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The Influence of Spirituality, Race/Ethnicity and Religion on Parent Grief and Mental Health at one month and three months after their Infant's/Child's death in the Neonatal or Pediatric Intensive Care Unit

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THE INFLUENCE OF SPIRITUALITY, RACE/ETHNICITY AND RELIGION ON

PARENT GRIEF AND MENTAL HEALTH AT ONE AND THREE MONTHS AFTER

THEIR INFANT'S/CHILD'S DEATH IN THE NEONATAL OR PEDIATRIC

INTENSIVE CARE UNIT

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Dawn Hawthorne

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To: Dean Ora Lea Strickland
       College of Nursing and Health Sciences

This dissertation, written by Dawn Hawthorne, and entitled The influence of Spirituality, Race/Ethnicity and Religion on Parent Grief and Mental Health at Time One and Three Months After Their Infant's/Child's Death in the Neonatal or Pediatric Intensive Care Unit, having been approved in respect to style and intellectual content, is referred to you for judgment.

We have read this dissertation and recommend that it be approved.

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Date of Defense: March 29, 2012

This dissertation of Dawn Hawthorne is approved.

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Florida International University, 2012

DEDICATION

I dedicated this dissertation to my daughter and granddaughter who provided meaning and purpose to a changing and challenging period of my life. This dissertation is also dedicated to my brother Howard, sister-in-law Bernice and best friend Judith whose support during times of adversity was immeasurable.

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ABSTRACT OF THE DISSERTATION

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The death of an infant/child is one of the most devastating experiences for parents and immediately throws them into crisis. Spiritual and religious coping strategies may help parents with their loss. The purposes of this longitudinal study were to: 1) describe differences in bereaved parents' use of spiritual coping strategies across racial/ethnic and religious groups, mother/father dyads, and time – one (T1) and three (T2) months after the infant's/child's death in the neonatal (NICU) or pediatric intensive care unit (PICU), and 2) test the relationship between spiritual coping strategies and grief, mental health, and personal growth for mothers and fathers at T1 and T2. A sample of 126 Hispanic, Black/African American, and White parents of 119 deceased children completed the Spiritual Coping Strategies scale, Beck Depression Inventory-II, Impact of Events-Revised, Hogan Grief Reaction Checklist, and a demographic form at T1 and T2. Controlling for race and religion, spiritual coping was a strong predictor of lower grief, better mental health, and greater personal growth for mothers at T1 and T2 and lower

grief for fathers at T1. The findings of this study will guide bereaved parents to effective

strategies to help them cope with their early grief.

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CHAPTER I

INTRODUCTION

The death of a child is unimaginable since most parents expect not to outlive their

children. In 2008 over 50,000 infants (0-1 year old) and children under the age of 18

died in the United States with 28,033 representing infant deaths of which two-thirds

occur in the neonatal period and 22,844 deaths occurring to children and adolescents

ages 1 to 19 years old (Matthews, Minino, Osterman, Strobino & Guyer, 2011). More

than half of all infant deaths were attributed to congenital malformation (20.1%),

complications of prematurity (16.9%) and sudden infant death syndrome (8.2%).

Children and adolescents ages 1 to 19 years died as a result of accidents (unintentional

injuries) (38.8%), homicide (12.4%) and malignant neoplasms (8.6%) (Matthews et al.,

2011). The death of an infant/child is one of the most devastating experiences for

parents and immediately throws them into crisis. The stress created by this traumatic

event disrupts their mental and physical health resulting in physical and emotional

symptoms both during the early phase of grieving and for several years afterwards

(Lohan & Murphy, 2005-2006; Meert, Thurston, & Thomas, 2001; Song, Floyd, Seltzer,

Greenburg, & Hong, 2010). In response to their child's death, bereaved parents often

exhibit numbness, shock, despair, acute distress, anger, and loss of control (Aho,

Tarkka, Kurki, & Kaunonen, 2006; Bellal & Papadatou, 2006; Laakso & Paunonen-

Iimonen, 2001).

Purpose

The purposes of this longitudinal study are 1) to describe differences in bereaved

parents' use of spiritual coping strategies across racial/ethnic and religion groups,

mother/father dyads and time at one and three months after the infant's or child's death in the neonatal intensive care unit (NICU) or pediatric intensive care unit (PICU) and 2) to test the relationship between spiritual coping strategies and grief, mental health, personal growth for mothers and fathers separately at one and three months post death.

Parental grief has been described as a devastating and traumatic experience that generates negative feelings, consumes energy and disrupts parents' emotional and social world, causing severe and even prolonged emotional and physical distress (Klass, 1997; Laakso & Paunonen-Iimonen, 2001; Meert, Thurston, & Briller, 2005; Meert, Thurston, & Thomas, 2001;). In response to their grief, bereaved parents may choose to use spiritual strategies to cope with their loss. Spirituality involves caring for the human spirit; achieving a state of wholeness; connecting with oneself, others, nature and God/life forces; and an attempt to understand the meaning and purpose of life (O'Brien, 2008; Parks, 2000, Schneiders, 2003). Through spirituality the individual may find meaning and purpose in the most difficult of circumstances. Being able to transcend one's situation beyond despair to focus instead on finding meaning even in the face of tragedy is recognized as a vital coping strategy (Lyon & Younger, 2001).

Spirituality has been identified as being very important in coping with grief and illness. Research on spirituality as a coping strategy has demonstrated its ability to help people achieve a state of wholeness or equilibrium and to evoke healing practices (Chiu, Clarke, & Daroszewiski, 2000; Tuck, McCain, & Elswick, 2001; Woods & Ironson, 1999). Additionally, spirituality can be a source of support to alleviate the stress associated with a traumatic event, to provide the individual with inner strength, to heal the spirit, to make sense of the experience and to move forward (Glass, 2007).

Bereaved parents may rely on religious or spiritual beliefs throughout the period of grieving to obtain comfort, create meaning from the loss, and help in the healing process that will ultimately result in a resolution of their grief (Amentrout, 2007; Klass, 1999; Meert, Thurston, & Briller, 2005). Spiritual beliefs and faith may serve as a counterforce to the despair and negativity associated with death and illness and provide hope and direction for a positive outcome (Benson, 1996; Wilson & Miles, 2001).

Significance

Parent NICU/PICU experiences

The NICU and PICU are specialized units that care for infants and children with critical and life threatening illnesses or injuries. Although the aim of these units is to restore health to critically ill children, approximately 80% of infant and childhood deaths within the hospital occur in the intensive care unit (Angus et al., 2004). Deaths in the NICU are attributed to complications of extreme prematurity, as well as chromosomal and congenital anomalies. For children admitted to the PICU, accidental injuries, congenital malformation, malignant neoplasms and homicide have been reported as the leading cause of death (Matthews, et al., 2011). An infant's/child's admission, stay and subsequent death in the NICU/PICU is recognized as overwhelming and painful for parents as they are often faced with the difficult decision of limiting or withdrawing life support from their very sick infant/child (Carter, Hubble, & Wise, 2004).

Infants admitted to the NICU are often born at the edge of viability (22-25 weeks gestation weighing below 600 grams). Some develop complications related to prematurity or have congenital or chromosomal anomalies which require their parents to make difficult decisions about their care. Singh, Lantos, and Meadow (2004), over a three

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year period, identified 155 infants who had died in the NICU; in 78 (50%) of these deaths, orders to withhold or withdraw life support and do not resuscitate (DNR) were written on their charts. Withdrawal of life support occurred with premature infants whose medical conditions had deteriorated despite maximum ventilator and treatment support. Neonates who were hemodynamically and medically stable (40%) but had devastating diagnoses of trisomy 13, holoprosencephaly, severe intraventricular hemorrhage and severe asphyxia were removed from the ventilator for quality of life reasons. For these infants the neonatologist's and the parent's decision was guided by the prediction of the infant's poor quality of life based on their neurologic status.

Parental involvement is important in the decision making process when the decision to withhold or withdraw life support is being considered (McHaffie, Lyon, & Hume, 2001; Singh, et al., 2004). McHaffie et al. (2001) interviewed 108 Scottish parents three to13 months after the death of their infant in the NICU. Most of the deaths occurred in the first week of life as a result of extreme prematurity and complications of prematurity. The majority of parents reported that the discussion to withdraw life support was initiated by the neonatologist within a few days of birth and multiple meetings were held between the physician and the parent(s) before a decision was reached. Many parents (56%) felt that they had made the decision to limit or withdraw life support and 13.9% felt that the decision was made jointly with the physician. The parents identified several factors that assisted them in making their decision including watching their infant's condition deteriorate and wanting to minimize their infant's suffering. Information from the physician that identified a poor prognosis and outcome for the infant also affected the parent's decision to limit or withdraw life support. Three months

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after the death, 88% of mothers and 89% of fathers felt confident that they had made the correct decision, but of the 108 participants, one mother and three fathers felt the decision had been wrong. Six mothers and two fathers expressed some misgivings as they felt inadequately prepared to assess the information they received regarding the poor prognosis of their infant. Parents who were dissatisfied felt that their decision was made too quickly.

The suffering experienced by the deceased infant/child was identified by many bereaved parents as a major contributor for their decision to remove their infant/child from life support (McHaffie et al., 2001; Sharman, Meert, Ashok, & Sarnaik, 2005; Wocial, 2000). Armentrout (2007) interviewed 15 bereaved parents whose infants (25-41 weeks gestation at birth) had died in the NICU following their decision to withdraw life support. Diagnoses included extreme prematurity, congenital anomalies, anoxia, and sepsis. When the decision was made to withdraw life support the infants ages ranged from 2 to 12 days and death occurred within 2 minutes to 6 hours following removal from the ventilator.

All bereaved parents stated that they knew their infant was suffering and there was no hope for survival. Some bereaved parents described their decision as an act of kindness as the baby was slowly dying and was being kept artificially alive with no hope for a cure or full recovery from their illness. They believed that continuing with mechanical ventilator support and medical care was an act of selfishness. All bereaved parents felt that they had exhausted all their options regarding medical care and their decision was in the best interest of the child.

Additionally, the decision to remove the infant from the ventilator allowed many bereaved parents to bathe and dress their infants. Many who had not previously held their infant were now able to hold and talk with their infant without tubes and wires as death occurred. This was described by the bereaved parents as a time of peace where the family could be together (Armentrout, 2007).

Similar studies also found that parents of infants who had died in the NICU and PICU expressed similar feelings of the importance of participating in end-of life decisions. Receiving support from family, friends and healthcare professionals; actively participating in caring for their dying child; being present at the time the death occurred; and having a supportive environment were seen as being helpful in coping with their grief (Kavanaugh, Savage, Kilpatrick, Kimura, & Hershberger, 2005; Meert, Briller, Myers-Schim, Thurston, & Kabel, 2009; Meyer, Ritholz, Burns, & Truog, 2006; Sharman et al., 2005; Wocial, 2000).

Brosig, Pierucci, Kupst, and Leauther (2007) interviewed 19 bereaved parents. Of these, 14 (76%) had had an infant or child die either in the NICU or PICU, 4 (19%) in the pediatric ward and 1 (5%) infant at home. Irrespective of the unit where the death occurred, parents identified honest, open communication from healthcare professionals and the need to be involved in the decision making process, especially regarding the withdrawal of life support, as important. These factors affected how parents felt about the overall end-of-life care that their child received. Parents who expressed anger with the healthcare team felt that they were not informed about options to complete a DNR form or that their decision to withdraw life support measures was not respected. This had a negative effect on their evaluation of the quality of their child's overall end-of-life care.

Parents coping with NICU/PICU hospitalization and death

Studies on death in the NICU/PICU have predominately investigated parents'

decisions to limit or withdraw life support with limited studies on emotional expenditure

and coping strategies used by parents during their infant's/child's hospitalization and

subsequent death in the NICU/PICU. Meert et al. (2009) interviewed 33 bereaved

parents between 10 months and 3.5 years after their child's death in the PICU. Their

focus was to identify parent needs from the time of their child's hospitalization to when

the death occurred. Four themes emerged: 1) Who I am, 2) While my child is dying, 3)

My child's death context and 4) My bereavement journey.

The theme of "who I am" referred to ways that bereaved parents defined

themselves and how that influenced their needs during the death of their child (Meert et

al., 2009). Maintaining a relationship with their child during the illness, when death was

imminent and after the death was very important to these bereaved parents. Being present

to hold and touch their child during the dying process was paramount. Presence allowed

the parents to function in their role as parents which included participating in the child's

care and assuming an authoritative role in decision making. All of these attributes were

considered important contributions to caring for their child.

The second theme identified by Meert et al. (2009) was "being present during the

death" of their child. Parents placed great emphasis on the need to say good-bye to the

child as death became imminent. Expressions of good-bye rituals such as baptism,

sacrament and giving the child permission to die were comforting for many bereaved

parents. Support from families, friends and hospital staff was described by the bereaved

parents as comforting and helped them come to terms with their child's death. Support

was also described as positively helping those parents with their decision to limit or withdraw life support.

Meert et al. (2009) described the third theme, "my child's death," as including the environmental support within the PICU. Creating a private space and a sacred atmosphere, providing enough time for parents to be alone with their dying child, having privacy that allowed family members to be present, and also allowing parents to be alone with their deceased child were identified as being very important to bereaved parents. Failure to provide these services resulted in unhappiness and a deep sense of loss for some parents in both the early and long term phases of their bereavement.

The fourth theme that emerged from the Meert et al. (2009) interviews was "my bereavement journey" for the parents after the death of their child. During this period, support from family and friends was reassuring and helpful for some bereaved parents and unhelpful for others especially when the topic of the child's death was avoided. Professional support was also described by some parents as being comforting especially if they were able to speak with other bereaved parents. Maintaining contact with the PICU staff was seen as a gesture of caring and acknowledgment of their grief.

Bereaved parents used several coping strategies to help them through this devastating time. Family support that was described as helpful included their assistance with the care for other children at home and being present with them at the hospital, at home, when the child died, and also when making decisions to withdraw life support. Some family members' support was described as not being helpful when they tried to minimize the parents' talking about the deceased child. Another theme found to be important to bereaved parents was keeping the memory of the deceased child alive. This

was accomplished through keeping of memory boxes that contained personal items of the deceased child, planting a tree in memory of their deceased child, and creating rituals such as celebrating their deceased child's birthdays (Meert et. al. 2009).

Another coping strategy (Meert et al., 2009) that bereaved parents found helpful in coping with the death of their child was to refocus their lives by keeping busy in caring for their other children, engaging in altruistic endeavors such as participating in fundraising activities that benefited the hospital and being involved in a bereavement support group. Receiving the autopsy report for many parents was helpful as the information validated their decision to withdraw life support.

Similar findings were reported by Rini and Loriz (2007) who interviewed 11 bereaved parents, nine mothers and two fathers, to determine their grief reaction, 4 months to 2 years after the death of their child in the NICU (2), PICU (8) and on the general pediatric floor (1). Length of stay in the hospital ranged from less than a day to 4 weeks and the diagnoses included prematurity, drowning, heart disease, respiratory/ kidney failure and terminal illness. Themes that emerged emphasized the health care team's role of providing in-depth information to parents as to why their child would not survive and allowed them to be better prepared in accepting the inevitability of death. Attitudes and actions of the health care team were critical in assisting parents who expressed an awareness that their child would not survive to begin the grieving process. Bereaved parents stated that how they were treated by the staff created a lasting impression on their grief experience. The staff's attitudes and demonstration of caring, compassion, and sensitivity during the time surrounding the death of their child were identified as being crucial to positively affecting the grieving process of bereaved

parents. Attitudes and actions of healthcare professionals that were viewed as insensitive, callous and routine were found to negatively affect the grieving process of bereaved parents.

Rini and Loriz (2007) found that actively participating in the child's care and being present prior to and immediately after the death was a pivotal time for parents. It provided them with a time to fulfill their role as parents and to say good-bye to their infant/child before they died. These activities were later described by parents as being very helpful in preparing them for imminent death. Parents who were not allowed or were not given the opportunity to hold their infant/child before they died found this to be detrimental to the grieving process as it resulted in the constant reflection of negative memories. One mother described how she was devastated when her child died without her being present as she was asked to leave the room during the failed resuscitation process. Activities cited by parents as positively affecting their grieving included being offered privacy in the form of a designated space in the NICU/PICU and performing rituals that were considered important by the parents prior to their child's death. Bereaved parents who participated in the study by Rini and Loriz (2007) were White and predominately women; therefore, the experiences of fathers and parents of other racial ethnic groups remain unknown. The researchers also expressed concern that, for some bereaved parents, the child's death had occurred up to two years prior to the interview taking place and reliance on the participant's memory could result in inaccurate recollection of events.

Religion and Spirituality

    Religion

The literature has clearly differentiated spirituality from religion. While spirituality is seen as a search for existential meaning, religion is viewed as being organized systems of faith (Burkhardt & Nagi-Jacobson, 1989; McSherry & Cash, 2004; Turner, 1996). Religion is also viewed as the outward practice of spiritual understanding, an explicit expression of spirituality, and a specific framework of beliefs and values that are used to guide a person's life (Horsburgh, 1997; Subone & Baider, 2010). Koenig (2009) defined religion as practices, beliefs, and rituals that are related to the Sacred. The Sacred refers to the mystical, supernatural, or God. Religious beliefs were seen as a set of rules that are used by individuals as a framework for guiding their lives within a social group and providing a specific viewpoint about life after death. The core of religion, as stated by Koeing, is established traditional beliefs that are held by a group of people who have similar beliefs and practices related to the Sacred.

Schneiders (2003) describes religion as a spiritual tradition that emerged from some introductory experience of divine or cosmic exposure to the mystic. For example, Christians decree Jesus as the divine Son of God, and in Buddhism Buddha became divine through his spiritual journey where he experienced enlightenment. Religion is about the development of socially mediated human relationships with the sacred/the divine/ God or Gods. Religion is described as an institution that embraces a particular spiritual tradition, for example Lutheranism, Roman Catholicism, Soto Buddhism and Reformed Judaism. The institutional pattern of belief that is considered important is determined by cultural, societal and/or group norms and utilized by individuals/groups to

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transcend their lives and lead to salvation either in this life or in the after-life. Exposure

to religious teachings results in individuals developing specific ways of understanding

themselves and having a relationship with other human beings and the world.

Horsburgh (1997) identified religion as a specific expression of spirituality that

includes a structure of formal belief used by individuals to guide their lives. Through

rituals, religious people often express their faith in a church, synagogue, mosque or other

form of organization. Therefore an individual may be spiritual without espousing a

religion and an individual may be very religious without having a well-developed sense

of spirituality. Peri (1995) stated that religious practices may encompass spirituality, but

spirituality need not include a religious practice. Religion and spirituality hold similarities

as they both can provide guidance on how individuals live harmoniously with self, others,

nature and the environment.

Spirituality

Spirituality is viewed by many researchers as the core of human beings that gives

meaning and purpose to each person's existence irrespective of their faith (Surbone &

Baider, 2010). All human beings are considered to be spiritual. Broader than religion,

spirituality is defined as a search by individuals to connect with whatever aspects of their

experiences in life that are sacred to them versus only a belief in God or higher power

(Kramer, Ironson, & Kaplan, 2009). Others have viewed spirituality as a search for

meaning and purpose in life, caring for the human spirit, a connection with oneself,

others, nature, and God/life forces (Burkhard & Nagi-Jacobson, 1989; O'Brien, 2008;

Turner, 1996). Thomas and Retsas (1997) viewed spirituality as an inherent characteristic

of each person that is used as a source of strength and is developed as a result of the

individual's faith in self, others and/or a higher power. They also agree that spirituality

provides meaning and purpose to individuals' lives as they transcend their everyday

experience.

 Unlike religion that is organized with sets of rules and regulations, Koenig (2009)

defined spirituality as a personalized belief that is defined by the individual and is free

from rules and regulations. Spirituality, for some people, is characterized as

individualistic and secular, that is, free from any religious connections. McSherry, Cash,

and Ross (2004) have suggested that individuals will utilize their values and world-views

to create their own interpretation and understanding of spirituality.

Horsburgh (1997) focused the definition of spirituality on tangible activities of

beliefs and practices that inspire and motivate a person's life. These practices include

non-material beings such as Gods, spirits, a higher power, or humanistic activities that

transcend the daily lives of the individual and help the person move toward a

transformation of self. Martsolf and Mickley (1998) identified five attributes of

spirituality: 1) having meaning and purpose used by the individual to make sense of life,

2) having cherished beliefs and standards that are valued by the individual, 3) achieving a

state of transcendence that involves a dimension beyond the self, 4) connecting and

relating to others/God/higher power/the environment, and 5) using reflection to become

the person through empowerment.

Frankl (1997) equates human existence with spiritual existence which makes all

humans spiritual. Spirituality is described as being the core, the center of all humans that

takes precedence over the mind and body. The spiritual core of the individual integrates

the body and the mind to create this wholeness. The body and mind of a person cannot be helped unless the spiritual domain is addressed.

Schneiders (2003) identifies spirituality as a characteristic of human beings who have the capability to transcend or reach beyond themselves through knowledge and love and develop a relationship with self, others and the world. Spirituality for the individual can be religious or non-religious; however, by transcending the self and defining their ultimate value, spirituality becomes the ultimate goal of self-actualization for all humans irrespective of whether the experience is religious or not. Spirituality, is therefore, expanded to include the activity of the human spirit not only its original reference to God/Holy Spirit. Spirituality can incorporate religious beliefs and can also have different meanings for different traditions/cultures. Christian spirituality involves a life of faith, hope and love within the community of the church, and its ultimate value is related to the trinity; Father, Son and Holy Ghost. Judaism, Hinduism and Islam also have a religious affiliation and identify their holy being as their ultimate value. Other traditions/cultures, for example, Buddhism and Native American spirituality, include a belief of self-transcendence similar to their religious counterparts, but their ultimate value is non-religious as they do not identify with a personal God. Other spiritual traditions such as communing with nature are explicitly non-religious, recognizing no self-transcendence and nothing beyond the universe.

In clarifying the definition of spirituality, Schneiders (2003) identified four attributes: 1) Spirituality is personal and is developed from the lived experience of the individual; 2) An individual's spirituality is not developed by accident. It is not an episodic event or the practicing of certain rituals; instead, it is a conscious rational

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approach to life that is actively pursued and is ongoing by the individual; 3) Spirituality is viewed as a project of integrated holistic living of body, mind, spirit, emotion, and thoughts. It is actively pursued leading to the creation of ongoing growth and development; and 4) Spirituality is viewed as being positive and is not associated with self-destructive or violent behaviors. Rather, the result of pursuing and integrating spirituality into a person's life results in self-transcendence. The individual identifies and pursues a purpose of ultimate value and can include personal/social well-being, the good of the earth, justice for all people, or a relationship with God/Sacred.

Mosely (1997) characterized the spirit as being broken for all individuals who are faced with traumatic events resulting in the manifestation of grief, fear, and anxiety. These stressful events often throw individuals into crisis as they wrestle with the question, "Why me?". Those individuals who believe in God and experience negative thoughts about their faith may question their faith, feel deserted by God, or become angry with God which may increase their feelings of hopelessness, depression, and isolation.

Use of Spirituality/Religion as a coping strategy

Stressful life events occur at some point in an individual's life and the suffering that results from the event has the ability to profoundly affect, negatively or positively, the life of each person. Friedemann, Mouch, and Racey (2002) believe that stress creates disequilibrium within the individual and that all humans have the ability to buffer the distress and restore equilibrium to their lives by utilizing spiritual coping strategies. The use of spirituality in times of crisis can help the individual counteract the difficulties and pain caused by the situation, to transcend their immediate world to cope with the crisis,

and to examine their circumstances within a broader universal context (Frankl, 1997; Friedemann et al., 2002; Levine, Yoo, Aviv, Ewing, & Au, 2007).

Stressful or traumatic life events often evoke feelings of anger, hopelessness, and despair in individuals. Spirituality is one of the coping strategies that an individual can use when dealing with personal crisis, stressful/traumatic life events or loss of a loved one. Spirituality can be a source of support to alleviate stress, to provide individuals with inner strength to heal the spirit, to make sense of their experiences of suffering, and to move forward with their lives (Glass, 2007; Mosely, 1997; Rozario, 1997).

Stressful or traumatic events cannot be changed, but finding meaning as to why they occur can help the individual confront the situation, and through self-transcendence, connect to a higher power/God/Universe and rise above the stressful event (Rozario, 1997). Spirituality also provides the individual with the ability to find meaning and purpose in the most difficult of circumstances. Transcending one's situation beyond despair to focus instead on finding meaning even in the face of tragedy is recognized as a vital coping strategy (Frankl, 1997; Lyon &Younger, 2001).

The spiritual lives of bereaved parents (Klass, 1999) describe how these parents use spirituality and/or religion to find solace. The meaning that manifests from believing in God as a Higher Power often is used to provide a sense of security and bring peace. Some mothers in the Christian faith have reported an affiliation with Mary, Jesus' mother, whose son also died at a young age. The belief in God being the Father who directs and plans their lives can often provide solace to bereaved parents who believe in divine intervention, as they equate the death of their child with God's plan.

Parents who believe in a heaven find comfort in believing that their deceased child is in a better place and that when they die, they will be reunited with their child (Amentrout, 2007; Klass, 1999). Bereaved parents can also find healing or bring meaning to their lives through spirituality not connected to religion, including meditation, inspirational writings, poetry, nature walks, listening to or creating music, painting or sculpting, and therapeutic touch (Klass, 1999; Laakso & Paunonen-Ilmonen, 2001; Meert, Thurston, & Briller, 2005).

In summary, bereaved parents experience severe emotional and physical symptoms following the death of their child. The literature has identified characteristics of spirituality to include providing meaning and purpose in life, transcending the suffering of individuals who are faced with stressful or traumatic life events, evoking hope and healing, and obtaining peace. Bereaved parents have identified spirituality as being very important in coping with their grief but little is known about spiritual coping strategies used by parents after their infant's/child's death in the NICU or PICU. Even less is known about different uses of these coping strategies for different racial/ethnic groups. There are no studies that have explored spirituality as a coping strategy used by bereaved parents over time in their grieving process.

Research Questions

This study was designed to address the following research questions.

1. Are there differences in the use of spiritual coping strategies across racial/ethnic groups, religious groups, mother/father dyads and time at one and three months post-death?

2. What is the relationship between spiritual coping strategies and grief, personal growth, and mental health for mothers and fathers at one and three months post-death?

3. Do these relationships hold when race/ethnicity and religion are controlled?

A longitudinal design allows for the spiritual coping strategies of the same sample of participants to be examined at one month and three months after the death of their child. Analysis of the data will determine what changes, both negative and positive, have occurred in the same individuals over time. The selection of one month as the first data collection time point will allow for the parents' initial crisis reaction to the death of their child to have subsided but the use of spiritual coping strategies would be recalled accurately. Three months will allow for comparisons as to the frequency that spiritual coping strategies are being used.

Conceptual Framework

Hogan's grief theory (1996) defines grief as "a process of coping, learning and adapting" (p. 44) and was developed from qualitative grounded theory research. The model posits that irrespective of the relationship of the bereaved person to the deceased, the process of bereavement remains unchanged. The model consists of six phases. The first phase "Getting the news" is when the person is informed of a terminal diagnosis, or "finding out" is when the death of their loved one has occurred. The bereaved person responds to the news often in shock, especially if the death was sudden. "Facing reality" is the second phase where the bereaved person experiences intense feelings of grief. The third phase is "becoming engulfed in the suffering" where the bereaved person longs and yearns for their deceased. Feelings of sadness, loneliness, guilt, and reliving the past are often experienced at this phase. As the bereaved person gradually "emerges from the suffering" in the fourth phase, they begin to experience good days and by the fifth phase, "getting on with their lives," hope and happiness gradually begin to return. In the final

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phase "experiencing personal growth," the bereaved person develops a new perspective on life; they often reorganize and prioritize their lives, making life more purposeful and meaningful. The model hypothesizes that these stages are not linear but cyclical (Hogan, Morse & Tason, 1996).

In the proposed study, bereaved parents are expected to respond to the news of their infant's/child's death with intense emotional and physical symptoms of grief especially if the death was unexpected. As they begin to face the reality of their infant's/child's death, their grief is further intensified as they cannot imagine a life without their infant/child. Feelings of despair, loneliness and depression often occur (Armentrout, 2009; Laakso & Paunonen-Ilmonen, 2001). As bereaved parents become engulfed in their suffering, they spend a considerable amount of time talking about the deceased infant/child and keeping the deceased infant's/child's room unchanged (Bellali & Papadatou, 2006). At some point, most bereaved parents emerge from their grief and begin to gradually move forward with their lives. The model suggests that they use their cultural, religious and/or spiritual beliefs to remain connected with their deceased child and to find meaning in their infant's/child's death. In adjusting to their loss and moving forward with their lives bereaved parents become emotionally stronger (Bellali & Papadatou, 2006; Buchi, et al., 2007). Their values and priorities are redefined, often finding material things less significant and developing a greater appreciation for family relationships (Armentrout, 2007; Barrera, et al., 2009; Bellali & Papadatou, 2006). In the final phase, many bereaved parents experience personal growth by beginning to find meaning and purpose in their lives. They experience changes in themselves, their family lives and their social lives (Bellali & Papadatou, 2006; Meert, Thurston & Thomas, 2001,

Seugin et al., 1995). They may become involved in activities within their community that transform their lives and honor the memory of the deceased infant/child and/or join organizations whose goals are to help others (Armentrout, 2007). The proposed study focuses on the grieving experiences of bereaved parents as outlined by the grief phases depicted in the model. Greater parent use of spiritual coping strategies is expected to be related to less severe parent grief (despair, detachment and disorganization) and better parent mental health (depression, post-traumatic stress) and personal growth. The expected effects of spiritual coping strategies are consistent with crisis (Glass, 2007; Mosely, 1997; Rozario, 1997) and bereavement frameworks (Hogan & Schmidt, 2002).
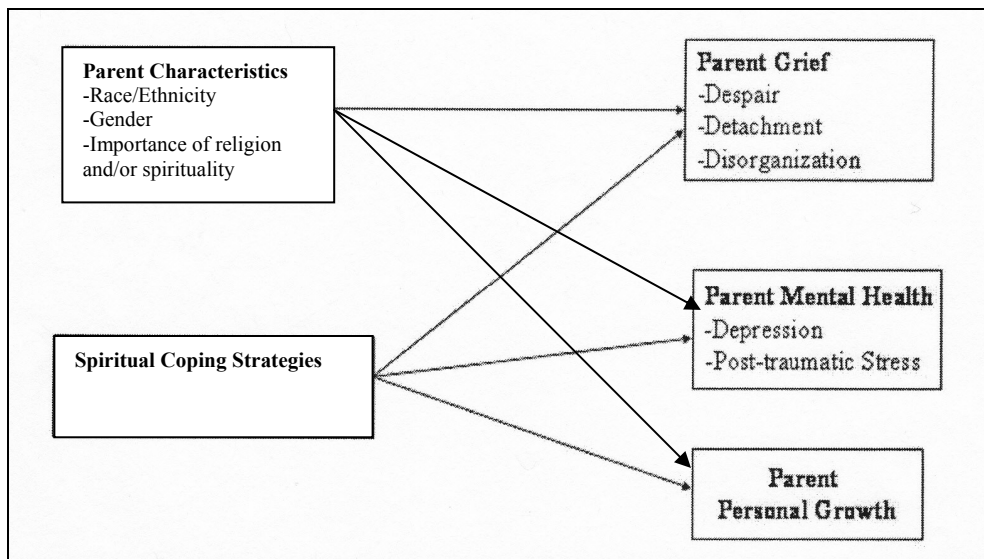
Figure 1: Bereavement framework

CHAPTER II

REVIEW OF THE LITERATURE

In the United States (U.S.) 51,000 infants and children under the age of 18 die annually with 52% representing infant deaths and 48% representing children and adolescents deaths (Matthews et al., 2008). These figures are indicative of approximately 102,000 U.S. parents losing their child each year. Cause of death for infants, children and adolescents include congenital anomalies, complications of prematurity, sudden infant death syndrome (SIDS), trauma, homicide, suicide, Human Deficiency Virus/Acquired Immune Deficiency Syndrome (HIV/AIDS) and cancer (Matthews et al., 2008).

The loss of a child is an event that severely taxes the parent's and family's ability to cope. Parental grief has been described as a traumatic event that generates negative feelings, consumes energy, disrupts the parent's emotional and social world, and causes severe and even prolonged distress (Klass, 1997; Laakso & Paunonen-Iimonen, 2001; Meert, Thurston, & Thomas, 2001). Anger, blame and guilt may also be a manifestation of the grieving process for bereaved parents. Depending on the circumstances surrounding the infant's or child's death, blame can be self-directed. Parents feel that their role is to protect their children from harm and parents who perceive that they could have done more to prevent the death experience self blame and guilt (Laakso & Paunonen-Ilmonen, 2001). In response to their grief, bereaved parents may rely on their religious or spiritual beliefs to obtain comfort, create meaning from the loss, and help in the healing process that will ultimately result in a resolution of their grief (Robinson et al., 2006; Lichtenthal, et al., 2010).

This chapter reviews the literature on grief symptoms in bereaved parents, the effect of bereavement on parent mental health and personal growth, the use of spirituality/ religiosity as coping strategy for parents facing death of an infant/child in the NICU/PICU and differences in the use of spiritual coping strategies across racial/ethnic groups and mothers and fathers.

Grief in Bereaved Parents

Armentrout (2009) interviewed 15 bereaved parents whose infants had died in the NICU to determine how bereaved parents coped with their grief following their decision to withdraw life support. Ages of participating parents ranged 27-42 years (M = 31.6 years). Most of the bereaved parents were White (98%), with education levels ranging from one year of college to master's degree; annual household incomes ranged from $50,000 to $100, 000, and 99% identified themselves as Christians. The gestational ages of the deceased infants at birth ranged from 25-41 weeks. Bereaved parents were recruited from a support group for parents who had experienced a neonatal death. Time since the death ranged from 0.5 to 12 years (M = 3.9 years). Eight bereaved parents had surviving children and 6 bereaved mothers had another child after their loss.

Most of the bereaved parents described feeling shocked, lost, emotionally devastated and nonfunctional during the first year following the death of their infant. Performing routine tasks of daily living, for example getting out of bed, taking a shower and getting dressed, or just going out of the house required tremendous amounts of energy. One mother felt that she was not emotionally present for her surviving child for about a year after the death. Another mother stated that each day she would sit on the sofa and just stare all day. Most of the mothers describe having difficulty in staying focused.

Bereaved fathers described keeping busy as ways of helping to cope with the pain associated with the loss; this included returning to work, doing household tasks or projects and getting on with their lives (Armentrout, 2009).

Bereaved parents described moving forward with their lives as a long and difficult process. They had felt powerless during their infant's illness and death but as the pain associated with the loss subsided they were forever changed. They became more appreciative of life, felt stronger and a better person as a result of their terrible ordeal. As they emerged from this period of intense grief their priorities shifted and their perspective on life changed; they became more compassionate, less judgmental of others and connecting more with family and friends (Armentrout, 2009).

Bereaved parents also reported (Armentrout, 2009) that not only were their lives changed but a void was created following the death which they filled by incorporating the presence of the deceased child into their everyday lives. This included having the deceased infant's framed footprints and pictures displayed with other family members' pictures. One father found that talking to his deceased infant each time he visited the cemetery helped in coping with his grief. Bereaved parents with surviving children described the importance of keeping the memories of the deceased child alive. They achieved this by including the brother/sister in the creation of a baby book that included the personal belongings of the deceased child and also having family discussions about the sibling that died. All bereaved parents reported that as time passed the pain associated with their grief lessened but never goes away.

Armentrout (2009) described the negative feelings about religion that bereaved parents experienced following the death of their infant. Anger at God was a predominant

emotion. Some bereaved parents questioned God by asking why He allowed this to happen to them while they maintained their faith, attended church and discussed their anger with their priest. Others abandoned their faith in a perfect omniscient and omnipotent God, instead choosing to believe in a higher power that can make mistakes.

Buchi et al. (2007) examined the grief reactions and post-traumatic growth in bereaved parents 2-6 years after the death of their extremely premature infant in the NICU. Fifty four bereaved parents participated in the study of which 22 were couples, 5 were non-partnered bereaved mothers and 5 were non-partnered bereaved fathers. Ages of the participating mothers averaged 34.7 years (SD = 5.1) and of fathers 38.9 years (SD = 8.6). The majority of bereaved parents (48%) had 10-12 years of education and at least one surviving child (80%). Time since the death of the baby averaged 3.6 years (SD = 1.2). Of the 40 premature babies who died, 12 were twins and 3 were triplets, mean gestational age and birth weight was 25 weeks (SD 0.9) and 693 grams (SD = 1.32) respectively.

Buchi et al. (2007) found that most of the bereaved parents (80%) showed signs of grief, including feelings of sadness, anxiety of the loss, anger and searching for meaning 2-6 years after the infant had died. Bereaved parents also identified their deceased infant as occupying a central place in their lives with 12 (19%) indicating substantial suffering and 38 (70%) still missed their baby 2 to 6 years after the loss. Bereaved parents who did not have other children had higher grief scores. Some bereaved parents (7%) had scores that were indicative of depressive disorder; 15 (28%) bereaved parents (8 mothers, 7 fathers) had scores indicative of possible anxiety disorder, and 4 (7%) mothers and one (2%) father had scores indicative of probable anxiety disorder. The

Munich Grief Scale was used to measure perinatal grief, the Post-Traumatic Growth

Inventory (German version) to measure post-traumatic growth and Pictorial

Representation of Illness and Self-Measure (PRISM) to measure suffering in the study

participants.

Buchi et al. (2007) found differences in grief symptoms by gender. Bereaved

mothers had higher grief scores than bereaved fathers, specifically they were sadder and

needed to talk about the loss more than bereaved fathers but they experienced higher

post-traumatic growth (78%) than fathers (44%) following the loss of an infant. Post-

traumatic growth for bereaved mothers included becoming more compassionate, feeling

stronger, better able to handle difficulties, able to count on others in times of trouble and

having new priorities on what is important in life.

An important limitation of the study was its small sample. Differences were not

found in anxiety and depression among bereaved mothers and fathers related to the small

sample. Other studies have found that grief symptoms were intensified shortly after the

infant's/child's death and subsided as time since the death increased. The researchers

found that the majority of bereaved parents had continued grief symptoms including

continued suffering, and probable anxiety and depression 2 to 6 years after the loss but

specific time since the death and demographics of bereaved parents, including number

with surviving children were not stated. Another limitation is the study's cross-sectional

design.

Bellali and Papadatou (2006) explored the grieving process with 22 bereaved

parents (13 mothers, 9 fathers) whose ages ranged from 31- 51 years. The deceased

children's ages ranged from 2 – 14 years, and all had died from head injuries in the

PICU. Time between the death and participation in the study ranged from 8 months to 7 years.

Three core categories were identified by bereaved parents as being essential to their grief: 1) feelings of emptiness, 2) deep suffering and 3) finding meaning. They attributed their feelings of emptiness to the physical and psychological absence of the child. This deep feeling of emptiness and sorrow was stated to be indescribable and occurred each time that they went to events, places or situations that reminded them of the deceased child. Some bereaved parents, in an attempt to fill the empty void left by their deceased child, became pregnant shortly after their child died. Four bereaved mothers had another child 10 to 24 months after their loss and found that this distracted them from their suffering (Bellali & Papadatou, 2006).

All bereaved parents reported their grief (Bellali & Papadatou, 2006) to include a void in their lives and the physical pain created by the death resulted in deep suffering that was incomparable to any other loss experienced in their lives. The pain was described as deep and long lasting but was minimized by attributing meaning to the deceased child's life and death. To help with the pain associated with the void in their lives caused by the physical absence of the deceased child, bereaved parents described remaining connected to their deceased child by feeling their child's presence or their spirit especially during the first months following the death. Connection was also maintained by regular visits to the cemetery, and keeping the child's room and belongings intact.

Deep suffering resulting from their loss was described by bereaved parents (Bellali & Papadatou, 2006). The majority of bereaved parents lost their child to sudden

and traumatic death and the events; experiences and interactions at the time of their child's death profoundly affected them. Parents described the event as surreal as their world fell apart because of their difficulty in accepting the death. Strategies used to cope with their suffering included social support and activities where they could talk about their deceased child. Going back to work or resuming a hobby helped some bereaved parents cope with their pain and suffering. Religious beliefs also eased their suffering as they were comforted with images of their child in heaven being close to God, or being in paradise, and if they led a good life they would be reunited with their child when they die. They also believed that their deceased child was being protected by other deceased relatives who were watching over them. A few parents who were unable to find coping strategies to ease their pain and suffering stated that life held no purpose for them, they had given up on life and were contemplating or having thoughts of suicide.

Bereaved parents (Bellali & Papadatou, 2006) described that finding new meaning to the child's life was helpful in coping with their suffering. This involved bereaved parents trying to find answers to questions surrounding their child's death and making meaning from their suffering. Those bereaved parents who were engaged in positive meaningful activities found them to be helpful in minimizing their suffering. Others with feelings of anger, injustice, guilt and bitterness had more pronounced difficulties in dealing with their grief.

The length of time since the death affected bereaved parents' grieving process. The bereaved parents whose child's death occurred 4- 6 years before participating in the study described experiencing personal growth in themselves and in their relationships with others. Most (n = 13, 59%) emerged from their suffering by accepting the changes in

their lives and finding purpose and meaning in their lives despite their pain and suffering. Parents reported a change in their perceptions of themselves, others and life. Their values and priorities changed, attributing less significance to material things and work, and instead focusing on developing a loving relationship with family members. Positive changes for many bereaved parents included viewing life differently as they became more compassionate and understanding (Bellali & Papadatou, 2006).

Bereaved parents who had other children described themselves as being more patient and flexible in their role as parents. They also became closer to their surviving children and demonstrated more affection and love towards them. The death of a child also resulted in changes in their marital relationships. Bereaved parents reported the loss as either bringing their relationship closer or increasing the distance between them. Couples whose relationship was deteriorating had pre-existing marital difficulties prior to their child's death (Bellali & Papadatou, 2006).

Negative attribution of grief by bereaved parents included anger at self, God and others. Bereaved parents expressed feelings of guilt for not protecting their child from harm, bitterness as they felt responsible for not providing a good life for the child and a deep sense of injustice that the deceased child was robbed of longevity. Additionally, some bereaved parents felt God was punishing them for their sins, or the envy of others towards their family or the casting of spells with the evil eye resulted in their child's death. These negative feelings of grief affected 9 (41%) of the bereaved parents who saw their lives as worthless and meaningless 3-7 years after their child had died. They also had difficulty moving on with their lives and continued to experience feelings of anger, rage or guilt, depressive symptoms and a desire to die (Bellali & Papadatou, 2006).

Barrera et al. (2007) conducted a mixed method study that examined the patterns of coping with grief in 20 bereaved parents (13 mothers, 7 fathers) 4-19 months after the death of their infant/child. Ages of participating mothers ranged from 29 to 56 years (M =39.4, SD = 6.48) and fathers' age ranged from 31 to 48 years (M =39.2, SD = 6.48). Most bereaved parents (65%) had completed high school and were from a middle-class socio-economic background. Ninety percent of the participants were White with the remainder (10%) Asian-Canadian and African-Canadian. At the time of death the deceased infant's/child's ages ranged from 9 days to 17 years (M = 8.3, SD = 7.29). Most of the deaths (n = 9) were related to cancer, three from congenital heart disease and three from other causes and almost all of the children died in the hospital.

Bereaved parents were found to use three patterns of coping with their grief: Integration of grief, Consumed by grief and Minimal expression of grief. The Beck Depression Inventory (BDI) and the modified version of the Grief Measurement scale (MGMS) were used to measure depressive and grief symptoms in the study participants. The majority of parents (65%) (7 mothers, 6 fathers) used Integrated Grief to cope with their loss. Bereaved parents in this category were able to balance coping with the pain associated with losing a child and continuing to function in their daily lives. The characteristics of these bereaved parents included finding inner strength that helped them to move forward with their lives and redirected their grief experience to finding new purpose in their lives. Bereaved parents in this category all had surviving children which they described as giving them hope and purpose in life. One mother stated that the reason she got out of bed each day was because of her surviving child (Barrera et al., 2007).

Additional factors that helped these parents cope with their grief included receiving support from family and friends, keeping busy and engaging in physical activities. Within this category length of the child's illness before death was (M = 23.4 months, SD = 35.42), age of the deceased children at the time of death was (M = 7.5 years, SD = 7.5) and the parents had been bereaved for 5 to 19 months. All the bereaved parents in the Integrated Grief category reported fewer symptoms of depression and lower levels of grief which was reported as more than one standard deviation below clinical range (Barrera et al., 2007).

Only five bereaved mothers were overwhelmed and Consumed by Grief which affected their activities of daily living. Irrespective of the time since the death these bereaved mothers had difficulty accepting their infant's/child's death and described feeling empty, unfulfilled, crying all the time and being unable to see a future for themselves without their deceased child. One mother stated that events/activities that were insignificant before the death were now stressful. Other mothers described their symptoms of overwhelming grief to include incessantly reliving the last few moments of their infant's/child's life, crying constantly at work, having difficulty conversing with others, feelings of guilt, lack of control, and abusing alcohol (Barrera et al., 2007).

All the mothers describe their relationship with the deceased child as being extremely close. Two mothers who had lost their only child described the death as representing a loss of their parenting role and difficulty in seeing/being around other children. Bereaved mothers with surviving children expressed difficulty in parenting their surviving children. Within this Consumed by Grief category length of the illness before death ranged from 5.4 to 73 months; ages of the deceased infants/children at death ranged

from .54 to 10.6 years, and the parents had been bereaved from 4.5 to 11 months. These bereaved mothers had clinical levels of depression and high grief (Barrera et al., 2007).

The two Bereaved parents (one mother and one father from separate families) who showed Minimal Expression of their Grief had difficulty in expressing their emotions associated with the loss. They described their daily activities as being unchanged and maintained a very busy schedule that incorporated multiple activities throughout each day. The father described his child's death as unimportant as he had more urgent issues needing his attention and the mother kept busy with managing household activities. These two parents reported the lowest depression and grief of all the bereaved parents. The deceased children were adolescents (M = 17.5 years, SD = .12) and had died unexpectedly of meningitis and drowning. The mother had been bereaved for 4 months and the father, 10 months.

Laakso and Paunonen-Ilmonen, (2001) interviewed 52 bereaved mothers one to three years after their child's death about their grief experience and how they coped with their grief. All of the mothers were White, 20-49 years old, with the majority being married or partnered. The deceased children were under 7 years old (75% less than one year) and the majority of deaths (75%) resulted from life-threatening illnesses. These mothers described feeling hopeful and having moments of despair when they were told about their child's illness and prognosis. In the early phase of their grief, bereaved mothers expressed anger, guilt and a belief that they had failed their deceased child. They also reported experiencing physical symptoms of pain, malaise and fatigue with psychological symptoms of depression and feelings of emptiness. Some of the bereaved

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mothers became fearful of being alone especially after the funeral when contact with friends diminished and their spouse/partner returned to work.

Some bereaved mothers viewed the child's death as a positive experience as they experienced joy, happiness and relief knowing that their child's pain and suffering was over. The child's death led to feelings of rejuvenation and gaining strength as they had spent a long time in the hospital caring for their sick child. Bereaved mothers used a variety of mental and physical activities to cope with their grief and bring meaning to their lives. These included returning to work, changing careers or resuming hobbies of reading, writing, painting, and listening to music. Bereaved mothers who chose to delay returning to work often relied on alcohol and drugs to cope with their grief especially if the loss was their only child. These negative behaviors were discarded as the negative feelings associated with their grief diminished (Laakso & Paunonen-Ilmonen, 2001).

Bereaved mothers (Laakso & Paunonen-Ilmonen, 2001) described positive and negative changes to their values and meaning about their lives. Positive changes included increased personal growth, growing up, having a new appreciation for life, establishing a deeper relationship with their own parents and not being afraid of dying. Negative effect of grief included losing their enthusiasm and creativity for living and intensification of fear and bitterness.

Limitation of the study was that bereaved parents were interviewed 1-3 years after the death but differentiation was not made between responses to grief and length of time since the death. Age of the deceased child and the effect, if any, on bereaved mother's grief symptoms was not reported.

Aho, Tarkka, Kurki, and Kaunonen (2006) described the grief reaction of 8 bereaved fathers recruited from a closed internet contact group between 2 months to 2 years after the death of their child. Average age of the fathers was 35, and all were married or partnered. The deceased children's ages ranged from 40 minutes to 2 years, 80% were under 4 months old and 60% died from complications of congenital heart disease. Place of child's death was not reported.

Aho et al. (2006) found that bereaved fathers experienced feelings of agony, migraine, and arrhythmias shortly after the death of their child. Emotionally, they were angry and blamed themselves for their child's illness and death because of their imperfect genes. Expressions of their agony included weeping, kicking objects, sleep disturbance and difficulty in concentration especially when they returned to work. Socially they chose to isolate themselves from family and friends. Bereaved fathers who directed blame at themselves and described their lives as empty also experienced depressive symptoms and inability to continue working. Unlike bereaved mothers in the Laakso and Paunonen-Ilmonen, (2001) study these bereaved fathers coped with their grief by repressing or concealing their feelings from other people. To cope with their grief they became immersed in some form of activities, for example returning to work, resuming hobbies and excessive drinking of alcohol. Bereaved fathers cited acceptance of their child's death as helping them in overcoming their grief especially since they could do nothing to change the situation. Within 3-4 weeks they began to move forward with their lives, feeling less anxious but still experiencing times of sorrow.

The death of a child changed these bereaved fathers' lives both positively and negatively. Positive growth included feeling more mature and emotionally stronger. Their

values and priorities changed, becoming less materialistic, placing more emphasis on good health and maintaining a good relationship with their spouse/partner and surviving children. The reality of death made these bereaved fathers acknowledge the fragility of life; they became emotionally stronger, expressed a greater appreciation for life and preferred to live one day at a time. Relationships with their friends also changed; some severed ties with friends, preferring to socialize with other bereaved families. Negative experiences described by bereaved fathers included social isolation from family and friends, unemployment, financial difficulties, depression and mental illness (Aho et al., 2006).

Woodgate (2006) described the changes in the lives of 28 bereaved parents (17 mothers, 11 fathers) resulting from their child's death in the hospital. Most bereaved parents were White (93%), married or partnered (89%). All were 35-67 years old and had at least one surviving child. The deceased children's ages ranged from 3 days to 28 years, the majority of deaths (98%) were related to life-threatening illnesses and time since death and participation in the study was from 7 months to 18 years after the death.

Transitioning through their child's death included extreme sadness as they tried to move forward with their lives. Bereaved parents emphasized their conscious decision in not seeking closure as that would be synonymous with ending their relationship with the deceased child. Instead they strived to remain connected to the deceased child by keeping their memories alive with objects, articles or pictures of the deceased child that held special meaning for them. Bereaved parents also kept their deceased child's memory alive by remembering them on their birthday, and 25% created websites depicting their child's life (Woodgate, 2006).

Bereaved parents emphasized that being a good parent was important in the parent-child relationship and in keeping the memory of their deceased child alive. Attributes of being a good parent included doing everything possible for their child during their illness, ensuring that the child was in minimal pain and not suffering, providing emotional support throughout their child's illness, being able to advocate for their ill child during the hospitalization and being present at the time of death (Woodgate, 2006).

Additionally, bereaved parents described how important it was to have good memories during their child's illness and at the time of death. The type of care the child received during hospitalization affected quality of the memories for bereaved parents. Family and friends of the bereaved parents and health care providers who cared for the deceased child in a loving and compassionate manner helped the parents to recall good memories after their child's death (Woodgate, 2006).

Most parents expressed dissatisfaction with the care that their child received in the final stage of life. They described how their role as parents was eliminated as they felt underappreciated or ignored by heath care providers at a time when their child needed them most. This resulted in them questioning their ability to be good parents. Bereaved parents who were involved in the decision making surrounding the treatment needs of their child and who felt that their choices to continue in their role of parenting their ill child was respected by health care providers felt confident that they were good parents (Woodgate, 2006).

Barrera et al. (2009) conducted a longitudinal qualitative study that explored parents adjustment to the death of their child from cancer. Eighteen bereaved mothers and

13 bereaved fathers, including seven couples, participated in the study at 6, 12 and 18 months post-death. Most of the bereaved parents were White (74%) and married (90%) with a college education (84%). Other races/ethnicities represented in the study included Middle Eastern (20%) and Asian (6%). Age of the child at the time of death ranged from 8 months to 20 years old, 98% of the bereaved mothers were the primary caregiver throughout the child's illness, and length of their illness ranged from four days to 14.7 years. All of the deceased children were treated in the Hematology/Oncology unit but place of death was not reported.

Most of the bereaved parents (55%) described their lives as empty and lonely and they yearned to hold, touch and kiss their deceased child. Many parents (48%) expressed overwhelming sadness and physical pain since the loss; 5 mothers and 6 fathers expressed anger of the unfairness of the loss and having to cope with such overwhelming grief. Over half of bereaved parents described their child's illness as long and arduous and expressed relief that their child had died because their suffering was now over (Barrera et al., 2009).

The majority of bereaved parents (90%) describe maintaining a spiritual bond with their deceased child. The memories of their deceased child, knowing that their child was in a better place, visiting the graveside, lighting candles around the house, kissing the deceased child's photograph every morning and talking with the deceased child daily were ways bereaved parents maintained a connection with their deceased child (Barrera et al., 2009).

Explorations of bereaved parents' current health, changes in their work schedules, daily routines and relationships with family and friends were conducted through open-

ended interviews at six months after the death of their child. Four ways of how bereaved parents adjusted following the death of their child emerged. These included maintenance of a relationship with their partner, with surviving children, and with self, and reengaging/reinvesting in their social network. Most of the bereaved parents described the relationship with their partner/spouse as supportive. They felt that the time spent caring for their ill child and then coping with extreme feelings of grief strengthened their relationship. Bereaved parents also stated that they became closer in their relationship in the six months following the death of their child as they now had more time to spend together (Barrera et al., 2009).

Barrera et al. (2009) found that approximately one-third of bereaved parents felt that the death of their child had a deleterious effect on partner/spousal relationship, especially if the mother had been the sole caretaker of the terminally ill child and most of the family activities were centered on the sick child. Lack of time spent with their partner during the child's illness resulted in disconnection from their partner or spouse. Bereaved parents also described their partners as being distant, grieving excessively or too little, and making little attempt to understand how the other person was feeling. Bereaved parents who described their partner/marital relationship as unstable also expressed a deterioration in communication which resulted in feelings of loneliness, frustration, and even disdain toward each other. The development of partner discord increased the likelihood of separation or divorce.

Barrera et al. (2009) identified the effect of bereaved parents' grief responses on their relationships with their surviving children. The majority of bereaved parents found their surviving children to be a source of strength and support. They identified their

surviving children as their reason for living. Spending more time with them and demonstrating more love and care were often stated as being very important to these parents. They expressed feelings of guilt about ignoring their other children while caring for the sick child and how they were now grateful to be able to make up the lost time. Spending time with the surviving sibling was also stated by parents as an important part of their grieving as it provided an opportunity for them to speak about the illness and death of the brother/sister as a family. Most bereaved parents who did not have other children also felt positive about subsequent pregnancies as it would provide them with someone to love and care for again.

Barrera et al. (2009) found that a small percentage of bereaved parents felt disconnected from their surviving child(ren). They expressed how difficult it was to maintain a relationship with their living child(ren) throughout the extensive treatment regime that was required by the sick child, especially if they were the sole caretaker. Following the death of the child, these parents further described how life in the family home and their relationship with the surviving child(ren) worsened because of the stress that accompanied the loss. The existence of detachment or hostility also occurred between some parents and their surviving child(ren). This developed because of extended periods of separation that occurred between the parent, who was the primary care provider to the sick child, and the surviving child(ren). Following the death, parents described their relationship with their surviving child(ren) as superficial and found it difficult to relate to them. These feelings were expressed irrespective of gender and age of the surviving child or parent.

Additionally, bereaved parents expressed that the death of their child resulted in redefinition of their self-identity. Through exploration of their feelings and gaining insight about their child's illness the majority of bereaved parents were able to re-examine and redefine their identities which helped them adjust psychologically to the death of their child. At six months following the death, most of these bereaved parents were able to move forward with their lives. Bereaved parents described how caring for a child with terminal illness was time consuming and after the death they could pursue their own personal interests and find new goals and purpose in life. All fathers and 61% of mothers by six months had returned to work and begun participating in family activities. Approximately 40% of parents irrespective of gender were still struggling to adapt to the loss of their child. Moving on was seen for them as rejecting their deceased child and ending their function as a parent. Parents who expressed these feelings also had difficulty dealing emotionally with their surviving children and partner/spouse (Barrera et al., 2009).

Barrera et al. (2009) also described the changes that occurred within the social world of bereaved parents following the death of their child from cancer. Most of the bereaved parents described extended families and close friends as being very supportive which helped them to cope with their loss. Being able to connect with people who would make them feel comfortable and listen openly when the parents spoke freely about their thoughts and emotions related to their deceased child provided additional support that helped them adjust emotionally. Some bereaved parents felt isolated from their social support, as they described receiving minimal or no help from friends and family members when their child was ill or dying. They did not ask for help as they felt that they would be

a burden to others. After their child's death they felt betrayed and resentful of friends and family members and refused to accept help from them.

Barrera et al. (2009) found that making meaning of the experience was important for many parents to cope with their loss. Bereaved parents sought meaning from religious beliefs as to why their child had died. They felt that fate or forces beyond their control, for example God, determined whether their child lived or died. Parents also described how their child's death was meaningful as they made changes in themselves and their perspective of the world. They became less appreciative of frivolous and materialistic things and placed greater importance on connecting to others by spending quality time with family and with others.

Limitation of the study is that all the children had died from cancer and their parents spent a significant amount of time caring for them during their illness. Results may differ for bereaved parents whose loss was caused by a sudden event.

The cause of a child's death, by sudden or expected illness, may affect bereaved parents' grief reactions and family relationships. Seguin, Lesage, and Kiely (1995) compared bereaved parents grief responses 6 and 9 months following the death of their son after suicide or motor vehicle crash. Participants included 18 bereaved mothers and 12 bereaved fathers in the suicide group and 17 bereaved mothers and 13 bereaved fathers in the motor vehicle crash group. The average age for the deceased child in the suicide group was 22 years old and 23 years old in the crash group. Fifty percent of bereaved parents in both groups were married for over 28 years and all the parents had surviving children. Most of the bereaved parents (59%) were employed and 50% had completed high school. Race and ethnicity was not reported.

Seguin et al. (1995) identified differences between the bereaved parent's mental distress and grief reaction. Parents of children who had committed suicide exhibited greater symptoms of depression at 6 and 9 months than parents whose children had died in a motor vehicle crash. However, bereaved parents whose children had died following a motor vehicle crash showed lower grief reaction at six months but higher grief reactions at nine months than parents whose children had committed suicide.

On examination of family adjustment, about 50% of bereaved parents whose child had died from suicide experienced more feelings of disengagement and distancing among their family members. Bereaved parents in both the suicide and accident groups saw their grief experience as having a positive impact on the family. They felt that this traumatic experience brought the family closer together. Bereaved parents in the suicide group who viewed this grief experience as positively affecting the family had deceased children who were diagnosed with a mental illness or had a history of drug abuse which created stress and tension in these families. The deaths brought calm into the lives of the families, as they did not have to worry about their own safety (Seguin et al., 1995).

Seguin et al. (1995) examined bereaved parents' ability to function in their social, family and professional life, and their personal habits. Comparison of the two groups of bereaved parents identified differences in life events. Bereaved parents whose child had committed suicide were twice as likely to go out less and socialize less with family members. Individuals who provided support to these bereaved families also differed between groups. The suicide group of bereaved parents received support from co-workers, friends or their extended family while the majority of support for parents in the crash group was provided by immediate or extended family members. In the professional

sphere, bereaved parents in the suicide group were twice as likely to change their jobs or take a leave of absence. Within their personal health habits, bereaved parents in the suicide group experienced more changes in sleeping and eating patterns, had more complaints of physical illness, and sought help from health professionals more than bereaved parents in the crash group (Seguin et al., 1995).

Further comparisons were made in this study between the two groups of bereaved parents regarding personal vulnerability. This was described as parents experiencing more stressful life events and relationships and having a history of mental disorders in their family. Parents in the suicide group had a higher incidence of being raised in a divorced or separated household, were raised outside of the home before the age of 15, and had more family members who were diagnosed with mental illness. In their personal lives, bereaved parents in the suicide group reported more marital difficulties and higher incidence of divorce and separation from their spouse. They also had more problems raising the deceased child than bereaved parents in the accident group (Seguin et al., 1995). The family difficulties experienced by bereaved parents in the suicide group in their early childhood may have resulted in difficulties with parenting the deceased child.

Limitation of the study is the use of the FACES III questionnaire to measure family functioning. The deceased children were young adults and it is conceivable that they were not living at home therefore the FACES III questionnaire which measures the relationships of families who are interacting daily might not have been appropriate.

In summary, parent grief has been described as a devastating and traumatic experience and generates negative feelings, disrupts parent's emotional and social world causing severe and even prolonged emotional and physical distress. Research findings

have indicated that the ability of families to cope with this traumatic event is influenced by cause of death, presence of surviving children, social support and the cohesion and flexibility of the families to adjust to the stressor associated with bereavement. Bereaved parents may rely on spiritual/religious beliefs throughout the period of grieving to obtain comfort, create meaning from the loss and help in the healing process that will ultimately result in the acceptance of their loss.

A major limitation of the studies that examined parent's grief reaction following the death of their child consisted of participants who were predominately White and highly educated which makes the findings of the studies not generalizable to other ethnic/racial and lower socially economically groups of bereaved parents. Severe gaps about the grief responses of other races and their use of spiritual/religious coping strategies are absent in the research literature. Further research on parental grief responses of other races especially Blacks and Hispanics are needed.

Parents mental health and personal growth

Kreicbergs, et al. (2004) compared 449 bereaved parents (266 mothers, 191 fathers) whose children had died of cancer with 457 non-bereaved parents (251 mothers, 191 fathers) on risk for psychological distress (anxiety and depression), physical well-being and quality of life at 4- 6 years and 7-9 years after the death of their child. The majority of parents in both groups were married (73% for the bereaved group and 68% for the non-bereaved group), employed (82% for both groups) and 41% of bereaved parents and 45% of non-bereaved parents, stated they were not religious. Ages of the deceased children were not reported. Bereaved parents were identified from the Swedish National Register of Cancer and non-bereaved parents from the Swedish population

register. Study participants were obtained via recruitment letters and follow-up phone calls.

Kreicbergs et al. (2004) found bereaved mothers and fathers were more likely to experience depression, anxiety, and lower quality of life than non-bereaved parents 4-6 years after the loss. Bereaved mothers (32%) were more likely than bereaved fathers (23%) to have moderate to high levels of depression and 60% of bereaved mothers and 45% of bereaved fathers experienced low to moderate levels of psychological well-being. This included having low to moderate quality relationships with family members and involvement in social activities. However, bereaved parents were highly satisfied with their marital relationship, relationships with their surviving children and quality of life 4-6 years after their child's death. This suggests that these bereaved parents may have voluntarily reduced their social activities, socialized more with family members and become more focused on the relationship with their spouse and surviving children.

Time since the death influenced bereaved parents acceptance of their child's death. At 4-6 years after the death 32% of bereaved parents stated that they had not come to terms with their child's death but 7-9 years after the death only 20% of bereaved parents had not worked through their grief. Seven to 9 years post loss bereaved mothers were more satisfied with their relationship with their surviving children than non-bereaved mothers. As suggested in other studies the loss of a child changes bereaved parents' perceptions of life, placing more emphasis on family relationships including their surviving children than before the death. The deceased child's age also was related to bereaved parents' mental health. Bereaved parents, especially fathers, whose children had died at 9 years of age or older had higher levels of anxiety and depression than non-

bereaved parents with children of similar ages 4-6 years after the loss. These symptoms

subsided 7-9 years after the death but long term anxiety and depression were higher for

bereaved mothers than non-bereaved mothers (Kreicbergs, et al., 2004).

Murphy et al. (1999) conducted a longitudinal study that examined the prevalence

of post traumatic stress disorder (PTSD) among 260 bereaved parents (171 mothers, 90

fathers) at 4 months, 12 months and 24 months after the violent death of their child. Ages

of participating parents ranged from 32-61 years (M = 45, SD = 6.01). The bereaved

parents were mostly White (86%) and employed (65%), with a mean of 13.8 years of

education and 80% identified with a religious organization. Cause of death was accident

(58%), suicide (24%) and homicide (10%). Mean age of the deceased child was 20.1

years (SD = 4.4) and time since death ranged from 6 weeks to 7 months (M = 130 days,

SD = 2.0). Bereaved parents were identified from death certificates but place of death

was not reported.

Murphy et al. (1999) found 40% of bereaved mothers and 14% of bereaved

fathers exhibited symptoms of PTSD 4 months after their child's death, however at 24

months bereaved mothers became less symptomatic for PTSD (21%) but the 14% of

bereaved fathers remained symptomatic for PTSD. Cause of death also affected the

manifestation of PTSD symptoms. At 4 months post death 60% of bereaved parents

whose child had died from homicide developed PTSD: 35% for parents whose child's

death was accidental and 36% for parents whose child's death was suicide.

Differences in gender and PTSD symptoms were described by Murphy et al.

(1999) who found that bereaved mothers exhibited higher levels of mental distress

(depression, anxiety, hostility) and more severe grief symptoms than bereaved fathers at 4

months post death. Bereaved mothers with PTSD also consumed more alcohol/week than bereaved fathers with PTSD. Most bereaved parents (51% mothers and 54% fathers) perceived themselves to be non-productive at work, were frequently absent from work, and had poorer health outcomes than bereaved parents who did not have PTSD symptoms. Bereaved fathers whose scores were reflective of PTSD also had poorer health than bereaved mothers. When compared with bereaved parents who had no symptoms of PTSD, bereaved parents with PTSD also had lower self-esteem and lower self-efficacy.

One of the limitations with the study was the instrument selection to measure PTSD. The instrument was developed by the principle investigator for the purpose of the study and the psychometric properties of this newly developed instrument are not established.

Dyregrov, Nordanger, and Dyregrov (2003) examined differences in bereaved parents' grief reactions to losing a child who had died suddenly/traumatically and cause of death. Two-hundred and thirty-two bereaved parents participated (139 mothers, 93 fathers) of which 128 (55%) children died by suicide, 68 (29%) by accident, and 36 (16%) infants to SIDS. The average ages of bereaved parents were 51 years (SD = 8.0) in the suicide group, 40 years (SD = 8.5) in the accident group and 30 years (5.7) for the SIDS group. Time of death and participation in the study was between 6 and 23 months with an average of 15 months for the SIDS and suicide and 14 months for the accidental group. Place of death and recruitment of study participants was not reported.

Dyregrov et al. (2003) found that most of the bereaved parents in all three groups experienced severe grief reactions of psychological distress. Bereaved parents whose

children had died accidentally had higher scores on the total Impact of Event scale that measure post traumatic stress (M = 36.3, SD = 14.4), and the subscale intrusion (M = 22.7, SD = 7.6) and physical complaints (M = 10.4, SD = 7.8) than the other two groups. Bereaved parents of the SIDS group experienced significantly less physical and psychological problems than bereaved parents in the suicide or accident group.

Similarities and differences were predicted between the three groups of bereaved parents in general health, post-traumatic psychological distress, and complicated grief. For bereaved parents in the suicide group, variables of social isolation, minimal education, short time elapse since the time of death and not working outside the home were best predictors of reduced general health and post-traumatic psychological distress. (Dyregrov et al., 2003).

Variables that predicted reduced general heath for bereaved parents in the SIDS group were: not working outside the home, social isolation and short time since the death. Developing post-traumatic distress was best predicted by: social isolation, minimal education, bereaved mother, not having a surviving child, and losing a male child. For bereaved parents in the accident group social isolation and not having a surviving child were the best predictors of reduced general heath. Predictors of post-traumatic psychological distress were: social isolation, bereaved mother, and having minimal education (Dyregrov, et al., 2003). Similarities were found in the variables of the best predictors of complicated grief in all the three groups. Social isolation, bereaved mothers, and not having surviving children were best predictors of high scores on the Inventory of Complicated Grief reaction among bereaved parents whose children had died from suicide, SIDS or accidentally.

Song et al. (2010) examined the effects of a child's death on bereaved parents' health-related quality of life (HRQoL). Bereaved couples were compared with non-bereaved couples to determine whether marital closeness, as a source of support helped bereaved parents maintain better mental and physical health. Bereaved married couples (n = 233) and a comparison of 229 non-bereaved married couples were selected from a subset of a larger prospective longitudinal study that investigated the long term effects of grief of bereaved parents over 40 years. Most of the bereaved and non-bereaved parents were 64 years old at the time of the study and years since the death of their child ranged from 16 years to 38 years. Most of the deceased children had died after their first birthday with 90 deaths (39%) occurring from chronic illness and 86 (37%) from violence. Fifty-seven infants (24%) died before their first birthday as a result of prematurity, congenital anomaly or sudden infant death syndrome.

Controlling for demographic factors Song et al. (2010) found that bereaved parents had significantly poorer mental and physical health than non-bereaved parents. Differences were seen in bereaved mothers' mental health status by cause of the child's death. Bereaved mothers whose child died from violence or illness (39% and 37%, respectively n = 176) experienced more episodes of depression than bereaved mothers whose child died in infancy (24%, n = 57). Bereaved parents who had a close marital relationship had higher HRQoL and less depressive episodes than bereaved parents who had lower marital closeness. One of the major limitations of the study was the length of time between the child's death and the time that bereaved parents were surveyed. Bereaved parents completed the HLQoL survey when they averaged 64 years old and their children had died when they were much younger. Relying on the accuracy of the

study participant's memory when there was a long time delay between their child's death and completing the HLQoL survey at the time of the study increases the risk of recall bias. The homogeneity of the participants limits the application of the study's findings to other racial/ethnic groups.

In summary, studies have found that bereaved parents have a higher rate of mental distress, ill-health and marital problems when compared to non-bereaved parents but studies that have examined bereaved parents' psychological adjustment following the death of their infant/child in the neonatal intensive care/pediatric intensive care units are limited. Most studies examine the influence of spiritual/religious practices and mental health outcomes are with adults who were diagnosed with life-threatening illnesses. There are no studies identified that have examined the influence of spiritual/religious practices and mental health outcomes in bereaved parents whose children have died in the NICU/PICU.

Spiritual coping strategies and bereavement

Meert, Thurston, and Briller (2005) explored the spiritual needs of bereaved parents two years after their child had died in the PICU. Participants consisted of 32 bereaved parents and one bereaved grandmother who was the deceased child's legal guardian. Of the 33 bereaved parents interviewed, 55% were White and 45% were African-American. Median years of education were 13 years with 65% of bereaved parents attending some college or trade school. Religious affiliation was 64% Protestant, 21% Catholic and 6% Jewish. The median age of the deceased child was 4.5 years with 69% of deaths related to chronic conditions and 31% to acute illness. Almost all of the bereaved parents (80%-100%) described using prayer, ritual, sacred text; finding meaning

and purpose in their child's death; connecting with the deceased child and connecting with others as important spiritual/religious coping strategies that helped in alleviating their pain and providing inner strength and comfort during this stressful time. Anger and blame at themselves and God was express by 30-60% of bereaved parents.

Meert et al. (2005) found that before the death of their child, bereaved parents relied on prayer and intercessionary prayers from family, friends and the community for a favorable outcome and healing for their child. One bereaved father stated that his request was for God to show mercy by letting his child live and also for strength to bring him through this terrible ordeal. Prayers from the community were described by bereaved parents as being very supportive. They requested the hospital chaplain to visit and pray with the family. Reading inspirational/spiritual text or the scriptures and listening to spiritual songs were described as important spiritual activities that parents used to alleviate the stress prior to their child's death. Bereaved parents reported that these activities strengthened their faith. Religious rituals of baptism and last rites were important to some parents as they believed it ensured their child's soul was committed to the after-life.

Meert et al. (2005) reported that bereaved parents described their connection to others as an additional source of spiritual support. Sympathetic presence and reassurance from spouses, family, friends, co-workers, clergy, and healthcare professionals was perceived by bereaved parents as being helpful in relieving their pain and stress. One mother described the caring actions of others, connecting to other bereaved parents, receiving hugs, and being able to talk about their deceased child were helpful connections that was supportive. Just telling their story was described as spiritually supportive.

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Similar findings were described by Robinson, Thiel, Backus, and Meyer (2006) who surveyed 56 bereaved parents 1-2 years after their child's death in the PICU. Ages of the deceased children ranged from newborn to 18 years old. Bereaved parents were predominately White (91%), with 50% identifying their religious affiliation as Catholic, 34% as Protestant, 5% Jewish, 2% Muslim and 9% had no religious affiliation. Bereaved parents responding to open-ended questions identified using spiritual/religious coping strategies to deal with their loss.

The use of prayer, relying on their faith in God, having access to and care from the clergy, and a belief that the parent-child relationship transcends to a life beyond death were all coping strategies that they identified as being helpful during their child's last days prior to their deaths. Praying for strength, putting their trust in God who was in charge of their child's life, knowing that their child's suffering would be over, and that they were in heaven provided comfort to these bereaved parents. Access to their spiritual adviser was helpful especially when the decision whether to withdraw life support had to be made. Several parents found comfort in their belief that their connection to their child continues into a life beyond death (Robinson et al., 2006).

Raingruber and Milstein (2007) conducted a phenomenological study that described the lived experience of parents whose infants were admitted to the NICU with life threatening illness. Of the four mothers and three fathers who agreed to be interviewed two parents had suffered the loss of their child. Parents described the use of spiritual/intuitive experiences and searching for circles of meaning as coping strategies that provided comfort and relieved their stress (Raingruber & Milstein, 2007).

Parents whose children had died stated how important it was to know that their child's life was valued by others. That their child mattered helped to ground the parents during this time of crisis. One bereaved father stated that in making meaning of his daughter's death, he found comfort in the numerous lives she touched by her presence. The bereaved father further stated that his daughter's premature death signified that God must have had a plan for her to accomplish other things in heaven. He described this belief as giving him peace (Raingruber & Milstein, 2007).

Connecting to others was another spiritual experience that provided comfort and relieved stress. One mother described how her estranged father's visit to see his sick grandchild helped her to cope during this stressful time. His presence demonstrated that he cared about them which gave her joy and revitalized her spirit (Raingruber & Milstein, 2007).

Lichtenthal, Currier, Neimeyer, and Keese (2010) conducted a mixed method study to identify how 153 bereaved parents (124 mothers, 29 fathers) made sense or meaning of their child's death and grief outcomes. Ages of the bereaved parents ranged from 23-77 years (M = 49.4, SD = 10.58). Ninety-two percent of the participants were White with the remainder, 3.8% African-American and 3.2% biracial. The deceased children's ages ranged from 0-47 years (M = 17, SD = 10.54) and the average length of time since death was 6 years. Causes of deaths were: motor vehicle crashes (45%), heart attack (20%), cancer (12%), suicide (11%), homicide 6% and miscarriage/stillbirth (6%). The majority of bereaved parents (91%) had surviving children. Place of death was not reported.

Bereaved parents were found to use three patterns of meaning-making to cope with their grief: Sense-making, benefit finding and other salient meanings. The Core Bereavement Items (CBI) and the Inventory of Complicated Grief (ICG) were used to measure normal emotional reactions and maladaptive reactions to bereavement. Within the sense-making category the most common theme that emerged from parents trying to understand why their child died was the reliance on spirituality and religious beliefs. A number of bereaved parents (n = 28, 17.9%) believed that their child's death was God's will and a part of His plan (Lichtenthal et al., 2010).

Similarly, belief in the afterlife, that their child was safe in heaven, and that they would be reunited with their child was another common theme that parents (n = 25, 16%) used to make meaning of their child's death and proved helpful in coping with their grief. Significant differences were found in the use of spiritual beliefs to validate their child's death with more mothers than fathers describing the death as God's will (Lichtenthal et al., 2010).

In the benefit-making category enhancement of spiritual and personal growth was another theme that most bereaved parents (52.6%) saw as making meaning of their child's death. Parents identified several positive changes in themselves. They stated that becoming more compassionate, caring and sensitive to the needs of others (16.7%), having a greater appreciation for life (14.7%), strengthening their relationships with spouse, surviving children and family members (12.2%) and reaching out to other bereaved parents (21%) were meaningful changes that resulted from their child's death. Forty-five percent of bereaved parents reported seeing no benefit in their child's death (Lichtenthal et al., 2010).

In the salient category bereaved parents described both positive and negative feelings they experienced following the death of their child. For some parents, talking about their loss (12.2%) was helpful or healing; for others appreciating the time spent with the child before their death (12.2%) and accepting the death because they cannot change the circumstances (10.3%) were described as beneficial in coping with their loss. Other parents (14.1%) continued to feel sadness and pain associated with the death and 3 parents stated that they were unable to accept the death (Lichtenthal et al., 2010).

On the ICG, 55% of bereaved parents had scores above the clinical cut off which was indicative of being very distressed ($M = 29.8$, $SD = 16.1$) and on the CBI, bereaved mothers obtained significantly higher scores than fathers. Higher scores were related to more recent deaths ($r = -.42$, $p<.05$) and older child ($r = .19$, $p<.001$) Bereaved parents whose child's death was related to violence had higher CBI scores than parents whose child's death was anticipated. Content coding from the qualitative responses of bereaved parents were compared with their CBI scores to determine predictors of prolonged grief disorder. Bereaved parents who found no sense to their loss ($\beta = .24$, $p<.002$) and no benefit to their loss ($\beta = .17$, $p<.002$) had higher CBI scores than parents who were able to derive at least one benefit from their loss ($\beta = -.21$, $p<.01$). Parents who were able to make sense of their loss ($\beta = .18$, $p<.01$) and make meaning from their loss ($\beta = -.16$, $p<.05$) had lower severe grief scores on the ICG. Bereaved parents had less severe grief scores if they believed in the existence of a higher power/God, that it was His will and a part of His plan that their child died, were able to change their life priorities because of their loss, and were relieved that their child was no longer suffering. The limitation of

this study included the underrepresentation of other ethnicities/races and therefore the results of the study can only be applied to white mothers and fathers.

McIntosh, Silver, and Wortman (1993) examined the role that religion played over time in the lives of 124 bereaved parents, 98 (79%) bereaved mothers and 26 (21%) bereaved fathers, as they adjusted to the death of their infant to sudden infant death syndrome. Fifty percent of the participants were Black, 45% White, and 5% other ethnicities. The ages of the deceased infants were 2-4 months. Bereaved parents were contacted by mail seven days after their baby had died and interviews were conducted two to three weeks post death with follow-up interviews at three months and 18 months. Bereaved parents were asked to describe, on a scale of 1-5 how important religion was to them and how often they attended religious services. Religious affiliation consisted of 45% Baptist, 37% Catholic, 3% Jewish, and 15% other religious groups.

Bereaved parents who reported greater church attendance had greater social support to help them deal with the loss. They also had better emotional adjustment three weeks after their infant's death and, at 18 months, had lower levels of emotional distress and higher levels of well-being. Bereaved parents who identified religion as being very important to their lives were also more likely to engage in activities that would help them to work through the loss and search for meaning that would help them make sense of their infant's death (McIntosh et al., 1993).

The results of the study indicated that religion alone had no direct effect on bereaved parents' adjustment to their loss. Bereaved parents who attended religious services and stated that religion was important to them but also had greater social support

and could find meaning as to why their infant died had greater levels of well-being at 18 months after the death of their infant (McIntosh et al., 1993).

In other studies where most of the participants are White, this is one of the few studies by (McIntosh et al., 1993) where African-Americans, compromised 50% of the participants. The major limitation of the study was that the two religious questions asked of the participants were single item measures. A single item measure may offer a less comprehensive explanation on the importance of religion as a coping strategy and its effect on bereaved parent's adjustment to their infant's death. As most of the participants were Christians, the results cannot be generalized to people with other religious beliefs.

To cope with their grief bereaved parents also maintain a spiritual connection to their deceased child (Klass, 1999). Sormanti and August (1997) explored the feelings/beliefs of the existence of a spiritual connection between 43 bereaved parents (79% mothers and 21% fathers) and their deceased child and its effect on their grief. Most participants were White (98%), had one or more surviving children (95%), and were 36-45 years old. Most of the study participants (86%) were Catholic, 26% Protestant, 12% none and 2% other. Length of time since death and participation in the study for most parents (56%) was 24-72 months, 26% 12- 24 months and 18% 12 months. All of the children died from cancer with 46% dying within a year of being diagnosed, 23% dying between 1-2 years and 10% dying more than 5 years after their diagnosis.

Bereaved parents described remaining spiritually connected to the deceased child in their dreams. These dreams were described as receiving a visit from their deceased child and included feeling their presence through holding of hands with them or receiving

a kiss on the cheek from them while dreaming. The dreams and presence were interpreted as a sign that the deceased child was still with them, assisting them in their daily life by helping them to cope with their grief. One mother stated that several times she would be crying excessively and the phone would ring and it was always someone calling that would help her to feel cheerful. She attributed these phone calls to the deceased child intervening and making that person call her. Another mother describe how when she is feeling tired she can always feel a kiss on her neck from the deceased child which she described as comforting. One father stated that on his frequent walks he often felt the presence of his deceased child and this resulted in feelings of inexplicable joy and exhilaration (Sormanti & August, 1997).

Several bereaved parents stated that when they were troubled, they would request a sign from the deceased child indicating their presence. Seeing a very bright star on a cloudy night at the time of the request, or hearing a special music that reminded them of the deceased child were, to them, signs indicative that their deceased child was at that moment present with them. Talking with the deceased child frequently and holding firmly to the belief that the deceased child will always live in their heart and soul were other ways that bereaved parents stayed spiritually connected to their deceased child (Sormanti & August, 1997).

For the majority of bereaved parents the spiritual existence of their deceased child provided them with peace and happiness during their time of sorrow as they felt closer to their deceased child and God. Additionally, some bereaved parents (33%) believed in heaven which they saw as a peaceful, happy and safe place where pain was eliminated and where they would later be reunited with the deceased child. They were comforted in

knowing that their deceased child was with God and with other deceased relatives who would meet and greet them when they arrived in the after-life. The majority of bereaved parents (79%) stated that their religious belief, cultural background or community influenced their belief which gave them a sense of hope and tolerance for the uncertainty of life after death (Sormanti & August, 1997).

Most parents also stated that their beliefs about life after death had changed following the death of their child. Some parents stated that their belief in God was strengthened following the death of their child, others reported that their belief in God emerged after their child died, others, especially those who were ambivalent about life after death, became convinced that an after-life existed following their child's death while others stated that their belief in the after-life changed following their loss. One father stated that it was impossible to believe that the spirit of his deceased son had gone to an after-life and while he accepted the non-existence of his son's body the spirit of his deceased child became a part of him and lives with him forever (Sormanti & August, 1997).

The majority of participants in the Sormanti and August (1997) study were White and Christians therefore the results of the study are applicable only to this population. Examination of bereaved parent's spiritual connection with their deceased child who used coping strategies not related to religious practices to provide comfort would provide information on non-religious coping strategies. Ages of the deceased children were not reported, even though other researchers have reported a correlation between age of the deceased child and intensity of bereaved parent's grief response.

Gilbert (1992) explored the ability to find comfort in religious beliefs of very religious bereaved parents following their loss. Additionally, the research investigated whether their religious beliefs and/or their views of religion and God changed following their loss. Twenty-seven bereaved couples described their grief experience 6 months to 7 years following the death of their child. Ages of the bereaved couples ranged from 26 to 42 years and they had been married for 3 to 14 years. All of the study participants were White; education, socio-economic status and religious affiliation were not stated. Most of the bereaved parents (67%) had experienced a neonatal death (12 died during the first month of life and 6 died after one month) and 33% had first and second trimester losses.

Some parents stated that their belief in God was helpful to them during this traumatic event. Finding strength through their religious beliefs, not questioning God's actions because He is in control and had their best interest in mind, and not blaming God for the terrible event were some of the feelings expressed by bereaved parents. Bereaved parents expressed their belief that the death of their infant was God's will and only God knows why their child died. They said that deepening their relationship with God through prayer gave them comfort and brought peace into their lives (Gilbert, 1992).

Gilbert (1992) also found that when the bereaved parents were asked the question of "Why me," they did not express anger with God nor did they feel that God was punishing them, and they did not blame their tragedy on Him. Instead, through their faith, they believed that God's intent was for them to have a greater appreciation for life and to change their lives for the better. Several bereaved parents became more involved in their church activities, becoming lay ministers and helping other bereaved parents.

Gilbert (1992) identified 8 women and 4 men in the study who did not find religious beliefs to be helpful during their time of grief. Although most of them attended church and maintained their religious values, their views of God changed following the death of their child. They were angry with God and described Him as being judgmental, punitive, hateful and vengeful and could not believe that God had allowed this to happen to them. These bereaved parents who did not find religious beliefs helpful also expressed anger when support was offered by ministers or priests. They were not comforted with pastoral support that described their infants as being angels in heaven, or that it was God's plan that we may not understand, or this event will make them have a greater appreciation for life. Many of these bereaved parents also felt that they failed their child and now they were being punished by God. Only the group of bereaved parents that expressed negative feelings about God presented with suicidal ideation or a desire to die so that they could be with their child. Conversations with other bereaved families and support from church members resulted in a reduction of their feelings of anger toward God over time.

Another group of bereaved parents, 5 mothers and 7 fathers, stated that religious beliefs was not relevant prior to their infant's/child's deaths and were not utilized during their time of grief. Coping strategies used to provide comfort included maintaining a strong marital relationship, receiving support from family members and obtaining medical information about their infant's illness, cause of death, risks of a similar occurrence with future pregnancy and receiving information that helped them to understand the grief process (Gilbert, 1992).

Research has shown a positive correlation between spiritual/religious coping strategies and psychological adjustment of parents whose children are diagnosed with life-threatening illness (Cardella & Friedlander, 2004; Elkin et al., 2007). The Cardella and Friedlander (2004) study aimed at identifying a relationship, if any, between the use of five religious coping strategies and psychological distress experienced by parents whose children were diagnosed with a terminal illness. One hundred and sixty-six parents, (113 mothers, 53 fathers), whose children were being treated for cancer or were in remission for one year were asked to complete a mailed survey that addressed their religious coping strategies and psychological distress. The majority of parents stated that they were Catholic (46%) or Protestant (35%), married (85%) and had a socio-economic index above midrange.

The results of the study revealed two demographic variables, annual household income and gender, to be significantly related to higher levels of psychological distress. Parents with fewer financial resources and mothers showed greater psychological distress. Two of the religious coping strategies, collaborative religious coping and pleading for direct intercession from God, were related to higher levels of psychological distress. Parents who believed that they had collaboratively entered into a partnership with God to help them find solutions to treating their child's illness and parents who pleaded with God for a miracle to heal their child had greater psychological distress. Parents who identified themselves as Christians and whose children were being treated for cancer or in remission and reported using collaborative religious coping had lower levels of psychological distress than parents who were not affiliated to a religious organization or whose children were in the terminal stages of cancer.

Elkin et al. (2007) examined the use of religion as a coping strategy in 27 mothers of children diagnosed with cancer and its relationship to the mother's psychological adjustment. Parents were recruited from a follow-up clinic and completed a set of questionnaires that included their religious beliefs and practices and current emotional functioning. The participants were White (56%) or African American (41%). Most of the mothers stated that they were Christians, with 63% being Baptist, and two mothers reported no religious affiliation. The mothers who stated that they were Christians also stated that they have a high level of religious beliefs and behaviors. The mothers who reported no religious affiliation reported low levels of religious belief and behavior. The average child's age M = 12.78 (SD = 4.1) years, 56% were males and they had been receiving treatment for 17 months.

Elkin et al. (2007) found that 74% of the mothers reported an increase in religious belief since their child's diagnosis, 15% reported no change and 11% reported a decrease in their religious belief. Most mothers also reported an increase in religious behaviors, for example giving money to church groups and actively participating in religious organization. The average depression score for these mothers identified them as mild to minimally depressed (M =13.7, SD = 12.4) with 4 mothers exhibiting severe depressive symptoms, 3 being moderately depressed, 1 mildly depressed and 19 minimally depressed.

Mothers with few depressive symptoms reported higher levels of religious beliefs and behavior. Mothers whose scores identified them as being depressed reported significantly less religious beliefs. Although the results showed a positive correlation between religious beliefs and mental health, this small sample with predominately

Christian mothers which make the results applicable only to mothers of the Christian faith. The mother's level of education and income were not reported.

The meanings that manifest from believing in God or a higher power often are used to provide a sense of security and bring peace. The Schineider and Mannell (2005) phenomenological study explored the use of spirituality as a coping strategy by four mothers and four fathers whose children were diagnosed with a terminal illness. All held college degrees and all identified themselves as being infrequent church goers who subscribe to some form of organized religion.

Most of the parents identified spirituality as being important in providing some support throughout their child's illness. Belief in God or a higher power was identified as a source of strength and comfort throughout these stressful times. One father stated that his belief that God was in control over his child's journey with cancer helped him to deal with the reality of his child's illness and not to blame others for his child's diagnosis (Schineider & Mannell, 2005).

Schineider and Mannell (2005) found that faith was a significant theme that emerged from the parent's description of the religious aspect of their spirituality. Having faith was another important religious coping strategy used by these parents as they attempted to navigate the tragedy associated with their child's illness. Both mothers and fathers described their faith as a source of comfort as they grappled with the uncertainty of the outcome of their child's cancer diagnosis.

Some parents discussed their doubts about their faith and the existence of a God that allows children to suffer. Some parents described how their faith wavered especially when their child's condition deteriorated, but eventually they returned to their original

beliefs in God. Church attendance was also viewed by these parents as valuable in helping them to cope with their child's illness. Parents described the following benefits of attending church: renewal of energy, regrouping, reflecting on their situation, and serenity. Parents stated that these benefits helped in negating the feeling of loneliness (Schineider & Mannell, 2005).

Praying was found to be an important and powerful religious coping strategy. Parents referred to prayer as having the power to heal their child and also helped them to cope with their child's illness. Prayer was described as strengthening their resolve to fight for their child to survive. Some parents spoke about the power of prayer and its impact on their child's health. One father stated that his prayer to God was for an improvement in his child's health and the next day his prayers were answered. Parents described an additional benefit of praying as actively doing something beneficial for their child in an otherwise uncontrollable situation (Schineider & Mannell, 2005).

Intercessional prayers from church members, prayer networks organized within the community of their church, family members and friends were perceived by these parents to be helpful. Additionally, communicating with their priest was described by parents as another religious coping strategy that provided support and guidance. The priest became their counselor and spiritual advisor, made home visits when requested, and performed various rituals of the church to their children in their homes (Schineider & Mannell, 2005).

Parents also used spiritual coping strategies that were not related to religious practices. These strategies included seeing the positive side of things and appreciating what nature had to offer. Parents described sitting on the porch and soaking up the

sunshine as feeling very peaceful, meditating, being in the outdoors and communing with nature, being in the woods and watching the animals moving around, or hearing the birds sing as activities that were comforting, calming, relaxing and peaceful (Schineider & Mannell, 2005).

Wilson and Miles (2001) explored the use of spirituality as a coping strategy for 14 African American mothers whose chronically ill infants were admitted to either the NICU/PICU. Mothers' mean age and years of education was 27 and 13 years respectively. Most of the mothers were single (60%) and unemployed (70%). Children at the time of interview were M = 19 months old and all of the children had chronic respiratory disease with 29% also having congenital heart defect.

Praying to God for help with their child's illness and acknowledging that He is in control of their child's fate was coping strategies used by 79% of mothers. Reading the bible and receiving support from others provided hope and comfort. Knowing that God would take care of their child was described as effective in reducing these mothers' anxiety and feelings of helplessness. Prayer for 43% of the mothers provided a conduit to establish and maintain a personal relationship with God who helped them to cope with their child's illness (Wilson & Miles, 2001).

Prayer also provided additional support from church members, pastors, family members and friends. Pastors often visited the hospitalized child and performed rituals, for example, praying at the bedside and baptizing the sick child. The mothers described the support received from their pastors as helping them to believe in the power of prayer. Intercessionary prayers from church members, family and friends also helped the mothers to believe that their child would survive (Wilson & Miles, 2001).

The mothers believed that because God had the ability to keep their child alive they were willing to become emotionally attached and physically involved in caring for their child. Hesitancy to become emotionally involved with her child may be indicative of the mother's belief that without God's help her child would not have survived illness (Wilson & Miles, 2001).

Two mothers (14%) described how their faith in God was tested as they were unable to comprehend why God allowed their child to be sick. One mother expressed bitterness and anger at God and was experiencing difficulty in maintaining a relationship with God. Six (43%) mothers described their faith as strengthened and some of the mothers became more active in their church. These mothers also felt that they became a stronger person and others stated that they recognized the fragility of life and placed a higher value on life (Wilson & Miles, 2001).

In summary, Studies that examine spiritual/religious beliefs and practices and can reduce negative psychological symptoms for bereaved parents and parents of children with a life threatening illness. There are few current studies that have examined spiritual coping strategies and bereavement and no longitudinal study that examined the use of spiritual coping strategies among bereaved parents whose infant/child died in the NICU/PICU were identified. Additionally, most of the bereaved parents who participated in the studies were Christians, leaving a gap in knowledge about bereaved parents from other religious and non-religious groups.

Gender differences and spiritual coping strategies

The differences in gender role in our society where the mother is seen as being very emotional and the father as the stoic one who is not suppose to cry has lead to the assumption that fathers grieve differently and recover at a faster rate than mothers.

Lang, Gottlieb, and Amsel (1996) examined how gender bereavement reactions changed over time and its impact on marital relationships of couples whose infant had died under the age of one year. The study sample consisted of 31 bereaved couples who were predominately White, of low to middle income, and had been married or living together for an average of 10 years. Cause of death ranged from congenital anomalies to sudden infant death syndrome.

Bereaved couples completed the surveys 1-2 years after the death of the infant and the follow-up survey was completed 2 to 4 years later. Bereaved couples' were interviewed in their homes with husbands and wives completing their surveys independently. Bereaved couples' emotional, physical and behavioral reactions to their grief and perceptions of marital intimacy were explored. Emotions such as fear, guilt, anger, yearning, depersonalization, isolation and meaninglessness were examined. The responses of the bereaved couples were compared with 36 non-bereaved couples of similar demographic background (Lang et al., 1996).

Changes were evident in bereaved couples' grief reactions from the initial visit at 1-2 years to the follow-up visit 2-4 years later. With the exception of somatization, the intensity of the bereaved couples' grief reactions were lower at the follow-up visit than the initial visit. However, bereaved wives continued to exhibit higher grief reactions than their husbands at both the initial and the follow-up visit. Bereaved fathers had less guilt,

meaninglessness, yearning and morbid fear than their wives two to four years after the death of their infant. Compared with non-bereaved couples, bereaved couples had increased feelings of depersonalization 2 to 4 years after the death of their infant (Lang et al., 1996).

Lang et al. (1996) found that marital intimacy was compromised for some bereaved fathers. Bereaved husbands who reported having less sexual intimacy two to four years after their infant's death also had increased feelings of fear and isolation. They experienced more somatic symptoms and feelings of being blamed by the other partner for the death (stigma). However, fathers who shared common interests with their wives (social intimacy) experienced less grief symptoms of meaninglessness and stigma. The risk of marital separation increased if they were unable to share their partner's interests, and if sexual intimacy occurred shortly after the death of their child. Husbands also reported having more guilt, yearning, depersonalization and stigma if the data were collected close to the anniversary date of the child's death.

Communication was another factor identified by Lang et al. (1996) as important in the marital relationship two to four years after their infant's death. Bereaved mothers experienced less guilt, anger, yearning, depersonalization and morbid fear if they were able to share their thoughts and feelings soon after the death with their partner. Bereaved mothers who had poor communication with their partners experienced more guilt and yearning. Greater social intimacy with their husband resulted in less isolation, anger, meaninglessness, stigma and morbid fear. Similar to their partners, bereaved mothers also experienced increased emotional and physical symptoms if the interview was conducted close to the anniversary date of the infant's death.

Kamm and Vandenberg (2001) examined the impact of communication, whether negative or positive, on 36 bereaved couples' marital relation and adjustment to their grief for their child who had died between the ages of 2 and 18 years old. The majority of the bereaved couples were White (93%), their mean age was 47 years (SD = 8.2) and average time since the death of their child was 4 years and 10 months. Most parents (89%) reported that the death occurred suddenly.

Kamm and Vandenberg (2001) found that bereaved couples who were able to communicate positively about their grief and those for whom there was longer time since the death of their child had less grief reactions. Time since the death also affected bereaved couples' grief scores with couples who communicated negatively about their grief irrespective of time since the death of their child had intermediate levels of grief reactions. Grief reactions were high for couples who were able to communicate positively about their grief but whose child had died more recently.

Kamm and Vandenberg (2001) also found that bereaved husbands' and wives' grief communication scores were moderately correlated r = .45, and bereaved couples had significant differences in their attitude of grief communication with wives exhibiting significantly more positive attitudes about grief communication than their husbands. Bereaved fathers who valued communicating openly with their spouses about their grief reported higher levels of grief if the time since death was greater or equal to 5 years. Bereaved fathers whose children had been dead for over five years and practiced open communication with their spouses reported lower grief scores. Bereaved fathers who had minimal communication about their grief with their spouses had intermediate levels of

grief reaction irrespective of the time since their child's death. Bereaved mothers' valued open communication about their grief more than their spouses.

Examination of grief communication between couples and marital satisfaction found that bereaved mothers who valued and had open grief communication with their spouses also reported higher marital satisfaction during the first 5 years after their child's death. Bereaved mothers who reported having a negative attitude about grief communication expressed having more marital dissatisfaction during the same time period (Kamm & Vandenberg, 2001). Limitation of the study included the small sample and recruitment of participants from a support group which stressed grief communication. The majority of participants were White. Causes of the children's death were also not reported.

Vance, Boyle, Najman, and Thearle (2002) in their longitudinal study examined bereaved couples' emotional and marital distress following the sudden death of their infants. One hundred and thirty-eight bereaved couples whose infants had died from sudden infant death syndrome or perinatal death participated in the study. Their responses were compared with 158 non-bereaved couples with similar demographics. Couples were interviewed in their homes at 2, 8, 15 and 30 months following the death of their child. The bereaved couple's anxiety, depression, marital satisfaction and alcohol use was examined to determine their adjustment over time to the death of their infant.

Bereaved couples (43%) at two months after their child's death had increased levels of anxiety and depression than non-bereaved couples (13%). Bereaved couples distress decreased over time with 25% reporting symptoms of anxiety and depression at eight months versus 13% of non-bereaved couples. Only a few bereaved couples (11%)

experienced anxiety and depression simultaneously at two months but the number decreased to 3% by 30 months. Anxiety and depression of bereaved mothers and fathers varied with bereaved mothers reporting a decline from 21% at 2 months to 10% at 30 months. However, the bereaved fathers' levels of anxiety and depression increased from 12% at 2 months to 15% at 30 months. Bereaved mothers, but not their partners, who had increased anxiety and depression at two months had greater dissatisfaction with their marriage at 30 months. If bereaved mothers were not distressed irrespective of time and whether their partners were distressed, they were more likely to experience marital satisfaction. Distress for bereaved fathers was not associated with marital satisfaction irrespective of their partner's distress soon after their infant had died. Among the non-bereaved couples 91(81%) experienced no symptoms of anxiety or depression at all four time points.

Alcohol use was more prominent in fathers of both groups with 7-12% of bereaved fathers and 5-6% of non-bereaved fathers consuming five or more alcoholic drinks a day. In contrast, only 1% of bereaved and non-bereaved mothers reported a similar consumption of alcoholic beverage. The differences in psychological distress seen between bereaved mothers and fathers were possibly due to alternative response of coping with grief rather than less intense feelings about the loss of their child (Vance, et al., 2002).

Moriarty, Carroll, and Controneo (1996) described the grief responses of 50 bereaved couples or mothers who were living with a significant other and had experienced a sudden unexpected death within two weeks to two years. The sample was described as heterogeneous in income, education and ethnicity/race with 33% of mothers

and fathers White and 32% of the mothers and 28% of the fathers Black. The mean age of the bereaved mothers was 28 years (range 19 to 35 years) and bereaved fathers 31 years (range 19-59). Most of the deceased infants had died from SIDS (84%) and 16% were stillbirths. Ages of the deceased infants and place of death was not reported. Bereaved parents were recruited from a bereavement support network and the SIDS information counseling program.

On the Global Severity Index, bereaved mothers obtained higher scores than fathers on the subscales of somatization, obsessive-compulsion, interpersonal, sensitivity, depression, anxiety, phobic anxiety. Bereaved mothers and fathers scores on the anger and hostility subscale were similar. Feelings of being easily annoyed, having frequent arguments, shouting and throwing things were reported by both parents.

Armentrout (2009) interviewed four couples who had participated in a larger study on bereaved parents' grief reaction following removal of their infant from life support. Most of the mothers felt that initially they were on the same page with their husbands but after about five to six months things began to change; they were still tearful, visiting the cemetery daily, researching on the internet and wanting to talk frequently about their deceased child. Fathers had to be engaged in physical activities that included sorting out the garage and doing repair jobs around the house. One mother stated that her husband was very uncommunicative about the death of their child and she would insist that her husband share his feelings with her. All the mothers felt that their husbands went through the grieving process more quickly, but they were not resentful of their husbands as they understood that their husbands were not indifferent to the death of their child but that they were grieving differently.

In summary, the grief responses of bereaved couples to the death of their infant/child can affect their mental health and marital relationship. Studies that have explored differences in bereaved couples grief reactions have found mother's to experience poorer mental health outcomes and longer recovery time in adjusting to their grief than their spouse. Marital closeness, greater social intimacy and being able to communicate openly with their spouse/partner about their grief resulted in less negative grief reaction and higher marital satisfaction. Studies that have examined the differences in bereaved parents coping with grief have focused on psychological distress or differences in communication. Research studies that describe differences in grief reaction between mothers and fathers who have used spirituality as a coping strategy have not been reported.

Influence of Race/Ethnicity and bereavement

Culture, race/ethnicity and religious beliefs influence an individual's response to death and grief. They influence their grief reaction to the death of their loved one and their perception of the afterlife (Kongnetima, Lai, & Berg, 2008). Doran and Hansen (2006) explored the ways that Mexican-American families maintained a bond with their deceased child. Semi-structured interviews were conducted which allowed parents to describe their grief experience. The families remained connected to their deceased children in a variety of ways. Bereaved parents reported having ongoing dreams where they would see and talk with their child. Sensing the deceased child's presence and believing that the child is a guardian angel for the family were other ways that the family remained connected to the child. One mother described how her children would serve the deceased brother tea during their daily tea party play game. Bereaved parents often

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reminisced through storytelling about their last interaction with the child before he or she died. Keepsakes and cherished objects such as toys, blankets and clothes were frequently unpacked, washed and repacked, or slept with as a reminder of their child.

Doran and Hansen (2006) found that spiritual and religious beliefs were an additional source of comfort for the families. Believing that their child is in heaven and that they will be reunited with their deceased child later in life provided additional consolation to all the bereaved parents. One family hung the Virgin of Guadalupe over the deceased child's bedroom door to provide protection for him in the afterlife. Ongoing rituals that connected and honored the deceased child were maintained by the families. They included visiting the grave and requesting special mass to be said on the birth and anniversaries of their child's death.

Neighborhood religious Day of the Dead celebrations were held annually. On this day some families prepared and ate the deceased child's favorite meal which they described symbolic of eating with their child. One mother stated that she placed a special type of flower, believed to attract the spirit to the dead into the house, to try to get her son to visit them. The deceased parents described these rituals as comforting. Photographs of the deceased child would be placed on an altar and prominently displayed in the homes. The altar was elaborately decorated, with the child's picture being surrounded by religious figures, candles and flowers. This ritual served as a constant reminder of the child which the family expressed as keeping the deceased child close to them (Doran & Hansen, 2006).

Spiritual coping strategies are reported as being effective in minimizing the grief reaction associated with pregnancy loss. Van and Meleis (2003) using semi-structured

interviews explored the coping strategies used by 20 African-American mothers following involuntary pregnancy loss. The average age of the bereaved mothers was 32 years; 60% were married/partnered, college educated, and employed; 45% reported incomes ranging from $50,000 – 99,000, and 70% were Christians.

Having supportive family and friends and talking to others with similar experience were described as being very helpful. The mothers who held religious beliefs identified prayer and asking God for strength as being very important in coping with their grief. Praying frequently provided them with peace and guidance. Bereaved mothers who believed that their sins resulted in a miscarriage/stillbirth or fetal death used prayer to apologize to God for the sins, asked for forgiveness and assistance in the provision of a positive outcome with future pregnancies. Maintaining or developing a relationship with God was identified as being very important. Believing in a God who was their protector and their source of strength, who does things for a reason and who has the ability to resolve their problems was described as comforting for these bereaved mothers (Van & Meleis, 2003).

Meditation was an additional spiritual coping strategy used by bereaved mothers. Looking internally and connecting to self was described as a way of gaining inner strength to determine how best to cope with their loss and to evoke peace and healing. The time spent looking inward was described by one mother as sitting quietly, talking to herself, reflecting, and searching for understanding about the events surrounding the death. It was also a time used to try to forgive herself for not doing more (Van & Meleis, 2003).

Smith (2001) in a qualitative exploratory study examined the importance of religious beliefs in bereaved African-American daughters to provide meaning and ways of coping with the loss of their elderly mothers. The majority of participants believed in God or a higher power that came down and carried their mother to heaven and that she is in God's hands who is taking care of her. This provided comfort to the daughters of the deceased because they believe their mother is in a better place, is free of pain and suffering, and is reunited with other family members who had died. It was also believed that communication with their mothers was ongoing because the death occurred with the body, but the spirit lived on; they believe in an after-life which, if they are good in this life, will allow for later reunion with their mothers.

In summary, the research have identified religious/spiritual practices of different race/ethnic groups as being very important in helping with the resolution of the grieving process. Rituals across race/ethnic and religious/spiritual groups are carried out to provide comfort to the bereaved and in remembrance of the deceased. Religious/spiritual rituals also serve to help the bereaved family cope with the loss, provide emotional peace and comfort against the pain that accompanies the loss, and provide continued connection with the deceased. Cultures that embrace a religious background view death as the end of a physical presence, but it does not preclude a sense of connectedness (Harrison, Khan, & Hsu, 2005). Bereaved families maintain ties to the deceased in a variety of ways including remembrance of the occasion of death through dreams, conversations, mass and other rituals. Studies on the influence of race/ethnicity on bereavement in the neonatal/ pediatric population were not identified.

Summary

The highly technologic and fast-paced environment of the NICU/PICU is often overwhelming, frightening and extremely stressful to parents. Parents are faced with numerous decisions regarding the care that their critically ill infants/children receive including the decision to limit/withdraw life support. It is clear from the literature that when death is imminent in the NICU/PICU bereaved parents are often active participants in their infant's/child's care prior to and immediately after the death had occurred. Being able to perform certain rituals, for example having the infant/child baptized before death or receiving last rites, and having a designated space where other family members can be present and say good-bye before the infant/child died are important in helping bereaved parents cope emotionally with their loss (Brosig et al., 2007; Kavanaugh et al., 2005; Meert et al., 2009; Meyer et al., 2006).

The stressors created by the death of a child in the NICU/PICU often result in the manifestation of emotional and physical symptoms by bereaved parents. Grieving parents experience emotional, physical and social changes. Emotionally bereaved parents exhibit signs of anxiety and depression, anger, blame, guilt, loss of control and disorganized thought processes. Physical symptoms of health problems and behavioral changes can result in loss of appetite, changes in sleep patterns, headaches, muscular pain, fatigue, and gastrointestinal changes such as nausea and vomiting. Socially, parental grief is associated with feelings of emptiness, loneliness, and yearning. These feelings have the potential to threaten inner self especially if they become focused on self-blame and perceive themselves as failing to protect their child from harm (Barrera et al., 2009; Hagemeister & Rosenblatt, 1997; Lohan & Murphy 2005-2006; Meert et al., 2005).

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Parents may also rely on alcohol or drugs to relieve their grief (Laakso & Ilmonen, 2001; Vance et al., 2002).

The cause of the infant's/child's death by sudden or expected illness and the negative feelings associated with the death may affect bereaved parents' mental health status. Bereaved parents whose infant/child had died suddenly or violently often experience severe psychological distress including more episodes of depression and physical complaints (Dyregrov et al., 2003; Murphy et al., 2003; Seguin et al., 1995). Bereaved parents whose only child died appeared to have more difficulty in adjusting to the death and experience higher incidence of complicated grief reactions than bereaved parents with surviving children (Dyregrov et al., 2003; Barrera et. al., 2007).

The grief reactions associated with the death of a child also may (or often) affect the spouse/partner relationship. Communication was identified as a critical component in helping bereaved couples cope with their grief. It was often assumed that the stress associated with losing a child increases the risk of bereaved couple's separating or divorcing. However, research identifies this event as multifactoral and has found other factors that may disrupt bereaved parents' marriages. These include poor communication, especially shortly after the infant's/child's death and not feeling supported by their partner especially if one partner blames the other for the death. Having a close supportive relationship and being able to share their feelings shortly after the death of the infant/child were some of the factors that were helpful in minimizing marital discord (Armentrout, 2009; Kamm & Vandenburg, 2001; Lang et al., 1996). However, as most of the studies of bereaved parents' grief reaction were conducted more than 14 years ago, current research is also needed to determine if these older findings hold true, as gender

roles have changed; fathers have become more involved in child care and couples appear to be more open in the expression of their feelings.

Stressful events or life crises have the potential to challenge a person's sense of identity. Depending on the circumstances surrounding the infant's or child's death, parental grief can be viewed as a positive experience with personal growth. (Amentrout, 2007; Brosig et al., 2007; Laakso & Paunonen-Ilmonen, 2001). Their perspectives and values on life also change and this period is described as a transition in the lives of bereaved parents. Parents emerge from their grief experience transformed into a new role. This includes participation in events such as walkathons to support the diagnosis that caused the death of their child, setting up foundations to provide monetary support that benefits others and also to remember their deceased child, facilitating bereaved parents support groups, and ministering to other bereaved families (Amentrout, 2007; Klass, 1997; Laakso & Paunonen-Ilmonen, 2001; Meert et al., 2005; Woodgate, 2006).

Studies have shown that spirituality plays an important role in coping with stress. Religious and spiritual coping strategies are resources that can be used effectively in times of crisis or stressful daily life events to reduce the physical and psychological symptoms that the stressor creates in the individual. Spiritual coping strategies are also useful in buffering the effects of the stressful event by instilling hope, providing comfort and strength, and bringing meaning and purpose to the crisis event. As evident in the research studies, spiritual beliefs and practices are used by individuals to mitigate the effect of stress on their mental health by reducing anxiety and symptoms of depression, increasing their self-esteem, providing purpose and meaning to their lives and instilling hope.

Recognizing the emotional needs of parents during this period of crisis in their lives was found important in many research studies, with spirituality being identified as an important coping strategy. For many parents, spirituality assisted them in relieving their emotional pain and gave meaning to their child's death. However there are several limitations with the research studies that have explored spirituality as a coping strategy for bereaved parents. The majority of participants have been Caucasian, college educated and of the Christian faith, leaving a gap in knowledge about parents from other racial/ethnic groups or other religions. Differences in using spirituality as a coping strategy based on the participant's socio-economic status were rarely addressed. Current studies that examine differences in gender use of spirituality to cope with traumatic/stressful life events are needed.

Issues and gaps in the research

There are very few studies on the use of spirituality as a coping strategy by bereaved parents, gender differences and grief across racial/ethnic groups for deaths that have occurred in the neonatal and pediatric intensive care units. Many of the grief studies are qualitative that provide valuable insight into parents' emotions following the loss of a child but the quantitative, longitudinal studies that examine parental grief over time are lacking. Bereaved parents have identified spirituality as being very important in coping with their grief but there is very limited systematic study on the use of spirituality as a coping strategy in the grieving process especially over time. Anderson, Marwit, and Vandenberg (2005) identified the need for more studies that compare religious coping among bereaved parents.

The concept of spirituality has posed numerous obstacles as to its definition and meaning. Description of spirituality in the literature includes interconnectedness to self, others, and the environment (Burkhardt, 1989), and making meaning of one's situation that transcends the self towards empowerment (Reed, 1991). McSherry and Cash (2004) suggested that clarification of spirituality within a theoretical framework could lend greater clarification to spirituality versus the traditional approach to defining spirituality through concept analysis. Hill, et al. (2000) suggests that individualized spirituality is a personal journey which is consciously undertaken by the individual to find what or who is sacred to them. Description of the sacred includes a divine being, object or principle that has the ability to evoke a personal transformation.

Difficulties have arisen in understanding the meaning of spirituality and religiosity (Burkhardt & Nagi-Jacobson, 1989; Hill et al., 2000; McSherry & Cash, 2004; Peri, 1995). This may have occurred because the earlier definition of spirituality was rooted in the Judeo-Christian religion and systems of faith (Schneiders, 2003). The newer understanding of spirituality has emerged from the phenomenologic qualitative studies that have identified spirituality as having a sense of meaning and purpose, and a connectedness with the environment (McSherry & Cash, 2004). McSherry, Cash, and Ross (2004) have suggested that individuals will utilize their values and world-views to create their own interpretation and understanding of spirituality.

The difficulty surrounding the definition of spirituality is related to the interpretation of the concept. The literature emphasizes the difficulty in creating a world-view of spirituality is directly related to individualized interpretation, the elusiveness in the terminology such as transcendence, and the difficulty, for many, in separating

spirituality from religious practices. The definition of spirituality could remain elusive because the defining characteristics of the term may not be transferable or universally recognized (Cash & McSherry, 2004).

Hill et al., (2000) describe individuals whose spirituality is separate from religion as less likely to hold Christian beliefs, attend church or pray. They are often individuals who are engaged in group experiences that involve personal growth, believe in a connection with the force of the universe, hold non-traditional new-age beliefs or claim to have had a mystical experience. However, what is considered vital to both spirituality and religion is a sense/search of the sacred, as identified by the individual and is held in respect, reverence and devotion.

Berry (2005) in critiquing several research studies on religion and health found that the difficulty in defining spirituality and the variety of definitions among authors makes it difficult to conceptualize and operationalize spirituality/religion. The instruments used to measure the complex concept of religion/spirituality are often limited in the questions being asked and this makes it difficult to interpret the results of a highly complex construct measured with an oversimplified tool.

It will always be difficult to use empirical data to support spirituality and or religious studies because both these concepts are highly individualized and deal with human emotions. The qualitative studies provide a clearer interpretation of the meaning of spirituality and religiosity as it describes the lived experiences of each person. The results from the qualitative studies suggest that the definition of spirituality is individualized and therefore a common definition may not be attainable.

Gaps in the study of spiritual coping strategies and bereaved parents were clearly identified. All the studies that examined spirituality as a coping strategy have focused on religious coping and neglected the non-religious spiritual strategies. The use of spirituality as a coping strategy by bereaved parents and its impact on their psychological adjustment was not identified. This study will begin to address those gaps.

CHAPTER III

METHODS

This study builds on a longitudinal study being conducted by Dr. JoAnne Youngblut and Dr. Dorothy Brooten by testing the relationships between bereaved parents' use of spiritual coping strategies and parent grief, personal growth and mental health, and identifying differences in the use of spiritual coping strategies among racial/ethnic and religious groups for mother/ father dyads and across time at one and three months post death. Data on parent coping strategies (spirituality), grief (despair, detachment, and disorganization), mental health (depression and post-traumatic stress disorder), and personal growth were collected at one and three months post-death of an infant/child in the neonatal intensive care unit/pediatric intensive care unit.

Abstract of larger study

The parent study entitled, "Death in the NICU/PICU: Parent and Family Functioning," is a longitudinal repeated measures design study that uses both quantitative and qualitative data collection methods and analysis. Quantitative data were collected at 1 month (T1), 3 months (T2), 6 months (T3), and 13 months (T4) after the death of the infant/child. Data on parent supportive resources (religiosity, social support), parent grief (despair, detachment, disorganization), parent mental health (depression, PTSD), personal growth, and family functioning (mother-father couple relationship, parent-surviving child relationship, and family functioning) were collected at all time points. Data on characteristics of the situation surrounding the infant's/child's death were collected only at T1. Full parent demographic data were obtained at T1; demographic data that could change were collected at each time point. Infant/child hospital record data

were collected after the T1 interview. Data were collected from both parents whenever possible. The Hogan Grief Reaction Checklist (HGRC), Beck Depression Inventory (BDI-II), Impact of Event Scale-Revised (IES-R), Inventory of Social Support (ISS), the Multidimensional Scale of Perceived Social Support (MSPSS), Family Adaptability and Cohesion Evaluation Scale (FACES II), Parenting Stress Index (PSI) and Dyadic Adjustment Scale (DAS) were used to collect the quantitative data. Interviews were conducted in the language (Spanish or English) selected by the parent with bilingual data collectors.

Setting and Sample

Mothers (n = 176) and fathers (n = 73) whose infant or child died in the NICU/PICU at Broward General Medical Center (BGMH), Miami Children's Hospital (MCH), Jackson Memorial Hospital/University of Miami Medical Center (JMH/UMMC) and Joe Di Maggio Children's Hospital (JDCH) participated in the study. The four NICUs are level III referral facilities that care for extremely low birth weight infants and those infants requiring surgical procedures. The four PICUs are trauma and referral centers. Both JMH/UMMC and MCH are organ transplant centers. Parents were also recruited through state death records obtained from the Office of Vital Statistics, Florida Department of Health.

Inclusion criteria

For parents to be included in the study, their deceased newborns had to have been from a singleton pregnancy, born alive and lived for more than 2 hours in the NICU. Infants/ children who died in the PICU had to have been 18 years old or younger and a

patient in the PICU for at least 2 hours. All parents understood spoken English or Spanish. Parents who could not read English or Spanish had the questions read to them.

Exclusion criteria

Exclusion criteria included multiple gestation pregnancy if the deceased was a newborn, a child who was in a foster home before being hospitalized and/or whose injuries were suspected to be due to child abuse to eliminate extreme family conditions, and death of a parent in the illness/injury event, such as a motor vehicle crashes, because the surviving parent would be dealing with the death of a spouse and a child simultaneously. Families were not excluded based on race/ethnicity.

Dissertation

Sample

The convenience sample consists of 119 families, 67 with an infant who died in the NICU and 52 with a child who died in the PICU, from the larger study. No additional inclusion/exclusion criteria beyond those in the parent grant were necessary for this study.

Procedure

This study was approved with the larger study by the Institutional Review Board (IRB) at Florida International University and all recruitment facilities prior to recruitment of study participants. Eligible families were identified by the clinical co-investigators of each unit. The project director (PD) called these co-investigators each week to see whether there were any deaths in their units during the past week. The PD sent a letter to each family (Spanish on one side, English on the other) describing the study. At 3 to 4 weeks post-death, a research assistant (RA) called the family, screened for inclusion and

exclusion criteria, described the study to them further with a verbatim script provided in both Spanish and English, answered any questions they had, obtained their verbal consent to participate and scheduled the T1 interview. All interviews were conducted in the family's home or another place of their choosing at a time that was convenient for them.

Parents were told that the purpose of the study was to learn about the experience of losing an infant or child in the intensive care unit and the effects it might have for the parent and the family during the first year after the infant's or child's death. They were told that there would be four interviews – at 1, 3, 6, and 13 months after the infant's or child's death and that these would take about 1.5 hours each. Only the data from 1 month (T1) and 3 months (T2) were used in this study.

Most of the RAs were bilingual and fluent in Spanish and English. They asked each parent to indicate which language they preferred for the questionnaires and the qualitative interview. At the T1 home visit, and before the interview, the RA reminded the parent(s) about the study using the text from the letter, answered any questions, and obtained written consent from the parent(s) in their preferred language for their own participation and for abstraction of data from the infant's or child's chart. At T1 and T2, parents completed the family demographic data form together in interview format. Each parent also completed the individual demographic data form, HGRC, BDI-II, IES-R, and the SCS among others separately. Each parent received a $25 gift card for a major department store for each of the completed interviews, for a possible total of $200 for families where both parents participated in all four quantitative interviews.

Research assistants were trained to look for signs that the parent was in need of immediate psychological attention and to respond by obtaining help for the parent before

they left the family's home. The RAs had a list of mental health providers for Miami-Dade and Broward counties (and other counties when needed) that they could contact to obtain help. In addition, at T1 all parents were provided with a list of resources that could help them with their grief. At each team meeting, bereaved parents' responses on the BDI-II and the IES-R were reviewed and the RA's impression of the parents was discussed. Parents who were identified as being at risk were encouraged to seek psychological assistance.

The need for confidentiality during data collection, coding, and entry was stressed to all project personnel during the initial training session and was reviewed periodically throughout the study. All of the investigators and study personnel completed the required human subjects research training.

Dependent Variables Measures

Hogan Grief Reaction Checklist (HGRC) was used to measure the bereaved parents' grief. The 61-item HGRC contains 6 subscales: Despair (13 items), Detachment (8 items), Disorganization (18 items), Panic Behavior (14 items), Blame and Anger (7 items), and Personal Growth (11 items). Although parents responded to all 61 items, the Despair, Detachment and Disorganization subscales were used in the analysis. Respondents rated each item on a 5-point Likert scale ranging from 1 "Does not describe me at all" to 5 "Describes me very well" with higher scores indicating higher grief symptoms over the past two weeks (Hogan, Greenfield, & Schmidt, 2001).

Hogan, et al. (2001) developed the items on the HGRC from the content analysis of a qualitative study with a sample of bereaved adults. Confirmatory factor analysis and correlations between the HGRC subscales and subscale scores on the Texas Revised

Inventory of Grief, the Impact of Event Scale, and the Grief Inventory scale supported its construct validity (Hogan, et al., 2001).

Hogan et al. (2001) reported Cronbach's alpha coefficient for the 3 subscales used in the current study as: Despair = .89, Detachment = .87, and Disorganization = .84. Hogan, et al.'s four week test-retest reliability of the HGRC revealed strong cross-time correlations on these 3 subscales: Despair, r = .84; Detachment, r = .77; and Disorganization, r = .85 supporting the stability reliability of the subscales. Cronbach's alphas in this study were: Despair = .92 and .93; Detachment = .87 and .89; and Disorganization = .84 and .86 for mothers at T1 and T2, respectively; and Despair = .89 and .88; Detachment = .79 and .85; and Disorganization .79 and .87 for fathers at T1 and T2, respectively.

Personal Growth was measured with the HGRC personal growth subscale described by Hogan et al. (2001) as becoming more caring, understanding and optimistic. Hogan et al. (2001) reported a Cronbach's alpha coefficient of .82 and a test-retest correlation of .81. The Cronbach's alpha in this study was: .77 at T1 and .88 at T2 for mothers and .83 at T1 and .89 at T2 for fathers.

Depression was measured using the Beck Depression Inventory (BDI-II) developed and revised by Beck, Steer and Brown (1996). Respondents rated each of the 21 items on a scale from 0 to 3 with higher scores indicating greater severity of depressive symptoms. Beck, et al. (1996) reported an internal consistency reliability of .92 for outpatient adults with psychiatric disorders and .93 for college students. The one week test-retest reliability of the BDI-II for outpatient adults yielded a correlation of .93 demonstrating strong stability of the scale from one testing time to another.

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The BDI-II has been used extensively with diverse populations exhibiting different types of diagnoses. In a study by Arnau, Meagher, Norris, and Bramson (2001), internal consistency reliability of the scale was .94 in a sample of 340 medical patients, predominately White (69.4%), who attended a primary health care clinic. A strong correlation of .65 was found between the mental health subscale of the Health and Functioning Perception scale and the BDI-II which supported its construct validity.

Similar findings were reported by Penley, Wiebe, and Nwosu (2003) who evaluated the Spanish version of the BDI-II with 122 Mexican American patients undergoing hemodialysis treatment. Internal consistency reliability was .92. A subsample of 23 bilingual patients completed both the English and Spanish BDI-II. Their English and Spanish scores were strongly correlated, r = .70. Gary and Yarandi (2004) reported a strong internal consistency reliability of .91 on the BDI-II in a sample of 206 southern rural African-American women. Internal consistency in this study was .90 at T1 and .93 at T2 for mothers and .90 at T1 and .89 at T2 for fathers.

Post-Traumatic Stress Disorder was measured with the Impact of Events Scale-Revised (IES-R). The 22-item IES-R contains 3 subscales: Intrusive thoughts (where the individual re-experiences the trauma), Avoidance (reminder of the trauma), and Hyperarousal (persistent increased arousal). Respondents rated each item on a scale from 0 "not at all" to 4 "extremely" to indicate how distressing each item had been for them during the past two weeks with respect to the death of their infant/child.

The IES-R has been used widely in diverse populations who have experienced a variety of traumatic life events. Beck et al. (2008), in a sample of 182 individuals following a motor vehicle crash, reported internal consistency reliabilities of .95 for the

total scale and .90 for Intrusion; .86 for Avoidance and .85 for Hyperarousal subscales. Confirmatory factor analysis of the IES-R supported the fit of the three factor model. Beck, et al. (2008) reported that the IES-R subscales were highly correlated with the similar subscales of the original IES scale, with the Post-Traumatic Stress Disorder Symptom Scale-Self Report and the State Trait Anxiety Inventory supporting the revised version's construct validity. Internal consistencies in this study for mothers were .90 and .91 for the total scale; .86 and .86 Intrusion; .79 and .76 Avoidance, and .76 and .83 Hyperarousal at T1 and T2, respectively. Internal consistencies for Fathers were: .91 and .89 for the total scale; .80 and .79 Intrusion; .82 and .80 Avoidance, and .71 and .73 Hyperarousal at T1 and T2, respectively.

Independent Variable Measures

Spiritual Coping was measured using the Spiritual Coping Strategies (SCS) scale (Baldacchino & Buhagiar, 2003). The 20-item instrument contains two subscales: Religious coping strategies (9 items) and Spiritual coping strategies (11 items). Respondents rated each item on a 4-point scale ranging from 0 "never used" to 3 "used often" with higher scores indicating greater use of spiritual and religious coping strategies. Baldacchino and Buhagiar reported Cronbach's alphas of .82 for the religious coping strategies subscale and .74 for the spiritual coping strategies subscale and test-retest reliability of r = .47 after a 3 week interval. They also reported correlations of .40 between the spiritual coping strategies scale with the well-established Spiritual Well Being instrument, supporting construct validity of the SCS and the subscales.

Hawthorne, Youngblut, and Brooten (2011) conducted a pilot study to evaluate the psychometric properties of the newly translated Spanish version of the SCS scale. A

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convenience sample of 50 bilingual adults who had experienced a stressful event completed the English and Spanish version of the SCS; 25 of these bilingual adults completed the English and Spanish versions of the SCS again 2 weeks later for test-retest reliability. Internal consistency reliabilities were .75 for the religious coping strategies subscale and .80 for the spiritual coping strategies subscale. The test-retest reliability was $r = .84$ for the English religious coping strategies subscale and $r = .61$ for the Spanish religious subscale. For the English spiritual coping strategies subscale $r = .78$ and .77 for the Spanish spiritual coping strategies subscale, demonstrating stability of the subscale across time. Internal consistencies in this study were: .88 (both T1 and T2) for religious coping and .80 (T1) and .82 (T2) for spiritual coping for mothers and .90 (T1) and .87 (T2) for religious coping and .80 (both T1and T2) for fathers

Race/Ethnicity was categorized as "White, non-Hispanic," "Black non-Hispanic," or "Hispanic/Latino(a)" based on parent self-identified race (White, Black, Asian, Native American) and Ethnicity (Hispanic-yes/no).

Religion indicated by the parent was categorized as Protestant, Catholic, None (Atheists, Agnostics) and Other (Jewish, Buddhist, Muslim, Santeria/Espiritismo, Mormon and Rastafarian).

Demographic information

Family demographics collected at one month (T1) included the number of parents living in the home, marital status, years living together, annual family income, number and ages of surviving children in the family and age of the deceased infant or child at death. Individual parent demographics included the parent's age, race/ethnicity, education, employment status, and occupation. Data about the infant's or child's

hospitalization and medical history were collected from the hospital record. Age of the infant or child at death was obtained from the parents and converted to months. Marital status was dichotomized as "partnered" (parent is married or living with adult intimate partner) or not partnered.

Data Management and Analysis

One set of instruments was used for each participant (mother, father) and time point (one month and three months post-death). All form pages were labeled with the family's unique identification code and the time points. The RAs maintained a checklist of necessary forms to verify packet completeness before administering the questionnaires. The RAs reviewed all forms for completeness before ending the interview session. Data files were identified by numbers only. A master log book included the assigned family identification code, dates and times each family was contacted, date and time each interview was completed and by whom.

Strategies for maintaining data integrity during coding and entering included measures to assure accuracy of the database. Data packets had two levels of coding. First-level coding by the Principal Investigator (PI) of this study or a RA consisted of placing missing codes where respondents chose not to respond and assign numbers to responses for open-ended items. Second-level coding by the PD, the PI of this study or a RA occurred at the time of data entry and served to increase the accuracy in decisions made during first-level coding. All decisions made during coding were recorded in the codebook for consistency in decision-making. The codebook was updated frequently. Data were entered into Statistical Package for Social Sciences (SPSS) separately by two different RAs. Means and standard deviations were run for each variable in both data

entry file and compared to identify entry errors. All discrepancies identified were

resolved by referring to the raw data and the codebook.

CHAPTER IV

RESULTS

This research included 167 bereaved parents of 119 deceased infants/children who

participated in the larger longitudinal study conducted by Drs. Youngblut and Brooten.

The purpose of the research was to: 1) describe differences in bereaved parents' use of

spiritual coping strategies across racial/ethnic and religious groups, mother/father dyads

and time at one and three months after the infant's or child's death in the neonatal

intensive care unit (NICU) or pediatric intensive care unit (PICU) and 2) test the

relationship between spiritual coping strategies and grief, mental health, and personal

growth for mothers and fathers at one and three months post death. Parents of children

who died in the NICU or PICU at one of the four level III tertiary hospitals were

recruited. Data collected in families' homes were demographic information and responses

to questionnaires (HGRC, BDI-II, IES-R and SCS). This chapter presents the sample

characteristics and quantitative findings for each research question.

Description of the sample

The 167 bereaved parents included 116 mothers and 51 fathers (30 couples). The

mothers' ages ranged from 18-50 years and fathers' ages ranged from 17-58 years. The

majority of mothers were Black non-Hispanic and fathers, Hispanic. Most mothers and

fathers were married or living with a partner, had graduated from high school were

employed and were of the lower to middle income socio-economic status. More fathers

held college degrees. More mothers than fathers rated religion as being very important to

them but more fathers than mothers reported spirituality as being very important. Most

reported Protestant as their religious affiliation (table 1).

Table 1

Description of parents

Characteristic		Mothers	Fathers
		(n = 116)	(n = 51)
Age	[M (SD)]	31.1 (7.73)	36.8 (9.32)
Race/ethnicity [n (%)]	White	22 (19%)	14 (28%)
	Black	51 (44%)	16 (31%)
	Hispanic	43 (37%)	21 (41%)
Education [n (%)]	< High school	13 (11%)	7 (14%)
	High school graduate	42 (36%)	13 (25%)
	Some college	26 (23%)	12 (24%)
	College degree	35 (30%)	19 (37%)
Partnered? [n (%)]	Yes	85 (73%)	43 (84%)
Employed? [n (%)]	Yes	42 (47%)	32 (78%)
Religion [n (%)]	Protestant	51(57%	23 (56%)
	Catholic	24 (27%)	7 (17%)
	Jewish	4 (4.5)	1 (2%)
	Mormon	1 (1%)	1 (2%)
	Santeria	1 (1%)	0 (0%)
	Rastafarian	0 (0%)	1 (2%)
	None	8 (9%)	8 (21%)
Importance of	[M (SD)]	7.85 (3.00)	7.28 (3.39)

Characteristic		Mothers (n = 116)	Fathers (n = 51)
Religion			
Importance of Spirituality	[M (SD)]	7.21 (3.09)	7.90 (2.59)

More infants/children in the sample died in the NICU than the PICU. Most of the deaths were males and both groups had stayed in the NICU/PICU for approximately one month. Admission diagnosis included prematurity, congenital anomalies, respiratory disease, sepsis and neurological conditions. Mothers were initially interviewed at a mean of 7.7 weeks ($SD = 3.5$) and fathers, 7.2 weeks ($SD = 2.98$) after the death of their child/infant. The second interview was conducted at an average of 10.8 weeks ($SD = 4.90$) for mothers and 12.9 weeks ($SD = 1.72$) for fathers.

Table 2

Description of deceased child and family

Characteristic	NICU	PICU	Statistic
	($\underline{n}$ = 67)	($\underline{n}$ = 52)	
Child's age in months [$\underline{M}$ (SD)]	3.9 (14.13)	67.5 (68.02)	t = 6.20**
Child's sex [$\underline{n}$ (%)]			X^2 = 1.65
Female	27(38.6%)	28 (50.0%)	
Male	43 (61.4%)	28 (50.0%)	
Admission Diagnosis [$\underline{n}$ (%)]			X^2 =94.80**
Neurologic conditions	2 (1.6%)	8 (6.4%)	
Prematurity	25 (20.5%)	0 (0%)	
Respiratory conditions	17 (14.0%)	7(5.7%)	
Congenital anomalies	11 (8.9%)	5 (4.0%)	
Sepsis	4 (3.2%)	12 (9.7%)	
Days in ICU before death [$\underline{M}$ (SD)]	32.7 (46.55)	28.9 (77.75)	t = 5.50**
Family Income [$\underline{n}$ (%)]			X^2 = 3.27
< $3,000	4 (4.3%)	0 (0.0%)	
$3,000 – 29,999	19 (20.4%)	14 (15%)	
$30,000 – 49,999	13 (14.0%)	9 (9.7%)	
$\geq$ $50,000	18 (19.4%)	16 (17.2%)	

* p<.05   ** p<.01

Differences in the use of Spiritual Coping Strategies

Research Question 1: Are there differences in the use of spiritual coping strategies across racial/ethnic groups, religion groups, mother/father dyads and time at 1 and 3 months post-death?

Hypothesis 1. *There will be differences in use of the SCS for each of the specified comparisons.*

One-way ANOVAs with Scheffe tests for post-hoc comparisons were used to test differences in means by racial/ethnic and religion groups on use of religious and spiritual coping strategies at T1 and T2 for bereaved mothers and fathers. For bereaved mothers at T1, racial/ethnic group differences in use of religious and spiritual coping strategies were not statistically significant. Scheffe Post-Hoc tests at T2 showed that White non-Hispanic mothers used significantly less religious coping strategies than Black non- Hispanic mothers.

Significant differences in the use of religious coping strategies but not spiritual coping strategies were found at T1 and T2 by religion group. Scheffe Post-Hoc tests showed that Protestant mothers' use of religious coping strategies was significantly higher than mothers in the no religion and other groups. Catholic mothers' use of religious coping strategies also was higher than mothers in the no religion group (table 3).

Table 3

Differences in mothers' use of spiritual coping strategies by race/ethnicity and religion

Mothers' Groups	1 Month Post-death		3 Months Post-death	
	Religious Coping Strategies M (SD)	Spiritual Coping Strategies M (SD)	Religious Coping Strategies M (SD)	Spiritual Coping Strategies M (SD)
Racial/ethnic group	F = 2.84	F =.42	F = 5.09**	F = .42
Black non-Hispanic (n = 37)	18.7 (4.90)	25 (5.91)	18.1 (5.23)	23.8 (6.0)
White non-Hispanic (n = 16)	13.1 (8.01)	23.4 (4.86)	12.5 (7.84)	23.1 (5.90)
Hispanic (n = 36)	16.1 (10.23)	24.2 (6.34)	15.9 (7.73)	23.7 (6.24)
Religion group	F = 13.44**	F =1.19	F =16.76**	F = .96
Protestant (n = 47)	19.8 (6.82)[a]	25.3 (5.86)	18.5 (4.98)[a]	24.5 (6.40)
Catholic (n = 21)	15.4 (7.07)[b]	23.0 (6.14)	16.5 (6.71)[b]	23.0 (5.90)
Other[1] (n = 6)	11.0 (8.29)[a]	23.8 (4.79)	10 (8.58)[a]	24.7 (4.68)
None (n = 8)	4.8 (4.53)[ab]	22.14 (6.09)	4.1 (4.67)[ab]	20.8 (7.44)

[1]Other includes 4 Jewish, 1 Mormon, 1 Santeria

* p<.05 ** p<.01 Means with the same letters indicate statistically different groups.

Significant group differences in the use of spiritual coping strategies were found at T1, with Protestant fathers scoring higher than those in the other religion groups. Protestant and Catholic fathers' use of religious coping strategies was significantly higher than fathers in the no religion group at T1. At T2, differences in fathers' use of religious, but not spiritual, coping strategies was statistically significant, with Protestant fathers

scoring higher than those in the no religion group. Differences in fathers' use of religious

and spiritual coping strategies by racial/ethnic groups was not significant (table 4)

Table 4

Differences in fathers' use of spiritual coping strategies by race/ethnicity and religion

Fathers' Groups	1 Month Post-death		3 Months Post-death	
	Religious Coping Strategies M (SD)	Spiritual Coping Strategies M (SD)	Religious Coping Strategies M (SD)	Spiritual Coping Strategies M (SD)
Racial/ethnic group	$F = 1.91$	$F = .75$	$F = .32$	$F = 1.09$
Black non-Hispanic (n = 12)	14.4 (7.05)	22.8 (6.81)	14.6 (6.72)	21.8 (6.78)
White non-Hispanic (n = 12)	12.1 (8.07)	22.4 (6.75)	12.5 (8.02)	23.9 (5.25)
Hispanic (n = 17)	17.3 (6.55)	25.0 (5.30)	13.8 (6.76)	24.8 (5.85)
Religion group	$F = 6.35*$	$F = 3.34*$	$F = 4.46*$	$F = 1.57$
Protestant (n = 23)	17.57 (5.88)[a]	25 (5.83)[a]	16.0 (6.03)[a]	24.6 (6.54)
Catholic (n = 7)	16.6 (7.66)[b]	24.7 (5.47)	9.0 (4.64)	21.2 (6.08)
Other[1] (n = 3)	12.7 (6.11)	14.3 (4.04)[a]	13.5 (9.19)	17.7 (3.51)
None (n = 8)	6.8 (5.70)[ab]	22.3 (5.80)	8.3 (5.26)[a]	22.1 (4.79)

[1]Other for fathers includes 1 Jewish, 1 Mormon, 1 Rastafarian

* $p<.05$ ** $p<.01$ Means with the same letters indicate statistically different groups.

Paired samples t-tests were conducted to evaluate differences between mothers

and fathers religious and spiritual subscale scores at T1 and T2. Significant differences

were found between bereaved mothers' and fathers' religious, but not spiritual, coping

strategies scores at T1 and T2 with mothers having higher scores than fathers. At T2 differences between mothers and fathers spiritual coping strategies scores were also significant. There were no significant differences across time (T1 to T2) in the use of religious and spiritual coping strategies for mothers and fathers (table 5).

Research Question 2. What is the relationship between spiritual coping strategies and grief, personal growth, and mental health for mothers and fathers at 1 and 3 months post-death?

Hypothesis 2. *Parent grief, personal growth, depression, and PTSD will be related to their scores on the SCS at each time point.*

Pearson product-moment correlations were used to determine the relationships between the use of SCS subscales and grief (despair, detachment, disorganization), mental health (depression, PTSD) and personal growth for bereaved mothers and fathers at T1 and T2. Mothers' higher use of religious coping strategies was significantly related to higher personal growth and lower intrusive thoughts at T1 and to higher personal growth at T2. Mothers' higher use of spiritual coping strategies was significantly associated with lower levels of despair, detachment, depression, intrusive thoughts, and hyperarousal, and higher levels of personal growth at T1 and T2. At T2, mothers' higher use of spiritual coping strategies was significantly associated with lower total PTSD scores (table 6).

Table 5

Mother-father and cross time differences in use of spiritual coping strategies

	1 Month Post-death M (SD)	3 Months Post-death M (SD)	Paired t value
Mothers (n = 81)			
Religious Coping Strategies	16.5 (8.42)	15.9 (7.28)	t = .97
Spiritual Coping Strategies	24.2 (6.13)	23.9 (6.35)	t = .68
Fathers (n = 36)			
Religious Coping Strategies	14.2 (7.0)	13.1 (6.68)	t = 1.35
Spiritual Coping Strategies	23.2 (6.17)	22.9 (6.16)	t = .39
	Mothers (n = 30)	Fathers (n = 30)	
1 Month Post-Death			
Religious Coping Strategies [M(SD)]	15.9 (7.87)	13.8 (7.69)	t = 2.08*
Spiritual Coping Strategies [M (SD)]	24.2 (5.30)	22.8 (5.91)	t = 1.21
3 Months Post-Death			
Religious Coping Strategies [M (SD)]	15.8 (7.96)	12.9 (6.75)	t = 3.28*
Spiritual Coping Strategies [M (SD)]	24.6 (6.47)	22.5 (5.97)	t = 2.16*

* p<.05   ** p<.01

Table 6

Correlations of mothers' use of spiritual coping strategies with grief, personal growth and mental health at 1 and 3 months after the infant's/child's death

	1 Month Post-death		3 Months Post-death	
	Religious Coping Strategies	Spiritual Coping Strategies	Religious Coping Strategies	Spiritual Coping Strategies
	r	r	r	r
Grief Despair	-.18	-.53**	-.11	-.51**
Grief Detachment	-.19	-.55**	-.09	-.53**
Grief Disorganization	-.01	-.38**	.02	-.55**
Personal Growth	.41**	.51**	.37**	.64**
PTSD Intrusive Thoughts	-.22*	-.35**	-.08	-.32**
PTSD Avoidance	.03	-.11	-.08	-.19
PTSD Hyperarousal	-.04	-.31**	-.06	-.39**
PTSD Total Score	-.10	-.30**	-.08	-.35**
Depression	-.19	-.54**	-.14	-.55**

* $p<.05$ ** $p<.01$

Significant correlations between bereaved fathers' SCS and grief, personal growth, PTSD, and depression showed different patterns at T1 and T2. At T1, fathers' higher use of religious coping strategies was related to lower grief (detachment, despair and disorganization), intrusive thoughts, hyperarousal, and depression. However, at T2, fathers' higher use of religious coping strategies was related significantly only to personal

growth. Fathers' higher use of spiritual coping strategies was related to lower grief (detachment, despair, and disorganization), avoidance, hyperarousal, and depression at both T1 and T2, and to lower intrusive thoughts at T1. Fathers' higher use of spiritual coping strategies also was significantly related to greater personal growth at both time points (table 7).

Table 7

Correlations of fathers' use of spiritual coping strategies with grief, personal growth and mental health at one and three months after their infant's/child's death

	1 Month Post-death		3 Months Post-death	
	Religious Coping Strategies	Spiritual Coping Strategies	Religious Coping Strategies	Spiritual Coping Strategies
	r	r	r	r
Grief Despair	-.32**	-.47**	-.15	-.29*
Grief Detachment	-.26*	-.61**	-.10	-.35*
Grief Disorganization	-.25*	-.43**	-.10	-.23*
Personal Growth	.10	.51**	.31**	.49**
PTSD Intrusive Thoughts	-.25*	-.38*	-.17	-.10
PTSD Avoidance	-.02	-.27*	-.13	-.29*
PTSD Hyperarousal	-.23*	-.32**	-.06	-.27*
PTSD Total Score	-.12	-.29*	-.03	-.07
Depression	-.27*	-.46**	-.01	-.39**

* p<.05   ** p<.01

RQ# 3: Do these relationships hold true when race/ethnicity and religion are controlled?

Hypothesis 3. Relationships between the SCS and parent grief, depression, PTSD and personal growth will remain at each time point after controlling for race/ethnicity and religion.

Hierarchical multiple regression analysis was used to test if the SCS subscales (religious and spiritual coping strategies) significantly predicted levels of bereaved mothers' and fathers' grief (despair, detachment, disorganization), mental health (depression and PTSD) and personal growth at one and three months post death after controlling for race and religion. Analyses were conducted for each of the dependent variables (grief subscales [despair, detachment, disorganization], the BDI-II, IES-R, and personal growth) for mothers and fathers separately at T1 and T2. In the first set of regression analyses, race and religion were entered in block one as control variables and religious coping strategies subscale was entered in block two as the independent variable. In the second set of regression analyses, race and religion were entered in block one as control variables and spiritual coping strategies subscale was entered in block two as the independent variable.

Mothers' higher use of spiritual coping strategies predicted significantly lower symptoms of grief despair, detachment and disorganization at T1 and despair and detachment at T2. Hispanic mothers had greater grief detachment at T2, and Protestant mothers had higher disorganization at T1. However, their use of religious coping strategies did not have a significant influence at T1 or T2 on their grief despair, detachment and disorganization (table 8).

Table 8

Effects of mothers' use of spiritual coping strategies on grief at 1 and 3 months after their infant's/child's death

	Grief Despair		Grief Detachment		Grief Disorganization	
	1 Mo	3 Mo	1 Mo	3 Mo	1 Mo	3 Mo
	β	β	β	β	β	β
Black non-Hispanic[1]	.13	.07	.16	.21	-.24	-.02
Hispanic[1]	.18	.17	.23	.32	.01	.13
Protestant Religion[1]	.24	.28	.44	.67	.43	.44
Catholic Religion[1]	.23	.23	.39	.52	.23	.27
Other Religion[1]	.02	.02	.12	.25	.14	.21
Religious Coping	-.28	-.24	-.35	-.37	-.01	-.11
F	1.19	.69	1.84	1.8	.90	.55
Adj R^2	.01	.02	-.007	-.06	.06	-.04
Black non-Hispanic[1]	.12	.03	.14	.15	-.23	-.04
Hispanic[1]	.10	.10	.18	.33**	.04	.15
Protestant Religion[1]	.13	.21	.27	.47	.45**	.42
Catholic Religion[1]	.01	.12	.21	.30	.19	.22
Other Religion[1]	.01	.06	.09	.26	.15	.24
Spiritual Coping	-.55**	-.53**	-.58**	-.59**	-.41**	-.29
F	6.29**	4.90**	7.34**	7.51**	3.69**	.539

	Grief		Grief		Grief	
	Despair		Detachment		Disorganization	
	1 Mo	3 Mo	1 Mo	3 Mo	1 Mo	3 Mo
	β	β	β	β	β	β
Adj R²	.27	.23	.31	.33	.16	.04

[1]Scored yes = 1, no = 0. Suppressed groups are White non-Hispanic and no religion.

* p<.05   ** p<.01

Mothers' use of spiritual coping strategies predicted significantly lower symptoms of PTSD and depression and significantly higher personal growth at T1 and T2. However, Hispanic mothers had significantly higher PTSD at T1. Mothers' use of religious coping strategies had a significant positive influence on personal growth at T1 and T2 but not on their level of depression or PTSD (table 9).

Fathers' higher use of spiritual coping strategies predicted lower grief (despair, detachment and disorganization) at T1 but not T2. Religious coping strategies was not a significant predictor of bereaved fathers' grief (despair, detachment, disorganization), or personal growth at T1 or T2 (table 10).

Religious or spiritual coping strategies were not significant predictors of bereaved fathers' PTSD and depression, at T1 and T2 (table 11)

Table 9

Multiple regressions of mothers' mental health and personal growth.

	PTSD		Depression		Personal Growth	
	1 Mo	3 Mo	1 Mo	3 Mo	1 Mo	3 Mo
	β	β	β	β	β	β
Black non-Hispanic[1]	.25	.28	.09	.20	.04	.04
Hispanic[1]	.34	.31	.16	.22	-.12	-.04
Protestant Religion[1]	.11	.15	.25	.41	.12	.10
Catholic Religion[1]	.04	.11	.21	.30	-.04	-.04
Other Religion[1]	.04	.02	.11	.13	-.08	.05
Religious Coping	-.17	-.20	-.27	-.34	.34**	.33**
F	1.18	1.16	.84	1.15	4.17**	2.53**
Adj R^2	.01	.01	-.01	.01	.18	.10
Black non-Hispanic[1]	.25	.25	.09	.15	.04	.09
Hispanic[1]	.35**	.33	.18	.24	-.12	-.07
Protestant Religion[1]	.04	.07	.15	.26	.30	.23
Catholic Religion[1]	-.05	-.02	.08	.11	.13	.14
Other Religion[1]	.03	.03	.10	.15	-.04	.02
Spiritual Coping	-.33**	.37**	-.56**	-.59**	.46**	.62**
F	2.62**	2.90**	5.86**	6.61**	7.65**	10.74**
Adj R^2	.10	.13	.26	.30	.32	.43

[1]Scored yes = 1, no = 0. Suppressed groups are White non-Hispanic and no religion.

* $p<.05$ ** $p<.01$

Table 10

Multiple regressions of fathers' grief and personal growth

	Grief Despair		Grief Detachment		Grief Disorganization		Personal Growth	
	1 Mo	3Mo	1 Mo	3 Mo	1 Mo	3 Mo	1 Mo	3 Mo
	β	β	β	β	β	β	β	β
Black non-Hispanic[1]	.01	.27	.07	.19	-.06	-.08	-.11	-.23
Hispanic[1]	.31	.29	.13	.13	.13	.06	-.03	-.22
Protestant Religion[1]	-.17	-.25	-.18	-.04	-.14	.04	-.18	.08
Catholic Religion[1]	-.15	-.06	-.09	.04	.15	.18	-.04	-.04
Other Religion[1]	-.06	.12	.08	.44	.08	.31	-.12	-.04
Religious Coping	-.32	-.12	-.20	-.11	-.24	-.08	.02	.29
F	1.21	.86	.67	1.35	1.09	.84	.301	1.31
Adj R^2	.03	-.02	-.05	.06	.01	.03	-.13	.05
Black non-Hispanic[1]	-.06	.19	-.03	.12	-.12	-.13	-.05	-.11
Hispanic[1]	.34	.35	.19	.18	.16	.01	.-09	.14
Protestant Religion[1]	-.23	-.27	-.15	-.02	-.17	.03	.09	.13
Catholic Religion[1]	-.19	-.13	-.12	-.01	.11	.14	.05	.04
Other Religion[1]	-.26	.02	-.21	.35	-.13	.24	.01	.12
Spiritual Coping	-58**	-.28	-.69**	-.25	-.50**	-.19	.54	.46
F	3.06*	1.25	4.30**	1.81	2.45*	1.06	1.92	2.23
Adj R^2	.24	-.04	.34	.11	.18	.01	.13	.17

[1]Scored yes = 1, no = 0. * $p<.05$ ** $p<.01$

Table 11

Multiple regressions of fathers' mental health

	PTSD		Depression	
	1 Mo	3 Mo	1 Mo	3 Mo
	β	β	β	β
Black non-Hispanic[1]	-.09	.10	.02	.23
Hispanic[1]	.27	.16	-.20	-.16
Protestant Religion[1]	-.09	-.23	-.15	-.01
Catholic Religion[1]	-.13	-.10	.06	.06
Other Religion[1]	.04	.04	.02	.21
Religious Coping	-.22	-.02	-.25	-.02
F	.57	.22	.69	.61
Adj R^2	-.07	-.18	-.62	-.07
Black non-Hispanic[1]	-.13	.18	-.04	.14
Hispanic[1]	.30	.17	.23	-.09
Protestant Religion[1]	.05	-.23	-.18	.02
Catholic Religion[1]	-.16	-.11	.09	-.03
Other Religion[1]	-.14	.06	-.23	.10
Spiritual Coping	-.42	-.06	-.54	-.33
F	1.28	.24	2.00	1.26
Adj R^2	.04	-.17	.14	.04

[1]Scored yes = 1, no = 0. * $p<.05$ ** $p<.01$

CHAPTER V

DISCUSSION

In 2008 over 51,000 infants and children under the age of 18 died in the United States (Matthews et al., 2011) resulting in parents having to cope with the devastating death of their child. Children, according to Klass (1999), are perceived as an extension of their parents and provide a new social value and status to the role of parenting; therefore, the death of an infant/child profoundly affects bereaved parents emotionally and physically as the death represents the loss of a future. Parents describe the death of their infant/child as losing a part of themselves that they now have to learn to live without. Spirituality is one of the coping strategies that bereaved parents may choose to use when dealing with the death of their infant/child. Spirituality has the capability of acting as a source of support to alleviate the stress, to help them adapt to the loss by reducing their emotional and physical distress to heal their spirit, make sense of their experiences of suffering and to move forward with their life (Glass, 2007; Mosely, 1997; Rozario, 1997).

This study investigated differences in bereaved mothers' and fathers' use of spiritual coping strategies across race/ethnicity and religious groups at one month and three months after the death of their infant/child. This study also examined the relationship of spiritual coping strategies to grief, mental health and personal growth for bereaved mothers and fathers at one and three months after the death. Additionally, the relationship of religious and spiritual coping strategies to grief, mental health and personal growth was further examined when race/ethnicity and religion were controlled.

The significant findings related to each research question as well as the strength and limitations of the study will be discussed.

Discussion of Findings

One hundred and sixty-seven bereaved parents participated in the study. The mothers' average age was similar to fathers with a fairly equal representation across the races of Black non-Hispanic and Hispanic mothers and fathers. There were less White non-Hispanic fathers and mothers. The majority of mothers and fathers were partnered, had some college education, and were of low to middle income. More fathers than mothers were employed. The majority of mothers and fathers reported their religious affiliation as Protestant. An equal number of mothers and fathers reported having no religious affiliation.

RQ# 1) Are there differences in the use of spiritual coping strategies across race/ethnic groups, religious groups, mother/father dyads and time at 1 and 3 months post death? At one month (T1) use of religious and spiritual coping strategies for bereaved mothers and fathers of different race/ethnicity was very similar. The conceptual model of Hogan's grief theory (1996) hypothesizes that during the early phase of grieving the bereaved person experiences severe feelings of grief. It is possible that irrespective of parent's race and gender, at one month facing the reality of their infant's/child's death and being engulfed in an overwhelming feeling of loss and suffering, bereaved parents experience similar feelings of sadness, loneliness, and guilt. This finding would be consistent with Hogan's (1996) grief theory.

The few studies that have reported on bereaved African American women after pregnancy loss have identified similar patterns of grieving to Caucasian women. Both

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African-American and Caucasian bereaved mothers experience intense emotional feelings following the loss of the infant and create memories through photographs, memory boxes with their baby's identification bracelets and clothes that the baby had worn (Kavanaugh & Hershberger, 2005; Van & Meleis, 2002).

Black non-Hispanic mothers used more religious coping strategies at three months (T2) after the death of their infant/child than White non-Hispanic mothers. It could be that as the initial phase of intense grief begins to subside, more Blacks, who are considered to be more religious than Whites (Laurie & Neimeyer, 2008; Levine, Yoo, Aviv, Ewing, & Au, 2007), relied on religious rituals to cope with their grief. Laurie and Neimeyer (2008) sampled bereaved college students and found African-Americans to have a higher degree of religious belief, to use more religious and spiritual strategies and less professional services for coping with their loss than Whites. Further, DiMarco, Menke and McNamara (2001) found more bereaved White mothers attended and relied on support groups to cope with their grief than Black mothers following the death of their infant.

Differences were found for mothers and fathers who identified themselves as Protestant or Catholic and those of other religion groups as well as those who do not identify with any religious groups. This indicates that there are different religious coping practices used by Christians than those used by other religious groups. Additionally, parents who identified with the Christian faith, either Catholic or Protestant, used more religious practices to cope with their loss and bereaved parents with other or no religious affiliation relied on other coping strategies to deal with their loss.

Schneider (2003) suggests that Christians, whose spirituality is synonymous with their religion, have a strong belief in God related to the trinity (Father, Son and Holy Ghost) while other religion groups also have a religious affiliation, but not with the trinity. The non-religious groups do not identify with a personal God, choosing to have spiritual traditions such as communing with nature and the universe (Schneider, 2003).

In comparison, significant differences were not found with bereaved mothers' and fathers' use of spiritual coping strategies regardless of their religious affiliation. This suggests a commonality among bereaved parents use of non-religious coping strategies to cope with their loss irrespective of their religious affiliation. But Protestant and Catholic fathers and fathers with no religious affiliation used different spiritual coping strategies at T1 to cope with grief. For many people the concept of spirituality is synonymous with religion and perhaps for these fathers religiosity was viewed as their spirituality. Religious practices can include spirituality, but spirituality need not include a religious practice (Peri, 1995; Schneider, 2003).

Examination of bereaved mothers' and fathers' use of religious and spiritual coping strategies found that both mothers and fathers were consistent in their use of spiritual coping strategies at one month and again at three months to deal with the death of their child. There was higher use of religious coping by mothers than their spouse at one month and three months and also higher use of spiritual coping at three months. This demonstrated differences in coping styles between mothers and fathers. Research findings that identified the differences in coping styles between bereaved mothers and fathers found that fathers move through the grieving process faster and also begin to move forward with their lives earlier by engaging in activities such as returning to work

earlier than bereaved mothers after the death (Aho, et al, 2006; Armentrout, 2009). Differences in the use of coping styles for bereaved fathers can also include alcohol consumption. Vance et al. (2002) reported that fathers consumed more alcohol than mothers to cope with their grief.

Unlike religious coping strategies, spiritual coping strategies were effective in reducing mothers' symptoms of grief and mental health but bereaved fathers used more religious coping at one month. The use of the spiritual coping strategies was also effective for mothers and fathers in managing their symptoms of depression and PTSD (intrusive thoughts and hyperarousal) than the use of religious coping strategies.

Some of the non-religious strategies include maintaining relationship with friends/family, confiding in them, appreciating the arts and using reflection to identify their potential strengths (Schineider & Mannell, 2005). This suggests that bereaved parents valued the social support received from family and friends. Meditation and reflection, as stated by Schneider & Mannell (2006), are additional non-religious coping strategies that provide comfort and peace and also relieve loneliness. Moreover, Klass, (1999) described how bereaved parents can bring healing to their lives by using spiritual coping strategies not connected to religion. This includes reflection through journaling, meditation, reading inspirational writings, poetry, nature walks, listening to or creating music, painting or sculpting, and therapeutic touch. These activities allowed bereaved parents to connect with their inner-self to acknowledge their strength and ultimately find peace (Laakso & Paunonen-Ilmonen, 2001).

Additionally, some research studies found that bereaved parents expressed negative feelings such as anger at God for their infant/child's death; some felt that God

was punishing them and others questioned God their faith (Armentrout, 2009; Bellali & Papadatou, 2006). Further, Meert, Thurston, and Briller (2005) found that 30 to 60% of bereaved parents expressed anger and blame at themselves and God for their infant's/ child's death and this may result in using less religious coping strategies to cope with early grief.

RQ #2) What is the relationship between spiritual coping strategies and grief, personal growth, and mental health for mothers and fathers at 1 month and 3 months post-death? Research studies have found that bereaved parents are more likely to experience high rates of grief and mental distress following the death of their child (Dyregrov et al., 2003; Kreicbergs et al., 2004; Murphy et al., 1999). In this study the strong association between spiritual coping strategies and lower levels of grief and mental health symptoms suggests that spiritual coping is a strong positive mediator in the reduction of grief and mental health symptoms for bereaved parents.

Research studies with adults who were diagnosed with a life threatening illness found that the use of spiritual coping strategies, which include having a secure relationship with a higher power, having a belief that there is meaning to be found in life after experiencing a traumatic event, and maintaining a connectedness with others experienced less mood disorders of anxiety and depression, had less feelings of hopelessness and greater functional and physical well-being (Boscalaglia, Clarke, Jobling, & Quinn, 2005; Graham, Furr, Flowers, & Thomas-Burk, 2001; Levine & Targ, 2002).

Religious and spiritual coping also positively affected bereaved parents' personal growth at one month and three months. However the stronger relationship with spiritual

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coping strategies and personal growth suggests that bereaved parents used non-religious strategies, for example, accepting and finding meaning and purpose in their infant's/ child's death and helping other bereaved families through the creation of websites and foundations to positively influence the outcome of the tragic circumstances. The conceptual model also states that as bereaved parents emerge from their grief their lives are transformed to become more compassionate and caring (Hogan, et al., 1996).

RQ# 3) Do these relationships hold true when race/ethnicity and religion are controlled? In the early phase of grieving both bereaved mothers' and fathers' elicited similar spiritual coping strategies. For example, receiving and maintaining support from friends and family, accepting the current difficulties of life by taking one day at a time and hoping for a better future. Research studies have found that bereaved parents described spiritual coping strategies that were helpful in coping with their grief included sympathetic presence and reassurance from spouses, and caring actions of family, friends, co-workers, clergy, and healthcare professionals. Spending time with family and friends after their child's death was also described by bereaved parents as spiritually helpful in coping with their grief (Barrera et al., 2009; Meert et al., 2005).

The cultural, religious and spiritual beliefs used to cope with the death of their infant/child may have influenced Hispanic mothers who had higher detachment grief scores at T2 and PTSD at T1. Religious beliefs, which can be viewed as an individual's spirituality (Schneiders, 2003), can have different meanings for different traditions/ cultures; therefore, religious and spiritual beliefs may have negatively influenced bereaved Hispanic and Protestant mothers' grief response and mental health.

The current study found that at three months following the death of their infant/child spiritual coping strategies remains a strong predictor of reducing bereaved mothers grief symptoms of despair and detachment but not bereaved fathers' grief symptoms. Despair is characterized by hopelessness, sadness and loneliness and detachment is characterized by withdrawing an avoiding others. The current study found that bereaved mothers and fathers grief differently. Bereaved mothers used spiritual coping strategies for a longer time than fathers to deal with their grief. This finding support other studies that have identified differences between mothers' and fathers' patterns of grieving. Lang, Gottlieb, and Amsel (1996) found that over time bereaved wives continued to exhibit higher grief reactions than their husbands. Armentrout (2009) also found that bereaved wives initially felt their husbands shared similar feelings of grief, but five to six months after the death their spouses had moved forward with their lives at a faster rate than the wives.

The use of religious and spiritual coping strategies were strong predictors of personal growth for bereaved mothers and fathers at one month and three months after the death of their infant/child. This is consistent with most other research studies where bereaved parents describe a transformation with their lives. They became more compassionate, caring and sensitive to the needs of others; they also became more giving of themselves by reaching out to other bereaved parents (Armentrout, 2009; Lichtenthal, Currier, Neimeyer, & Keese, 2010). These findings were also validated in conceptual framework that described bereaved parents emerging from their suffering and begin to reprioritize their values and to find meaning and purpose in this tragedy. It is possible that personal growth in the early grief phase is unusual. In this study the average time before

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the infant/child died in the ICU was one month which may have allowed the parents to assimilate the death by saying goodbye to their infant/child.

Unlike bereaved fathers, bereaved mothers' use of spiritual coping strategies resulted in lower symptoms of depression and PTSD at T2. It is possibly that bereaved mothers had greater levels of mental distress than fathers and the use of spiritual coping strategies was beneficial in reducing their levels of depression and PTSD. Research has identified differences in bereaved mothers' and fathers' level of mental distress, with bereaved mothers having higher levels of mental distress at baseline that remained higher up to two years post death while bereaved fathers level of mental distress decreased over time (Logan & Murphy, 2005-2006).

Additionally, research studies have found that bereaved parents experience many benefits associated with the use of religious coping to dealing with their grief and mental health (Lichtenthal et al., 2010; Meert et al., 2005; Raingbruber & Milstein, 2007). In this study religious coping was found to be ineffective in lowering bereaved mothers and fathers symptoms of grief and mental health. Parents in this study placed greater reliance on spiritual coping strategies to help cope with their loss.

Significance

Findings of this study contribute to the current understanding of religious and spiritual coping strategies as predictors of bereaved parents' grief responses, mental health and personal growth, as it is the first study to focus on parents whose infant/child had died in the NICU/PICU. The study's diversity in parent race/ethnicity and improved methodologic rigor make its findings more generalizable.

This study is one of the few to have sufficient numbers of bereaved parents of different racial/ethnic groups to allow comparisons of Hispanic, Black, and White parents' responses to their child's death in a NICU/PICU. The findings of this study will provide valuable information about the use of religious and spiritual coping over time that is representative of a minority population who has been under represented in previous bereaved studies. The diverse composition of the study participants increases the generalizability of the findings of this study beyond White bereaved parents. Unlike other research on bereavement parents were recruited directly from the unit that their infant/child died and from the state's death records, decreasing bias inherent in recruiting from other lists or settings.

The stress associated with the death of a child often disrupts bereaved parents daily routine, relationships with family and friends and their ability to resume and function at work (Barrera et al., 2009; Gibson, Gallagher, & Jenkins, 2008). The findings of this study suggest that spiritual coping may assist bereaved parents to reduce the intensity of their grief, depression and PTSD. A reduction in bereaved parents' grief and mental health symptoms may decrease the duration of their grief, help them function in their daily lives and ultimately move forward with their lives as the pain associated with the death begins to subside. Additionally, spiritual coping strategies were found to increase bereaved mothers' and fathers' personal growth. Finding meaning and purpose in their infant's/child's death, being optimistic about life and having new priorities and values on what is important in life are positive responses to grief that can help to reduce the development of complicated grief (Engelkemeyer & Marwit, 2008; Riley, LaMontage, Hepworth, & Murphy, 2007).

The results of this longitudinal study provide a clearer understanding of the differences in the use of religious and spiritual coping between bereaved mothers and fathers over time whose children have died in the NICU/PICU. It also shows differences in the use of religious and spiritual coping strategies between bereaved fathers and mothers at different phases of their grief. The ability to recognize what religious or spiritual coping strategies are helpful to bereaved mothers and fathers over time have the potential to reduce the negative effect of grief on bereaved parents grief distress and mental health. This study finding also provides healthcare professionals with guidance for intervention and staff development in how to best help bereaved parents.

Limitations of the Study

There are several limitations to the study. At one and three months post-death, parents were in early stages of grieving. This may have resulted in the non-significant differences that were found for both mothers and fathers responses to the use of religious and or spiritual coping strategies across time. Thus, these findings may not apply to parents who are further away from their child's death in time.

Bereaved parents were asked how religious or spiritual they were and how important religion or spirituality was to them but it was not determined if their religious or spiritual beliefs increase, decrease or stay the same following the death of their infant/child. Having this comparative information may provide additional information about the reasons for the choices bereaved parents make when using religious or spiritual coping strategies.

Bereaved parents were recruited from the NICU and PICU but comparisons were not made as to the different religious or spiritual coping strategies used by these parents.

Therefore differentiation cannot be made as to the effectiveness of religious or spiritual strategies for bereaved parents whose infant/child died in the NICU/PICU.

In this study most of the bereaved parents reported spiritual coping, not religious coping, as effective in helping them to cope with their grief and mental health. The average age for these bereaved parents was early to mid thirties and it is possible that individuals of this age may not be strongly affiliated to a religious group (Fowler, 1995). As parent age was not controlled in this study it cannot be determined if age influenced the lower use of religious coping strategies by bereaved parents.

Implications for Nursing

The findings from this research can be beneficial for nursing education and nursing practice. The results from the study on the use of religious and spiritual coping strategies by a diverse racial/ethnic group of bereaved parents provide NICU/PICU nursing educators with additional pertinent information on the types of coping strategies that are found to be beneficial to bereaved parents. Dissemination of this information in the clinical areas to nurses and other healthcare team members will enable bereaved parents to receive relevant and appropriate support following the death of their infant/child.

Additionally, the interdisciplinary team of physicians, social workers, child life specialist and additional personnel who are involved in palliative care in the NICU/PICU should be informed, through continuing education on the importance of spiritual coping in addition to religious coping. This information when used to help bereaved parents in the NICU/PICU has the potential to minimize the symptoms of grief, depression and PTSD that often accompanies the loss of a child.

Healthcare providers who provide counseling and support to bereaved families in the community during their early stage of bereavement should also be educated on the significant research findings of this study. Healthcare providers in the community should also be aware of the differences that exist in the use of religious and spiritual coping strategies between bereaved mothers and fathers at different times so as to further help their bereaved parents move through the grieving process.

This new knowledge can also be used in the academic setting to prepare undergraduate and graduate nurses on the benefits of spiritual coping and its effect on bereaved parents' grief mental health symptoms. Racial/ethnic and gender differences and the use of different religious and spiritual coping strategies at different times in the early stages of bereavement, as identified in the results of this study, should be used by healthcare professionals to provide appropriate bereavement care to the NICU/PICU bereaved parents.

Future research

Findings from this research study have provided implications for future research. The responses obtained from bereaved parents at one month and three months are applicable to parents in the early stages of bereavement. Further research is needed to determine if any changes, whether negative or positive, occurred in bereaved parents' use of religious and spiritual coping strategies and the effect on their grief response, mental health and personal growth in the later stage of bereavement.

Differences may exist in the grieving process between NICU and PICU parents. The majority of infants are admitted to the NICU immediately after birth and for those infants who do not survive they were never discharged home. In contrast, most infants/

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children who have died in the PICU are older and have lived at home for an extended period of time. Future research that specifically examines NICU/PICU bereaved parents use of religious and spiritual coping strategies can determine if differences exists and specific supportive spiritual care can be used to help bereaved parents cope with their grief.

Another potential area of research is to explore the use of religious/spiritual coping strategies by NICU/PICU parents in influencing their decision to continue or withdraw their infant/child from life support.

Summary

This longitudinal study described differences in bereaved parents' use of spiritual coping strategies across racial/ethnic and religious groups, mother/father dyads and time at one and three months after the infant's or child's death in the neonatal intensive care unit (NICU) or pediatric intensive care unit (PICU) and tested the relationship between spiritual coping strategies parental grief, mental health, personal growth for mothers and fathers at one and three months post death. The results of this study provided new insight into bereaved mothers and fathers use of religious and spiritual (non-religious) coping strategies at one month and three months. Additionally, the results identified significant predictors on the effect of bereaved mothers' and fathers' grief (despair, detachment and disorganization), depression, PTSD and personal growth and their use of religious and spiritual coping strategies. The results added new knowledge to the state of science about differences between religion groups and between bereaved mothers and fathers use of religious and spiritual coping strategies at one and three months. This new knowledge should be used to help bereaved parents cope

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VITA

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EDUCATION	DEGREE	DATE	MAJOR
Florida International University Miami, FL	PhD Candidate in Nursing	2012	Research
Florida International University Miami, FL	Master of Science in Nursing (M.S.N.)	2000	Advanced Child Health Nursing
Barry University Miami Shores, FL	Bachelor of Science in Nursing (B.S.N.)	1993	Nursing
West Middlesex Hospital Isleworth, England	Certificate	1978	Nurse Midwife
West Middlesex Hospital Isleworth, England	Diploma	1977	Nursing

PROFESSIONAL LICENSURE AND CERTIFICATION

Florida, License Number RN 1429612, Expiration July 31, 2012

Critical Care Registered Nurse (CCRN), Expiration June 2010 (presently inactive for two years with option to activate)

International Board Certified Lactation Consultant (IBCLC), Expiration July 2012

PROFESSIONAL EXPERIENCE

Position	Organization	Dates
Research Assistant (student)	Florida International University Miami, FL	Florida 2008-present
Family Educator/ Discharge Coordinator	Memorial Regional Hospital Neonatal Intensive Care Unit Hollywood, FL	2000-2010
Adjunct Professor of Nursing	Nova Southeastern University Davie, FL	2004-2005

Adjunct Professor of Nursing	Florida International University Miami, FL	2000-2001
Staff Nurse Neonatal Intensive Care Unit	Memorial Regional Hospital	1988-2000 Hollywood, FL

PRESENTATIONS AND AWARD

Hawthorne, D, Brooten, D., Youngblut, J. (2008, October). *Psychometric evaluation of th English and Spanish versions of the Spiritual Coping Strategies Scale.* Paper presented at the 2008 South Florida Nursing Research Consortium conference, Boca Raton, FL.

Hawthorne, D., Youngblut, J.M., & Brooten, D. (2009, February). *Psychometric properties of the English and Spanish versions of the Spiritual Coping Strategies scale.* Poster presented at the 22nd Annual Conference of the Southern Nursing Research Society, Baltimore.

Hawthorne, D., Youngblut, J.M., & Brooten, D. (2010, October). *The importance of religion and spirituality and the use of spiritual coping strategies by parents after a child's ICU death.* Paper presented at the 4th Annual South Florida Research Consortium: Best Evidence from Research: The Gateway to Excellent Care, Miami.

Hawthorne, D., Youngblut, J.M., & Brooten, D. (2011, October). *Grandparent health & functioning after a grandchild's death.* Paper presented at the 5th annual research conference," Nursing at the Helm of Research for Quality Practice," the Nursing and Health Research Collaborative of South Florida, Miami.

Hawthorne, D., Youngblut, J.M., Brooten, D., Hannan, J., Blais, K., & Seagrave, L. (2012, Februrary). *Grandparent health & functioning after a grandchild's death.* In J.M. Youngblut (chair), Parent, grandparent, and sibling responses to child death in NICU/PICU. Symposium conducted at the 26th annual Southern Nursing Research Conference, New Orleans.

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RESEARCH ACTIVITIES

2000, Principal Investigator, Spiritual Care Practices of Neonatal Nurses (thesis research).

2009, Principal Investigator, Psychometric Evaluation of the English and Spanish versions of the Spiritual Coping Strategies Scale: A Pilot Study.