The Role Of The Nurse Practitioner In Support Of Families Experiencing Chronic Sorrow

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THE ROLE OF THE NURSE PRACTITIONER IN SUPPORT
OF FAMILIES EXPERIENCING CHRONIC SORROW

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An Evidence Based Practice Project Presented to the Graduate Faculty
of Mississippi University for Women in
Partial Fulfillment of the Requirements for
The Degree of Master of Science in Nursing

by

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Master of Science in Nursing

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Approved

Committee Member

Approved

Committee Member
DEDICATION

This research project is dedicated to my children and my dad. To Lauren, thank you for being a big sister when I most needed you to step in to help daddy with your little brothers. As a twelve-year-old, I know this was not easy. Thank you for never complaining, for understanding when I had to be away in school, and for always offering me that beautiful smile when I was most in need. To Aaron, thank you for helping Lauren and daddy take care of your little brother, for being quiet when I needed to study, and for constantly giving me a much needed hug. Maybe now you can once again be a seven-year-old and mommy will take care of you. To Kerrigan, thank you for helping mommy with her studies, for teaching me the proper method of high-lighting important parts of my textbooks, for showing me how to discard reports in the trash, and for teaching mommy (in the midst of typing my research paper) that turning off the computer saves electricity. I couldn’t have managed without your assistance.

To daddy, I love you and I would not be here without your unfailing encouragement. Thank you for your kindness, your compassion, for all that you have taught me through the years, and for being the one person who most influenced me and provided direction for my life. You taught me that nothing was impossible and that the results of persistence are rewards. Thank you for being my daddy, for loving me, for providing for me, and for setting the standard for achievement. You are the best.

I would be remiss if I didn’t acknowledge and thank my many mentors who have provided me a hands-on education. To all of you I offer hugs and kisses.
THE ROLE OF THE NURSE PRACTITIONER IN SUPPORT OF FAMILIES EXPERIENCING CHRONIC SORROW

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Abstract

Chronic sorrow is the periodic recurrence of permanent, pervasive sadness or other grief-related feelings associated with ongoing disparity resulting from a loss experience (Eakes, 2004). As a concept, chronic sorrow speaks to the emotional strain in the lived experiences of caregivers of the chronically ill and disabled. The term chronic sorrow was first used by Olshansky (1962) to describe the grief and sadness that parents felt when their child was first diagnosed as being mentally retarded. Research on chronic sorrow has proven its presence not only in parents, but in other family members, caregivers, and those with an illness or disability. Furthermore, chronic sorrow as a phenomenon has also been recorded in caregivers of the physically ill, mentally ill, and those disabled. Healthcare providers across all disciplines are in constant contact with individuals who are dealing with hopeless situations and many of them are experiencing chronic sorrow. It is inconceivable that with modern medicine and technological advancements, the majority of healthcare providers are at a loss in dealing with those caregivers who suffer. Therefore, this author has chosen to look at the progress made since the original usage by Olshansky.

To this end, a systematic integrated review of the literature using computer
searches of CINAHN, MEDLINE, the Cochrane Library, and electronic media was done in an effort to identify the current level of healthcare knowledge regarding the role of the nurse practitioner in providing support to families experiencing chronic sorrow. These searches produced a limited number of articles regarding support by any healthcare professional and none that referenced nurse practitioners. However, the literature was rich with progressive information and noted enormous gains in understanding of this phenomenon over the past two decades. Of particular importance was information about the instigation of the Nursing Consortium for Chronic Sorrow, the development of the Chronic Sorrow Questionnaire, and the ongoing work to further develop the middle range nursing theory of chronic sorrow.

The Uncertainty in Chronic Illness Model developed by Merle Mishel was used as the theoretical foundation for this review. This model is used to describe and to establish an understanding of the uncertainty or unpredictability and lack of consistency that is ever present in chronic illness (Mishel, 1990). Within this review the theoretical and operational definitions of chronic sorrow, nurse practitioner, healthcare provider, and family support were explored.

From this review, it is evident that there is a need for further considerations regarding the role of the nurse practitioner in support of families experiencing chronic sorrow. Further evidenced is the need to fill the void in education of advanced practice nurses as it relates to this phenomenon. Within this review, implications for nursing theory, nursing research, advanced nursing practice, nurse practitioner education, and health policy are provided as they emerge from the concepts explored.
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CHAPTER 1

Dimensions of the Problem

Chronic sorrow is the periodic recurrence of permanent, pervasive sadness or other grief-related feelings associated with ongoing disparity resulting from a loss experience (Eakes, 2004). Chronic sorrow is, in fact, a form of grief in that it constitutes a normal reaction to the significant loss of normality in the affected individual or the caregiver. Click, Weiss, & Parkes (as cited in Burke, Hainsworth, Eakes, & Lindgren, 1992) report that acute grief is time limited, ending in resolution. In acute grief, individuals pass through stages of avoidance, confrontation, and reestablishment in response to a loss. A reestablishment releases individuals of their encumbrances while the presence of a chronic condition or disability serves as a continuous reminder of loss and clutches the individual or caregiver in an emotional bondage from which they can not escape. The term chronic sorrow was first used by Olshansky (1962) in describing the grief and sadness felt by parents when their child was diagnosed as mentally retarded and this hopeless feeling persists throughout the lives of the parents and their child.

One can then describe chronic sorrow as unresolved grief, yet it also differs from pathological grief that occurs when the reaction is excessive and prolonged or inhibited and tends to emerge in distorted forms (Burke, et al, 1992). In both instances, the grieving experience does not end with resolution, but for differing reasons. Glick, Weiss, & Parkes (as cited in Burke, et al, 1992) state that pathological grief most often occurs when there is a sudden, unexpected, and inappropriate death and the relationship with the deceased was traumatic or excessively dependent. Pathological grief can result in
continual feelings of guilt, anger, sadness, crying, developmental regression, labile affect, and difficulty in expressing loss. However, the person experiencing chronic sorrow is typically highly focused and functional in the presence of an ongoing loss. The disability or chronic condition may require performing new tasks, making far-reaching decisions, and modifying life-styles. Chronic sorrow does not impede the ability to meet these challenges (Burke et al, 1992).

Furthermore, chronic sorrow is readily distinguished from major depressive disorders that may be physiologically based, exhibiting chronic symptoms and lacking known precipitating events. These depressions are considered mental disorders that require medical intervention, frequently in the form of psychotropic medication. Depression is sometimes characterized as an inability to grieve whereas chronic sorrow constitutes the subjective states that accompany a continuing loss (Burke, 1989). Unfortunately, there are no studies that differentiate between chronic sorrow and depression yet; pathological grief, depression, and chronic sorrow each have distinguishing characteristics (Hobdell, 2004). As such, the treatment, responsiveness, and coping abilities differ among classification.

**Problem Statement**

It is important to first clarify and establish the definition of chronic sorrow before applying the concept in clinical practice. It is equally important to recognize that although much is known, there remain some unknowns about this concept. The dictionary definition provided a basis for a review of the characteristics of the concept. Webster (2001) defined sorrow as mental suffering caused by loss or disappointment, and expressed as mourning or lamentation. Synonyms are grief, affliction, sadness, regret,
and lamentation. Webster (2001) further defined grief as an intense emotional suffering caused by loss, misfortune, injury, or evils of any kind.

Freud’s work (as cited in Jacob, 1993) defined the phenomenon of grief as a process of gradual withdrawal of the energy that ties the bereaved individual to the lost object or the deceased. Worden (as cited in Teel, 1991) explained that grief reactions are considered abnormal if the mourning is delayed, chronic, exaggerated, or masked. Consequently, the terms grief and sorrow are comparable. Because Webster (2001) defined sorrow as mental suffering and grief as emotional suffering, an enhanced understanding is appropriate. Suffering has been described and defined by many authors over the years, but for purpose of this review, only two will be examined.

Reich’s work (as cited in Melvin & Heater, 2004) described suffering as: Anguish experienced as a threat to our composure, our integrity, and fulfillment of our intentions, and more deeply as a frustration to the concrete meaning that we have found in our personal experience. Cassell (as cited in Melvin & Heater, 2004) defined suffering as a specific state of severe distress induced by the loss of integrity, intactness, cohesiveness, or wholeness of the person, or by the threat that the person believes may dissolve his integrity. The remaining synonyms for sorrow and grief illustrate particular uniqueness’ for these terms.

The term chronic can be defined as unceasing, unending, continual, unrelieved, and never-ending. When chronic is put together with sorrow, the result is a sadness, affliction, regret, grief, suffering, and lamentation that do not subside. It should be noted that although grief and sorrow are comparable, grief differs from chronic sorrow. Grief is
the response to a single event that has ended, while chronic sorrow represents an ongoing loss situation with no end in sight (Melvin & Heater, 2004). It is crucial that healthcare professionals understand the concept of chronic sorrow in order to provide needed support and guidance. For that reason, the problem statement initiated in this review focused on the role of the nurse practitioner in providing support to caregivers experiencing chronic sorrow.

Statement of Purpose

The purpose of this review was to examine the knowledgebase as it related to the role of the nurse practitioner in support of caregivers who are suffering from chronic sorrow and to identify interventions that may be useful in providing this support. The current health care environment is changing rapidly with emphasis placed on cost-reductions and reduced length of stay. As such, it is becoming increasingly difficult to perform thorough psychosocial assessments and interventions with families in lieu of giving top priority to the physical care needs of the patient. As a result, caregivers often feel alone as they struggle with their ongoing day-to-day stresses (Melnyk, Moldenhauer, Feinstein, & Small, 2001). It is important to remember that intensive interventions often are implemented at the time of diagnosis with little support at subsequent times of crises and transitions. An examination of the literature regarding the role of the nurse practitioner in support of caregivers experiencing chronic sorrow can be beneficial. This examination may provide direction and assistance to all health care providers in identifying interventions that are useful to those caring for the chronically ill or disabled.
Significance of the Study

Although the current knowledgebase as it relates to the role of the nurse practitioner in support of caregivers experiencing chronic sorrow was limited, it was noted that the literature is filled with information for nurses and other health care providers. This data should be common across many disciplines and therefore applicable to the nurse practitioner.

Chronic sorrow is a term originated by Olshansky (1962), to describe persistent sadness that he observed in parents of mentally retarded children. Although the term was quickly adopted and immediately began to appear in nursing and psychosocial health care literature, almost two decades passed before it was documented by research. Nevertheless, since 1980 numerous studies have focused on chronic sorrow and those experiencing chronic sorrow have been expanded to include not only parents of mentally retarded children, but also the affected person, the bereaved, parents of premature infants, caregivers for the disabled, and those who provide care for the chronically or progressively ill.

Therefore, it is clear that a growing segment of the population is experiencing the phenomenon of chronic sorrow. As such, the social considerations for this segment and the affected persons necessitate a better understanding and improved support mechanisms. In a report by Melvin & Heater (2004), it was stated that society isolates those individuals who suffer from chronic sorrow. These individuals must bear continuing loss and at the same time endure the sorrow alone. A research article by Burke, Eakes, & Hainsworth (1999), reported that social norms are defined as people or
situations that evoke the realization that the affected person is viewed as different; that is, there is a disparity in how the individual sees him-or herself as compared to others. Recognition of these differences is likely to evoke grief-related feelings in individuals with chronic conditions as they realize the disparity between their situations and societal norm.

Because of this increasing segment of the population, it is crucial that healthcare professionals not only understand the distinctive needs of this segment of the population, but also strive to meet these needs. Furthermore, as medical technology continues to advance, life expectancy too will increase. The result will be an increase in those individuals experiencing chronic sorrow and a prolonging of this phenomenon among those now suffering. Chronic sorrow surpasses clinical nursing and is apparent in many healthcare arenas. Caring for such individuals acknowledges the deepest of pain, legitimizes their experiences, and gives them a feeling of personal integrity, wholeness and value (Younger, 1995). “Because the nature of suffering is to call forth deep questioning of the truth of one’s being and its meaning, care becomes a midwife of rebirth (Younger, 1995, p. 66)”.

**Theoretical Foundation**

For the purpose of this review, Merle Mishel’s Uncertainty in Chronic Illness Theory (1988, 1990) served as the theoretical foundation and provided a guide to this investigation. The bases for this selection is because many people who either experience chronic conditions or care for those with chronic conditions not only live with uncertainty, but also experience chronic sorrow. Uncertainty is the deficit in ability to understand or decide the meaning of illness-related activities, when one is unable to
determine the definitive significance of events and is unable to foretell the outcome of these occurrences accurately (Mishel, 1990). Uncertainty is a ceaseless way of life for those with a chronic illness because of the unpredictability and lack of consistency of symptoms and the ever-present question of recurrences and exacerbations. There is also uncertainty in the future of living with the debilitating illness or disability. Therefore, Mishel reconceptualized the Uncertainty Theory to accommodate responses to uncertainty over time in people with chronic conditions. It has been reported in research studies that parents of children with chronic conditions live in constant uncertainty. As such, they attempt to develop timetables and decide probabilities about the course of the child’s illness for themselves. This lived experience of constant uncertainty often produces chronic sorrow. Much of the uncertainty may be linked to the cause of the disease and the prognosis thereof (Mishel, 1999).

It has been shown that uncertainty may produce a negative impact on the quality of life, affect the relationships within families, as well as satisfaction with healthcare services. In certain qualitative studies of parents with chronically ill children, interactions with healthcare providers precipitated uncertainty. In general, the lack of information about the future is a major antecedent of uncertainty (Mishel, 1990). Mishel’s investigation into the causes and consequences of uncertainty in parents of children with chronic illness revealed fractional information from the perspective of the children. The vast majority of the work centered on the areas involving the parents of these chronically ill children. The lack of specific and complete information and the lack of clear biomedical guidelines to direct the care of the child was a factor that increases parents’ uncertainty in illness (Mishel, 1999).
Definition of Terms

For the scope of this review the following definition of terms are provided:

Chronic Sorrow

Theoretical. For the purpose of this review, chronic sorrow is defined as the periodic recurrence of permanent, pervasive sadness or other grief-related feelings associated with ongoing disparity resulting from a loss experience (Eakes, 2004). Within this definition, distinct critical attributes were established by Lindgren, Burke, Hainsworth, & Eakes (1992). These attributes include a perception of sorrow or sadness over time in a situation that has no predictable end, the sadness or sorrow is cyclic or recurrent, it can be triggered either internally or externally, and it is progressive with the potential for intensity. Lindgren et al. (1992) views periodic to be those times when a sadness or sorrow that is triggered either internally or externally and brings to mind the person’s losses, disappointments, or fears. Lindgren et al. (1992) further established that this sadness or sorrow is cyclic or recurrent. Permanence is observed as a perception of sadness or sorrow over time in a situation that has no predictable end. Additionally, they determined that this sadness or sorrow is progressive and can intensify even years after the initial sense of disappointment, loss, or fear.

Operational. For the purpose of this review, chronic sorrow is the presence of pervasive grief-related feelings that have been found to occur periodically throughout the lives of individuals with chronic conditions, their family caregivers, and the bereaved. These feelings emerge in response to an ongoing disparity that results from the loss of the anticipated “normal” lifestyle of these persons (Burke et al., 1999). While the term chronic sorrow may convey a sense of passivity for those who suffer, the manifestations
range from withdrawal to outburst of anger. The feelings of anger permeate the experience of chronic sorrow. These feelings come through loud and clear as parents describe their care giving responsibilities and their attempts to negotiate the health care system (Eakes, 1995). It is perhaps most important to remember that parents who appear to be coping successfully and have adapted to the situation may still suffer from emotional responses which fit the description of chronic sorrow (Hainsworth, Eakes, & Burke, 1994).

**Nurse Practitioner**

**Theoretical.** For the purpose of this review, a nurse practitioner is defined as a registered nurse with advanced training, who is credentialed and qualified, and one who can manage most common and many chronic illnesses.

**Operational.** For the purpose of this review, a nurse practitioner is a primary care provider who may provide care in ambulatory, as well as acute and long-term care. Nurse practitioners are registered nurses who have received certification and who have specialized advanced educations with clinical proficiency to provide health as well as medical care for assorted populations in a multiplicity of primary care, acute, and long-term care settings. The entry level for practice requires a Master’s degree (American Academy of Nurse Practitioners, 2002).

**Healthcare Provider**

**Theoretical.** For the purpose of this review, a healthcare provider is defined as one who provides professional health care to a patient, family, or community.

**Operational.** For the purpose of this review, a healthcare provider is any advanced practice nurse, mid-level care provider or higher, or a physician in a position to
provide healthcare and or guidance thereof, for the promotion of health and prevention or treatment of illness or disease.

**Family Support**

*Theoretical.* For the purpose of this review, family support is defined as taking care of families needs from a holistic perspective.

*Operational.* For the purpose of this review, family support means providing information, resources, and referrals to families as appropriate. This may or may not involve monetary resources.

**Family**

*Theoretical.* For the purpose of this review, family is defined as all individuals within the immediate family and/or close relatives.

*Operational.* For the purpose of this review, family includes those individuals who are charged with, and have the responsibility of, providing care and management of the patient. This care may be direct and involve professional training or, encompass management through a trained specialist.

**Research Questions**

For the purposes of this review, the following research questions were generated:

1. According to the literature, what is the role of the nurse practitioner in support of families experiencing chronic sorrow?

2. According to the literature, are nurse practitioners providing support to families experiencing chronic sorrow?
Limitations

Literature was delimited, for the purpose of this integrative literature review, to the following:

1. Literature that pertained to chronic sorrow.
2. Literature that is available in the English language or translated into English abstracts.
3. Literature available through the electronic media or through CINAHL, MEDLINE, and COCHRANE Libraries.
4. Literature that is available through the Mississippi University for Women Library and Interlibrary loan program.

For the purpose of this review, a particular limitation identified is that the information obtained cannot be generalized beyond the scope of the research reviewed. The generalizability of the findings is further impacted by the lack of nursing research related to the role of the nurse practitioner in support of families experiencing chronic sorrow.

Summary

This chapter of the review provided foundational information on the phenomenon of chronic sorrow and established the background for the research project as it relates to the role of the nurse practitioner in support of families experiencing chronic sorrow. Merle Mishel’s Uncertainty in Illness theory served as the theoretical foundation for the research regarding the role of the nurse practitioner in support of families experiencing chronic sorrow. Research questions are provided to channel the systematic literature review.
CHAPTER II

Review of Literature

This chapter presents the literature reviewed regarding the role of the nurse practitioner in support of families experiencing chronic sorrow. This is an integrated literature review which summarizes research on a topic of interest by placing the research problem in context and identifying gaps and weaknesses in prior studies to justify new investigations (Polit & Beck, 2004). For the purpose of this review, data-based and theory-based manuscripts were reviewed and critiqued as they related to the role of the nurse practitioner in support of families experiencing chronic sorrow. Literature reviewed totaled 19 data-based manuscripts and 10 theory-based manuscripts which represented reviews of another 1,131 references. In this chapter, an overview of the study variables is presented as it emerged from the developing knowledge.

An Overview of the Healthcare Literature

Related to Support of Families Experiencing Chronic Sorrow

Literature Related to the Concept of Chronic Sorrow

In a review of literature by Mishel in 1999 the concept of chronic sorrow was evaluated from the perspective of uncertainty of chronic illness in adults as well as investigating the source and consequences of the uncertainty in parents of children with a chronic illness. Mishel’s Reformulated Uncertainty in Illness Theory (1990) was used to assess a large study size that was a culmination of information reported from various preceding studies. This evaluation was restricted to the chronically ill and the primary focus was on the parent’s experiences of uncertainty with minimal consideration given to
the experiences of the children. This assessment detailed a number of the probable causes of uncertainty including a lack of symptom predictability, uncertain expectations, the potential for disease recurrence or progression of the child’s illness or disability, and a lack of information to assist in predicting the future.

Data was also presented suggesting that healthcare providers may be adding to the uncertainty in parents by presenting an overly simplistic and/or over optimistic approach to caring for the child. It was further suggested that healthcare providers may be increasing the potential for uncertainty by destroying the self-management component in the chronically ill. Although limited to the chronically ill population, the study provided considerations for future research. These include research in the uncertainty experienced by families or parents of children with acute and chronic illness, and further research into the child’s lived experiences with uncertainty in illness. However, the findings of this evaluation do indicate that persons living with uncertainty are extremely imaginative in finding approaches to living with long-term uncertainty (Mishel, 1990).

According to a data-based study by Burke, Eakes, and Hainsworth (1999), research on the phenomenon of chronic sorrow has been limited to parents of children with various identified mental and physical disabilities or premature infants with a potential for some degree of disability. In this work, this base was expanded to include the chronically ill, the bereaved, and family caregivers.

This article also explored the milestones shown to trigger chronic sorrow in people across an array of loss situations such as comparisons with developmental norms and unending caregiving. Further advocated, was the necessity for healthcare providers to be aware of the high potential for chronic sorrow to occur in persons with chronic
conditions their family caregivers, and bereaved persons. Because these individuals are encountered in a variety of settings at times when they may be particularly vulnerable, it is also important to recognize milestones and events that may trigger a resurgence of grief-related feelings. “Recognizing chronic sorrow and supporting those who experience it are important components of family nursing (Burke, Eakes, and Hainsworth 1999)”. This study was limited to the current knowledge and research on chronic sorrow, but provided a foundation for inquiry and considerations for future research.

The study additionally suggested and supported that the phenomenon of chronic sorrow can not be limited to parents of children with disabilities or potential disabilities, but must be expanded to include the chronically ill, the bereaved, and family caregivers. Suggestions for further research include a qualitative approach to studying a variety of populations across the life span and comparing the findings to the issues found in studies of parents of children with disabilities. The identification of chronic sorrow in these groups will allow for generalization of findings.

Furthermore, comparisons of the phenomenon in diverse populations will disclose underlying linkages of subconcepts to support further expansion of the chronic sorrow theory, moving research on the phenomenon into the discovery mode of theory development. From this knowledge, interventions can be developed to increase the psychological comfort of those afflicted and their caregivers.

A theory-based article published in 1998 by Eakes, Burke, and Hainsworth introduced the middle-range nursing theory of chronic sorrow and wherein sorrow was presented as a normal response to ongoing disparity due to loss. Chronic sorrow was defined as the periodic recurrence of permanent, pervasive sadness or other grief related
feelings associated with a significant loss. These researchers presented a framework for understanding and working with individuals subsequent to a single or ongoing loss. Included in the model were antecedents, trigger events, and internal and external management methods. The theory was developed using concept analysis, critical review of research, and was validated in 10 qualitative studies of various loss situations. During the investigative component of the research, 196 individuals were interviewed with ages varying from young adults to the elderly.

Also included were individuals with chronic conditions, family caregivers, and bereaved family members. The conclusion was that chronic sorrow has been shown to explain the experiences of people across the lifespan who encountered ongoing disparity because of significant loss. However, the researchers also noted that their research revealed numerous implications for further research on the theory of chronic sorrow.

Specifics include a need to develop a concise instrument to identify the presence of chronic sorrow to facilitate future research and further study is needed to test the theory and its generalization to populations and loss situations not yet studied. In conclusion, the researchers noted the need for all health care professionals to recognize that chronic sorrow is a common experience across the lifespan. Further, it is important that all health care professionals view the recurring periodic episodes of sadness and other emotions characteristic of grief by the loss and provide needed support when chronic sorrow is triggered (Eakes, Burke, & Hainsworth, 1998).

A separate article published in 1992 by Burke, Hainsworth, Eakes, and Lindgren focused on individuals with chronic illness and their family caregivers across the lifespan. Heretofore, the phenomenon of chronic sorrow had been limited to samples of
parents of children with disabilities. This article was the original work by these researchers during the establishment of the Nursing Consortium for Research on Chronic Sorrow (NCRCS) and utilized the Chronic Sorrow Questionnaire developed by Burke in 1989 and revised by the NCRCS. This research tool was used in their study and involved the combination of both quantitative and qualitative data.

The purpose of the study was to assemble current data on the concept, identify measurement tools, and produce guidelines for additional studies. Consequences of this work confirmed the clinical relevance in alerting professionals to the need for ongoing support measures. The results of the study can be used to identify interventions that can be developed to increase the psychological comfort of those affected by chronic illness as well as their caregivers as they experience chronic sorrow.

Chronic sorrow is an experience, which can be expected to occur with individuals and caregivers of those experiencing chronic illness or life threatening conditions. Findings from this study can alert healthcare professionals to the need for specific continuing support measures, especially during times of milestones and other events that trigger chronic sorrow (Burke, Hainsworth, Eakes, & Lindgren, 1992).

The purpose of a data-based article by Lindgren, Burke, Hainsworth, and Eakes (1992), was to clarify and establish the meaning of chronic sorrow for use of the concept in nursing theory, research, and application in clinical practice. To establish a working definition, it was necessary to trace the development of the concept from its origin by Olshansky (1962) through Burke’s research (1989). Data gathered from this historical
search of literature provided the authors with a compiled list of the critical attributes of chronic sorrow. In reviewing these attributes, they were then able to differentiate between chronic sorrow and prolonged grief.

Furthermore, they were able to distinguish chronic sorrow as a phenomenon as opposed to depression. From a review of specific cases, the authors defined the antecedents and consequences associated with chronic sorrow as opposed to grief and depression. They traced this illness trajectory across the lifespan and concluded that chronic sorrow is a normal reaction to a complicated, difficult situation in life. Understanding what chronic sorrow is and how it operates in the lives of patients and their caregivers is fundamental for providing effective nursing care to those suffering (Lindgren, Burke, Hainsworth, & Eakes, 1992).

Although Lindgren, Burke, Hainsworth, & Eakes differentiated between chronic sorrow and grief, the concept of grief should be understood to assist in differentiating the characteristics. Cowles & Rodgers (1991) performed a comprehensive and systematic review of both current and classic literature concerning grief within the disciplines of nursing and medicine. This was done in an effort to clarify the category of the concept of grief as it has been employed in the literature and to develop a basis for additional research.

During their research they found a propensity toward inconsistency in definitions of grief as well as frequent uses of interchangeable surrogate terms. As such, they identified a need for expanded knowledge concerning the unique and significant concept in both a systematic and a legitimate conceptual basis. In spite of these many variables, the researchers were able to identify the principle attributes, antecedents, and
consequences of the concept of grief. The conceptualization of grief that resulted from this research offered a significant contribution to the realms of nursing practice.

However, it was evidenced that the majority of nursing knowledge concerning grief had been derived from conceptualizations presented in other disciplines. Therefore, future research by nurses based on this research rather than on medical conceptualization may be of value in identifying approaches to grief that are specific to the nurse practitioner. The results of this investigation did not provide a definite answer to all conceptual problems concerning grief. Additionally, the insights gained through this analysis give needed direction to future efforts to expand existing knowledge concerning this unique and significant concept as well as interventions for nursing practice (Cowles & Rodgers, 1991).

Teel (1991), in her analysis of the concept of chronic sorrow also analyzed the concept of grief. The purpose of which was to appreciate the salient differences between bereavement following death and the emotional pain that occurs with ongoing loss. This is a theory-based document which expanded the development in the concept analysis of chronic sorrow. This work contrasts the perception of the known person who has become disabled with the hoped for child or disabled child. It was noted that the loss of relationship whether hoped for or actual can trigger chronic sorrow. This analysis was non-specific to a particular group or to the relationship of individuals who experience chronic sorrow.

In comparison, grief is identified as bereavement created by the death of another with recovery along a temporal sequence though progression is not necessarily at a
constant pace. Chronic sorrow is acknowledged to be the loss of attachment due to a permanent disability. Further review of the literature identifies elements of periodicity, variability, and permanence of psychic pain and sadness as the conceptual elements present in response to an ongoing loss. These components, when considered as a whole, are termed chronic sorrow.

In conclusion it was stated that current models of bereavement cannot be applied to understanding of those who suffer an ongoing loss or the normalcy of chronic sorrow will be lost. Eventually, development of an instrument to quantify the components of chronic sorrow may assist in the identification of additional populations in whom the phenomenon may occur. Analysis of the concept of chronic sorrow provides a first step in these future endeavors (Teel, 1991).

In another article on the concept of grief, Jacob (1993) approached the analysis of the concept from the perspective of the nursing discipline. She acknowledged that the current nursing knowledge was built on conceptualizations of grief from other disciplines. She further emphasized the need for nursing science to develop a knowledge base to eradicate the ambiguity created by a lack of consensus among the other disciplines. In this analysis, Jacob executed a literature review beginning with Freud’s work in 1915 through the 1991 work by Cowles & Rogers.

In general, the research reviewed focused on the symptoms which accompany grief to try and arrive at a clear concise nursing definition which could be agreed upon by all disciplines. In this work, Jacob utilized the theoretical framework by Walker and Avant (1988). This analysis of grief clarified the ambiguity which plagues the concept. The attributes and resulting definition(s) of grief pointed to a need for more appropriate
instrumentation and longitudinal qualitative studies to measure the dynamic process.

Consensual agreement on a concise definition of grief can facilitate research endeavors which will fill the knowledge gap regarding grief (Jacob, 1993).

In a concept analysis on the cultural perspectives of grief Cowles (1996) acknowledged that there are many aspects of grief about which little is known. However, she focused on the role that cultural perspectives plays in influencing the individual, intrapersonal experiences of grief. This research was conducted, in part, to discover how individuals from a variety of cultural heritages defined and described grief based on their personal experiences. To this end, the investigator explored the concept of grief using six focus groups from varying cultural backgrounds. Her finding indicate that although cultural differences may exist in mourning rituals, traditions, and behavior expressions of grief, there was no noted particular differences in the individual, intrapersonal experiences of grief. As such, cultural heritage and ethnicity alone are not major contributors to the grief experience.

The findings additionally reinforce the need for nurses to attend to the very universally experienced pervasiveness of grief. Nurses must also perform thorough and ongoing assessments of client’s needs and concerns to discover all areas of his or her life that may be affected by grief and how these may change over time. However, there is much work that must be accomplished to build upon these findings. Further studies are needed to include the perceptions of many other cultural and ethnic groups and further questions regarding the normative component of grief need to be empirically addressed (Cowles, 1996).
A data-based article by Melvin and Heater (2004) differentiates between suffering and chronic sorrow. This work constituted a literature review which provided the information necessary to define both the concepts of suffering and the concept of chronic sorrow. Through an understanding of the differences, healthcare providers were then able to intercede with caring interventions in assisting the client with expert communication skills, compassion, honesty, and trust.

Another goal was to develop a paradigm for nursing intervention because the nurse-client relationship dictated that nurses be a close traveling companion on an uncertain journey. This included bringing together a multitude of nursing interventions to provide ultimate client results. These interventions included presence, honesty, compassion, communication skills, trust, and human touch. Since nursing is most often the discipline closest to those suffering or experiencing chronic sorrow, nursing must provide the core of caring.

Therefore, nursing is put to the test to expertly interface with these clients. This is a responsibility of nursing and a responsibility that is cherished. Nurses are capable of offering the kind of caring that heals and is the heart of nursing practice (Melvin & Heater, 2004).

**Chronic Sorrow in Caregivers of the Progressive or Chronically Ill**

A theory-based article by Clubb (1991) analyzed the adaptation patterns of parents with children who are chronically ill. Through a literature search, Clubb identified two major approaches to explain parental reaction to a child’s disability. These were the time-bound model and the chronic sorrow model. The time-bound model suggests a progression in the adaptation process.
These levels of progression include impact which usually occurs at the time of medical diagnosis. This is followed by denial which is deemed to be a defensive mechanism. Following denial is grief which is manifested through feelings of anger, guilt, and sadness. After a grieving period, the parents begin an outward focus which is classified as the stage during which parents demonstrate coping measures. Finally, there is closure wherein the parents accept the fact that their child's diagnosis has disrupted and will continue to disrupt normal family life.

The second approach was the chronic sorrow model which produced a different conclusion. Although the stages of progression coincide with those of the time bound model, there is one major difference. Advocates of this approach dispute the parent’s arrival at the closure stage. Rather, the recurrence of sorrow prohibits parent’s ability to reach closure. The chronic sorrow model is based on the concept of Olshansky (1962). Clubb’s investigation included a variety of children with special help needs and was not limited to severity or disability. As a result of the small sample size and nonrandomization of the parent sample, there is a potential for bias.

The results of the investigation clearly reveal the need for additional research. Some of the suggested areas of research included the parental role differences, order of birth, the effects of death, social class reactions, and research which identifies positive as well as negative aspects. There is an identifiable need for additional coping strategies in families dealing with chronic sorrow. The study of chronic sorrow in populations with impaired cognition has advanced only slightly beyond documentation of the phenomenon (Clubb, 1991).
A Canadian article by Gravelle (1997) explored the lived experiences of parents caring for a child at home who has a progressive life-threatening illness. This qualitative study focused on a certain point in the child’s illness trajectory. This focal point was specific to the time when the child lives with a complex chronic condition, and is in need of specialized and time-consuming care, but is not yet in a terminal phase. The researcher examined eight subjects using audio taped interviews. The data collected were analyzed using Giorgi’s steps for data analysis (Omery, 1983) and Anderson’s (1992) recommendations for phenomenological data analysis.

The central theme of the research was conceptualized as an ongoing dual process of facing adversity. The first component of facing adversity was the family’s ability to define adversity. Since all families and their circumstances are unique, the definition of adversity was discovered to be individual to each specific situation. The second component of facing adversity is the family’s ability to manage adversity. This was characterized by parents managing changes related to the child’s condition and subsequently, the caregiving role. Concepts of normalization and chronic sorrow were considered in the conceptualization of facing adversity. Also considered were the challenges of caregivers who faced numerous hardships including the myriad of changes related to the increased burden of care.

Based on the findings of this research were several implications for nursing practice. These included a need for a more thorough nursing assessment that includes the family’s present situation and past events. It was also recommended that provisions be made for ongoing assessments to monitor the family’s coping ability and for nurses to be responsive to the changing needs of the family including recommendations for such
services as respite care. Ongoing assessment would enable a smooth transition between levels of care from a trained caregiver to nursing care as the child’s disease progresses (Gravelle, 1997).

In a paper by Lowes and Lyne (2000), the researchers explored chronic sorrow in parents of children with newly diagnosed diabetes. This was the first paper in an empirical study of the way that parents of children with newly diagnosed diabetes experience and cope with home management. This part of the work included a broad review of the literature on the experiences of parents in both early and later stages of caring for a child with diabetes.

Not surprisingly, two contrasting theoretical positions emerged on the progress of grief thus forcing the researchers to conduct a subsidiary review. These two theoretical positions were the time-bound theory of grief and the theory of chronic sorrow. The research material was reviewed to discover the strength of the empirical evidence in support of each of the two theoretical positions. Both theoretical perspectives were described in the paper and a critical appraisal of each theory was presented.

While the findings were not concrete, it was suggested that parents who appear to be coping successfully may still suffer from emotional responses which fit the description of chronic sorrow. Therefore, the balance of the available data evidence supports the view that some parents of children with diabetes may never fully recover from the impact of the diagnosis. These parents may experience the recurring sadness described by Olshansky (1962) as chronic sorrow. For them, acceptance and resolution are continually postponed (Lowes & Lyne, 2000).
The findings further advocate a need for health care professionals to better understand and respond to parental emotions and needs. They need to be aware of the losses suffered by parents of newly diagnosed children and recognize that their grieving experience may not always follow a particular course to resolution. The researches also suggest that further work is needed to investigate the range of parent’s emotional responses to children with diabetes and to develop supporting strategies which recognize the differences.

An article published by Hobdell (2004) explored the relationship between chronic sorrow and depression in parents of children with neural tube defects. King’s (1981) open system framework was used to guide this study and the researcher used the following research tools to assist with this study: Adapted Burke Questionnaire, Form A and Form B (Burke, 1989); Direct Question (Damrosch & Perry, 1989); Adjustment graph (Damrosch & Perry, 1989); Brief Symptom Inventory (Derogatis & Spencer, 1982); and Modified Participant Observation (Phillips, 1991).

The research was investigated from both quantitative and qualitative analysis involving 132 parents of children aged six months to six years. The subjects were recruited from two tertiary pediatric care facilities which receive referrals from various socioeconomic backgrounds as well as varied geographic locations. The results of the research provided empirical evidence that supports diverse dimensions of chronic sorrow. The research also indicated an association of modest magnitude between chronic sorrow and depression and further suggested that depression may be associated with chronic sorrow.
Suggested future avenues for research would first be to replicate this work with extension to parents of older children. Next, use of an instrument that measures situational rather than clinical depression would provide a clearer comparison between chronic sorrow and depression. Finally, variation in the sequence of instrument administration would aid in eliminating a potential bias from the structured sequence used for this study. Chronic sorrow is a potential barrier to parental understanding of their child’s care and diagnosis. This study provided evidence for three dimensions of chronic sorrow that may impact and interact, creating this barrier in both mothers and fathers (Hobdell, 2004).

Scornaienchi (2003) examined the middle-range theory of chronic sorrow and its application to one mother caring for two children with lissencephaly. This was a qualitative research into one mother’s experience using the Nursing Consortium for Research on Chronic Sorrow (NCRCS) Chronic Sorrow Questionnaire Caregiver Version (Burke, Hainsworth, Eakes, & Lindgren, 1992) as well as personal interviews. The study was restricted to one family which did limit validity and reliability to the general population.

The results of this research provided directions for both additional research and nursing implications. Some suggested future research included studies on cultural differences and differences in family structure, research on the effectiveness of specific interventions, and research on the positive benefits of a child with disabilities has on the family. It was further emphasized that additional research on the concept of chronic sorrow and on the application of the theory of chronic sorrow is needed.
Nursing implications included the need for nurses and nurse practitioners to allow parents to express joy and hope and not interpret it as a denial of reality. Secondly, nurses should use the results of research to help them assess parents’ coping styles and promote psychologically healthy coping. Thirdly, nurses and nurse practitioners should not be afraid to ask how they may help because parents of children with disabilities become adept at recognizing helpful and non-helpful behaviors on the part of health care professionals. Finally, nurses must develop good listening skills and understand that parents of children with special needs are navigating uncharted waters.

Understanding parents’ experiences of chronic sorrow can help nurses to plan interventions that are effective and supportive and, the nurse, acting as an advocate for the child, improves the family’s coping skills. More importantly, connecting to the lived experience of another human being leaves both lives changed for the better (Scornaienchi, 2003).

Northington (2000) researched the process of chronic sorrow in caregivers of school age children with Sickle Cell Disease (SCD). The purposes of which were to examine the process of chronic sorrow in caregivers of school age children with SCD, identify the characteristics of chronic sorrow, and generate a substantive theory of chronic sorrow. The convenience sample consisted of 12 African-American caregivers of children diagnosed with SCD. The ages of the children for this study were between 6 and 12 years of age.

The researcher used the Grounded Theory of Glaser and Strauss (1967) as the theoretical foundation for this project. Data were generated through a demographic data questionnaire and two interview guides developed by the investigator over a period of 11
months. The interviews were audio taped, transcribed, and validated along with the field notes. Data were then combined to provide a comprehensive picture of chronic sorrow in relation to the experience of African-American caregivers of school age children with SCD.

The results indicated a process of evolution with three overlapping stages. In the first stage, caregivers learned about the diagnosis, learned to deal with the disruptions created by the diagnosis, and began to incorporate the diagnosis as part of their family lives. The second stage proved to be dynamic, cyclic, variable in duration and intensity, and not always predictable. The third stage was acceptance by the caregivers that although they had no control over the disease and its outcome, they did have control over their actions and responses. It was during this stage that the caregivers found a way, despite the chronic sorrow experience, to incorporate these new patterns into everyday life.

Data from this study suggested that the diagnosis of SCD had an immediate effect on the caregiver and as the child grew older and experienced complications related to SCD, chronic sorrow became increasingly evident. Recommendations from this research included further refinement of the theory and improved recognition of triggers, manifestations, and responses to chronic sorrow. Furthermore, nursing research on the concept of chronic sorrow is very limited. Therefore, replicated and expanded studies need to be conducted. In the educational arena, greater attention needs to be placed in curricula regarding chronic illness and its effects on the individual, family, and caregivers (Northington, 2000).
Using a phenomenological approach, Johnsonius (1996) asked three participants to tell a story that described how they felt with a chronically ill child. The participants in this study agreed to private audio recorded sessions which were transcribed by the researcher to visual text for a continued search for researcher understanding. Participants were from the same geographical area, were healthcare providers, and were acquaintances of the investigator. It was noted that within other research paradigms, these would have been considered research limitations. However, in the lived experience method of inquiry, the sharing of the story is the essence of the investigation.

Data was sorted in a search for recognition of structural components that shared in a description of the essence of chronic sorrow. The process began with the search for shared stories as exemplars of chronic sorrow. The shared stories were also the keys to understanding the essence of the phenomenon. When the results of the interviews were transcribed into visual text, a common pattern emerged. Although each participant’s words and phrases were different, these words and phrases are all descriptors of chronic sorrow. The pattern begins with an initial disappointment followed by times of fear, sorrow, stress, sadness, uncertainty, and recurrence of sadness.

Phenomenological stories strive to help us understand the essence or core of the reality. It is the ontological position that asserts that there is a reality, but one cannot know it fully. When small numbers of stories about parental perceptions of chronically ill children are available, few exemplars of perceived reality exist; however, many stories reflect multiple facets of the reality. Common meanings illuminate the darkened passageway in the search for a complete understanding of the chronic sorrow in the lives of parents with chronically ill children. Health professionals search for the candle that
will illuminate the darkened passageways of the mind, soul, and spirit. Understanding of the essence of chronic sorrow will be the candle in a passageway for parents with chronically ill children (Johnsonius, 1996).

**Chronic Sorrow in Caregivers of the Mentally Disabled**

A data-based article by Hainsworth, Busch, Eakes, and Burke (1995) explored whether women with chronically mentally disabled husbands experienced feelings of chronic sorrow. This article published the results of one of a multiple of studies by the Nurses Consortium for Research on Chronic Sorrow (NCRCS) in their work to expand the understanding of chronic sorrow. Chronic sorrow for this research is observed as a normal state associated with chronic or life-threatening conditions, occurring both in the individual with the chronic condition and in family members. However, chronic sorrow was operationally defined as a pervasive sadness that is permanent, periodic, and progressive in nature (Burke, 1989).

In this study, interviews with 11 women were analyzed using the NCRCS questionnaire (Caregiver version) as a guide. The tool is a modification of the instrument developed by Burke (1989) in her research of mothers of children with spina bifida. Validity and reliability had been established on the original instrument. Content analysis was used in this research wherein the data from all 11 transcripts were reviewed independently by the researchers. The presence or absence of chronic sorrow was determined by applying Burke’s definition to the data. The sample consisted of 11 women whose average age was 42.7 years. They had been married to their disabled husband for an average 20.4 years. All of the husband’s mental illnesses were of a psychotic nature and had lasted for at least 6 months.
The results of the research evidenced that all 11 women experienced feelings of chronic sorrow. Their feelings were consistent with the feelings of chronic sorrow reported in other studies. The overwhelming request of the 11 women interviewed was that nurses and other professionals be available to listen to them and to recognize their pain. If chronic sorrow is unrecognized or is viewed as pathologic, it seems likely that this will contribute to the pain of the chronic experience. Conversely, when chronic sorrow is recognized as a normal phenomenon and healthy coping strategies are identified and supported by nursing, the outcome is likely to be increased comfort for women with chronically mentally ill husbands (Hainsworth, Busch, Eakes, & Burke, 1995).

According to a data-based manuscript by MacGregor (1994), unrecognized grief in parents with mentally disabled children causes many parents to be misunderstood and misaddressed at a core level. Such misunderstanding is seriously disabling to both families and patients because it can interfere significantly with a parent’s ability to move forward emotionally and to deal effectively with the uncertainty that lies ahead. Society most often fails to recognize the loss that the parents are experiencing and as such offers no consolation.

Therefore, because parents of mentally ill children are less likely to find the level of support and confirmation they need in their community, they may turn to professionals for help. It is crucial that professionals recognize grief and respond to it appropriately to validate and normalize the experience for families. Unfortunately, mental health professionals are more likely to identify parental responses as pathological thus leaving the parents to deal with their losses alone.
This parental grief is normally experienced in cycles and can be caused by stressor events, medical crisis, and missed developmental steps. It can surface each time at the same intensity as at diagnosis similar to the chronic sorrow of parents of mentally retarded children (Fraley, 1990). MacGregor cautioned that mental health professionals must not continue to ignore this issue and must strive to meet the educational and emotional needs of these parents. Mental illness has many unknowns, but the grief of parents has been with us since the beginning of time. Mental health professionals who are knowledgeable and experienced in the healing process of bereavement can offer much to suffering families (MacGregor, 1994).

Eakes (1995) investigated the incidence of chronic sorrow in parents of chronically mentally ill children. A sample size of 10 parents was recruited from a regional mental health center. These were parents of an adult child who had been diagnosed with either bipolar disorder or schizophrenia. The average age of the parents was 62 years and the average age of their children was 36.3 years.

The Middle Range Theory of Chronic Sorrow (Eakes, Hainsworth, Lindgren & Burke, 1991) was used as the theoretical framework for this investigation. A quantitative research approach was used, with the Burke/NCRCS Chronic Questionnaire (Caregiver Version) serving as the interview guide. Audio-taped interviews were conducted by the researcher in private settings and were approximately 1 hour in length.

The presence or absence of chronic sorrow was determined by comparing subjects’ responses to the operational definition. Reliability between the independent ratings of the researcher and a NCRCS colleague was 1.00. The findings of this research suggested that chronic sorrow is likely to be experienced by parents of chronically
mentally ill individuals. Indeed, 8 out of 10 parents interviewed showed evidence of chronic sorrow.

Areas for future research included continued studies on chronic sorrow involving family coping strategies and interventions that families experiencing chronic sorrow perceive as helpful. Recommendations to nurses and other health care professionals included offering practical tips, delivering situation-specific information, communicating in a clear and honest manner, and involving the parents in the treatment plan. The parents’ predominant need for nurses and other healthcare professionals to function in the role of Teacher/Expert is consistent with the fact that most used cognitive styles of coping (Eakes, 1995).

**Chronic Sorrow in Caregivers of the Developmentally Disabled**

A research study by Kearney and Griffin (2001) explored the experiences of parents who have children with significant developmental disabilities. This was an extensive exploration of the subjects involved in the study and was driven largely by Van Manen’s (1990) eclectic hermeneutic phenomenology. The heart of the research was the interpretation of the experience from the individual’s unique perception. The study focused on limited families and therefore cannot be generalized to the general population and subsequently cannot be used as a generalized model.

The research came about as a result of Kearney’s dissatisfaction with previous interpretative paradigms that led her to question the conceptual base for the impact of disability on the lives of families. It was argued in the research that positive aspects of being a parent of a child with a developmental disability have received scant attention in the professional literature.
Furthermore, the responses of parents with children with disabilities are frequently interpreted within theoretical frameworks of pathology. The research presented some alternative interpretations and language that afford these parents greater justice. The researchers also argued that, in line with the phenomenological underpinning of this project, parents’ expressions of their being-in-the-world with their children must be accepted as their reality. This work argues for a professional approach that acknowledges hope, one that should be included in the education of professionals (Kearney & Griffin, 2001).

The researchers, Mallow and Bechtel (1999) studied the concept of chronic sorrow as experienced by parents of developmentally disabled children and compared the experiences of mothers and fathers separately. The researchers utilized the Burke’s Chronic Sorrow Questionnaire (Caregiver Version, Burke, 1989); Open ended questions (Burke et al., 1992; Hainsworth et al., 1989) and Drawn graph design (Damrosch & Perry, 1989) to develop their qualitative study and quantitative investigation.

Their research involved 28 subjects comprised of 19 mothers and 9 fathers who shared their experiences of living with 24 developmentally disabled children. Criteria for the study indicated that the parents be married, both be members of the support organization, and have a developmentally disabled child. This investigation included a mixing of families whose children had various diagnoses, which provided data not previously available.

This study attempted to differentiate between mothers and fathers in perception of intensity of feelings. The research was limited due to the rural and distance nature of the geographic location being surveyed because a broader spectrum of locating families was
not available. This was a limitation of the research. It was found that while both mothers and fathers experienced chronic sorrow, a greater proportion of mothers experienced recurrence than did fathers. Recommendations from this study suggests that nurses and other health care providers have a significant role in facilitating positive coping mechanisms in both mothers and fathers.

Also, providing holistic, individualized care that recognizes differences in adaptation among women and men should be the focus of care. Proactive involvement by health care professionals has the possibility of significantly reducing the extent and duration of chronic sorrow while enhancing the quality and cost effectiveness of care (Mallow & Bechtel, 1999).

A research article by Hummel and Eastman (1991) explored the reaction of parents to the premature birth of a child. Subjects for this research project were selected over an eight-month period until the sample size reached 103. All of the subjects were parents of premature children enrolled in a follow-up program in a Midwestern state. In addition, all respondents were married, were biological parents with legal custody of the child, were able to speak, read, and understand English, and consented to participate in the study. All infants included in the research were less than 37 weeks gestation at birth, a single birth, free of congenital anomalies, and present at the clinic for an exam at 4, 9, 18, and 30 months of age.

Participants were given identical questionnaires developed by Fraley (1986) and modified for this study. The questionnaire asked the parents to recall the time of the birth of their child and to indicate the presence or absence of 27 feelings. Happiness, relief, and hope as well as 24 feeling of loss, grief, and fear were included. Although there were
gender differences in the responses from mothers and fathers, the results of this study supported the hypothesis that parents of children born prematurely experience grief, loss, and fear when their child is born.

However, even considering the stress related to developmental delays, it was difficult to label the parental feelings as chronic sorrow. It is also important to note that the sample was quite homogeneous in that all parents were married, nearly all were Caucasian, and most had at least a high school education and were of middle to upper class. Therefore, caution should be used when generalizing the results of this research.

Coping with the Phenomenon of Chronic Sorrow

A theory-based manuscript by Schmidt, Peterson, and Bullinger (2003) provided a framework for the study of coping with chronic conditions in childhood and adolescence. This process included focusing the developmental, contextual, and interpersonal facets of coping and highlighting its relevance for participation. Data collection for the research project was obtained using a Medline search from 1975 to 2001 which resulted in 391 articles related to coping with chronic disease.

Findings from this research suggested that childhood coping can be characterized by a heterologous development, with behavioral strategies being more predominant in early childhood and being the basis for the evolving, more stable cognitive process (Gil et al. 1992, 1993; Fournet et al. 1998). In addition, the dynamics involved in the development of coping strategies is shaped partly by the interpersonal environment and partly by disease-related factors. Interpersonal, in particular attachment relationships are important in coping because the attachment system is more likely to be activated in times of disease (Feeney 2000; Schmidt & Strauss 2002).
Furthermore, it was found that coping may serve as a mediator of attachment-related emotions. However, a determination of whether coping is more a mediator or moderator of adaptational responses to a disease was not tested. Suggested future research included measurement approaches in the area of childhood coping, investigation of the content of coping with chronic conditions, and developmental research on various types of interventions. The study of how individuals adapt to their disease and develop new competencies by participating in medical decision-making will emerge as a new field for clinical practice (Schmidt, Petersen, & Bullinger, 2003).

A data-based article by Melnyk, Feinstein, Moldenhauer, and Small (2001) explored the stressors encountered by parents of chronically ill children and their responses to these stressors over time. Also investigated were the summary of instruments that can be used to assess parental coping with childhood chronic illness, inclusion of important factors to assess when dealing with parents of chronically ill children, and a concise review of intervention studies that have been conducted to enhance coping in these parents.

In addition, the authors presented a theoretical model that can be used in guiding assessment and interventions. They also provided an assessment guide to facilitate nurse psychosocial assessments and identify areas needing intervention. Theoretical framework guides included in this analysis were the Control theory (Carver, 1979; Carver & Scheier, 1982); Self-regulation theory (Johnson, Fieler, Jones, Wlasowicz & Mitchell, 1997; Leventhal & Johnson, 1983; Johnson, 1984); and the emotional contagion hypothesis (Jimmerson, 1982; Vanderveer, 1949).
Based on the integration of these three theories, it was determined that nursing interventions which prepare parents for what to expect as their child moves through developmental transitions and illness exacerbations will strengthen parents belief about their coping abilities. As a result of empowering parents to function more effectively in their role and enhancing parent coping, both children with chronic illnesses and their parents will have improved outcomes (Melnyk, Feinstein, Moldenhauer, & Small (2001).

Wittman, Hobbs, and Lee (2001) investigated the effects of chronic sorrow on parents and ways to help them cope. This was further expanded to include how occupational therapist can be of help to those affected by this phenomenon. This was part of an ongoing research project and three mothers of children with disabilities were interviewed using an adapted version of the Chronic Sorrow Questionnaire developed by the NCRCS. The purpose of this investigation was to learn more about the coping strategies used by these parents, how other professionals were and were not helpful, in what roles they were and were not participating, and which of these roles they viewed as helpful and healthy for them.

The results were a list of behaviors that these mothers perceived as helpful. Their responses included doing what they asked them to do, doing work for free, becoming the child’s “buddy”, being willing to let parents talk to them at any time, giving their home phone numbers, doing extra research, and telling them not to blame themselves for their children’s disabilities. In essence, the participants seemed to be asking professionals to express a sense of real, personal caring about them as parents and about their child as a person. It was also noted that there was general frustration with professionals who were not helpful.
Recommendations for professionals were to encourage parents to vent their feelings, discuss openly the concept of chronic sorrow which gives creditability to their feelings, explore various coping styles or strategies, demonstrate a personal as well as a professional commitment to clients, and stay informed of current research and intervention techniques.

In a research article by Doornbos (1997) the problems and coping methods of caregivers of young adults with mental illness were critiqued. The research sample consisted of 108 caregivers obtained by means of a nonprobability sampling strategy. Subjects were given two open-ended questions to answer and provided written responses to these questions. The procedure used was the mailing of the questionnaires with a stamped envelope for return of the materials. Respondents were assured of confidentiality. Completion of the questionnaire was interpreted as informed consent. The results were a part of a larger study in which a middle-range theory of family health in the families of young adults with persistent mental illness was tested (Doornbos, 1995), and strengths of these families were explored (Doornbos, 1996).

The results of the research indicated that caregivers of individuals with mental illness experience an array of problems. The primary problems were burden of care, symptomatology, negative impact on family, grief, and fear of the future. The caregivers also identified numerous coping mechanisms including assuming facilitative attitudes, relying on faith, increasing knowledge of illness, and attending support groups. The results of this study paralleled the results from previous research and strengthened nursing’s research-based practice relative to this population.
Also, the results of this study suggested several other roles for the professional nurse. Among these were the nurse as a teacher, the nurse as a referral agent, and the nurse as a spiritual caregiver. In summary, the caregivers of young adults with serious and persistent mental illness have multiple challenges as well as definite ideas about positive coping. Professional nurses must use this information to increase their understanding of the caregivers’ perspective and use it in the design of care (Doornbos, 1997).

An article by Hewson (1997) reviewed the grief models and provided an overview of all the apparent assumptions of grief models in the context of death. This was done to provide a background for the second section of the research in which the models were evaluated for their applicability to responses to loss of ability. The third part of her research considered an alternative framework and stress responses. Finally, an episodic Stress Response Model is proposed to conceptualize loss of ability experiences.

It was noted in discussing the resolution part of the grief models that ongoing or repeated sadness can be a part of the long-term response of parents to the changing demands of caring for a child who has experienced a loss of ability. Chronic sorrow was noted as not necessarily being a static state in which grief responses are always dominant. Rather, it is a changing phenomenon, with peaks of sorrow and stress and valleys of calm and happiness. Coping was viewed as a process used in an attempt to manage the stress and in which coping processes can operate as cyclic phases of retreat and encounter responses.

Finally, an Episodic Stress Response Model was proposed for conceptualizing responses to loss of ability. This model was derived from the stress-appraisal-coping
model (third section) and chronic sorrow research (second section) although the term episodic replaced chronic to avoid implications of pathology and constancy. Stress response replaced sorrow to highlight the recurrent, localized triggers of the multitude of responses rather than focusing on the response of sorrow which is neither the universal nor exclusive response.

Although the episodic stress response model had not been subjected to direct empirical testing, it did face validity in that it did fit the empirically validated recurrent pattern of loss responses by people who live with loss of ability (Burke et al., 1992; Copley and Bodensteiner, 1987; Wikler et al., 1981). In summary, it was suggested that the episodic stress model provided a nonpathological, descriptive framework for conceptualizing common responses to loss of ability.

Fraley (1990) investigated the parental responses of parents with a premature, disabled, or chronically ill child. Included in her investigation were the stressor events that triggered recurring grief, differing methods of coping with their situations, and an understanding of the loss felt by parents of the children. This study was a look at chronic sorrow from the perspective, not of mental retardation, as originally described by Olshansky (1962), but from the perception of the parents of premature, disabled, or chronically ill children (Fraley, 1990). This work by Fraley did not differentiate between mentally or physically delayed children or those disabled by a chronic illness.

The results of her study provided a number of implications for nursing practice and intervention. Among those was the necessity for nurses to be aware of the fact that the growth and development of a disabled, chronically ill, or premature child generate a variety of psychosocial stresses for the family. These specific crises or stressor events
that should alert nurses for signs and behaviors of recurrent parental grief were identified. It was also noted that nurses should recognize chronic sorrow as a normal process in order to give parents the opportunity to continually ventilate their feelings and assist them in adapting to the many concerns and problems associated with their child.

The importance of providing support to these families was also stressed in this article. Areas of support included recognition that parents, especially mothers, are usually physically and mentally exhausted. Therefore, the mother should be given opportunities to be away from the child and the home and parents should be encouraged to spend time alone together. It was further suggested that nurses be familiar with respite care services and encourage parents to utilize these services.

Additionally, nurses and other health care providers should be able to provide education and or educational material to the parents as available. It was also suggested that further studies are needed to explore the response of families to prematurity, disabilities, and chronic health problems. Furthermore, studies are needed to explore the concept of chronic sorrow in relationship to this population. Research ultimately will reduce long-term suffering and promote family health (Fraley, 1990).

The purpose of an article by Warda (1992) was to apply concepts of role theory to the understanding of phenomenon of chronic sorrow and to suggest clinical and research applicability for nurses working with families of chronically disabled children. Research findings in the area of chronic sorrow, family adaptation, and role theory were used to formulate propositions specific to the application of role theory.

In this study, Warda applied clinical and research applicability for nurses working with and supporting families of children with disabilities and chronic illness. The Role
Theory of Pearlin (1983) was used to discuss chronic sorrow and the family. In summary, Warda states, “chronic illness and disability are precursors of chronic sorrow in families; however, the intensity of the sorrow and the family’s effectiveness in living with and managing chronic illness and disability should be the focus of nursing interventions”.

Suggested nursing interventions included the use of therapeutic role supplementation in their work with families and providing information about illness and patient care needs as well as information about normal psychological reactions to tragic events. Furthermore, nurses can help family members to identify intrafamilial support such as spousal support and social support from friends and, teach families to master the intricacies of modern medical equipment.

Proposed future research included empirical studies to help identify what family characteristics are most likely to result in adequate adjustment to chronic sorrow and the development of a measuring instrument to gauge family status evaluations and individualized interventions. Development of new sources of knowledge to address the critical needs of chronically ill children and their families is an area specially suited to be studied by practicing nurses (Warda, 1992).

**Summary**

This chapter presented the literature reviewed regarding the role of the nurse practitioner in support of families experiencing chronic sorrow. However, as noted in the limitations, there is a lack of research information related to this role specific. Nevertheless, there was overwhelming consensus in the literature which evidenced caregivers of the developmentally or chronically ill need the support of all healthcare
providers. This consensus advocated a need for healthcare professionals to better understand and respond to parental emotions and needs. They also need to be aware of the losses suffered and recognize that the grieving process may not always follow a particular course to resolution. More specifically, the data verified that nurses as the primary healthcare providers are oftentimes the only available outside support for these caregivers. As such, the literature emphasized the need for nurses to be trained in recognizing chronic sorrow in caregivers and respond with understanding, comfort, and informative facts. Therefore, nursing is put to the test to expertly interface with these clients. The literature also accentuated that future nursing research focus on existing research rather than on medical conceptualization to identify approaches to chronic sorrow that are specific for nursing.

Chronic sorrow is an existent phenomenon in the lives of the chronically ill and disabled, their families, and other caregivers. It is comprehensive and can encompass all areas of life for those who suffer. The emotions associated with chronic sorrow can range from happiness to hopeless grief and can be a life-long experience. Moreover, the number of those experiencing chronic sorrow is expected to increase as continuing technological advances in healthcare increase longevity in the population. Understanding chronic sorrow and how it operates in the lives of patients and their caregivers is fundamental for providing effective care to those suffering. Therefore, it is essential that all healthcare providers understand the concept of chronic sorrow and position themselves to provide support to those living with this phenomenon.
CHAPTER III

Design and Methodology

This chapter will present the specific parameters used to investigate the current level of nursing knowledge among nurse practitioners in support of families experiencing chronic sorrow and the role of the nurse practitioner in support of these families. The approach that was used was that of an integrative literature review which is a systematic summary of data-based and theory-based literature representing the status of current knowledge available on the topics of interest (Polit & Beck, 2004).

Approach

An integrated literature review, which is a review of research that amasses comprehensive information on a topic, weighs pieces of evidence, and integrates information to draw conclusions about the state of knowledge, will be used for this study. This investigation is an evidence-based practice systematic review. While an integrative literature review summarizes research on a topic of interest, by placing the research problem in context and identifying gaps and weaknesses in prior studies to justify the new investigation (Polit & Beck, 2004), evidence-based practice seeks to integrate best research evidence with clinical expertise and patient values (Sackett, Straus, Richardson, Rosenberg, & Haynes, 2000). A summary of the current literature regarding the role of the nurse practitioner in support of families experiencing chronic sorrow is provided.

Literature Selection Procedure

A systematic search of CINAHL, MEDLINE, Cochrane library, and electronic media was conducted for the relevant literature concerning the role of the nurse practitioner in support of families experiencing chronic sorrow and the role of the nurse practitioner in support of these families.
practitioner in support of families experiencing chronic sorrow. The reference list accompanying each article was then manually reviewed for further articles pertaining to the subject. Articles were selected based on inclusion of at least one of the relevant concepts, whether as the focus of the article or as part of a broader topic. Other informative articles were also included to explore further this knowledge.

The systematic review of the literature began with CINAHL to find relevant nursing literature regarding the role of the nurse practitioner in support of families experiencing chronic sorrow. Next, MEDLINE and then the Cochrane Library were evaluated for further relevant literature. Journal articles were also obtained through the Mississippi University for Women library, via electronic media, and interlibrary loan. In addition, several journal articles were retrieved from the World Wide Web by accessing specific databases associated with national healthcare. The review incorporated data beyond nursing literature to expand the knowledgebase for a thorough review, thus providing a multidisciplinary approach.

References utilized were relevant and applicable to this investigation. The references were obtained from reputable and respected scholarly journals in the healthcare fields. The evidence-based practice procedure (Sackett, et al., 2000) for the systematic review comprises the following steps:

1. convert the need for information (about prevention, diagnosis, prognosis, therapy, causation, etc.) into research questions.
2. track down the best evidence with which to answer the questions using a variety of database strategies.
3. critically appraise the evidence for its validity (closeness to the truth), impact
(size of the effect), and applicability (usefulness in our clinical practice addressing both sensitivity and specificity).

4. integrate the critical appraisal with clinical expertise and the patient’s unique biology, values, and circumstances (p. 3-4).

**Literature Analysis Procedure**

For the purposes of this study, the knowledgebase was organized as it related to specific areas of chronic sorrow. The knowledgebase was reviewed for content and also an appropriate association to the topic under evaluation. The findings document the current state of knowledge available that is discussed in Chapter Four according to the research questions regarding the role of the nurse practitioner in support of families experiencing chronic sorrow.

**Summary**

In providing an organized selection of the literature and a thorough review of the data collected, the investigation of the concept of chronic sorrow does allow the reader to further their level of knowledge related to the role of the nurse practitioner in support of families experiencing chronic sorrow. In addition, this investigation indicated the need for additional research, education, and practice to be identified that are allied to this role. Understanding of this project encourages family nurse practitioners and other healthcare providers to continue the development and implementation of interventions targeted to all caregivers experiencing chronic sorrow.
CHAPTER IV

Knowledgebase Findings and Practice-Based Application

The aim of this chapter was to present the findings of the knowledgebase that was derived from this evidenced-based systemic literature review. Tables showing pertinent findings from the knowledgebase developed are provided with practice-based applications from current clinical practice guidelines. Findings from the literature reviewed are addressed in this section in terms of each research question produced for the scope of this investigation.

Knowledgebase Findings

In order to obtain the knowledgebase findings, this author carried out a systematic literature search of CINAHL, MEDLINE, and the Cochrane Library. The literature search also included the Mississippi University for Women Library, via the electronic media, the interlibrary loan program, and the World Wide Web. The results of the search are as demonstrated in Table 1.

Table 1

Summary of Literature Searches

<table>
<thead>
<tr>
<th>Search Terms</th>
<th>Number of Citations</th>
<th>Database</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chronic sorrow and nurse practitioner</td>
<td>1</td>
<td>CINAHL</td>
</tr>
<tr>
<td></td>
<td>0</td>
<td>COCHRANE</td>
</tr>
<tr>
<td></td>
<td>0</td>
<td>MEDLINE</td>
</tr>
<tr>
<td></td>
<td>1,260</td>
<td>INTERNET</td>
</tr>
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</table>
Table 1 (continued). Summary of Literature Searches

<table>
<thead>
<tr>
<th>Search Terms</th>
<th>Number of Citations</th>
<th>Database</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chronic Sorrow</td>
<td>66</td>
<td>CINAHL</td>
</tr>
<tr>
<td></td>
<td>9</td>
<td>COCHRANE</td>
</tr>
<tr>
<td></td>
<td>45</td>
<td>MEDLINE</td>
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<tr>
<td></td>
<td>112,980</td>
<td>INTERNET</td>
</tr>
<tr>
<td>Chronic sorrow and nursing</td>
<td>40</td>
<td>CINAHL</td>
</tr>
<tr>
<td></td>
<td>5</td>
<td>COCHRANE</td>
</tr>
<tr>
<td></td>
<td>31</td>
<td>MEDLINE</td>
</tr>
<tr>
<td></td>
<td>3,662</td>
<td>INTERNET</td>
</tr>
<tr>
<td>Chronic sorrow and parents</td>
<td>11</td>
<td>CINAHL</td>
</tr>
<tr>
<td></td>
<td>0</td>
<td>COCHRANE</td>
</tr>
<tr>
<td></td>
<td>4</td>
<td>MEDLINE</td>
</tr>
<tr>
<td>Chronic sorrow and children</td>
<td>33</td>
<td>CINAHL</td>
</tr>
<tr>
<td></td>
<td>1</td>
<td>COCHRANE</td>
</tr>
<tr>
<td></td>
<td>16</td>
<td>MEDLINE</td>
</tr>
<tr>
<td>Chronic Sorrow and disability</td>
<td>3</td>
<td>CINAHL</td>
</tr>
<tr>
<td></td>
<td>0</td>
<td>COCHRANE</td>
</tr>
<tr>
<td></td>
<td>1</td>
<td>MEDLINE</td>
</tr>
</tbody>
</table>

*Note.* CINAHL = Cumulative Index to Nursing and Allied Health Literature, MEDLINE = Medical Literature Online, COCHRANE = Cochrane Library (Cochrane Database of Systematic Review, Cochrane Database of Abstracts of Reviews of Evidence, and Cochrane Clinical Trials Register), INTERNET = World Wide Web.
The literature reviewed totaled 29 citations, which represented 1,131 references.

Two research questions were posed in Chapter One and the pertinent findings will be discussed according to each of the research questions.

**Research Question One**

Research question one asked: According to the literature, what is the role of the nurse practitioner in support of families experiencing chronic sorrow? Based on the ten articles reviewed and found to have some relevance to the above question, there are no findings specifically addressing the role of the nurse practitioner in support of families experiencing chronic sorrow. However, the literature does have suggestions for the role of all healthcare providers in support of families experiencing chronic sorrow. These discoveries indicated and supported a need for healthcare providers to have an understanding of chronic sorrow relative to the effect on caregivers. The literature also disclosed numerous complex attributes of chronic sorrow. The literature reviewed points toward an enormous need for further investigations into interventions to assist and to provide alternative coping strategies for families experiencing chronic sorrow. In addition the obvious lack of research relative to the role of the nurse practitioner in support of families experiencing chronic sorrow supported the need for research studies linking advanced practice nurses to this population.
Table II

*Research Question One: Characteristics of Citations Reviewed*

<table>
<thead>
<tr>
<th>Citation</th>
<th>Type</th>
<th>Database</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clubb, 1991</td>
<td>Theory-based</td>
<td>CINAHL</td>
</tr>
<tr>
<td>Eakes, 1995</td>
<td>Data-based</td>
<td>CINAHL</td>
</tr>
<tr>
<td></td>
<td>(Qualitative)</td>
<td></td>
</tr>
<tr>
<td>Eakes, Burke, &amp; Hainsworth, 1998</td>
<td>Theory-based</td>
<td>CINAHL</td>
</tr>
<tr>
<td>Fraley, 1990</td>
<td>Data-based</td>
<td>CINAHL</td>
</tr>
<tr>
<td></td>
<td>(Literature Review)</td>
<td></td>
</tr>
<tr>
<td>Lowes &amp; Lyne, 2000</td>
<td>Data-based</td>
<td>CINAHL</td>
</tr>
<tr>
<td>Mallow &amp; Bechtel, 1999</td>
<td>Data-based</td>
<td>CINAHL</td>
</tr>
<tr>
<td></td>
<td>(Qualitative and Quantitative)</td>
<td></td>
</tr>
<tr>
<td>Melnyk, Feinstein, Moldenhauer, &amp; Small</td>
<td>Data-based</td>
<td>INTERNET</td>
</tr>
<tr>
<td>Melvin &amp; Heater, 2004</td>
<td>Data-based</td>
<td>INTERNET</td>
</tr>
<tr>
<td>Warda, 1992</td>
<td>Theory-based</td>
<td>CINAHL</td>
</tr>
<tr>
<td>Wittman, Hobbs, &amp; Lee, 2001</td>
<td>Data-based</td>
<td>CINAHL</td>
</tr>
</tbody>
</table>

Note. Total number of citations reviewed = 10.

*Research Question Two*

The research question two asked: According to the literature, are nurse practitioners providing support to families experiencing chronic sorrow? Based on the general lack of findings related to the above question involving nurse practitioners
support to families experiencing chronic sorrow, the investigation determined there was a large void in the research. This indicates an area of opportunity that should be explored to provide a better understanding of the extent to which nurse practitioners are carrying out the role of supporting families experiencing chronic sorrow. Furthermore, the literature evidenced that virtually all areas of healthcare are seriously negligent in their responsibilities to provide support to these families.

**Practice-Based Application**

In order to obtain the practice-based findings, this author conducted a search for best practices housed in the World Wide Web. Since clinical practice guidelines regarding support of parents or families experiencing chronic sorrow do not exist, attention was given to best practice approaches in regards to support of parents and families experiencing chronic sorrow. Using searches through web sites such as the Centers for Disease Control and the Office of the Surgeon General of the United States, no guidelines from the best practice approach in regards to parents or families experiencing chronic sorrow were revealed.

**Research Question One**

Research question one asked: According to the literature, what is the role of the nurse practitioner in support of families experiencing chronic sorrow? Based on an extensive investigative search of the World Wide Web, no best practice guidelines were found pertaining to the role of the nurse practitioner in support of families experiencing chronic sorrow.
Research Question Two

Research question two asked: According to the literature, are nurse practitioners providing support to families experiencing chronic sorrow? Based on an extensive investigative search of the World Wide Web, no best practice guidelines were found pertaining to the role of the nurse practitioner providing support to families experiencing chronic sorrow.

Summary

This chapter presented the findings and summary of the knowledgebase that resulted from this evidence-based systematic literature review. Pertinent findings were discussed according to each of the research questions as posed in Chapter 1. An extensive investigative search of the World Wide Web was performed to find best practice guidelines pertaining to the two questions posed in Chapter 1. There were no best practice guidelines identified through that search.
CHAPTER V

Evidence-Based Conclusions, Implications, and Recommendations

This literature review was undertaken with the focus on exploring the available literature regarding the role of the nurse practitioner in support of families experiencing chronic sorrow. This review revealed the need to further the level of healthcare knowledge regarding the role of the nurse practitioner in support of families experiencing chronic sorrow. There have been virtually no studies done involving nurse practitioners providing support to families experiencing chronic sorrow. The need of support by parents and families was documented throughout the literature search. However, the role of the nurse practitioner as well as other healthcare providers in providing this support was extremely limited. This chapter provides a summary of the literature review, including interpretations of the findings and conclusions drawn from the findings, as well as limitations of the study and recommendations for future research.

Summary of the Investigation

The purpose of this investigation was to explore the literature regarding nurse practitioners providing support to families experiencing chronic sorrow, which involve feelings of grief and sadness, and is an understandable and non-neurotic response to a painful tragedy (Olshansky, 1962). The role of nurse practitioners in providing this support is not well investigated or documented. With the technological advances in medicine and the extended lives of children who would not have survived in the past; the necessity for an understanding of the needs of these parents and families by healthcare professionals is of the utmost importance.
It was deemed appropriate to use Mishel's Uncertainty in Illness Theory (1988, 1990) as the framework for this investigation. There is a noted gap in nursing knowledge concerning nurse practitioners when providing support to families experiencing chronic sorrow. This lack of knowledge establishes the need for further investigation and research.

The review of literature uncovered the particularly limited documentation on nurse practitioners in support of families experiencing chronic sorrow. However, the literature did agree there is a tremendous need for future individual nurse practitioner studies as well as collaborative inner-discipline studies in all aspects of chronic sorrow to grasp the enormous scope of this phenomenon. These additional studies should be all inclusive covering not only nurse practitioners, but all healthcare professionals, the families, and the patients. There was also a general consensus within the literature search that all healthcare professionals need to have a better understanding of chronic sorrow as a normal reaction to ongoing losses rather than as an inability to attain resolution. The need for improved interventions to enhance coping skills and provide for stress management was also an area of agreement in the investigation of support of families experiencing chronic sorrow.

Interpretation of Findings with Conclusions

According to the literature analysis, the findings from this investigation demonstrate a gap in the literature regarding nurse practitioners in support of families experiencing chronic sorrow. This paper has attempted to consolidate the available resources on the role of nurse practitioners in providing support to families experiencing chronic sorrow. An examination of the literature revealed numerous areas that require
additional investigations because of this concept’s importance to the overall health of families. Conclusions that can be drawn from the findings consist of a need for healthcare professionals to possess a solid understanding of chronic sorrow and at least be in a position to recognize the triggers that induce recurrence. In so doing, the healthcare professional can recommend coping mechanisms and provide support to the caregivers in their daily lives. In this section, the interpretation of the findings will be presented in response to each research question.

Research Question One

The first research question asked, “According to the literature, what is the role of the nurse practitioner in support of families experiencing chronic sorrow?” The researched literature provided no discipline specific guidelines for the role of the nurse practitioner in support of these families. However, the researched literature did disclose general recommendations for healthcare providers in support of families experiencing chronic sorrow.

Though no practice guidelines were discovered for this question, the knowledge contained in the literature reviewed can be used to develop best practice guidelines for healthcare providers including nurse practitioners. In addition, the reviewed literature does note several specific areas of support for families experiencing chronic sorrow. While not inclusive, some of the areas most noted in the literature focused on providing accurate and honest information, providing current and future education for the families, and providing unlimited support at all times. Further noted in the reviewed literature was the necessity for healthcare providers to be advocates for both the families and those who are chronically ill or disabled.
Research Question Two

The second research question asked, “According to the literature, are nurse practitioners providing support to families experiencing chronic sorrow?” The conclusion is no, as the results of the literature reviewed provided no information relative to the extent to which nurse practitioners are providing support to these families.

Once again, no guidelines for best practice were identified in the literature reviewed. This was primarily due to a lack of literature related to nurse practitioners in support of families experiencing chronic sorrow. Furthermore, the reviewed literature did not provide a basis for the development of best practice as it related to this issue. Therefore, the lack of information on this subject reflected the enormous void that is currently present and identified many areas for future research.

Limitations

There were limitations previously identified in this review. There was a lack of published literature available to use as a resource. Therefore, information obtained from this investigation cannot be generalized beyond the scope of the research reviewed. The instruments used to measure nurse practitioner roles in support of families experiencing chronic sorrow were not developed for this purpose. Additionally, most of the research was not generalized to larger populations. Consequently, the findings may not prove reliable when tested in other locations and with different populations. The small sample sizes of populations may also limit the research as they may not prove reliable with researches in larger populations. There is also the potential for bias due to the use of questionnaires and surveys. Potential for literature selection bias is also possible because of the limited number of research studies available.
Implications and Recommendations

The results of the investigation of the literature regarding the role of the nurse practitioner in support of families experiencing chronic sorrow were minimal to none. Therefore, implications and recommendations must be directed toward healthcare providers in general. The recommendations focused on nursing theory, nursing research, advanced nursing practice, nurse practitioner education, and health policy. Each of these will be considered in this section.

Nursing Theory

Mishel's (1988, 1990) Uncertainty in Illness Theory provided the foundation in this investigation and was the framework that guided the literature review as it related to an understanding of chronic sorrow. Her theory examined the potential causes of uncertainty in chronic illness including a lack of symptom predictability, the indefinite future, the possibility or potential for disease recurrence, and progression in diseases and illnesses. Mishel's research further suggested there is evidence that healthcare providers may actually contribute to this uncertainty by providing overly simplistic or overly optimistic models of care. This knowledgebase review suggested that the causes of chronic sorrow parallel the same potential causes of uncertainty in illness. Therefore, uncertainty in illness may be a prelude to chronic sorrow.

Nursing Research

The level of healthcare knowledge regarding the role of the nurse practitioner in support of families experiencing chronic sorrow is minimal to none. Even when expanded to include all healthcare professionals, the literature is extremely limited. It was also noted in the review of literature that since most of the researchers were from a
nursing background, the majority of the literature involving chronic sorrow was from a nursing perspective. Future research on nurse practitioners in support of families experiencing chronic sorrow should come from the perspective of a nurse practitioner with the center of attention on the interventions and support mechanisms available to assist caregivers of the chronically ill or disabled. Future nurse practitioner research should also be directed to enhancing the tools currently in use to include the identity of specific interventions that can reduce the effects caused by trigger events in the lives of caregivers. This research can provide invaluable information to assist the nurse practitioner in his/her practice. Research empowers practice and enhances the status of nursing as a profession by expanding nursing’s scientific knowledge base. Research findings not only improve patient care, but also affect the health care system (Polit & Beck, 2004).

**Advanced Nursing Practice**

Literature specific to the role of the advanced practice nurse as it related to their support of families experiencing chronic sorrow was not found in this literature review project. Within the literature review, discussions in support of parents and families experiencing chronic sorrow were generalized and non-specific to all healthcare providers. Nevertheless, as the roles of advanced nurse practitioners expand, they will become more involved in providing care to a more diverse and complex population. In so doing, it will become important to have a grounded understanding of the concept of chronic sorrow and its implications on families and other caregivers living day-to-day with ongoing grief and sadness.
Nurse Practitioner Education

Education of nurse practitioners should promote an understanding of chronic sorrow within the scientific, theoretical, and contemporary clinical knowledge bases of learning. Included, but not exclusive to this understanding, should be an appreciation for the position of the families, knowledge of available coping mechanisms, and learned abilities to assess families at risk during periods of crisis. With increasing opportunities, graduated nurse practitioners are assuming the role of primary care providers to families in all circumstances. Increasing in number are those families experiencing chronic sorrow and it is crucial that the advanced practice nurse be positioned to provide the necessary and needed care. This understanding may facilitate a decrease in the parental feelings of uncertainty as discussed by Mishel (1988, 1990).

Health Policy

Current and future healthcare policies must take into account the need for the specialized support that is required for parents and families experiencing chronic sorrow. Nurse practitioners are in a good position to promote policy restructure that can meet all the demands of the current client base. While the development of healthcare policies based on effectiveness and outcomes are needed, these healthcare policies can not be to the detriment or exclusion of any segment. To do so will eventually result in a more costly program secondary to the original unmet responsibility.

Summary

This chapter presented the limited evidence-based conclusions, implications, and recommendations that were derived from this evidence-based systematic review of the
literature. Implications and recommendations for nursing theory, nursing research, advanced nursing practice, nurse practitioner education, and health policy were provided as they emerged from the concepts explored, as were limitations of the review and interpretation of the findings.

The purpose of this Evidence-Based Practice project was to develop a nurse practitioner knowledge base regarding the role of the nurse practitioner in support of families experiencing chronic sorrow. The research questions asked: (a) according to the literature, what is the role of the nurse practitioner in support of families experiencing chronic sorrow? (b) according to the literature, are nurse practitioners providing support to families experiencing chronic sorrow? A Boolean computer search of nursing and medical literature for theory-based, data-based, and controlled trials for citation utilizing CIHAHL, MEDLINE, and the Cochrane Library were conducted for this systematic literature review.

Merle Mishel's middle range theory of Uncertainty in Chronic Illness (1990) served as the theoretical foundation for this clinical project and guided the systematic review through the data collection of the healthcare literature. The definitions of chronic sorrow, nurse practitioner, healthcare provider, family support, and family are explored. The review of literature was used to determine the answer to RQ1: According to the literature, what is the role of the nurse practitioner in support of families experiencing chronic sorrow? RQ2: According to the literature, are nurse practitioners providing support to families experiencing chronic sorrow?

Information is provided to give guidance and education for healthcare providers designed for use as interventions, services to be provided, advice on what to do or what
not to do as indicated by families, management in times of crises, and triggers that cause sadness and grief to resurface. Conclusions were drawn and recommendations made for family nurse practitioners in the areas of linking nursing theory, nursing research, advanced nursing practice, nurse practitioner education, and health policy.
REFERENCES


