question arises and if he or she is unable to answer the question, someone who can should be contacted as soon as possible.

Use of Religion, Spirituality, or Life Philosophy

Holistic care of the patient includes providing health promotion and maintenance for the spiritual well-being of patients and their families along with their physical health. This suggests that the nurse should be active in determining religious and cultural preferences for a patient and his or her family and providing them with the appropriate resources to fulfill their needs, such as a Bible, a chaplain, or allowing quiet time for prayer should the parents request or mention the importance of these practices during the initial health interview and ongoing relationship with the healthcare professional. Furthermore, Kloosterhouse and Ames (2002) suggest that the nurse should have a good relationship and easy contact with pastoral care at his or her facility in order to refer parents and patients to their care if this shows to be an effective coping mechanism for families.

The importance of religion, spirituality, or a life philosophy as coping mechanisms for parents was mentioned as a source of hope in a small number of studies included in this review (Hexem et al., 2011; Kloosterhouse & Ames, 2002, Alam et al., 2012). Hexem et al. (2011) found that the majority of parents who did follow a religion, spiritual affiliation, or life philosophy "felt...[it was] very important in providing support,

peace, comfort, and moral guidance” (p. 42). Kloosterhouse and Ames (2002) determined that religion and spirituality were a “source of strength...[and] an anchor to help center the family during a crisis” (p. 74). Further, in a study conducted by Alam et al. (2012) on the experiences of parents bereaving the loss of a child to cancer, both mothers and fathers expressed the importance of trusting God in the circumstances and having hope for the future. However, this does not apply in all cases. Some families practice religions other than Christianity, such as Mormonism, Islam, Judaism, Buddhism, etcetera, and some may not be religious at all, suggesting that nurses should not assume families are religious when it comes to caring for the spirituality of families. If the nurse is unable to provide appropriate religious or cultural care to the patient and family, he or she should refer families to the appropriate provider.

Paternal and Maternal Coping

Most of the studies in this review discussed findings, interventions, and viewpoints of both parents, while one study conducted by Melnyk et al. (1997) specifically studied an intervention only implemented in mothers. This intervention, entitled the COPE intervention, was used in a control group to assess its helpfulness in mothers caring for ill children (Melnyk et al., 1997). Because of “parental role uncertainty [and] decreased parenting confidence,” the researchers implemented the COPE intervention to enhance the mother’s parenting abilities “by providing instruction and practice in parenting behaviors specific to the situation in order to increase maternal confidence and role certainty” in caring for her ill child (Melnyk et al., 1997, p. 5). The researchers found that mothers receiving the COPE intervention gave their child more “support...during intrusive procedure...more emotional support...[and] reported less

negative mood state” suggesting that the mother was having less psychological problems and more confidence in her parenting abilities than a mother in the comparison group (Melnyk et al., 1997, p. 9).

Though determining shared views and coping skills of the parents as a unit is important, Knafl and Zoeller (2000) determined that differences in parental coping and viewpoints does, in fact, exist and need to be examined to allow for coping enhancement of mothers and fathers as both as separate beings and together as a couple. Alam et al. (2012) studied parental differences in coping after six months of losing a child and then again after 18 months of the loss of a child. They found many differences in how mothers versus fathers coped with the illness and loss of their child. At six months, mothers stated they used coping mechanisms such as having “positive memories of the child, talking to others about the...child, having faith in God, caring for bereaved siblings, and spending time with family” (Alam et al., 2012, p. 11). Fathers, on the other hand, focused more on work and also reported trusting in God (Alam et al., 2012). At 18 months, mothers maintained many of their previous coping mechanisms, including “legacy building” and fathers “shifted their focus from work outside the home to engaging in household projects and legacy building” as well (Alam et al., 2012, p. 13). The main intervention implicated by this study was finding what types of support the parents need and then helping them find a support program that fits those needs (Alam et al., 2012).

Darbyshire et al. (2013) also determined, through their implication of a telephone support program after the death of a terminally ill child, that parents, mainly mothers, benefit from social support through the means of nurses who took care of their child

while hospitalized. This study allowed the parents to effectively cope with their child's loss by communicating with those who knew their child well and could provide emotional support and lend a listening ear (Darbyshire et al., 2013). Furthermore, Gage (2013) based her study on needing programs for parents of chronically or terminally ill children that helped them identify and provide for the family needs that were not being met.

In reviewing the literature, it is found that each member of the family cope differently, and thus, nurses should know and understand how to facilitate coping in mothers, fathers, and siblings. Most studies, as evidenced by the study conducted by Alam et al. (2012), states that "mothers were the primary caregivers," (p. 6). Hovey (2005) also stated that mothers were the "primary caregivers...and took responsibility for general childcare as well as doctors' appointments and other health maintenance issues" (Hovey, 2005, p. 92). This could show that there may be a lack of evidence in interventions for father shown by Darbyshire et al. (2013). In the telephone support program study implemented by Darbyshire et al. (2013), it was found that because fathers usually needed to maintain their work schedules, and the telephone calls from the healthcare professionals were usually made during work hours, the father was not given the opportunity to utilize the support program, and thus, it did not prove to be as effective of a coping mechanism or support group for the father.

Two studies in this review, however, focused specifically on fathers' experiences and viewpoints, rather than both parents', in a child with a chronic illness and how they cope (Hovey, 2005; Broger & Zeni, 2011). Hovey (2005) made a significant conclusion that "by strengthening the role of the father, the mother-child dyad is strengthened and

the entire family unit benefits,” supporting enhanced coping of fathers (p. 94). This concurs with the family systems theory mentioned by Hovey (2005) and Dodgson et al. (2000) in their studies. On the contrary, Hovey (2005) also described an ineffective coping mechanism used by fathers caring for a child with a chronic illness. Hovey (2005) mentioned that 13% of the fathers in her study admitted to using drugs and alcohol to cope. However, these coping methods only proved effective in half of the original 13%, suggesting that this would not be an effective coping mechanism suggested by healthcare professionals for parents of children with chronic and terminal illnesses (Hovey, 2005). However, other effective coping mechanisms suggested by Hovey (2005) “included trying to figure out what to do, looking at options, getting information, and weighing choices” (p. 92). Once again, as Hovey (2005) noted, it is important to provide information about the child’s illness to fathers (and mothers) of these children.

In another study conducted by Broger and Zeni (2011), coping in fathers with children who are chronically ill was the aim of the research. Before discussing the results, the researchers first defined coping mechanisms as “outward or inward efforts by fathers directed toward adjusting to a child’s chronic illness” (Broger & Zeni, 2011, p. 98). The top three coping mechanisms used by fathers in this study and determined through the use of the Ways of Coping Questionnaire included positive reappraisal, planful problem solving, and seeking social support (Broger & Zeni, 2011). Positive reappraisal includes reframing the situation and looking for positivity and “personal growth” and is said to have a religious background, supporting the research discussed above that was conducted by Alam et al. (2012), Hexem et al. (2011), and Kloosterhouse and Ames (2002) (Broger & Zeni, 2011, p. 100). Additionally, planful problem solving

is defined as “deliberate problem-focused efforts to alter the situation” and Seeking Social Support “describes efforts to seek informational support, [including] tangible and emotional” support (Broger & Zeni, 2011, p. 100). By using these coping mechanisms, Broger and Zeni (2011) describe that the fathers are able to provide increased health maintenance for the entire family, and especially the ill child. This study concludes by noting the importance of frequent assessment of the parents’ coping mechanisms and providing resources in order to enhance the coping mechanisms that the fathers have already begun to utilize effectively (Broger & Zeni, 2011).

As already mentioned, Hovey (2005) indicates the importance of “encouraging use of all family members’ informal social support systems, such as...extended family...church support, and close friends” (p. 93). Gage (2013) also supports this intervention in her study on the dynamics of the support systems used in families of ill children. Gage (2013) concluded in her study that it is imperative for nurses and other healthcare professionals to identify, with parents, who the parents can call on for support and what types of support is truly needed, such as care for their other children or maintaining the household duties. This kind of support is usually easily found in people who have had close relationships with the family prior to the child’s diagnosis, such as family and close friends (Gage, 2013).

Sibling Coping

Ritchie et al. (2000) supports the fact that parents of chronically ill children are “at an increased risk for health problems” (p. 26). However, siblings are another important group to consider when determining effective coping mechanisms of families of children with chronic or terminal illnesses. This is because, like parents, siblings are at

an “increased risk of psychological problems compared to the siblings of healthy children (Ballard, 2004, p. 294). According to Ballard (2004), in order to begin intervening in the psychological health and wellbeing of siblings of ill children, it is important to first determine the parent’s needs and coping mechanisms because of the possibility of learned coping in the children, both well and ill. Because of the possibility of learned coping and the fact that parents usually influence and understand their children and their needs the most, Ballard’s (2004) study determined, from a parent’s point of view, what interventions they thought would be helpful for their healthy children. One problem founded in this study was that 40% of parents expressed that no healthcare provider had acknowledged or made an attempt to discuss the feelings the healthy sibling was having in regards to their ill sibling, suggesting the need for a change in practice on this subject (Ballard, 2004). Ballard (2004) also found that half of the parents studied revealed they did not feel as if their healthy child would develop problems, suggesting the need for nurses and other healthcare professionals to teach families the importance of psychological health and the effects an illness in a family member can have on a person. However, the parents in Ballard’s (2004) study did implicate that if therapeutic sessions were implemented, it would be best to include the sibling in a visit with the entire family, at least until a trusting relationship is formed with a healthcare professional the well child feels comfortable discussing his or her feelings with.

Another study conducted by Williams et al. (2009) also described interventions for siblings with a child who is ill. It is noted in Williams’ et al. (2009) study that the most negative outcomes of siblings of these ill children were jealousy and envy and worry, fear, and anxiety. However, there were also positive aspects, including increased

family unity and relationships (Williams et al., 2009). Because of the nature of illness and possible death, siblings, just as parents, need time to grieve and opportunities to communicate with healthcare professionals regarding their questions and concerns for their siblings and their own “personal growth” through this time (Williams et al., 2009, p. 107). Communication can also come in the form of support groups with other siblings of ill children who understand the emotions and experiences that each sibling is facing (Williams et al., 2009). According to Williams et al. (2009), an imperative intervention for the siblings is to assess and discuss the parents’ ability to know their children’s needs and if they are providing for both their well and ill children effectively.

Conclusion

In conclusion, it is imperative for nurses and other healthcare professionals to stay up to date with current research findings on enhancing the effective coping mechanisms of parents of children with chronic or terminal illnesses. In doing so, nurses will provide practice that is evidence-based and will continue to support these parents and their families in an effort to provide holistic care of the patient and family, focusing not only on the physical care of the patient, but the spiritual, emotional, and psychological care as well.

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