

Beyond the Loss of a Child in the NICU: The Social Worker's Role

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Project Abstract

The following is a two-paper dissertation exploring the role of social workers in the Neonatal Intensive Care Unit (NICU). The classical and contemporary perspectives of grief theory provide the framework for understanding emotional responses of bereaved parents to the death of a child. The academic social work, medical, and nursing literature reviewed support the hypothesis that social workers are an insufficiently tapped resource in working with bereaved parents who have experienced perinatal loss in the NICU and revealed contributing factors for current medical social work practices. The accompanying article discusses the role of social workers and the areas that demonstrate their expertise. The article also conceptualizes the design of a bereavement program for perinatal loss using the established adult and pediatric hospice and palliative care models. This dissertation contributes to social work practice in the NICU and grief literature knowledge base by acknowledging the disenfranchisement of bereaved parents who have experienced perinatal loss in the NICU, supporting collaborations with other professionals on the NICU interdisciplinary team, and proposing a prospectus program design.

Keywords: NICU; neonatal intensive care unit; bereaved parents; perinatal loss; neonatal loss; NICU social work; medical social work; grief and loss; grief work; hospice care; palliative care

Table of Contents

Project Abstract	ii
Table of Contents	iii
Dedication	v
Acknowledgement	vi
Project Introduction	1
Literature Review	4
Theoretical Framework	7
Grief Theory	8
Disenfranchised Grief	16
Methods	18
Infant Mortality	19
Family-Centered Care	23
Hospice/Palliative Care	28
Social Work Discipline	42
History and Role of Medical Social Work	44
ICU Social Worker	48
Interdisciplinary Team	49
Bereaved Parents	52
Conclusion	63
References	67

Accompanying Article **Social Workers: An Untapped Resource for Bereaved Parents of the**

NICU

Abstract	78
Introduction	79

Grief Theory	81
Grief Theory and Social Work Practice	87
Methods	90
Literature Review Results	91
Interdisciplinary Team	94
ICU/Medical Social Worker	98
Hospice and Palliative Care Models	99
Bereaved Parents	101
Discussion/Implications	102
Recommendations for Future Research	104
Conclusion	105
Plans for Publication	106
References	107
Appendix	112

Dedication

To my dearest Elise Mone', whose life changed my entire world both personally and professionally. Your purpose in Psalms 91:11 was fulfilled in just 11 short days, which pushed me to fulfill mine eight years later. To my nieces, Taylor Carolyn and Skylar Edna, and all the babies who left this world too soon, you will forever be in our hearts.

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Project Introduction

King Solomon wrote, “To every thing there is a season, and a time to every purpose under the heaven: a time to be born and a time to die...a time to weep and a time to laugh; a time to mourn and a time to dance (Ecclesiastes 3:1-4 KJV). Death is a universal and inevitable experience. Conversely, how we mourn and for whom we mourn is unique and individual, yet socially and culturally influenced. Attachments in and meanings of relationships complicate the natural experience of death, making its impact difficult to process. People traditionally expect that while death may be anticipated for some (as in those with terminal illnesses or diseases), it usually comes in an orderly manner. Under this assumption, grandparents die first, then parents, then the next generation. This perceived order is disrupted when a child dies. Parents do not anticipate the death of a child, particularly an infant. Regardless of why the infant dies, this event is disorienting and hard to fathom, especially when there are no close references as to how one should handle the loss of a child. This type of loss produces pain both physically and emotionally, yet there are few established rituals for grieving a perinatal loss compared to the loss of a parent, spouse, or close family member (Wenzel, 2014).

The following literature review and accompanying paper examine the role of the medical social worker in working with bereaved parents of the Neonatal Intensive Care Unit (NICU) through the lens of grief theory. The nation’s 250,000 clinical social workers make up 45 to 70% of the mental health workforce in the United States and have specialties in various settings (American Board of Examiners in Clinical Social Work, 2017; National Association of Social Workers, 2017; Masiriri, 2008). Given these statistics, it is likely that social work clinicians will encounter clients with trauma and bereavement issues during their career. Despite advances in medical technology, the reality is that some babies will not survive birth and treatment in the

NICU. In the United States, the Center for Disease Control reported that two-thirds of infant deaths occur within the first 28 days of life (Center for Disease Control, 2009) and most occur in the NICU (Falck, Moorthy, & Hussey-Gardner, 2016). Infant death is traumatic and usually unexpected, requiring some parents to seek assistance with coping.

Research indicates that the circumstances leading to infant death and the lack of validation of loss can lead to complicated grief responses (Bhat & Byatt, 2016; Lang, Fleiszer, Sword, Gilbert & Corsini-Munt, 2011). However, there are no apparent standards for providing services to parents after the loss of their child in the NICU. Additionally, there are very few articles that discuss the role and/or interaction between social workers and parents (especially the bereft) in the NICU. The medical social worker brings a knowledge base in the areas of assessment, communication, discharge planning, and psychosocial counseling (Hartman-Shea, Hahn, Kraus, Cordts, & Sevransky, 2011). Grief theory is a researched-based framework that provides context for the human response to the death of a loved one. It includes both classical and contemporary perspectives that, when used appropriately, can help facilitate the mourner's journey to healing. It is hypothesized that social workers have the training and skills necessary to meet the needs of bereaved parents who have experienced perinatal loss.

The literature review and subsequent paper/article that comprise this dissertation seek to acknowledge gaps in research and service provision for bereaved families. These two papers seek to build the argument that the hospice and palliative care treatment are effective in providing supportive services to critically ill and/or dying patients and their families and can provide a reference to neonatal and perinatal treatment. They also emphasize the significance of social workers and the importance of including their perspective in providing services to bereaved parents of the NICU. With an understanding of grief theory, the social worker can

guide parents in a positive relationship with their deceased child, while making meaning of their loss.

The two papers in this dissertation will follow the guidelines of the University of Pennsylvania's Doctorate in Clinical Social Work (DSW) handbook (2016) to include "one article-length paper, accompanied by a critical review of the literature" (para.6). The formal literature review examines the following areas:

- Overview of Classical and Contemporary Grief Theories
- Infant Mortality and NICU Practices in the US
- Role of The Medical Social Worker
- Grief Experiences of Bereaved Parents of Perinatal Loss

The second paper/article will use a conceptual theoretical framework, expanding on the critical review of the literature. The hospice and palliative care models in the context of the NICU will be used to illustrate how parents need proactive systems in place after perinatal loss. Research demonstrates that parents can recover after the traumatic loss of losing a child, but they need to feel supported by a clinical framework that supports their phenomenological perspective.

Literature Review

Giving birth is a one of a kind of experience that comes with overwhelming emotions. For desired pregnancies, the anticipation of new life brings hope and expectation that extend far beyond the birth of the child. Many parents prepare and make accommodations for their newborn from conception to birth. Even with precise preparation and anticipation, parents are not usually equipped or prepared for babies who are born prematurely, critically ill, or underdeveloped (Boss, Urban, Barnett & Arnold, 2013). These premature newborns are usually admitted into the Neonatal Intensive Care Unit (NICU) for treatment; however, not all of them survive (Combs-Orme, 1987; Falck et al., 2016). Parents generally expect to protect the safety and well-being of their children from the potential ills of the world, but once they enter the medical environment of the NICU, they can feel vulnerable and inadequate. There are uncertainties throughout the entire process, and parents never foresee their babies dying.

In 2014, the death of infants up to one year old totaled 23,215 in the United States (Center for Disease Control, 2017). In other words, about 64 babies (more than half are less than a month old) die daily leaving parents and families to cope with this phenomenon. While death is a normal part of the life cycle, the loss of a child can have substantial psychological impact on parents and family members (Cacciatore & Bushfield, 2007; Sturrock & Louw, 2013). The death of a child is more than the loss of a loved one; it is the demise of creating memories, celebrating life, anticipating future, and is life altering. It creates a void. For many, death's finality is confounding and traumatic, making it one of the most difficult life events. Therefore, death of a child poses a unique challenge to how families recover (Barrera et. al, 2007), particularly in the NICU.

Prematurity continues to be a complex public health concern worldwide. Over the past 40 years, NICU design, clinical research, and adaptations of best practices have strongly focused on the survival of premature and medically fragile newborns. The range of health concerns for premature infants is vast and includes those who thrive to those who are critically ill. In spite of these advanced technology and medical successes, not all babies survive. Therefore, just as there is a range of medical treatment, comprehensive services geared toward bereaved parents must also be considered a part of the continuum of care.

The NICU is comprised of staff charged with medical treatment of extremely fragile newborns. The complexity of medical concerns usually requires a multi-disciplinary team of doctors, neo-specialists, nurses, technicians, and social workers. Because neonates require significant medical attention and equipment, NICU staff, particularly nurses, become “primary caretakers”. Parents tend to rely on nurses to indicate how involved they can be with caring for their child. Comparably, parents may look to hospital professionals as a resource when their child dies. The hurt of losing a child is not only traumatic but disorienting. Parents need assistance in transitioning back to their “normal” lives beyond spending last moments with their newborn and making funeral arrangements (Badenhorst & Hughes, 2007). Ideally, there should be a systematic process that guides parents into transitioning back to their lives after the loss of their baby. Currently, very few hospitals offer organized bereavement services, leaving parents to fend for themselves after leaving the hospital. Some bereaved parents of perinatal loss are vulnerable to mental health issues if no intervention is provided. The disconnection between the demise of the child to adaptation to the new reality of life after the death of a newborn child presents an opportunity to explore the gaps in service to bereaved parents of the NICU.

Bereaved parents of NICU infants experience death as more than the loss of their child

but the loss of a lifetime of “wished for” milestones like birthdays, school enrollment, graduations, and other significant life events. The transition of returning home without their newborn is arduous and can require guided interventions at various stages of bereavement. During the initial phases of loss, sensitivity and timing are important, especially from hospital personnel interacting with grieving families. By the time the bereft are ready and capable of dealing with grief in a counseling setting, it is imperative that the clinician is prepared to address bereavement in a conversant manner. Even for the most sensitive clinicians, comforting those mourning the death of a child can be difficult. Clinical education and training in appropriate theoretical frameworks are necessary for preparing clinicians for work with the bereft (Wright, Limbo, & Black, 2015). Understanding grief theory is integral for clinicians who witness families experiencing the anguish of the death of a loved one, particularly an infant.

This research study will analyze empirical data and use a conceptual theoretical approach to address the following research questions in the context of bereaved parents of the NICU: What practice models should influence and guide social work practitioners? What role should social workers play in providing services to bereaved parents who identify as disenfranchised? The aim of this research project is to expand knowledge regarding the frequency of perinatal deaths, to explore the current practices in the NICU, and to provide recommendations for social work practice for clinicians working with bereaved parents.

This study will explore literature focusing on social work values, beliefs, and educational training compared to current practices of the NICU. The bereaved parents’ perspective will provide context for some of the challenges and responses to experiencing the loss of a child in the NICU. The literature review will also provide a guide to understand various factors that influence current practice for medical social workers.

Theoretical Framework

This project will be rooted in the theoretical framework of grief theory. The literature review will reference the historical perspectives of grief and its pathologized origins compared to the post-modern constructionist view of grief. The grief theory discourse has evolved over the past century. The classical literature lends itself to the relinquishment of the deceased to promote healing, while the more recent perspectives focus on continuing bonds and making meaning with the deceased. Using grief theory will also provide a reference for how best practices have evolved to include populations that are disenfranchised, i.e. bereaved parents of perinatal losses.

Loss extends beyond illness and death to include broader unanticipated and adverse circumstances (Gwyther et al., 2005). As a result, many people can identify with the emotional response to loss. Universally, death marks a distinguished closure, or change, at minimum, to a relationship, but people memorialize their loved ones and cope with grief differently. “Grieving is one of the few rites of passage that is cross-culturally and cross-historically consistent” (Grenek, 2010, p.46). Herrman-Donnelley (1987) describes grief this way, “Our logical minds can explain a great deal, but they can’t explain the ‘why’ of death. It is illogical. It is irrational. It is crazy” (pgs. 19-20). Grief or mourning behavior can look like irrational acts (e.g. replaying last moments, wishing the world would stop, and holding on to a loved one’s belongings) that would otherwise be abnormal to those who are not mourning. To the bereaved, however, these acts provide comfort. The grief work hypothesis claims that bereaved persons must focus on feelings of loss or they will experience psychosomatic and other maladaptive symptoms and will never recover from their loss. Stroebe and Schut (2005) expound that in order to circumvent disordered grief reactions, the mourner must acknowledge and work through his/her painful feelings (cf. Stroebe, 1992). It is noteworthy to mention that the concept of grieving was

problematic because there was no protocol to distinguish normal reactions from pathological (Granek, 2010). Assisting the bereaved, however, has been explored through various lenses and has become a topic of significant research.

The abrupt termination of pregnancy or preterm birth and the uncertainty of medically fragile infants often come as unexpected crises for parents (McGrath, 2001). An unanticipated premature delivery presents its own challenges with parents having to navigate the NICU's logistical nuances along with feelings of disappointment, confusion, frustration and anger. The duration of pregnancy is about forty weeks of gestation, but a baby is considered full-term after 37 weeks. Any delivery prior to 37 weeks of gestation is considered premature. The premature birth experience strips parents of the "wished for" or traditional birth. To add to the complexity of the premature birth, the death of the child is traumatizing (Barrera et. al, 2007).

Grief Theory

Grief theory encompasses subtle losses and can reference the loss of a job, one's ability to be independent, diagnosis of a terminal or debilitating disease, or security, as in losing one's home. This project, however, will focus solely on the ultimate loss of a loved one via death and how bereaved parents cope beyond the loss of their newborn child. People can generally understand the hurt behind these various types of losses; however, they may only identify with feelings of isolation once they experience a loss directly. *Grief* is defined simply as the natural reaction to a loss (Winokuer & Harris, 2012). The feelings of isolation and lack of validation are considered disenfranchised grief and will be discussed further in describing the plight of the bereaved parent of perinatal loss.

There remain deliberations on which theoretical perspectives are the most accurate and relevant for the bereaved. Each experience with the death of the loved one is as unique as the

individual. Therefore, clinicians must consider the events leading up to the death and understand how they impact the connection with the deceased and the life functioning of the bereft (Rubin, Malkinson & Witztum, 2011). For efficacy, the clinician's approach must be grounded in a theoretical framework. Grief theory is broken down into the three major categories of task-based, stage-based, and post-modern/contemporary perspectives.

During the 20th century, researchers attempted to describe and contextualize grief symptomology and provide treatment solutions for it. Granek's (2010) seminal paper discusses the historical trajectory of grief becoming pathologized in the psychological context. He references Burton (1651) and Darwin (1872), among others that included grief in their writings prior to structured research studies (as cited in Granek, 2010). Many of these writers considered grief as an emotion of sorrow particular to contextual situations, like the loss of a loved one, rather than a disease or mental illness.

Freud's psychoanalytic theories, however, laid the foundation for the classic perspective of grief theory. His writing of *Mourning and Melancholia* (1917/1957) set the framework for the notion of grief work as practitioners understand it today. Freud defines mourning as "the reaction to the loss of a loved person, or to the loss of some abstraction which has taken the place of one, such as one's country, liberty, an ideal and so on" (p. 243). He offers that while mourning involves different behaviors than that of normal life, he does not regard it as pathological. He notes that the mourning process takes time to overcome and interference with the mourning process may prove to be useless or harmful. In this book, he compares the symptomology of mourning and melancholia (also recognized as major depression) to articulate how the psychological distress produces physical manifestations. Melancholia reflects an internal dissonance that can only be resolved by the will to continue living. While depression can look

similar to mourning, the depressed individual focuses on his own inadequacies. The bereaved, on the other hand, becomes preoccupied with the lost object (loved one). Freud suggests that in normal mourning, the bereaved “overcomes the loss of the object” by accepting the reality that the loved one is no longer physically present. He further states that “the work of severance is slow and gradual that by the [time]... it has been finished the expenditure of energy necessary for it is also dissipated” (p. 255). It is appropriate that the bereaved will mourn and be preoccupied with the notion that their loved one no longer exists and time will heal their heart’s discontentment.

Since Freud, others have sought to define grief and explicitly distinguish “normal” grief reactions from abnormal. The systematic studies of grief were expanded during a time when many psychoanalysts were migrating to America, leading to the expansion of psychiatry. The development of the Diagnostic and Statistical Manual of Mental Disorders (DSM) heightened the awareness of psychological deficits, moving the inclination of atypical and prolonged expressions of grief to be pathologized (Granek, 2010). Erich Lindemann is known as one of the first researchers to produce empirical exploration of the grief process by studying people’s responses to the Cocoanut Nightclub fire in Boston, MA in 1942 (Walter & McCoyd, 2009). He hypothesizes that normal grief includes somatic distress, preoccupation with the deceased, guilt, hostile reactions, and loss of normal behaviors (Goldsworthy, 2005). Lindemann’s stance in the treatment of the bereaved is that only the psychiatrist can sufficiently provide adequate assistance and all others, namely ministers, social workers, and family members, should refer the bereaved to the psychiatrist (Granek, 2010). He also recommends that grief work be managed by a psychiatrist over a month and a half of about eight to ten sessions. This practice supports the

notion that acute grief is short-lived and that grief that lasts longer than a month and a half is pathological (Walter & McCoyd, 2009).

Elizabeth Kübler-Ross (1969) introduced a new perspective of grief and loss with her extensive work regarding the terminally ill and dying, leading to the publishing of her book, *On Death and Dying*. Her work challenges physicians and other helping staff to consider the patients' perspective as they approach death. This approach encourages empathic listening rather than silencing patients' thoughts and concerns. She proposes that death is a process and that the individual follows a series of stages: denial, anger, bargaining, depression and acceptance. She warns that the danger in integrating these stages is that they will not become an organic progression of the patient-physician relationship but will be another method to help diagnose how close the individual is to death (Novak & Axelrod, 1979). She also advises that the stages do not follow prescribed sequences; however, this is rarely incorporated in application of her theory (Walter & McCoyd, 2009).

The stages of denial, anger, bargaining, depression, and acceptance have become known as the Five Stages of Grief. It should be noted though that the bereft was not the population Kübler-Ross researched, therefore, differences in how they respond to these stages compared to how the terminally ill respond should be taken into consideration. McCoyd and Walter (2016) attempts to clarify these differences and provide explanations for how Kübler-Ross's model was widely used in mental health counseling practice.

For the terminally ill, the denial stage is focused on getting accurate diagnoses and maintaining some hope for a better outcome regarding their illness. In clinical practice with the bereaved, this stage is often viewed as a pathological response, a refusal to accept that the loved one has died. The anger stage for the bereft is usually reflective of irritable grief reactions, rather

than the feelings of disappointment and frustration that the terminally ill may experience after being diagnosed with an incurable disease. Further, the instinctive thinking of the terminally ill patient lends itself to the bargaining phase. Oftentimes, the terminally ill hope if they make amends, there is a chance for their health condition to get better. For the mourner however, there is nothing to bargain for because the loved one is already dead. In spite of this, counselors have considered this stage to be reflective of final acceptance that the loved one is deceased. This stage moves the individual into the depressive stage that manifests in the form of crying, sadness, and yearning for the loved one. This stage is fairly similar for both populations. Finally, acceptance for the terminally ill patient is usually somber and void of emotion. The individual has found peace and is no longer preoccupied with recovering from his/her illness. Contrastingly, this stage is marked by revealing a of emotions, readjustment to extended relationships, and involvement with prior interests for the bereaved. The trajectory of the bereaved individual to the acceptance stage is gradual and fluctuates with circumstances. The differences between the responses of the bereaved and originally researched group of the terminally ill are rarely highlighted, but they provide some insight into the fallacy of some classically referenced grief models (McCoyd & Walter, 2016).

Another stage-based theorist is John Bowlby, who is recognized for his work in identifying the attachment styles of children i.e. secure, anxious, and avoidant. To fully understand the process of grief and the work that is required to gain acceptance, one must consider the role of relational attachments. The bereaved is no longer able to physically interact with their loved one and must adapt to this new reality. The underlying principle in Bowlby's attachment theory is that there is an innate mechanism that protects and ensures the individual's survival and need to feel safe. His hypothesis of grief work includes four phases: numbing,

yearning and searching, disorganization, and reorganization (Goldsworthy, 2005). He suggests that these attachment styles continue into adulthood and become evident in the individual's reactions to loss (Walter & McCoyd, 2009). Regardless of attachment style, clinical practice has shown that the level of fondness, relationship context, and positive connection correlate with the intensity of grief and mourning (McCoyd & Walter, 2016).

A more recent classical theorist, Therese Rando, looks at processes rather than stages, sharing similar concepts. Her work includes three major phases with sub-phases in each. The avoidance phase includes recognition of the loss and understanding the reality of death. The confrontation phase includes reaction to the separation (experiencing the pain of the loss), recollection of the relationship with the deceased (realistically remembering the experiences of the relationship), and relinquishing old attachments to the deceased including the world the individual lived in (developing a new normal without the deceased). The final phase of accommodation includes readapting into the new world without forgetting the old (developing a new relationship with the deceased) and reinvestment (establishing new relationships and roles, indicating resolution to active grieving) (McCoyd & Walter, 2016).

While the classical theories are well-known and have been implemented in clinical practice, they have limitations. Most of them focus on the psychological disruption or the physical symptomology of the bereaved but do not make considerations for contextual and individualized factors. Freud's grief perspective heavily influenced research and clinical practice, pathologizing bereaved persons who did not relinquish attachments to the deceased loved one. The task and stage-based theories imply prescriptive orders and suggest that the mourner must progress through each stage with no deviation. They also do not account for individual personality or relational differences. For a novice or uninformed clinician, the classical theories

can promote ‘policing’ behavior to ensure that ‘grief work’ is completed (McCoyd & Walter, 2016). If the social worker subscribes to any of these theories, he/she should include social work ethics that promote the right to determination and empowerment.

The grief work hypothesis is defined as the necessity to “confront the experience of bereavement to come to terms with loss and avoid detrimental health consequences” (Stroebe & Schut, 1999, p.199). Stroebe (1992) challenges the cultural and circumstantial relevance of the grief work hypothesis, concluding that while it is necessary for some people, others may need to avoid and/or take non-confrontational approaches to coping with the loss of a loved one. Discrepancies on the generalized definition and symptomology of normal versus pathological grief stimulated disagreement on how treatment should be approached in working with the bereaved. During this time, several contemporary approaches were introduced to work with the bereaved.

Klass, Silverman, and Nickman (1996) introduced the terminology of “continuing bonds with the deceased”. This ideology is significant because it presented a major perspective shift in the grief and loss discourse. Historically, the bereaved were encouraged to completely let go of the relationship with their loved one, while attempting to preserve that relationship was seen as taboo and/or pathological (in Western culture). This grief model promoted continued interactions with the deceased. Klass, Silverman, and Nickman (1996) desired to acknowledge ways in which the bereaved might incorporate the bond with their deceased loved one and demonstrate how that bond changes over time (as cited in Klass, 2006). In a reflective piece, Klass (2006) clarifies misinterpretations of the original definition. He discusses that interacting with the dead could actually be deemed as normal; however, both positive and negative consequences should be considered. He encourages clinicians to explore a multidirectional approach that considers the

intersectionality of an individual's identity, making meaning of the loss, and relearning relationships that influence the bereaved individual's adjustment.

Stroebe and Schut (1999) propose the Dual Process Model. This perspective incorporates the cognitive stress theory and the stress response syndromes to focus on effective ways of coping with the loss of a loved one rather than the reaction to the loss. The cognitive stress theory states that an individual experiences stress when a given situation which endangers the individual's well-being is perceived as overwhelming. The stressor among the bereaved would be the irreversible loss of the attached figure (loved one). The stress response syndromes coined by Horowitz (cf. 1986) are defined as the combination of intrusive and avoidance reactions to traumatic events. These two mechanisms were expanded to include coping in everyday life experiences. The loss-orientation component of the model highlights the need to yearn and reminisce for the deceased. Conversely, the model acknowledges the need to take time off from the pain to deal with everyday life needs and to embrace a new identity, known as restoration-orientation. The central component of this model is the ability to oscillate between these two states. This concept implies that for optimal adjustment, the bereaved may choose to be distracted from grieving to focus on daily living and rebuilding relationships. While taking time off is permissible, it should not be confused with the coping mechanisms of denial or avoidance of the death (Stroebe & Schut, 1999). The refusal of acknowledging the loss of the loved one or acting as if it never occurred are indicators of complicated grief which will be discussed later.

Robert Neimeyer (1999) expounds on the deficits of the traditional grief model that implies that the emotional responses of all bereaved individuals will be similar. Contrarily, he proposes a "meaning reconstruction" approach that acknowledges unique idiosyncrasies that make each person's grief different, even for the loss of the same individual (p.68). He further

discusses that while grieving may be a private process, societal and contextual factors must be considered. “Ultimately, reconstructing a world of significance in the wake of bereavement is more than a cognitive or emotional exercise; it also requires survivors to recruit social validation for their changed identities” (Neimeyer, 1997, as cited in Neimeyer 1999, p.69).

Culture influences which activities become traditions/societal norms and which emotional reactions are deemed acceptable after the death of a loved one (Klass & Chow, 2011). Direct discussion of specific sensitive topics like perinatal loss in Western culture can be seen as taboo (Shulman, 2015). Employment benefits for bereavement, funerals, and other bereavement entitlements are not always rendered to grieving parents who experience perinatal loss. When bereaved parents have no substantial community that understands and validates their loss, they can feel disenfranchised (McCoyd & Walter, 2016). This lack of qualification is usually not easily understood because the deceased baby plays no obvious significant role in the lives of the extended family or social community. Furthermore, those parents who have no other living children, may struggle with their identity as parents. The combination of these factors impacts the process by which bereaved parents attempt to recover and heal from the loss of their child.

Perinatal loss is one of the most devastating experiences and some parents will seek assistance in coping with the loss of their child with therapeutic interventions. The clinician’s framework in grief counseling and understanding of attachment is essential in guiding the bereaved individual through the journey to healing. Several factors to consider are that the loss of the baby is likely unanticipated, the presumed life with the child has vanished, and the identity of parenthood has been drastically altered for some parents. In a broader context, perinatal loss is complex and unique given that people deem it to be less significant than the death of an older

child, spouse, sibling, or parent and thus, bereaved parents feel disenfranchised (Lang et. al, 2011).

Disenfranchised Grief

There are distinct differences in the length of time people grieve, how intensely they grieve, and for whom they grieve. Expressions of grief that fall beyond socially normalized parameters are considered disenfranchised. Kenneth Doka (1989) coined the term disenfranchised grief to describe “grief that persons experience when they incur a loss that is not or cannot be openly acknowledged, publicly mourned, or socially supported” (p. 4). His introduction of disenfranchised grief (1989) describes disenfranchisement as:

1. Non-traditional relationships such as homosexual, extramarital or distant relationships (beyond immediate family like friends, co-workers, etc.).
2. Losses that are not recognized as significant i.e. abortions, perinatal loss, death of an animal
3. Grievers that are assumed to be incapable of grieving i.e. young children, the elderly, or individuals with disabilities.

In 2002, Doka expanded his definition to include:

4. Circumstances of the death i.e. suicides, deaths from AIDS or other stigmatizing diseases, and executions.
5. Ways individuals grieve, as in circumstances when the bereaved do not express a strong affective response or when the bereaved show too much emotion.

Disenfranchised grief essentially emphasizes the mourner’s right to grieve for any relationship that is experienced as a loss in a manner that is individually appropriate. Common examples of disenfranchised groups are those diagnosed with cancer, those giving birth to a child with a disability, and those experiencing infertility or perinatal loss i.e. miscarriage, stillbirth, or infant death. Mourners that fall within these domains may feel restricted to express their loss

openly and even feel shameful to openly describe their feelings as a loss (McCoyd & Walter, 2016).

Expressions of grief and typical arrangements honoring the deceased are socially, culturally and religiously influenced. The lack of social support requires the mourner to find ways to cope that may be antithetical to their feelings or desires. Physical silence, administrative failures (not honoring time off from work, not providing insurance coverage), and relational failures (unknowingly presenting offensive phrases like “at least they are not suffering anymore,” “at least they won’t struggle with medical issues,” or “you can try for another baby”) all question the significance of the mourner’s loss. This experience can be shaming, stigmatizing, and isolating.

Attig (2004) argues that Doka’s coining of disenfranchised grief is essential and relevant albeit limited. Its underlying assumption is that establishing respect for those suffering and affirming the mourner’s right to grieve are the primary solutions to addressing disenfranchisement of grief. He proposes rather that disenfranchisement of grief be expanded to include the “human drive to transcend suffering, or resilience, that makes a return to thriving and meaningful living possible” (p. 207). This notion supports Neimeyer’s focus on the importance of finding and making meaning considering a significant loss.

Whether one subscribes to the classical task-based theories or the contemporary theories of searching for meaning and embracing a new identity, it is crucial to understand that death is physically finite and mourning/grieving is a process. There is an acute period (immediately following the loss) that grief reactions will likely be most intense. Generally, grieving subsides with time, but for some people, external interventions like counseling are necessary to promote emotional stability and healing.

Methods

Multiple literature databases were searched to explore the concept of the occurrence of infant mortality in the NICU, the relationship of the NICU social worker and the parent or the interdisciplinary team, and bereaved parents. This section reviews relevant literature that comes from the fields of health education, medicine, public health, psychology, nursing, death studies, and social work. Notably, most of the literature reviewed focused on the interaction between the physician or nurse and the parent or from the nurse or parent perspective; however, only one article (Bosma et. al, 2010) included the social work interaction/perspective in connection with the NICU parent.

Infant Mortality and the Neonatal Intensive Care Unit

Infant mortality has decreased exponentially since the early twentieth century. In 1912, approximately 124 of every 1,000 live births died within the first year. In 1985, 10.6 of every 1,000 births died (Combs and Orme, 1987) compared to today's rate of 9.6 (March of Dimes, 2015). There are various causes for infant death; however, preterm birth continues to be the primary factor. In 2012, nearly 500,000 babies were born preterm (before 37 weeks gestation) in the United States (Laubach, Wilhelm & Carter, 2014). These rates are not exclusive to the United States (US). Worldwide, there are about 130 million infants born each year and 15 million infants are born prematurely (March of Dimes, 2017; Jenan et al, 2008). Of those, 4 million die within the first 28 days of life. Three-quarters of neonatal deaths occur within the first week, and more than one-quarter occur in the first 24 hours (Jenan et al., 2008). This epidemic demonstrates the need for the services of the NICU.

Parents of premature infants are in an unfamiliar world. The anticipated pregnancy is abruptly interrupted, their baby has different needs than a full-term or typically developed infant,

and their lives become consumed by the sterile and complex environment of the NICU (Fegran & Helseth, 2009). The NICU is often described as a roller coaster ride with many ups and downs, and parents rarely feel safe for fear of the uncertain medical outcomes of their child (McGrath, 2001). For the parents whose child does not make it out of the NICU alive, they have entered yet another unfamiliar world.

The March of Dimes (MOD) has been a leader in advocacy and funding supporting NICU operations. Originally MOD was called the National Foundation for Infantile Paralysis and was founded by President Franklin Roosevelt in 1938. Its initial agenda was to research and address polio and the effects of it. The organization funded pioneers in the field to develop an immunization for polio that eventually became the cure that would annihilate the disease. With an updated mission to address birth defects and infant mortality, MOD has expanded research, professional education, and public awareness. In 2003, the Prematurity Campaign was launched to decrease preterm birth rates and increase public knowledge about prevention. To date, MOD has funded physicians like Dr. Virginia Apgar, who created a standardized assessment of newborns and promoted genetic testing for pregnant women (Rose, 2010). Not only have infant mortality rates decreased by 90% within the second half of the twentieth century, but the number of women who die due to pregnancy complications has also decreased (CDC, 1999; March of Dimes, 2015).

Given the relatively new technology and essential progress that have been made, NICU practices have evolved significantly over the past 50 years. Treatment for premature infants in the United States began during the early 1900s. With the introduction of infant incubators and advancements in medical technology, infant survival has increased astronomically. The systematic and organized neonatal intensive care was not introduced until the mid-1960s (Raju,

2011). Methods to provide assisted ventilation to neonates were developed and surgical instruments and procedures were designed to accommodate tiny babies. Further, neonatology became a board-certified subspecialty of pediatrics in 1975 (Noble, 2003). As parents were permitted to visit their newborns for longer hours, the MOD NICU family support program was designed to provide information, comfort, and support to families during NICU hospitalizations (Rose, 2010).

There are four different levels in NICU care. Level I, most similar to a full-term baby nursery, is designed for preterm babies born at or later than 35 weeks old. At this stage, babies are usually monitored to ensure no life-threatening concerns are identified and appropriate growth is occurring. Level II is for babies who are 32 weeks old or older and need additional monitoring. These babies are treated for minor concerns like regulating temperature and boosting the immune system with antibiotics. Level III is for infants born at 28 weeks old or later. Babies at this age usually have difficulty breathing and need equipment to assist them. They are not able to swallow milk and need tube feeding equipment. Premature infants are monitored very closely for changes in status. Level IV is not available at all hospitals but treats extremely premature infants around 22 weeks. These babies are very ill and need 24-hour monitoring (AAP, 2004; Gardner, Carter, Enzman-Hines & Hernandez, 2016). The following is a description of the traditional open-bay NICU model:

The visibility of the incubator rooms is strengthened by the glass walls.

Each room contains from three to five incubators. Parents seem to be squeezed in between the technical equipment, sitting in chairs holding and nursing their infants, leaving little room for privacy. The noise is striking; alarms and sizzling sounds

from the surveillance equipment are mixed with nurses' and parents' quiet talk. The air feels dense and warm; the room is crowded. Curtains patterned with pastel-coloured animals and colourful hand-knitted blankets in the incubators seem to attempt to normalize the abnormal surroundings for newborn children; however, the high-tech impression and lack of privacy is striking (Fegran & Helseth, 2009, p. 671).

Ideally, babies remain in utero until they have reached full-term gestation. The third trimester is crucial for brain, organ, and growth development of babies. For premature neonates, the NICU is where very fragile infants must continue to grow attempting to reach critical milestones for healthy development. Risk factors for infants needing NICU treatment include: preterm birth (gestational age less than 37 weeks), late birth (more than 42 weeks), birth weight (less than 5 pounds, 8 ounces), birth defects, resuscitation in the delivery room, and medication administration. Other concerns that require critical treatment are respiratory distress, apnea (abnormal breathing), infections (particularly HIV, herpes, group B streptococcus, and chlamydia), seizures, and hypoglycemia (low blood sugar) (American Academy of Pediatrics, 2004). The complication of medical concerns usually requires a multi-disciplinary team of doctors, neo-specialist, nurses, technicians, and social workers.

Despite all efforts and updated technology, there is no guarantee that the babies will respond positively to treatments. Needless to say, this is an extremely stressful time for parents. The fluctuation of the infant's medical status and prognosis can be stressful and emotional, but still does not prepare the parent for the finality of death. Some infants will get better and be discharged. However, some babies do not recover. These babies die, leaving their parents to return home with no baby and uncertainty about how to handle life after experiencing this unexpected and traumatizing event.

Family-Centered Care

Families of infants diagnosed with life-limiting illnesses face emotional, social, spiritual, and financial challenges (Stayer, 2012). NICU parents are at a higher risk than parents of full-term infants for postpartum depression (PPD). The prevalence of PPD among NICU mothers is 28-70% compared to 10-15% for the mothers of term infants. Similarly, among fathers of premature infants, PPD rates are more than 50% greater than that of fathers of full-term births (as cited in Heru, 2015). The newborn's admission to the NICU is considered a crisis in the lives of expectant parents. Premature and critically ill neonates require specialized treatment and leave parents feeling powerless and intimidated because of the context of the NICU (Hall, Ryan, Beatty & Grubbs, 2015). They are bombarded with a lot of information, decision crossroads that they may not be prepared for, and uncertainty about the prognosis of their child. Given the stress factors of an infant being in the NICU, parents can easily become overwhelmed. Family-Centered Care (FCC) was designed to reduce some of the stress that parents and family members face in the NICU.

Family-Centered Care is the current philosophy of care for neonates in the NICU. This model considers how actively involved family members should be in their infant's care and embraces the notion that patient outcomes improve when considerations are made for parent-staff collaboration, diversity, respect, education, and parent empowerment (Gooding et. al, 2011). It also uses assessment of individual patient and family strengths and vulnerabilities to create treatment plans that are conducive to the infant's well-being and the family's capacity in this circumstance (Cooper et. al, 2007). The underlying principle of this model is that the NICU environment is not innately conducive to parent-child bonding because the infant's medical fragility is stressful and parents feel helpless in protecting their child. Family-centered care

expands the focus of treatment from the patient only to include the whole family (Cockcroft, 2012; Enke, Olivia-Hausmann, Miedaner, Roth, & Woopen, 2017; Gooding et al., 2011). Despite the various ways to operationalize FCC, there is a general consensus that it is the best way to treat hospitalized children (Raiskila et al., 2016) and reduces length of hospital stay for preterm infants in the NICU (Cockcroft, 2012). Fundamental components include engaging in open communication, including parents in critical decisions, and providing access to medical information (Cockcroft, 2012; Gooding et al., 2011; Harrison, 1993).

Although the term was coined in the early twentieth century, FCC is not a new phenomenon. Prior to babies being delivered in the hospital, they were usually born at home amongst family. Out-of-home deliveries significantly decreased from 44% in 1940 to 1% in 1969 and has remained consistent since then. After the transition, there was a need to control for infections and spreading of diseases, so the infant was separated from the mother until close to discharge, lasting about 10 days (Gooding et al., 2011). As a result, FCC has required some revision in the past several decades.

While infection control practices served a purpose, there were reverberations to collegial, mother-child, and staff-child relationships. Not only did this shift impact mother-child attachment bonds but also positioned physicians as the authoritarian figure heads, nurses as the gatekeepers of the infants, and families as bystanders (Gooding et al., 2011). For most parents, this practice was the way of life and no major concerns needed to be addressed. However, for some parents of critically ill and/or premature infants, the separation, the withholding of accurate medical information, the exclusion of participating in ethical decisions, and the helpless position of only adhering to physician orders were disturbing and unacceptable (Harrison, 1993).

As a result, Helen Harrison (1993) advocated for FCC for medically fragile and disabled

children through her writing “The Principles for Family-Centered Neonatal Care”. In this article, she articulates ten considerations that summarize parental concerns which include: respecting and acknowledging parents as key stakeholders by engaging in open and honest communication, having access to the same facts and interpretations of diagnostic information that medical staff have, partaking in and having the right to make decisions on whether aggressive treatment is necessary in high mortality situations. Other concerns include: having equal decision-making authority with physicians to determine treatment for pain alleviation, providing of adverse outcome information as early as possible, and having the option to make treatment decisions during pregnancy. Furthermore, the provision of appropriate developmental environments for premature infants, the ensured efficacy and safety of experimental treatment, and the development of policies around family interaction with the infant provided parents with guidelines for how they could engage in appropriate activities with and for their infant. Long-term efforts included promotion of meaningful follow-up for NICU survivors, education of compassionate care for providers, and universal prenatal care for women (Harrison, 1993).

Sharing information is essential to parents having collaborative decision-making abilities. Cooper and colleagues (2007) argue that parents usually make the best decisions for their children. In order for parents to make difficult medical treatment decisions, they must have access to comprehensive and accurate information. Similar to physicians and nurses, understanding the diagnostic implications is essential for parents to formulate well-informed treatment decisions for their child. Furthermore, the communication should not be unidimensional or unidirectional, as parents like to be active participants in the discussion. On the other hand, parents that choose to withdraw from the decision process should be relinquished to do so (Gooding et al., 2011). Having social workers available to assist with tense, emotional,

and sometimes, life-changing decisions can help facilitate this process in a manner that is conducive to leverage the best outcomes for the child, the parents, and the physicians.

Over the past 25 years, the implementation of family-centered care has expanded to include NICU department design, technology supports, and parent support groups (Hall et al., 2015; March of Dimes, 2017; Stevens et al., 2014). Recent research has begun to examine NICU design to determine what models are most cost-effective and family-centered. The open-bay NICU may have addressed the need to access multiple infants simultaneously, but is not conducive to parent-child interaction or bonding. The lack of privacy and other environmental factors have been examined in consideration for the developing neonate. Researchers have reported that high noise levels, various odors, unnecessary illumination, and constant activity interfere with an infant's ability to develop a normal circadian rhythm (Stevens et al., 2014).

NICU department design is a newer consideration for implementation of best-practices for neonatal care and FCC. Single-family rooms are more expensive considering overall costs, but have demonstrated their effectiveness in addressing some of the limitations of the open-bay design. When other FCC techniques and developmental care are considered, the costs balance out (Stevens et al., 2014). For hospitals that value parental partnership and have funding for creating optimal NICU design, this may be an option to explore.

March of Dimes (MOD) has become a leader in neonatal FCC by providing support to both parents and professionals. In 2014, MOD provided printed and on-line education to more than 93,000 families in 133 hospitals throughout the US. The organization provides staff development and educates 5,000 professionals through national health and medical forums of the American Academy of Pediatrics, Gravens Conference on the Physical and Developmental Environment of the High-Risk Infant, NICU Leadership Forum, National Perinatal Association,

National Association of Neonatal Nurses, and National Association of Perinatal Social Workers (March of Dimes, 2017).

NICU policies regulate the number of family members that can visit the infant, which can present difficulties when extended family attempts to see or interact with the baby. When used respectfully and appropriately, modern technology has proven to be an asset to FCC implementation. The internet serves as an easily accessible resource for families, particularly for families who are not ready for or open to face-to-face support groups. Web-based companies like BabyCenter and non-profit organizations such as March of Dimes and Nemours Children's Health System provide websites to assist parents with knowledge about the NICU and concerns for prematurity or child specific illnesses. March of Dimes provides families that are unable to visit the infant, due to distance or other stipulations, other technology-based resources such as pictures and videoconferencing (Gooding et al., 2011). For parents whose infant is critically ill and dying or has already died, a non-profit organization called, Now I Lay Me Down to Sleep, provides a free gift of professional portraiture of parents interacting with the infant (NILMDTS, 2017). For bereaved parents, portraits capture the last moments with the baby, creating memories for a lifetime and assisting in the healing process.

Hall and colleagues (2015) present parent-to-parent mentoring dyads and/or groups as a supplemental support to that of social worker or nurse. Some recommendations for pairing parents include matching as many variables as possible such as ethnic background, language, gestational age of infant, parent's age, family structure and size, education, and income level. While these factors influence the ability to establish rapport between veteran NICU parents/mentors and current NICU parents, the unifying experience is having a child admitted into the NICU, which sets this relationship apart from professional supports. Some researchers

endorse support and aid from other parents as a supplement to professional guidance. Parents who receive peer support have been shown to have increased confidence, empowerment, and problem-solving capacity. Other benefits to parental support include feeling capable of infant care and decrease in perceived depression, stress, and anxiety. Barriers to accessing parent supports whether hospital or community-based include transportation issues, limited time availability, lack of knowledge in services offered, and not feeling justified in using the service (as in having a full-term baby in the NICU, a short stay in the NICU, or the infant not having major health issues compared to other babies) (Hall et al., 2015).

The Family-Centered Care model has demonstrated positive outcomes, however, has limitations and barriers. Although the American Academy of Pediatrics endorses the FCC model (AAP, 2012), there are no apparent regulations that enforce actual implementation of these practices. Despite its recommendations and proven benefits, FCC has been implemented sporadically throughout the US (Gooding et al., 2011). Several studies have clearly articulated the fundamental principles and components of FCC; however, there is a lack of research in how to effectively implement it in the NICU setting with fidelity (Skene et al., 2015). The limitations that impel this research study specifically are that even with all of the financial provisions and research support, FCC does not include neonatal palliative care, neonatal hospice care, or the development of a comprehensive bereavement program as a requirement in the NICU.

As evidenced by the work of neonatal and perinatal advocates, significant research and policy development have been introduced over the past fifteen years. Much of the work has focused on the treatment of the neonate and the experience of the family while the infant is in the NICU. This work is unequivocally essential, however, should not supersede research of the social supports, policies and best practices for bereaved parents of the NICU. Given the medical

fragility of the neonates and the rate at which they die, concurrent considerations should be made to support these traumatized parents. In this department, parents face the fragility of life, requiring adjustment to post-delivery plans. Parents may not know what to expect or who to ask but may need guidance with transitioning from the NICU to daily functioning activities, especially after the death of their newborn.

Hospice and Palliative Care

Death is a reality in the NICU and healthcare providers will inevitably experience working with perinatal death and bereavement of parents/family (Kain & Wilkinson, 2013) and should be equipped to respond accordingly. Death in the NICU is an overt reminder of one's own mortality and should be acknowledged and addressed before dealing with it at work. Advances in medical technology have prolonged the lives of neonates that would have otherwise died. Due to successes in technological advances, societal belief in medical miracles can be unrealistic, particularly for neonates born at the extreme end of viability (22-26 weeks of gestation).

Infants born at the cusp of viability need several treatment interventions and social considerations for the family to determine whether an infant can survive outside of the womb. The primary factor is the length of gestation. While legal definitions of viability are regulated by individual states in the US, ranging from 19-28 weeks of gestation, contemporary standards use 22-23 weeks as a minimal standard for resuscitation (Arzuaga & Lee, 2011). Other factors that are considered for a newborn's likelihood of survival are weight, gender (Kain & Wilkinson, 2013), if the infant is a singleton or one of a multiple set, and if the mother was provided antenatal steroid therapy (Suresh & Fay, 2013). NICU staff work diligently to save the lives of

infants with life-threatening illnesses, but often face the reality that some babies will die, despite all treatment efforts.

Given the fragility of premature infants, medical staff must consider the ethical obligations of continuing curative treatment versus changing its focus to accepting that death is eminent and providing comfort care that is essential for the infant and family. In adult medicine, physicians can generally predict the indicators of terminal illness and when patient will no longer respond to treatment.

Hospice care and palliative care are often used interchangeably; however, this is a misconception and they have distinct meanings and purposes. Hospice care (HC), also called end-of-life care (EOL), is defined as “a cluster of comprehensive services that address the needs of dying persons and their families, including medical, spiritual, legal, financial and family support services” (World Health Organization (WHO), 2004, p.33). The current operating definition of palliative care (PC) is providing “an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual” (WHO, 2017, para. 1).

Admittedly, there are similarities between each service that include promoting quality of life, incorporating the family as a social system/resource, and considering the comprehensive domains that contribute to the patient’s and family’s wellness. On the other hand, understanding the distinct differences and the purposes that they serve allow patients and families to effectively and appropriately determine which service applies to their situation. Hospice care requires that the patient has a prognosis of living six months or less and does not allow for curative treatment.

Hospice providers are also required to have a bereavement program that minimally consists of memorial services and office or in-home individual and group counseling services. The program is designed to assist the family up to one year following the death of a patient (Hutcheson, 2011).

Conversely, palliative care permits both curative treatment and comfort care (pain management). Palliative care ensures that the patient's quality of life is at its best by supporting family needs and desires. Pediatric Palliative Care (PPC) addresses the needs of children between infancy through young adult (under 21) by providing treatments that aim to relieve suffering, improve the child's quality of life, facilitate informed decision-making by patients, family members and health professionals, and assist with on-going coordination of care among clinicians across various sites of care (AAP, 2013). While the coverage is not the same, both Medicare and Medicaid insurance cover hospice and palliative medical services. Legislative policy and funding guide practice, but they do not guarantee that all populations will receive the appropriate benefits. It is presumptive to explore the current gaps in service without the historical reference to both types of service.

Dame Cicely Saunders founded hospice treatment for patients in London whose illness could not be cured with medical treatment (Hutcheson, 2011). Her work heavily influenced end-of-life care in the US. Known for her work with the dying, Dr. Kübler-Ross advocated for the option of home care rather than institutionalized treatment for dying patients (NHPCO, 2017). Replicating practice and incorporating research was not sufficient in ensuring that patients received the best care at the end of their lives. Advocacy for legislative policies was necessary to require hospice care as an entitlement for terminally ill patients. The first hospice legislation in the US was introduced in 1974 to get federal funding, but was not enacted. In 1980, standards for hospice were created by the Joint Commission on Accreditation of Hospitals (JCAHO). During

the 1980s, hospice models were evaluated for its cost-effectiveness. After these demonstrations, the Medicare Hospice Benefit was made permanent. The 1990s marked a time of research, program initiative and public forums. Many years of justification and advocacy resulted in hospice being accepted as part of the continuum of health care (NHPCO, 2017).

Hospice services not only allow the terminally ill patient to die with dignity but improve family functioning and caregiver satisfaction (Hutcheson, 2011). Its core providers are nurses, physicians, social workers, bereavement services, nutritionists, and spiritual advisors. Some providers offer non-core services such as home-health aids, occupational therapy, and physical therapy. Others include therapeutic voluntary services like massage, companionship, music, and pet therapy. Each provider has a specific function in ensuring that the patient's and family's needs are assessed and treated (Mizrahi and Abramson, 2000).

Medical social workers provide services and references based on the patients and family's preferences. They can also assist with advanced care planning, funeral service planning and addressing needs of minor children affected. Hospice providers are required to have a bereavement program that minimally consists of memorial services, office or in-home individual and group counseling services. The program is designed to assist the family up to one year following the death of a patient (Hutcheson, 2011). Although the HC and EOL movement was expanding, medical care for patients with life-limiting illnesses was fragmented, health care costs continued to rise, and physicians provided minimal communication with patients and families. As a result, medical organizations began to consider what factors contributed to patient and family dissatisfaction (NHPCO, 2017).

Palliative care practices evolved out of the work of hospice care. The World Health Organization (WHO) established the first formal definition of palliative care in the 1990s to

highlight comfort care services, given the emergence of new technology and improved pharmaceuticals that prolonged life expectancies of advanced cancer patients (Stayer, 2012). By the late 1990's the HC and PC movement was strongly established, requiring additional education for medical personnel and increased awareness in public knowledge (WHO, 2017). Reports were published challenging health care providers to address issues around pain management, educational barriers, limited research in EOL care, and improving accountability for quality of care.

Pediatric palliative care (PPC) has become a recognized medical specialty and practice over the past 15 years. Some antecedents to PPC exist in the research conducted to improve the health care system for the populations of aging, HIV, and pediatric oncology. Pediatric palliative care addresses the needs of children between infancy through young adult (under 21) by providing treatments that aim to relieve suffering, improve the child's quality of life, facilitate informed decision-making by patients, family members and health professionals, and assist with on-going coordination of care among clinicians across various sites of care (AAP, 2013). In 1998, the Children's Project on Palliative/Hospice services (ChiPPs) was compelled to identify major issues facing the field of PPC. ChiPPs defined PPC as, "both a philosophy of care and an organized program for delivering care to children with life-threatening conditions" (Stayer, 2012, p.351). During that time, the American Medical Association reported that less than 1% of children who died annually received palliative care services prior to death (Stephenson, 2000).

National health organizations began acknowledging issues and concerns for pediatric patients. The Committee on Bioethics and Committee on Hospital Care of the American Academy of Pediatrics (AAP) (2000) reported on a policy statement for children's palliative care services. The report highlighted that an estimate of one-third of children's hospitals across the

country admitted to having palliative care. Yet, very few had organized palliative programs. This document also summarized principles recommended for integrated PC. Importantly, the family's needs were considered in addition to the needs of the child. The minimum standards of PPC were summarized in five major themes. Pediatric palliative care needed to have a mechanism to ensure a seamless transition between hospital, institutional and/or home settings, access to at least one consistent caregiver, availability of expert pediatric palliative medical care 24 hours a day/365 days a year, availability of an interdisciplinary team (with expertise in the physical, psychosocial, emotional, and spiritual needs of the child and family), and a core team that minimally consisted of a physician, nurse, social worker, spiritual advisor, and child life therapist (AAP, 2000).

The report reinforced that initiation of PPC should be made when a life-threatening diagnosis is made. Additionally, it should continue throughout the course of treatment, regardless of the outcome. Unlike adult hospice care, it was stressed that curative and palliative measures must be undertaken simultaneously. Therefore, patients under the age of 21 were permitted to have concurrent hospice and palliative treatment under the Patient Protection and Affordable Health Care Act of 2010 (ACA). Further, pediatric hospice care should be seamlessly continued, even if curative measures (palliative care) are abandoned. The one obstacle that arose was that the ACA covers physicians, but the non-clinical (medical) service providers are not covered for billing under public or private insurances. (AAP, 2000; AAP, 2013; Kang & Feudtner, 2012).

The first decade in the 21st century was crucial in creating standard practice. Key national medically-focused organizations created curricula for interdisciplinary teams addressing pediatric issues including perinatal and neonatal patients that included The Initiative for Pediatric Palliative Care, The End-of-Life Nursing Education Consortium, The National Hospice and Palliative Care Organization (NHPCO), and the American Academy of Hospice and Palliative

Care (NHPCO, 2017). Additionally, the Institute of Medicine's (IOM) Board on Health Sciences Policy released a report in 2003 targeting children who die and their families. This report noted the fact that medical and supportive care was lacking for children who were critically ill or dying. This was a significant turning point for the work of pediatric palliative care. In response, The Center to Advance Palliative Care (CAPC), a key proponent of PC, increased the availability of palliative care services to those facing life-threatening illnesses. CAPC provided the training and mentorship needed to create sustainable hospital-based and community-based PC programs (Kang & Feudtner, 2012).

Although much work had been done, research and practice continued developing. In 2006, Hospice and Palliative Medicine (HPM) was officially approved as a subspecialty (Kang & Feudtner, 2012; NHPCO, 2017). Its recognition established it as a field that “seeks to improve quality of life and reduce various forms of distress for patients and their families in the face of serious life-threatening or inevitably life-shortening conditions or when end-of-life care or bereavement services are needed” (AAP, 2013, p.966). The first set of national pediatric standards were created in 2009 (Standards of Practice for Pediatric Hospice and Palliative Care Programs) as an addendum to the national hospice standards. Since the AAP adheres to policy statements for only up to five years, it was revised in 2013.

The American Academy of Pediatrics' (2013) updated guidelines and recommendations included expectations for health care interdisciplinary teams, bereavement support, staff and education, curriculum development, and policy changes. For all hospitals and large health care organizations that frequently provide care to children with life-threatening illnesses, it suggests that dedicated interdisciplinary specialty PPC and pediatric hospice care (PHC) teams be provided. The team's collective expertise should address the child's and family's physical,

psychosocial, emotional, and spiritual needs. Mature teams include physicians, nurses, social workers, case managers, spiritual care providers, bereavement specialists, and child life specialists. All of these positions should be paid, full-time staff, trained in PPC and PHC, and available for consultation at any time.

Other recommendations included providing bereavement care for anticipatory grief, continuing after the death of the child, and throughout the bereavement period. Grief for bereaved parents usually last longer than a year and providing support to the family in carrying out important religious, cultural, and family rituals is essential to their healing process. The American Academy of Pediatrics continued with recommendations that stress PPC and PHC competencies should be offered as a core component of medical school, residency, fellowship, board certifying examinations, and continuing education curricula. Lastly, it was suggested that considerations be made to expand the criteria for HC eligibility by removing the six-month requirement for children, including respite services for family caregivers, and adequately covering treatment services beyond physician care (AAP, 2013).

In 2014, the World Health Assembly (WHA) (the decision-making and governing body of WHO) unanimously adopted a resolution urging all member countries to ensure access to PC for people with life-threatening illnesses. The resolution outlines clear recommendations that all national health policies and budgets include PC and that it be included in the curricula for health professionals. It highlights the critical need for countries to ensure that there is an adequate supply of essential PC medicines, including those needed to alleviate pain and other symptoms. The resolution continued with suggesting that the WHO and palliative care experts provide guidance in implementation of PC to countries facing significant barriers. Some of the countries

identified as having exemplar palliative care policies and practices are Australia, Costa Rica, and South Africa (De Lima & Pastrana, 2016).

Pediatric palliative care and pediatric hospice care are essential components of medical care for children and even more for perinatal and neonatal infants. Although the HC and PC industry continues to expand, more service providers are less willing to provide care to children (AAP, 2013) and PC for neonates is almost non-existent (Samsel & Lechner, 2015). Many Westernized countries are dealing with similar issues around the challenges of implementing PPC. There is limited access for newborns to get PPC even though they are identified as a ‘child’ in the policy statements of well-respected organizations like the AAP, the ChiPPs, and the WHO (Kain & Wilkinson, 2013; Samsel & Lechner, 2015). The two primary reasons that contribute to this disparity are that treatment plans are sometimes too radical and unfamiliar and that insurance coverage is usually restricted or limited (Kavanaugh et. al, 2015). Another reason for minimal implementation is that changing the focus of treatment from curative neonatal care to comfort care can be perceived as “giving up” or “failing,” which is antithetical to the NICU’s contemporary practices (Craig & Mancini, 2013).

Globally, guidelines of pediatric palliative care and end-of-life services also make provisions for perinatal support. In 2010, the British Association of Perinatal Medicine (BAPM) published guidelines that align with the AAP, the IOM, and the WHO, highlighting the benefits of parents taking an active role in treatment planning and the need for parents to care for their baby while alive and after death. Accepting that death is eminent and that there are no other treatments that can save the baby’s life is difficult. An option to permit parents and family time to privately interact with the baby and/or express the intense emotions as the infant is dying is to provide in-home or community-based settings for hospice and palliative care. Despite this, there

is controversy about whether parents should have the option to determine the location of palliative and hospice care services. In the United Kingdom (UK), 93% of neonatal units have access to a community-based children's hospice and only 63% refer babies for palliation and one-third never discharge babies home for hospice services. By the BAPM standards, certain infants qualify for in-home or facility hospice care, which include: 1) the seriously ill or extremely premature infant who is unlikely to survive, 2) infants who require long-term technological support, and 3) infants who have irreversible conditions that is likely to result in early death (Craig & Mancini, 2013).

The option to send a baby home or to a residential HC facility to die may be questionable, but this option is already standard practice for adults. Of the total number of adult patients receiving HC in the US, 66% of them receive services in their home (NHPCO, 2012). Likewise, this option allows the family to interact with the dying baby in a private setting with 24-hour access to skilled nurses and medical care, rather than experiencing this ordeal in front of other patients and families. Watching one's baby die is not ideal, but creating momentous memories of his/her life will be valuable to the parents and family in acknowledging the baby's role as a significant family member. Although there are well-developed community-based PC and HC services in the UK, 98% of neonatal deaths take place in the NICU (Craig & Mancini, 2013). Further research and best practices need to be documented; however, the UK has clearly established a precedent in serving infants with PPC. Whether parents opt to take their infant home to die surrounded by loved ones or remain in the NICU, the necessity for medical, social, and emotional support is evident and is a viable option.

Regardless of the challenges in implementing pediatric palliative care to neonates, some institutions are attempting to push boundaries by examining the needs of the infant and family,

while considering access to technology. Kaempf, Tomlinson & Tuohey (2016) conducted the largest single study with the descriptive of establishing formal guidelines for extremely premature infants (EPI) (between 20-26 weeks of gestation over an 18-year period). The Providence Saint Vincent Medical Center is a high-risk perinatology service and a Level III NICU with full array of subservice support in Rhode Island (RI), USA. Through a retrospective chart review, the authors found that when given a choice of PPC versus NICU treatment, most women choose NICU care. It was also observed that a significant portion of women choose PPC, especially for EPIs. When parent preferences of PPC occurred at 25 weeks or later, physicians had to follow the mandate of resuscitation, which also required NICU care. Families needed to determine whether the long-term chronic neurological and health issues of the newborn were acceptable for them to deal with. Medical staff needed to be cautious in challenging the family's perspective. Due to the fragility of the infant's condition, PPC versus NICU care could not be reduced to just doing what's best for the infant but needed to consider what is in the best interest for the woman, the family, and the infant. The recommendations stated that perinatologists and neonatologists should acknowledge their own biases that can be influenced by professional and career goals, research projects, income, and personal child-rearing circumstances. This study produced culturally and religiously sensitive counseling guidelines that promoted dialogue between staff and parents.

In the US, NICUs do not have sufficient funding or access to PPC programs, but the necessity of providing this service is evident in certain regions. Samsel & Lechner (2015) evaluated the practices in a regional level IV NICU in RI, USA after a neonatal palliative care (NPC) pilot initiative was implemented. The initiative included educating staff on the current status of NPC and EOL care, use of palliative medications (used to assist infants with comfort

and pain management), establishment of written guidelines, and review of electronic medical records. The research team, made of up of an exploratory group of current staff in the NICU, also created opportunities for parent/family bonding time with the infant. Results indicated that after the implementation of this initiative, physicians were more likely to redirect treatment to PPC when the likelihood of death was eminent. Recommendations for future research suggested that an evaluation of whether embedded teams versus ancillary teams provide the most effective NPC services (Samsel & Lechner, 2015).

Progressive work is being conducted by policy makers, staff, and researchers, but some changes occur because parents refuse to accept subpar treatment. The Association of Women's Health, Obstetric and Neonatal Nurses (AWHONN) conference (2016) featured Katherine Donaldson's work discussing the pros and cons of passing legislation that standardized medical and bereavement care for families dealing with perinatal loss. The bill entitled, "Autumn Joy Stillbirth Research and Dignity Act" was introduced in New Jersey (NJ) in 2013. This bill was the result of the efforts of a couple who found out that their baby no longer had a heartbeat during her second trimester and felt that their loss was not acknowledged. The parent advocates worked tirelessly for about three years to be justified in expecting better treatment after birthing a stillborn baby. While the legislation specifies "stillborn", the protocol on bereavement care will impact all perinatal infants (stillborn neonates who were 20 weeks or greater of gestation or neonates who had unintended deaths and weighed 350 grams or more) (Donaldson, 2016). The bill, enacted in 2016, mandates the NJ State Department of Health establish protocols for stillbirths, including autopsy and collection of other identifying data to be stored in a research database. It also requires the state boards of Medical Examiners, Nursing, Psychological Examiners, and Social Work Examiners to develop policies that will inform medical

professionals in helping families access psychological counseling and other emotional support (Livio, 2014). This type of support is necessary to ensure that bereaved parents are receiving a minimum standard of care regardless of hospital location.

As evidenced by the policy recommendations produced by several national and international organizations, there is a clear need, but seemingly there is one underutilized resource and that is social workers. Medical and nursing literature for hospice and palliative care models, and the interdisciplinary team, usually include social workers as essential members/staff, but do not articulate what they contribute. The intersectionality of finances, spiritual beliefs, family values, and family dynamics contribute to the family's response to infant's prognosis. Understanding the family's psychosocial contexts is necessary in how they are approached with sensitive information and connecting them with the appropriate resources can set the trajectory for their recovery (Hartman-Shea et al., 2011). Social workers are adept in advocacy, coordination of services, navigation of systems, provision of clinical counseling, and practice of self-reflection, and should be recognized for the expertise that they bring to medical treatment (Masiriri, 2008; McCoyd & Kerson, 2013; Mizrahi & Abramson, 2000).

Cost is an obvious factor in determining who is directly responsible for meeting the needs of the bereaved family after discharge and requires a complicated response. Hospitals and medical institutions create policies and protocol that support both patient's needs and business operations. The Institute of Medicine (2003) identified a hospital in New York that discussed their inability to hire a social worker, pastoral counselor, or volunteer coordinator due to funding issues. The administration was also concerned that adding the responsibility to current staff may generate greater levels of burnout. It is presumable that there are other hospitals that have similar perspectives, but making comprehensive bereavement support available to families is necessary.

In the weeks following a newborn death, parents experience shock, sadness, and difficulty completing “normal” daily tasks (Badenhorst and Hughes, 2007). It is unreasonable to expect that they would be coherent and or functioning well enough to follow-up on resources provided at the time of the loss. Since clinical practice is heavily driven by policies supported by funding, policy directives should be informed by current practice, examination of curriculum design of academic programs, institutional capacity, engagement of stakeholders (families and staff), and ethical obligation to the critically ill neonates (Kain & Wilkinson, 2013).

Recommendations for care clearly outline and define the work of physicians and nurses, but the expertise of the social worker appears to be overlooked in hospice/end-of-life and palliative care literature.

Social Work Discipline

In 2014, there were 650,000 social work jobs with the expectation that the profession would grow at least 12% between 2014 and 2024 (NASW, 2017). Social workers are employed in a variety of settings and specialize in a range of populations. Their general purpose is to assist people in overcoming difficult circumstances like physical illness, trauma, mental health issues, discrimination, abuse, and addiction; non-clinical activities include promotion of social justice through advocacy, research, and policy development. More narrowly, the National Association of Social Workers (NASW) defines the work of a clinical social worker as “interventions directed to interpersonal interactions, intrapsychic dynamics, and life-support and management issues. Clinical social work services consist of assessment; diagnosis; treatment, including psychotherapy and counseling; client-centered advocacy; consultation; and evaluation” (NASW, 2017, para 7). Social workers are guided by six core values that include social justice, dignity and worth of the person, importance of human relationships, integrity, and competence. The

person-in-environment perspective is the fundamental principle that influences how the worker provides appropriate services to clientele. The Council on Social Work Education (CSWE) accredits academic institutions to ensure the training for generalist and advanced clinical practice through the mastery of the core competencies (i.e. knowledge, research, values and practice skills) of social work (CSWE, 2015).

In a careful review of five CSWE accredited college and university websites in the Philadelphia metropolitan region, the Master of Social Work (MSW) or equivalent curricula was analyzed to determine criteria for graduation. All of the programs offered a variation of in-class, distance-learning, and weekend or professional work (part-time) scheduling with the option of two core tracks of clinical practice or macro/policy (administrative and advocacy focus). Some institutions have expanded options to include nonprofit management/leadership, integrated healthcare, and dual degree programs with business, public health, and law schools. The curricula design did not appear to focus on settings but specific populations or treatment modalities such as children and families, aging, LGBTQ, developmental disabilities, poverty, and substance abuse treatment. It is noted that only two of the five schools included an elective on grief and loss, but the remaining three schools offered classes with a trauma focus. Although students can choose a specific track to study, all of the schools required a minimum of 1,000 hours of supervised field study to graduate from the MSW program. The emphasis on students experiencing work with different groups of people in various settings prepares them for practice outside of the classroom.

While the traditional MSW programs are eclectic, existing end-of-life literature identifies gaps in the curricula. Because grief and loss, EOL, and trauma focused courses are not required as core content, some students may not be exposed to these noteworthy issues. Further, the core

courses like Human Behavior in the Social Environment and Practice of Social Delivery may address these issues, but only in a limited capacity (Csikai & Raymer, 2005; McCormick et al., 2010). The weaknesses in MSW education should be acknowledged but should not overshadow the expertise and skills that social workers have in working with individuals, families, communities, and institutions.

The History and Role of the Medical Social Worker

The function of social workers in medical settings has evolved with the adoption of a formal medical model from community-based dispensaries in the late 1800s (Reisch, 2012) to institutions and working jointly with doctors in the early 1900's (Kitchen & Brook, 2005). Dr. Richard Cabot acknowledged that medical treatment is futile without a social worker providing the education alongside of the physician. Cabot's perspective implied that social workers were more equals and established an inter-professional rather than a superior-subordinate relationship (Reisch, 2012). In 1912, Ida Cannon, known as a pioneer in medical social work partnered with Simmons School of Social Work and the Massachusetts General Hospital (both affiliates of Harvard Medical School). Her work led to designing a specialized course for medical social workers and a book entitled, *Social Work in Hospitals: A Contribution to Progressive Medicine* (Maramaldi et al., 2014). In 1918, she became one of the founders of the American Association of Hospital Social Workers (AAHSW) and helped to develop the Committee on Training for Hospital Social Workers which identified the need for professional education. During this time, over 100 hospitals in 35 cities created social work departments, and by the late 1930s, there were over 1,600 such departments in the US (Reisch, 2012).

Medical social workers operate in various capacities including assessment, discharge planning, referral facilitation, counseling, and psychoeducation. Medical social work roles have

progressively become more professionalized by significant social events (like the Great Depression, the World Wars I and II); the advocacy and professional movement of the social work discipline at large; the changing demands in medical policies (Social Security Amendment, Medicaid and Medicare Acts); the technological advances in medicine; public health orientations; and the societal expectations of receiving quality care (Combs-Orme, 1987; Kitchen & Brook, 2005; Reisch, 2012).

The practice of health care billing and payment systems have significantly changed in the past 40 years. Medicare and Medicaid regulations influenced hospital billing practices, requiring the adoption of the reimbursement system called Diagnostic Related Groups (DRGs) in the 1980s. Previous protocol for hospital billing was calculated after discharge. However, this new system anticipated of the length of a patient's hospital stay, the types of treatment required, the amount of resources the patient would consume, and the total cost of treatment. Therefore, hospitals were paid according to the patient's diagnosis rather than the types of services rendered (Ziegenfuss, 1985, as cited in Holliman, 1997). In efforts to survive medical costs and implementation of new reimbursement protocol, hospitals transitioned from a service orientation to a business-driven model.

As administrations, policies, and missions change, hospital social workers have accommodated the demands and needs of the hospital and patients, particularly around speedy discharge planning, often doing more with fewer resources (Mizrahi & Berger, 2005). The changes were made in lieu of ensuring that the hospitals received full reimbursement, but did not come without repercussion as sources of dissatisfaction were noted. Among social workers, the DRGs created larger caseloads, pressure to discharge patients quickly, and rivalry with other professions (Holliman, 1997; Judd & Sheffield, 2010). Progressing into the 1990s, it is well

documented that the reorganization of health care (called reengineering) negatively impacted the hospital social worker's role by requiring cross-training of disciplines, creating standardization of care, dismantling/decentralizing of social work departments, and increasing the demand for work in specialized areas like pediatrics, oncology, etc.

This process transferred social work supervisory/middle management tasks to other professionals with areas of expertise in relevant content areas, streamlined daily tasks into case management departments and promoted competition among social workers and nurses in addressing psychosocial outcomes (Auerbach, Mason & Heft LaPorte, 2007; Craig, Betancourt, & Muskat, 2015; Judd & Sheffield, 2010; Reisch, 2012). As a result, nurses have taken on a shared role of discharge planning and case management (Auerbach, Mason & Heft LaPorte, 2007). This practice makes the significance of the social worker questionable, especially when eliminations are made due to funding restrictions. Other factors that contributed to a shift in social worker roles are the growth of "managed care" under health maintenance organizations (HMOs), the increasing complexity of the national health care system, the expansion of the number of private hospitals, the limited support for social services by insurance companies, and the lack of evidence-based practices of social work contribution to health care (Craig, Betancourt, & Muskat, 2015; Holliman, Dziegielews, & Teare, 2003; Maramaldi et al., 2014; Reisch, 2012).

Compared to other industrialized countries with universal health care, the USA's health care system fares poorly. In 2012, the USA spent more than 2.8 trillion dollars on health care, which is more than the combined expenses for the United Kingdom of Great Britain and Northern Ireland combined (Rice et al., 2014). Despite the noted spending, affordable access to healthcare and other gaps remain. The ACA, fully implemented in 2014, was designed to

transform the healthcare system with cost containment options and to ensure that all Americans have access to quality and affordable health care (Patient Protection Affordable Care Act, 2017). It is unclear what full implications have transpired since the enactment of the ACA for medical social workers; notwithstanding, there have been presumptions of likely circumstances. With the expansion of Medicaid and Medicare coverage, access to inpatient and outpatient hospital care could require an increase in the provision of health education and community referrals, absorbing larger caseloads, or staffing cuts if budgets are in question (Reisch, 2012).

Some institutions and researchers questioned which hospital professionals are most qualified as discharge planners (Holliman, 1997). Holliman, Dziegielews, and Teare (2003) examined the differences between social work and nurse discharge planners. Initially it was noticed that smaller and private hospitals tended to use nurses as discharge planners while large federally and state funded hospitals tended to use social workers. A major difference between the two disciplines is that social workers perform psychosocial assessments and screenings for abused or high-risk patients and facilitate group and grief therapy while nurses primarily address needs around patient condition, symptoms, and treatment. Apparently, the tasks performed by nurses are more quantifiable, allowing for insurance reimbursement. Conversely, the social work tasks were identified as dispensable and less justifiable for reimbursements (Reisch, 2012). Descriptors such as “providing support,” “counseling,” and “working with family” do not capture the full extent of the interdisciplinary clinical social work practice (Maramaldi et al., 2014, p. 533). This practice lends itself to significant pay differentials between nurses and social workers.

Holliman, Dziegielews, and Teare (2003) indicate that both disciplines agree that social workers are better qualified to provide concrete services such as assisting patients in

understanding insurance and financial planning, setting up home health aides, and connecting patients with in-community support. On the other hand, both social workers and nurses felt they were competent and qualified enough to provide counseling support to patients and their families. There is dissonance in the health care practice that acknowledges that social workers are essential for assessing patient social supportive needs and discharge facilitation, yet they are also expendable when funding is a concern (Auerbach, Mason & Heft LaPorte, 2007; Maramaldi et al., 2014). More recently, other health professionals have recognized that social workers utilize strong assessment skills that incorporate systems and community knowledge to solve problems (Craig, Betancourt, & Muskat, 2015).

ICU Social Worker

Since there is minimal literature on social work practice in the neonatal and pediatric ICU, much of the information presented is drawn from the adult ICU. “Social work in the ICU has become a subspecialty of medical social work just as the ICU’s themselves have become more specialized” (McCormick, 2011, p. 55). Treatment in the ICU is typically aggressive for the survival of the patient but does not account for previous family dysfunction and how the admission of a loved one into the ICU disrupts daily interaction. In this setting, there is tension and anxiety due to fear of the unknown, uncertainty around treatment decisions, and a perceived lack of communication between staff, patients, and family members (Joseph, Berzoff, & Dobbie, 2009). Addressing issues around critical illness for a family member usually comes as a crisis to families and social workers provide the interventions to help patients, families, and staff cope (Hartman-Shea, 2011).

In their systematic review of the literature, Hartman-Shea and colleagues (2011) found several themes in social work activities in the ICU such as counseling professional, facilitator of

communication, and resource agent. Providing psychosocial counseling and familial support were identified as the most frequent activities and were indicators of family satisfaction. The social worker's assessment of the family's response to crisis and understanding their communication was found to support effective and empathetic interactions between the staff and family. The researchers determined that social workers are distinctively qualified to provide practice in critical care units and require an understanding of family dynamics, team functioning, crisis response and EOL care (Gwyther et al., 2005; Hartman-Shea et al., 2011).

Interdisciplinary Team

Determining the best approach to treatment is not always clear and each component of the medical team presents their perspective in pursuing the course of care. Should the interdisciplinary team focus solely on their perception of the infant's viability, the wishes of the family, or a combination of both? For decades, medical institutions and researchers have questioned the welfare of the child versus the welfare of the parents, the quality of life of the child versus the decision for treatment of the parent, or the life of the child versus the cost to society to save the life of the child (Silverman, 1992; van Manen, 2014). Given the complexity of health issues and approach to treatment, the full interdisciplinary medical team is necessary in determining the course of treatment for NICU infants.

Ida Cannon (1915) postulates that "the charge of the hospital social worker was to assume the role of "interpreter," and to bridge the communication gap between patients, families, and other providers" (as cited in Maramaldi et al., 2014, p.534). Almost a century later, the IOM (2008) report details the significance of communication to meet the psychosocial needs of the patient and the family. Social work's ecological perspective ideally positions social workers as the most qualified to facilitate meaningful interactions between patients, families, and

interdisciplinary teams (Maramaldi et al., 2014). Whether the social worker's role is primarily discharge planning or an active part of coordinated services, the support that the social worker provides to both the interdisciplinary team and the parents facilitates improved care (Kitchen & Brook, 2005). The social worker's role is unique in that he/she is the only member of the team that is not formally trained in medicine. Embedded among physicians, surgeons, nurses, nutritionists, and technicians, social workers provide comprehensive, integrative care for patients and their families. Social workers not only assist with connecting the family to resources and discharge planning, but also serve as a counselor and advocate, educating the medical team about the needs and wishes of the family (Maramaldi et al., 2014; Mizrahi & Abramson, 2000; Mizrahi & Berger, 2005; Smith, 1987).

Much of the research involving communication with parents focuses on the dynamics between the nurses and doctors, rather than social workers (Green, 2015). Mizrahi and Abramson (2005) examined the relationship between the physician and the social worker and found that doctors had limited knowledge regarding the breadth of skills possessed by social workers. Physician participants assumed that social workers primarily functioned as discharge planners. The social workers, however, provided a comprehensive biopsychosocial assessment along with relevant resources for the families served. In spite of the differences between how the physicians understood the social worker's role versus the social worker's identified role, the physicians acknowledged the value of having a social worker on the interdisciplinary team. Given the direction that insurance companies and other funders are moving toward in collaborating, it behooves social workers to both advocate and demonstrate the complexity of coordinating, assessing, and advocating skills to other professionals (Mizrahi & Abramson, 2005). This will not only improve communication in collaborative entities, but also keep social work relevant in

the ever-changing world of patient care. Ultimately, having the social worker on the team, will promote advocacy, support, and empowerment for the patients and families served.

In a longitudinal study, Mizrahi and Berger (2005) argue that with increasing demands and needs, it is necessary to have a social work component to the medical team. The team is formed to collaborate on the medical treatment of the infant. Mizrahi and Abramson (2000) define collaboration as “the undertaking of a joint initiative to solve shared problems and achieve common goals, usually characterized by reciprocity, equality, coordination, and shared decision making” (p. 3). Burns, Mitchell, Griffith, and Truog (2001) suggest that treatment of patients with life-threatening illnesses or conditions may be divided into three parts: the needs of the patient, the needs of the family, and the needs of the medical/clinical team. While the center of the interaction between the interdisciplinary team members revolves around patients and their families, the needs and concerns of the medical team cannot be overlooked. These teams may not work together easily or efficiently, but seem to accomplish necessary goals despite competing philosophies or inter-professional agendas (Lingard et. al, 2013). Social workers bring continuity and understanding when considering all stakeholders in medical treatment.

Generally, interdisciplinary teams collaborate around area of expertise. At hospitals, they are usually led by physicians (Mizrahi & Abramson, 2000). Physicians are primarily concerned with the life of the patient (in this case, the neonate), while the social worker is concerned with the overall quality and care of the family as a cohesive unit. Additionally, Kitchen and Brook (2005), propose that social workers who function as the coordinator of the medical teams not only increase access to accurate referrals upon discharge, but provide increased awareness to physicians of the family’s cultural preferences, financial resources, and access to community

services. The social work principle of looking at the family holistically allows for assessment of how each decision made for the child will impact the whole family (Kitchen & Brook, 2005).

Some of the issues that arise from the medical team stem from coordination and communication and secondary trauma for staff. Caring for medically fragile or dying children evokes feelings of hopelessness (Walsh, 2013) and can be emotionally draining and stressful (Janzen, Cadell, & Westhues, 2004) for medical staff. The combination of compassion, hopelessness, and uncertainty can be challenging for staff, causing miscommunication between staff and parents (Walsh, 2013). Boss and colleagues (2013) indicate that much of the distress that occurs for ICU clinicians stem from conflict between the family's wishes for treatment and what is in the best interest for the patient. Some staff are extremely committed and empathic to parents in this ordeal. In efforts to establish rapport and be supportive of the parents' needs, staff may blur the lines professionally by suggesting that what they desire for the family is the best treatment option. While advocacy is acknowledged, crossing professional boundaries should be avoided (Fegran & Helseth, 2009).

Mizrahi and Abramson (2005) discuss the importance for acknowledgement of the expertise that each medical team member brings. They further articulate that physicians are trained to make medical treatment decisions in isolation, not fully understanding the capacity of the social worker. Furthermore, Boss and colleagues (2013) emphasize that neonatologists are rigorously trained for the NICU service; however, communication skills have not been systematically incorporated into their training. Families describe physician communication to be brief and difficult to understand. In spite of these identified challenges, the interdisciplinary team approach reduces the autonomy for the physicians, promotes integrated and effective treatment, and encourages dialogue between staff that may not otherwise interact. The benefit of effective

communication between the team members is that parents and patients get the best coordinated care and support.

Bereaved Parents

While death is a normal part of the life cycle, the loss of a child can have substantial psychological impact and is life altering (Cacciatore & Bushfield, 2007; Sturrock & Louw, 2013). Between the time of conception through the first 28 days of life, 20-25% of all pregnancies result in some type of loss (Hutti, Armstrong & Myers, 2011). The terms prenatal, perinatal, and postnatal loss refer to losses prior to, during, or up to one year after birth, respectively (Christiansen, 2017). However, perinatal loss is typically understood as a comprehensive term to describe these losses. Infant death is devastating, traumatic, and can occur at various stages of pregnancy through the first year of life. Advances in medical technology and treatment in the NICU creates dissonance with the reality that all babies will not survive birth.

The practice of family-centered care has become a critical component in providing hospital treatment for children; however, in the mid-20th century, health care providers assumed that certain restrictive practices were for the benefit of the parent. Historically, treatment in the NICU has considered the family's psychological well-being secondary to the infant's needs (McGrath, 2001), so when the baby died, parents deferred to the guidance of medical staff. Infant loss during that time was considered a grief-producing experience, so mothers (and fathers) were separated from their stillborn or dying infant under the credence that grief could be prevented if no attachments were formed (Koopmans et al., 2013).

O'Leary and Warland (2013) showed that many parents who never saw or held their stillborn or dying baby regretted it years later. Adverse psychological outcomes were thought to

be exacerbated by holding one's stillborn or terminally ill newborn. Parents felt that opportunities to acknowledge the baby and mourn their loss were denied. Captured experiences of bereaved parents and adult subsequent children of bereaved parents noted that medical staff, families, friends and sometimes fathers discouraged mothers from seeing and holding the baby, attending the baby's funeral, or even talking about the death after returning home. It was still common practice for mothers to be excluded from memorializing and participating in the rituals well into the 1970s. Parents were encouraged to become pregnant immediately to help with the grieving process and "move on" with their lives. Some parents received clear messages that they needed to move on by the reactions from family members. One bereaved parent stated:

My granddaddy let me cry. He sat and cried with me. Everybody else praised me for having a stiff upper lip, being so strong." [Her husband, on the other hand, did not share any of her grief.] "He wouldn't allow me to talk about the baby. So we didn't share the grief, it was all bottled up, and it stayed that way. The death of my first child was totally unresolved as far as [grief] was concerned. (O'Leary & Warland, 2013, p. 333-334).

Mothers were in the hospital recovering for about ten days and did not have much control over if she could see her baby and felt silenced by medical professionals. Other mothers were silenced by well-meaning family and friends that arrived home to nurseries that were cleared away and baby clothes removed as if those acts could erase the existence of the baby. Even insurance policies minimized the loss of the babies by not covering them unless they were at least 30 days old (O'Leary & Warland, 2013).

Best practice models today recommend that all parents should be offered the opportunity

to see and hold their stillborn or deceased infant. There still remain some controversy on whether or not these accommodations are necessary for everyone. Hughes (2002), through a study based in the UK, found that mothers who opted to see and hold their stillborn infant had higher rates of post-traumatic stress disorder in the third trimester of a subsequent pregnancy. Despite these findings, symptoms of anxiety and depression had subsided (as cited in Koopmans et al., 2013). This particular study seems to be an anomaly among recent research, as several authors agree that seeing and holding a stillborn is a beneficial experience for most but not all women (Christiansen, 2017; Koopmans et al., 2013; O’Leary & Warland, 2013; Radestad et al., 2009). Overall, staff should be supportive and sensitive to individual family needs and desires.

Contrary to former practices, there is evidence that attachments are developed during pregnancy. With modern obstetric prenatal care, diagnostic testing, assisted-reproduction, and graphic ultrasound imaging, mothers (and fathers) can develop strong connections with the unborn baby (Koopmans et al, 2013). The degree of maternal-fetal attachment seems to be affected by mother’s attachment history and pregnancy history. Maternal-fetal attachments are initiated with observation of the fetal heartbeat, increases in frequency and intensity with advancement of gestational age around 18 to 22 weeks, and peaks in the third trimester of pregnancy (Mehran, Simbar, Shams, Ramezani-Tehrani, & Nasiri, 2013; Salisbury, Law, LaGasse & Lester, 2003). Behaviors that demonstrate these attachments are nurturance (prenatal care and abstaining from harmful substances such as alcohol), comfort (stroking the belly and eating well), and physical preparation (mother’s physical changes and buying baby clothes and equipment) (Salisbury et al., 2003). Therefore, should the baby die, bereavement support should consider both prenatal and postnatal attachments that were already formed.

After the death of a child, parents experience significant psychological distress

(McCarthy et. al, 2010). Mental health challenges, including anxiety, depression, complicated grief and posttraumatic stress are well documented for parents of perinatal and neonatal deaths (Koopmans et al., 2013; Vance, Boyle, Najman & Thearle, 2002). The more recent the death of the child, the more symptomology is present in bereaved parents (Vance et. al, 2002; McCarthy et. al, 2010). Symptoms include intense yearning, traumatic distress, avoidance of reality, and preoccupation of the child (Berrera et. al, 2007; McCarthy et. al, 2010). Due to the significant amount of distress that parents face after the loss of a child, it is a disservice to the family not to provide a continuum of care to assist with coping and adjusting.

For parents who suffered from perinatal loss, complicated and unresolved grief can lead to more severe mental health issues such as post-traumatic stress disorder (PTSD). Many studies indicate that the severity of PTSD decreases over time since the loss and is likely to stabilize after 3-5 years. During the pregnancy of a subsequent child, PTSD rates in mothers tended to range between 12.5%-20%, but prevalence rates decreased to 4%-11% after the successful birth of a subsequent child (Christiansen, 2017). These rates suggest that PTSD rates tend to resurface during pregnancy following perinatal loss but will usually subside after a successful delivery. It would seem likely that mothers are anxious around the time of gestation that they either had the loss or went into preterm labor, causing physical symptoms to reoccur. Similarly, bereaved fathers were reported to have prevalence rates of 5-8.4% from 7 weeks to 18 years post-loss, 15.6% during a subsequent pregnancy, and 0% following the birth of a healthy baby (Christiansen, 2017).

Bereaved parents have reported higher incidence of physical symptoms, increased anger and increased mortality from both natural and unnatural causes (Barrera et. al, 2007; Bonanno & Kaltman, 2001; Stroebe, Schut & Stroebe, 2007). One qualitative study (Gudmundsdottir, 2009),

interviewing bereaved parents of sudden death found that it was not until the sudden death of their child that they took into account the responses of their bodies. It was hard to comprehend that the world kept going as if nothing happened, when “[her] world had stopped” (p.260). Another interviewee discussed her body frequently “rocking the baby back and forth” (p.261) even though she could no longer hold her baby in her arms. One other interviewee described her grief as a “stomachache that sat at the bottom of her throat” (p.262). For many people, the body responds as if it does not know that the child is no longer alive. Regardless of the length of time the baby lived, the mother’s body still produces milk in anticipation for her hungry baby. If there was a cesarean birth, the wound is a daily reminder that a baby was birthed and is no longer alive.

Numerous studies have identified sources of stress and other factors that contribute to parent’s grief experiences (Bloomer, Endacott, Copnell, & O’Connor, 2016; Koopmans et al., 2013). Issues around the lack of honest and accurate communication about the infant’s medical status/condition, accommodations for food and technology while at the child’s bedside, and the necessity to rely on nursing staff to interact with the child were identified as concerns leading up to the infant’s death (Koopmans et al., 2013). It is not often considered, but sickly children have regular contact with medical staff and when they die, the relationship with the staff also expires. These relationships were a significant part of the child’s life; therefore, every termination of a relationship connected with the child is considered a loss (Bloomer et al., 2015).

Given that most children are hospitalized at the time of death, staff responses influence parent reactions. Bloomer and colleagues (2015) identified several factors that contributed to parental satisfaction after the death of a child. There are times when life-saving measures leave the area of the child in disarray, but taking time to clean up the medical equipment and make the

child's body presentable for the parents honors the personhood of the child. Creating opportunities for family involvement/connection and collecting mementos allow families to have a slightly normal experience in an abnormal situation. Respecting parents' wishes when death is eminent and permitting them to withdrawal treatment or to determine if they want to allow the child's death to take place outside of the hospital are examples of making parents' satisfaction a priority.

In reviewing the perinatal loss literature, those who experienced the loss of one baby of a twin or multiple are acknowledged as a subgroup. There are a couple of studies that focus specifically on this group of bereaved parents (Cox & Wainright, 2015; Richards, Graham, Embleton, Campbell, & Rankin, 2015). With childbearing becoming more delayed and increases in maternal age, assisted reproductive techniques are used with greater outcomes of multiple pregnancies (twins, triplets and higher order births). Compared to singleton births, research has shown that there are increased risks among multiples like prematurity, congenital abnormalities, and perinatal deaths (Richards et al., 2015). Likewise, it should be recognized that this group of bereaved parents may experience special needs both in the NICU and in the community.

Richards and colleagues (2015) identify three major themes among mothers of multiples in the NICU, which included feeling special, establishing trust, and empowerment of the mother. Mothers felt special and different from pregnancy through birth and death of their infant. Carrying twins or higher order of multiples is fairly different than the norm in a positive way. Mothers felt that carrying multiples was an honor because it is not common. If delivery is preterm, the pregnancy is abruptly discontinued, and the admission into the NICU is "different" than having one's newborn sleep in the same room post-delivery. Should one of the infants die, this is another "different" experience that creates distance from other mothers. Collectively, these

differences can impact how bereaved mothers perceive others identifying with them and understanding their specific needs.

Parents with surviving infants in the NICU needed to personally feel emotionally validated and supported in order to entrust the staff to take care of their infant. Health professionals who were less emotionally available were seen as “just doing a job”. Parents also saw them as less competent in providing quality care for their infant(s). While some parents felt that they needed to put their emotions “on hold” to address the needs of the surviving infant(s) in the NICU, they also felt some comfort in being able to stay strong in the initial stages of loss. Some parents reported that bereavement support was offered, but felt that it was too soon to address, given the trauma of their loss, and their attempt to deal with the surviving infant(s) (Richards et al., 2015).

Another key component of trust was the efficient transfer of both verbal and written information regarding the status of the infants. Parents discussed feelings of disappointment and frustration when having to repeat their story of losing one child or when medical staff would provide inaccurate details regarding the children (including the deceased infant). Although parents had limited ability to intervene in daily activities, some felt that they were the ones providing continuity of care rather than the staff.

Death and bereavement are a reality for parents who experience the death of one infant, so feelings of uncertainty regarding the surviving infant(s) are intense. Given the traumatic loss, parents felt that they were not fully capable of asking for what they wanted or needed at the time. Here are two scenarios where parents had regrets, but were overwhelmed and likely in shock after the baby died, causing them to accept the behavior and treatment given to them:

The night I had her [deceased baby], I was kind of put in a room on [my]

own and no one checked on us all night, I was kind of left which...I didn't ask for her to be brought in...I was on my own for about twelve hours.

[Midwife] left her [deceased baby] on the ward so I could see her...in hindsight she should have been with me, yeah she was in a different...I don't know whether they have a chiller room...I wasn't really sure, I mean I know she was somewhere on the ward and I knew I could get her if I wanted but I didn't and now when I think about it, I don't know why I didn't.

(Richards et al., 2015, p. 150).

I just got rail, not railroaded but swept along with what they generally do,

I just got railroaded into going for a cremation with nothing...and it's just...

I just think, I just think that I was given the options, you can have a burial.

It was just kind of 'this is what people do' and you, when your're just in a bit of a daze, I just think you go along with what people say and now I just think...

that's my biggest regret, I've got nothing. (Richards et al., 2015, p.150).

These two accounts shed light on in-the-moment decisions that bereaved parents have to make on behalf of themselves and their deceased infant. The NICU environment is unpredictable with babies responding positively to treatment sometimes and other times not so well. After one infant dies, the reality that life is not guaranteed is clear. This lack of control or perceived helplessness makes decision-making in the NICU difficult for the surviving infant(s). Parents felt they had to heavily rely on nurses, but found other ways to gain ownership in the environment. Some of these activities included recognizing infant idiosyncrasies of the surviving infant and passing along information with nursing staff, reading medical case notes, watching nursing staff carry

out procedures, and exchanging information with other parents. These opportunities, however, were contingent upon the relationships with specific staff members (Richards et al., 2015).

Grief is a unique experience that is created out of the context of the relationship with the loved one, the circumstances around the death of the individual and the prior grief experiences of the bereaved. Grief can take a long time to resolve and significant dates or events can trigger intense emotions. Previous bereavement provides the griever with references to necessary coping strategies, but if that grief is unresolved, it is also compacted with the recent loss (St. Clair, 2013). Similarities and differences in grief reactions have been identified among mothers and fathers after perinatal death. Common themes are shock, anger, emptiness, loneliness, and helplessness. Women frequently reported feelings of guilt that were rarely reported by men (Koopmans et al., 2013).

Parents who experience perinatal loss can feel disenfranchised when people within their social context do not recognize their loss as meaningful or significant (St. Clair, 2013).

Experiencing disenfranchised grief can have long-term impact on the bereaved.

Acknowledgement of the loss validates and sanctions the griever's reactions. Parents who receive social and familial support have more positive outcomes than those who do not (Barrera et.al, 2007). Grief literature suggests that mourners can draw inspiration from the life and legacy of the deceased; however, for the bereaved parent of an infant, this perspective may be disenfranchising.

Deceased babies live in the lives of their parents and family members in more ways than imaginable. With adequate support, "...grief and bereavement can enhance the personal growth of all involved, helping them to find greater meaning in life" (Egan & Arnold, 2003, p. 42).

Grieving is as much a social and cultural experience as it is a personal one for bereaved parents.

Rather than encouraging separation and letting go of the relationship with the deceased loved one, post-modern philosophy encourages continuing bonds and creating meaning about the loss. Parents who struggle to find meaning in their child's death but fail to do so find the grieving process more painful (Neimeyer, 2000). Embracing life beyond the loss of a child is uncertain and challenges the bereaved parents to get to a place of resilience.

Regardless of the defined stages of grief or the presenting symptomology, the bereaved will attempt to find some normalcy beyond the loss of their loved one. As they embark on this journey, the bereaved will never be the same. After a significant loss, the bereaved has changed causing them not to function as they did previously. The equilibrium of any remaining relationships and the presumptive world as a benevolent place no longer exists for the mourner (Herrman-Donnelley, 1987; Sturrock & Louw, 2013). During the acute period, immediately following the death of the loved one, the mourner's world has stopped. The challenge is in fathoming the concept that life continues as if a crisis did not occur. When the infant's life is short, especially within the first 28 days of life, it may be hard to understand the bereaved parent's plight. Parents need time to grieve without it being stigmatized or pathologized. For some, death of a child could mean a loss of social identity, causing them to question their individual purpose or role.

While the survival of premature infants in the NICU has strongly been the focus of NICU personnel, growing emphasis should include the exploration of services necessary for parents whose infant did not survive in the NICU. This can hopefully lead to more sensitivity and to the development of policies and procedures in the NICU that will make it more conducive for bereaved parents to be adequately supported during this devastating period in their lives. Hospice and palliative care literature suggests that optimal bereavement care is provided by an

interdisciplinary team approach, but there are limited organized resources available to bereaved parents (Snaman et al., 2017).

Koopmans and colleagues' (2013) systematic study of effective interventions determined that there is a lack of randomized control trials; therefore, they could not provide clear guidance on best-practices for supporting bereaved parents. In spite of this, other studies have shown consistent themes in providing support: respect for the deceased infant, acknowledgment of individuality and diversity of grief, and recognition that people are generally resilient and are open to process their healing (Attig, 2004). Research also supports that bereavement services mostly benefit those identified with complicated grief but also provide meaningful assistance to parents who do not suffer from complicated grief (Koopmans et al., 2013; Snaman et al., 2017).

When institutions are attempting to develop and implement bereavement programs, it is imperative to include bereaved parents as they provide a unique perspective and can assist with improving the experience of other bereaved parents (Snaman et al., 2017). St. Jude Children's Research Hospital is a research institution where doctors and scientists collaborate to treat and cure childhood cancers, Sickle Cell, and other deadly diseases. St. Jude has become known for its prestigious treatment, especially its medical strides in increasing the survival rate of childhood cancer from 20% to 80%. Because of the founder's commitment to no child dying in the dawn of life, the institution provides all services at no cost to the families (St. Jude, 2017). Even with all of its successes and medical breakthroughs, St. Jude acknowledges that some children will die. The institution has recently developed recommendations to improve the quality of palliative and end-of-life care to include bereavement support for surviving family members and hospital staff.

The recommendations included the creation of an institutional bereavement coordinator position, a quality of life steering committee, and bereavement resources and educational

interventions. The bereavement program provides a range of services throughout the bereavement period. The family is initially connected to the bereavement care team once a poor prognosis is determined or the child experiences a clinical decline near the end of life. Parents are provided an option to receive a mentor (a bereaved parent who has been screened and trained) and to participate in institutional remembrance ceremonies to honor the child's life. To ensure that all bereaved families receive grief resources, the program provides a standard package within a specified timeframe, a condolence card with a response card to indicate interest in receiving additional materials, and holiday and remembrance cards throughout the first year following a child's death (Snaman et al., 2017). The institution's program to intentionally provide multiple touches allows the parents to reengage when they are emotionally ready.

St. Jude's bereavement program can be noted in providing an organized proactive service that gives parents the opportunity to choose whether to make contact with the institution and staff. Not only are bereaved parents supported by this program but hospital staff too. All bedside nurses are mandated to participate in two didactic curricula and receive a minimum of 25 continuation credits in palliative care and end-of-life training. Medical fellow students are required to participate in an annual communication training facilitated by bereaved parent educators. These components are significant, but Snaman and colleagues (2017) identify some limitations to the program and developed strategies to address them. St. Jude has invested resources to strategically address bereavement services as a component of family-centered care. This program should serve as an example to hospitals with NICU departments.

Conclusion

Babies are born critically ill and underdeveloped, needing specialized units in hospitals called NICUs. Unfortunately, even with updated technology and advanced treatment, physicians

are unable to sustain the infant's life. In many hospitals, interdisciplinary medical teams perform various modalities of treatment to ensure that the neonate's and family's needs are met. Most NICUs include social workers as team members to address the psychosocial needs while in the unit, however, when the baby dies, there are few resources available. Due to the nature of the birth and sometimes quick demise of the infant, extended family members may not get to experience the life of the infant. The lack of support and/or full understanding of the perinatal loss to their family and social community make bereaved parents feel disenfranchised. The parents must attempt to transition back to their lives on their own while others may not fully understand the distress of their loss or their needs. Bereaved parents of the NICU may be underserved, leaving them vulnerable to mental health and other issues.

In an attempt to understand the gaps that exist for bereaved parents of the NICU, exploration of the influences of current social work practice was necessary. Current social work practice in the NICU is guided by the needs of the hospital, the stipulations of health insurance, and the lack of proven evidence of the clinical contributions of social workers to the interdisciplinary team (Craig et al., 2015; Maramaldi et al., 2014). It is apparent that the biological aspect of providing medical treatment is the expertise of physicians and nurses. The majority of the literature focus on the interaction between the physicians, nurses, and parents (Green, 2015). In spite of this, it has been demonstrated that social workers have the professional training and skills to facilitate difficult conversations regarding medical treatment of the infant between medical staff and parents. Social workers' expertise in coordination, clinical counseling, assessments, and discharge planning positions them to adequately provide services for bereaved parents of the NICU. Having an understanding of grief theory supplements the social worker's insight for the needs of the bereft. Due to the nature and sensitivity of perinatal loss, grief theory

sheds light on how one might make meaning of this traumatic loss, while maintaining a relationship that feels appropriate and acceptable to the parents. Providing this type of counseling also validates the infant as a valued member of the family, which bears witness to the suffering of the bereaved parents. It is unclear what controls the patient to staff ratio for social workers, but considering the acuity of the patient's needs should also inform practice standards.

Although there is no mandate to adhere to the recommendations of the Institute of Medicine or the American Academy of Pediatrics, it behooves hospitals to consider expanding the Family-Centered Care model to include neonatal hospice care, neonatal palliative care, and a comprehensive bereavement program. As possibilities are explored, social workers should be at the forefront advocating and positioning themselves to be the mediators, developers, and facilitators of this necessary resource. In hopes to provide appropriate services to all patients and families, it is advantageous to the hospital in fulfilling its mission and incorporating services for the bereft as a part of the continuum of medical care.

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Social Workers: An Untapped Resource for Bereaved Parents of the NICU

Abstract

The literature review exploring current practices in the Neonatal Intensive Care Unit and Pediatric Palliative/Hospice for bereaved parents with perinatal loss provides context for the necessity of social work expertise in working with bereaved parents. Although technological advancements have been made in the NICU, infants still die. Perinatal loss is one of the most tragic and traumatizing events, leaving parents to figure out how to cope with this new reality. Using grief work theory to conceptualized effective clinical practice with bereaved parents, this article will highlight an overview of grief theory, current practices in the NICU, and provide insight for how grief theory can inform clinical social work practice. The social worker's perspective is lacking in the literature and it is proposed that the social worker's holistic stance can fill the gap in service provision to bereaved parents of the NICU.

Introduction

The National Association of Social Workers (2017) reported that there were 650,000 social work jobs with the expectation that the profession will continue to increase by 12% within the next seven years. Social workers make up 45 to 70% of the mental health workforce in the United States (American Board of Examiners of Clinical Social Work, 2017; Masiriri, 2008; NASW, 2017). Given these statistics, it is likely that social work clinicians will encounter clients with trauma and bereavement issues during their career. Their general purpose is to assist people in overcoming difficult circumstances like physical illness, trauma, mental health issues, discrimination, abuse and addiction and to promote social justice through advocacy, research and policy. While social workers play an integral role in a variety of settings, acknowledgement of their skills and expertise is often lacking among other professionals. The full extent of social work practice is beyond the scope of this paper, however, will focus on the social worker's role in context of the Neonatal Intensive Care Unit (NICU).

Fifteen million infants worldwide are born prematurely annually and one million of those babies will die (March of Dimes, 2017). There are various causes for infant death; however, preterm birth continues to be the primary factor. The abrupt termination of pregnancy leading to a preterm birth presents as a crisis to the mother and the family. Preterm babies receive specialized treatment in the NICU, but the medical equipment and treatment process in this environment can be intimidating. The prognosis and progress of the fragile infants fluctuate, but usually parents do not foresee their newborns dying.

Infant death can occur at various stages of pregnancy throughout the first year of life. Between the time of conception through the first 28 days of life, 20-25% of all pregnancies result in some type of loss (Hutti, Armstrong & Myers, 2011). The terms prenatal, perinatal and

postnatal loss refer to losses prior to, during or up to one year after birth, respectively (Christiansen, 2017). However, perinatal loss is typically understood as a comprehensive term to describe these losses. The death of an infant is more than the loss of a loved one; it is the demise of creating memories, celebrating life and anticipating the future. It creates a void. For many, death's finality is confounding and traumatic, making it one of the most difficult life events. Therefore, death poses a unique challenge to how families recover from losing a child (Barrera et. al, 2007).

Perinatal loss is one of the most devastating experiences and some parents will seek assistance of therapeutic interventions to cope with the death of their child. The clinician's framework in grief theory and understanding of attachment is essential in guiding the bereaved individual through the journey to healing. Several factors for the clinician to consider are that the loss of the baby was likely unanticipated, the presumed life with the child as a family member is vanished, and the identity to parenthood has been drastically altered for some individuals. In a broader context, perinatal loss is complex and unique given that people deem it to be less significant than the death of an older child, spouse, sibling, or parent and thus, bereaved parents feel disenfranchised (Lang, Fleiszer, Sword, Gilbert, & Corsini-Munt, 2011).

Parents who experience the loss of an infant in the NICU can feel marginalized, especially if there is no organized bereavement program in the hospital or have access to social supports that acknowledge and accommodate their loss. Kenneth Doka (1989) coined the term disenfranchised grief to highlight bereavement scenarios that fall beyond socially normalized parameters. Common examples of disenfranchised groups are those diagnosed with cancer, those giving birth to a child with a disability, and those experiencing infertility or perinatal loss. Mourners that fall within these domains may feel restricted to express their loss openly and even

feel shameful to openly describe their feelings as a loss (McCoyd & Walter, 2016). People can generally understand the hurt behind these various types of losses; however, they may only identify with feelings of isolation once they have experienced a loss directly. Disenfranchise grief captures the suffering of individuals whose pain of a loss that is not openly validated. This project, however, will focus solely on the ultimate loss of a loved one via death and how bereaved parents cope beyond the loss of their newborn baby.

In many hospitals, NICU social workers engage infant patients and their families in conjunction with the interdisciplinary medical teams. In spite of this, the majority of the literature focus on the interaction between the physicians, nurses, and parents (Green, 2015). Therefore, it is important to determine what the current social work practices are and what gaps exist for bereaved parents of the NICU. Further, social worker training along with theoretical subscription can heavily influence the work conducted with the bereft. Considering the plight of the bereaved parent is not only beneficial to the individual, but advantageous to the hospital in providing appropriate services to all patients and families. By virtue of the training and skill development for social workers, they are an underutilized resource for the neonatal intensive care units. This article will explore potential options for NICU social workers interacting with bereaved parents.

Grief Theory

Deliberations continue on which grief theoretical perspectives are the most accurate and relative for the bereaved. Each experience with the death of the loved one is as unique as the individual. Therefore, clinicians (social workers) must consider the events leading to the death and understand how they impact both the connection with the deceased and the life functioning of the bereft (Rubin, Malkinson & Witztum, 2011). For efficacy, the clinician's approach must

be grounded in a theoretical framework that can provide insight into how an individual might adapt to the loss of a loved one (Winokuer & Harris, 2012). Grief theory is broken down into the three major categories of task-based, stage-based, and post-modern/contemporary. Using grief theory will be also be used to emphasize and validate the mourner's right to grieve for any relationship that is experienced as a loss in a manner that is individually appropriate. It is necessary to understand the contributing components of grief theory to gain insight on how it might influence clinical social work practice.

Freud (1917/1957) sets the foundation for classical theorists to analyze the concept of the mourner needing to let go of his/her attachment with the deceased in order to move on with life. He notes that the mourning process takes time to overcome and interference with the mourning process may prove to be useless or harmful. Although practice knowledge has embraced new understandings of grief, Freud's task-based model has heavily influenced clinical mental health practice (McCoyd & Walter, 2016).

Erich Lindemann expanded on Freud's perspective by considering the social context of the bereft and recognizing that people need time to adjust to their new presumptive world. He hypothesizes that normal grief includes somatic distress, preoccupation with the deceased, guilt, hostile reactions, and loss of normal behaviors (Goldsworthy, 2005). He ascribes that grief work be managed within six weeks and that mourners should only be seen by psychiatrists (Granek, 2010). His stance devalues other service providers creating a hierarchy, rather than a continuum of care and limits the acute period to about six weeks.

J. William Worden (2008) discusses grief counseling as a supplement to the traditional support of funerals and other social customs. He confers that there are four major tasks to be accomplished by the bereft: accepting that the loss is real, addressing emotional and behavioral

pain, overcoming the impediments to readjustment, and finding a way to maintain a bond with the deceased. Worden & Winokuer (2011) emphasize that tasks assist the bereft in adapting to life without their loved one.

Stage-based theories, also known as phases, are guided by the work of Elisabeth Kübler-Ross, John Bowlby, Colin Murray Parkes, and Therese Rando. Each of the theorists describe specific emotional markers that must be completed to achieve healing from grief. Some critics of these models argue that the rigidity and passive nature of the model suggest that the mourner passes through each phase with no effort (Worden, 2008). Albeit, these perspectives are also referenced in clinical settings.

Kübler-Ross' (1969) work identified themes among terminally patients which include denial, anger, bargaining, depression, and acceptance, also known as the "Five Stages of Grief." It should be noted that the population for which the model has been used to help is different from the population that Kübler-Ross researched. Therefore, the behavioral presentations manifest differently between the two groups. This factor is what post-modern theorists use to challenge this theory (McCoyd & Walter, 2016).

Colin Murray Parkes expanded James Bowlby's work on attachment. Bowlby is recognized for identifying the attachment styles of children i.e. secure, anxious and avoidant. His hypothesis of grief work includes four phases i.e. numbing, yearning and searching, disorganization, and reorganization (Goldsworthy, 2005). Parkes' (1996) examined the behaviors of bereaved widows and postulated that their attachment behaviors were similar to infants separated from their mothers (as cited in Winokuer & Harris, 2012). Regardless of attachment style, clinical practice has shown that positive connection, level of fondness, and relationship context correlate to the intensity of grief and mourning (McCoyd & Walter, 2016).

A more recent classical theorist is Therese Rando. Her work includes three major phases: avoidance phase (recognition of the loss and understanding the reality of death), confrontation phase (experiencing the pain of the loss, remembering and relinquishing old attachments to the deceased), and accommodation (readapting to the new world without forgetting the old and establishing new relationships and roles). Accomplishing these phases indicates resolution to active grieving (McCoyd & Walter, 2016).

Postmodernism assumes that individuals create constructs of how they perceive and understand the world. Whether the individual's perspective is in agreement with the standpoint of others is debatable, but unnecessary when considering his/her unique bereavement needs. In search to accommodate and address individual needs, contemporary approaches allow clinicians and mourners to customize interventions. Both therapeutic and informal methods will promote healing without insisting on closure or acceptance (McCoyd & Walter, 2016).

The grief work hypothesis is defined as the necessity to “confront the experience of bereavement to come to terms with loss and avoid detrimental health consequences” (Stroebe & Schut, 1999, p.199). In other words, the bereft must make an effort to fully address bereavement to prevent psychological or physical distress. Stroebe (1992) challenges this position and argues that some people need to take non-confrontational approaches to mourn the loss of a loved one. Other grief work deficits include cultural bias, circumstantial relevance, and a universal definition “normal” grief. Several contemporary approaches were introduced to explore alternative methods of grief treatment (e.g. disenfranchised grief, continuing bonds, dual process, and making meaning).

There are distinct differences in individual grief responses regarding the length of time, intensity, and for whom he/she grieves. Those who fall beyond socially acceptable parameters

are considered disenfranchised. Kenneth Doka (1989) coined the term “disenfranchised grief” to describe grief that cannot be openly acknowledged, publicly mourned, or socially supported. Disenfranchised grief essentially emphasizes the mourner’s right to grieve for any relationship that is experienced as a loss in a manner that is individually appropriate. Perinatal loss falls within this group because of the lack of acknowledgement of the infant as a true family member.

The notion of “continuing bonds with the deceased” presented a major perspective shift in the grief and loss discourse. Historically, attempting to preserve a relationship with the deceased was seen as taboo and pathological (in Western culture). They desired to acknowledge ways in which the bereaved might embrace a bond with their deceased loved one, which also changes over time (Klass, Silverman, & Nickman, 1996, as cited in Klass, 2006). In a reflective piece, Klass (2006) encourages clinicians to explore the intersectionality of an individual’s identity, making meaning of the loss, and relearning relationships that influence the bereaved individual’s adjustment.

Stroebe and Schut (1999) propose the Dual Process Model. The loss-orientation component of the model highlights the need to yearn and reminisce for the deceased. Equally, the restoration-orientation component acknowledges the need to take time off from dealing with the pain of mourning to address everyday life needs, and to embrace a new identity. The key component of this model is the ability to oscillate between these two states for optimal adjustment. While taking time off is permissible, it should not be confused with the coping mechanisms of denial or avoidance of the death (Stroebe & Schut, 1999).

Robert Neimeyer (1999) proposes “meaning reconstruction” as an approach that acknowledges unique idiosyncrasies between individuals, even for the loss of the same person (p.68). He adds that while grieving may be a private process, societal and contextual factors must

be considered. Besides emotional and mental adjustment, he stresses that the bereft need social validation (Neimeyer, 1997, as cited in Neimeyer 1999). Neimeyer (2000) expands on prior work to explain that safe social contexts are needed for the bereft to share their stories. The search to include meaning into the narrative of the bereft creates opportunity for the therapist to listen, reflect, and explore. Grief therapy then becomes the vehicle by which individuals share their stories and their losses. Creating a new narrative will guide how they embrace a new identity after the death of their loved one (McCoyd & Walter, 2016).

Culture influences the way grief is recognized by establishing societal norms/traditions (Klass & Chow, 2011). For example, the direct discussion of perinatal loss can be seen as taboo (Shulman, 2016). Employment benefits, funerals, and other entitlements are not always rendered to those experiencing perinatal loss. Notably, there is no singular word to identify bereaved parents. Widow/widower is used for death of a spouse and a child whose parent dies is considered an orphan. The use of language can also invalidate the experience of the bereft. Further, those who have no other living children, may struggle with their parental identity. The combination of these factors impacts the process by which bereaved parents attempt to recover and heal from the loss of their baby.

When parents who experience perinatal loss have no substantial community that understands and validates their loss, they feel disenfranchised (McCoyd & Walter, 2016). This exclusion may not be easily understood because the deceased baby plays no obvious significant role in the lives of the extended family or social community. By the time of the infant's death, many parents would have already experienced the stress of treatment in the NICU (Craig & Mancini, 2013). Having no organized bereavement services leaves bereaved parents vulnerable to mental health and complicated grief.

Grief Theory and Clinical Social Work Practice

One of the first lessons that a social worker learns is that to establish a positive therapeutic alliance, the clinician must meet clients where they are in that moment. In other words, attempting to address presenting problems is futile unless the social worker establishes an empathetic, safe, and trusting space should be established for the client to express their concerns (Winokuer & Harris, 2012). The loss of an infant is expressed in many ways. Before any therapeutic modality is considered, the clinician should have an understanding of client strengths, needs, and resources through a comprehensive biopsychosocial assessment (McCoyd & Walter, 2016). For bereaved parents of the NICU, the intensity of grief and bereavement reactions expressed have to do with the circumstances leading up to the death of the infant and the level of prenatal attachment. If there were medical complications during pregnancy, the mother may need to address the guilt and frustration of preterm labor in addition to experiencing the death of her infant.

Whether one subscribes to the classical task-based theories or the contemporary theories of searching for meaning and embracing a new identity, it is crucial to understand that death is physically finite and mourning/grieving is a process. There is an acute period (immediately following the loss) that grief reactions will likely be most intense. Generally, grieving subsides with time, but for some people, external interventions like counseling is necessary to promote emotional stability and healing. There is no set rule for grief counseling, practice depends on the setting, the purpose, and the circumstances of the death (Worden, 2008).

Freud's grief perspective heavily influenced research and clinical practice, pathologizing bereaved persons who did not complete the "grief work process". For novice clinicians, the classical theories can unintentionally promote rigidity to ensure that "grief work" is completed.

All of the classical theories expound on Freud's postulation that one must let go of attachments to the deceased and have closure with that relationship. The social worker should be mindful of individual differences and more importantly, some people will eventually heal without professional interventions (McCoyd & Walter, 2016).

On the other hand, usage of the task-based theories may provide hope in that there is something the mourner can actively do to adapt to the loss of his/her loved one (Worden, 2008). Task-based theorists argue that "tasks" are fluid (even if the author implies a linear process) of mourning in which tasks can be accomplished and revisited in any order (Winokuer & Harris, 2012). The clinician can extrapolate from this model that the mourner has some sense of leverage in the bereavement process. This perspective may be applied to someone who has issues with maintaining control.

Should the social worker apply any of these theories in work with bereaved parents of perinatal loss, he/she must recognize that there is no consensus on what is deemed as "normal." Factors such as family planning methods, mother's physical changes and medical concerns during pregnancy, attachment to the infant, and how/why infant died will contribute to the expressed grief reactions of the bereaved parents. Regardless of how long the infant lived, parents were making accommodations to embrace another member of their family and death abruptly interrupted that expectation. Furthermore, grief work is a significant component of all of the task theories. The social worker should take this into consideration when determining the appropriate time and approach to working with bereaved parents of the NICU.

NICU social workers are bombarded with caseloads of families who are in "crisis." When one of the infants dies, the worker must be available to meet the immediate needs of that family. The initial shock that the parents may experience aligns closely with the stage/phase based

theories. The social worker's response at that time is crucial to the therapeutic alliance for future work and may resort to using this framework to normalize some of the bereaved parent's initial behavior. The consideration that the worker must make during this time is that the mourner will not be immediately ready to deal with the bereavement process.

Respecting that grief reactions will look different for every individual and every loss should guide the clinician's approach. The contemporary models make provision for those needing to take a break from grieving to deal with daily life issues. For example, the parent who has a surviving twin in the NICU, may need to postpone his/her grief to support that baby (Richards, Graham, Embleton, Campbell, & Rankin, 2015). Neimeyer's theory of "making-meaning" is particularly significant because it allows the bereft to consider the meaning of events for themselves. Similar to a mother's nurturing hold for her infant, the clinician creates a safe "holding environment" for the client to express his/her perspective and 'truth' (Freshwater & Robertson, 2002, p.29). This environment presents opportunity for the clinician to witness and interpret the meaning that the client attributed to the death and allows the client to feel validated. Once the bereaved parents are emotionally available to incorporate meaning into their story, it gives them permission to hold on to the relationship with the deceased baby and determine other ways of remembering/honoring his or her life.

Further, McCoyd (1987) developed an intervention framework for especially for perinatal losses, called the Five V's (as cited in McCoyd & Walter, 2016). "The Five V's provide a model for grief therapists who desire some structure for the work, yet recognize the importance of allowing the bereaved to follow their own needs and inclinations" (McCoyd & Walter, 2016, p.45). The Five V's are validating, valuing, verifying, ventilating and being visionary. While not prescribed, this model gives the social worker a guide from substantiating the life of the infant

through creating a safe space for bereaved parents to genuinely express their thoughts and feelings about the loss in a meaningful way. Activities like touching the baby's belongings, creating a shadow box, planting a tree, or organizing photos can assist with bereaved parents both acknowledging the hurt and coming to peace with a new type of relationship with the baby. Realistically anticipating is a part of the ending process and helps the mourner to consider events that may be triggers for heightened emotions like the pregnancy due date of the deceased infant, the anniversaries of birth and death, or consideration for having another baby.

There are various benefits to referencing grief theory when working with bereaved parents of the NICU. Having an understanding of grief theory in its entirety and recognizing the purpose and limitations of each of the models would assist the clinician in his/her approach to treatment with the bereft. This is a crucial reference to include in the social worker's clinical toolbox. Ultimately, the appropriate modality will be determined by the location, the emotional availability, and the present life circumstances of the bereaved parents.

Methods

Multiple literature databases were searched to explore the concepts of infant mortality in the United States (US) and the NICU, the relationship of the NICU social worker and the parent or the interdisciplinary team, the role of medical social worker, the current hospice and palliative care practices, and the effects of perinatal loss among bereaved parents. This section reviews relevant literature that comes from the fields of health education, medicine, public health, psychology, nursing, death studies and social work.

While there is extensive evidence that social workers play a significant role in the medical setting of the hospital, in palliative care, and in hospice care, there remain gaps in service provision to bereaved parents of the NICU. Notably, most of the literature reviewed

focused on the interaction between the physician or nurse and the parent or from the nurse or parent perspective. There was only one article (Bosma et. al, 2010) that included the social work interaction related to parents.

Literature Review Results

Advances in medical technology over the past 50 years have prolonged the lives of neonates that would have otherwise died. In 2012, nearly 500,000 babies were born preterm (before 37 weeks gestation) in the US (Laubach, Wilhelm & Carter, 2014). Successes in the NICU have led to societal belief in unrealistic medical miracles, especially for neonates born at the extreme ends of viability (22-26 weeks of gestation) (Arzuaga & Lee, 2011). Ideally, babies remain in utero until they have reached full-term gestation, as the third trimester is crucial for brain, organ, and growth development. Needless to say, infant admission into the NICU is an extremely stressful time for parents. Having to navigate the NICU's logistical nuances along with feelings of disappointment, confusion, frustration, and anger, the premature birth experience strips parents of the "wished for" or traditional birth. While treatment in the NICU is often aggressive to sustain the lives of ill neonates, not all babies will survive.

Death is a reality in the NICU. Healthcare providers will inevitably experience working with perinatal death and bereavement of parents/family members (Kain & Wilkinson, 2013), but may not be equipped to respond accordingly. Death in the NICU is an overt reminder of one's own mortality and should be addressed or least acknowledged prior to dealing with bereaved parents. Death of an infant is a traumatizing experience that leaves parents having to return home with no baby and uncertainty for how to transition back to their presumed lives. While the baby is in the hospital, the interdisciplinary medical team guides treatment. However, when the baby

dies, there are very few resources and organized bereavement programs to assist parents in the transition.

Given the complexity of health issues and approach to treatment, the full interdisciplinary medical team is necessary in determining the course of treatment for NICU neonates. Embedded among physicians, surgeons, nurses, nutritionists and technicians, social workers provide comprehensive, integrative care for patients and their families. The social worker's role is unique in that he/she is the only member of the team that is not formally trained in medicine. Despite their lack of knowledge in physical health, social workers are well trained in system/family dynamics and mental health services. Medical social workers not only assist with connecting the family to resources and discharge planning, but also serve as a counselor and advocate, educating the medical team about the needs and wishes of the family (Mizrahi & Abramson, 2000; Mizrahi & Berger, 2005; Smith, 1987).

Family-Centered Care

The current philosophy of care for neonates considers how actively involved family members should be in their infant's care. The Family-Centered Care (FCC) approach indicates that patient outcomes improve when considerations are made for collaboration, diversity, respect, education, and parent empowerment (Cockcroft, 2012; Enke, Olivia-Hausmann, Miedaner, Roth, & Woopen, 2017; Gooding et al., 2011). Despite the various ways to operationalize FCC, there is a general consensus that it is the best way to treat hospitalized children (Raikila et al., 2016) and reduces length of hospital stay for preterm infants in the NICU (Cockcroft, 2012). Fundamental components include engaging in open communication, including parents in critical decisions, and providing access to medical information (Cockcroft, 2012; Gooding et al., 2011; Harrison, 1993). Although the American Academy of Pediatrics endorses the FCC model (AAP, 2013),

there are no apparent regulations that enforce actual implementation of these practices.

Over the past 25 years, the implementation of family-centered care has expanded to include technology supports, parent support groups, and NICU department design (Hall, Ryan, Beatty & Grubbs, 2015; March of Dimes, 2017; Stevens et al., 2014). When used respectfully, modern technology has proven to be an asset to FCC implementation. The March of Dimes provides families that are unable to visit the infant due to distance or other stipulations, other technology-based resources such as pictures and videoconferencing (Gooding et al., 2011). Web-based companies like BabyCenter and non-profit organizations such as March of Dimes, and Nemours Children's Health System provide websites to assist parents with knowledge about the NICU and concerns for prematurity or child specific illnesses. For parents whose infant is critically ill and dying or has already died, a non-profit organization called, Now I Lay Me Down to Sleep (NILMDTS), provides a free gift of professional portraiture of parents interacting with the infant (NILMDTS, 2017). For bereaved parents, portraits capture the last moments with the baby, create memories for a lifetime, and assist in the healing process.

Hall and colleagues (2015) present parent-to-parent mentoring dyads and/or groups as a supplemental support to that of social worker or nurse. Some recommendations for pairing parents include matching as many variables as possible such as ethnic background, language, gestational age of infant, parent's age, family structure and size, education and income level. While these factors influence engagement between veteran NICU parents/mentors and current NICU parents, the unifying experience is having a child admitted into the NICU. This connection sets this relationship apart from professional supports. Parents who receive peer support have been shown to have increased confidence, empowerment, and problem-solving capacity and a decrease in perceived depression, stress, and anxiety. Barriers to accessing parent supports

include lack of transportation, time restraints, and lack of knowledge in services offered (Hall et al., 2015).

The Family-Centered Care model has demonstrated positive outcomes, however, has limitations and barriers. Despite its recommendations and proven benefits, FCC has been implemented sporadically throughout the US (Gooding et al, 2011). Several studies have clearly articulated the fundamental principles and components of FCC, however, there is a lack of research in how to effectively implement it in the NICU setting with fidelity (Skene et al., 2015). The limitations that impact this study specifically are that even with all of the financial provisions and research support, FCC does not include neonatal palliative care, neonatal hospice care, or the development of a comprehensive bereavement program as a requirement in the NICU.

Interdisciplinary Team

Ida Cannon (1915) postulated that “the charge of the hospital social worker was to assume the role of “interpreter,” and to bridge the communication gap between patients, families, and other providers” (as cited in Maramaldi et al., 2014, p.534). Almost a century later, the Institute of Medicine’s (2008) report details the significance of communication to meet the psychosocial needs of the patient and the family. Whether the social worker’s role is primarily discharge planning or an active part of coordinated services, the expertise and support that the social worker provides to both the interdisciplinary team and the parents facilitate improved care (Kitchen & Brook, 2005). Social work’s ecological perspective ideally positions social workers as the most qualified to facilitate meaningful interactions between patients, families and interdisciplinary teams (Maramaldi et al., 2014).

Generally, interdisciplinary teams collaborate around specific areas of expertise. At hospitals, they are usually led by physicians (Mizrahi & Abramson, 2000). Physicians concentrate on physical treatment of the patient (in this case, the neonate), while social workers focus on the overall care of the family as a cohesive unit. Kitchen and Brook (2005), propose that social workers who function as the coordinator of the medical teams not only increase access to accurate referrals upon discharge, but provide increased awareness for physicians of cultural, financial, and community resource accessibility for families. Social work's holistic perspective considers how treatment decisions impact the entire family (Kitchen & Brook, 2005).

Some of the issues that arise in the medical team stem from coordination, communication, secondary trauma of staff, and competition among staff. Caring for medically fragile or dying children evokes feelings of hopelessness (Walsh, 2013) and can be emotionally draining (Janzen, Cadell & Westhues, 2004). The combination of compassion fatigue, hopelessness, and uncertainty can be challenging, causing miscommunication between staff and parents (Walsh, 2013). Boss, Urban, Barnett, & Arnold (2013) indicate that much of the distress that occurs for ICU clinicians stem from conflict between the family's expressed wishes and ethical obligation to the patient. Because social workers are not involved in medical treatment, their objective view can assist in the disappointment of staff (Bloomer, Endacott, Copnell, & O'Conner, 2016). Unfortunately, descriptors such as "providing support," "counseling," and "working with family" do not capture the full extent of the interdisciplinary clinical social work practice and is not fully valued (Maramaldi et al., 2014, p. 533). Contrariwise, social work tasks were identified as dispensable and less justifiable for reimbursements (Reisch, 2012). This practice lends itself to significant pay differentials between nurses and social workers and makes social workers feel marginalized and less qualified compared to physicians and nurses.

Families of infants diagnosed with life-limiting illnesses face challenges emotionally, socially, spiritually and financially (Stayer, 2012). NICU parents are at a higher risk than parents of full-term infants for postpartum depression (PPD). Prevalence among NICU mothers is 28-70% compared to 10-15% of term infants. Similarly, among fathers of premature infants, PPD rates are more than 50% greater than father of full-term births (as cited in Heru, 2015). The statistics on parental psychological distress increases exponentially after the death of a child in the NICU (McCarthy et. al, 2010).

Mental health challenges, including anxiety, depression, complicated grief and posttraumatic stress are well documented for parents of perinatal and neonatal deaths (Koopmans et al., 2013; Vance, Boyle, Najman & Thearle, 2002). The more recent the death of the child, the more symptomology is present in bereaved parents (Vance et. al, 2002; McCarthy et. al, 2010). Symptoms include intense yearning, traumatic distress, avoidance of reality, and preoccupation of the child (Berrera et. al, 2007; McCarthy et. al, 2010). Due to the significant amount of distress that parents face after the loss of a child, it is a disservice to the family not to provide a continuum of care to assist with coping and adjusting with bereavement.

Historically, parents felt that opportunities to acknowledge the baby and mourn their loss were denied. It was assumed that holding one's stillborn or terminally ill newborn exacerbated adverse psychological outcomes. O'Leary and Warland (2013) showed that many parents who never saw/held their stillborn, or dying baby regretted it years later. Physicians encouraged mothers to focus on having another baby rather than her current loss. Other mothers were silenced by well-meaning family and friends that arrived home to nurseries and baby clothes that were cleared away, as if those acts could erase the existence of the baby. Even insurance policies minimized the loss of babies by not covering them unless they were at least 30 days old

(O’Leary & Warland, 2013). This practice dismissed the infant as a family member and disenfranchised the grieving parents.

Contrary to former practices, there is evidence that attachments are developed during pregnancy. With modern obstetric prenatal care, diagnostic testing, assisted-reproduction, and graphic ultrasound imaging, mothers (and fathers) can develop strong connections with the fetus (Koopmans, Wilson, Cacciatore, & Flenady, 2013). The degree of maternal fetal attachment seems to be affected by mother’s attachment and pregnancy histories. Maternal fetal attachments are initiated with observation of the fetal heartbeat, increases in frequency and intensity with advancement of gestational, and peaks in the third trimester of pregnancy (Mehran, Simbar, Shams, Ramezani-Tehrani, & Nasiri, 2013; Salisbury, Law, LaGasse & Lester, 2003). Behaviors that demonstrate these attachments are nurturance (prenatal care), comfort (stroking the belly and eating well), and physical preparation (mother’s body changes and buying baby clothes/equipment) (Salisbury, Law, LaGasse & Lester, 2003). Therefore, should the baby die, bereavement support should consider both prenatal and postnatal attachments that were already formed.

Best practice models today, recommend that all parents should be offered the opportunity to see and hold their stillborn/deceased infant. There remains some controversy on whether or not these accommodations are necessary for everyone. Hughes (2002), a study based in the UK, found that mothers who opted to see/hold their stillborn infant had higher rates of PTSD in the third trimester of a subsequent pregnancy. This particular study seems to be an anomaly as several authors agree that seeing/holding a stillborn is a beneficial experience for most, but not all women (Christiansen, 2017; Koopmans et al., 2013; O’Leary & Warland, 2013; Radestad et al., 2009). Overall, staff should be supportive and sensitive to individual family needs.

Intensive Care Unit/ Medical Social Worker

Since there is minimal literature on social work practice in the neonatal and pediatric ICU, much of the information is drawn from the adult ICU. “Social work in the ICU has become a subspecialty of medical social work just as the ICU’s themselves have become more specialized” (McCormick, 2011, p. 55). Treatment in the ICU is typically aggressive for the survival of the patient, but does not account for interruption in family dynamics. In this setting, there is tension and anxiety due to fear of the unknown, uncertainty around treatment decisions, and perceived lack of communication between staff, patients, and family members (Joseph, Berzoff, & Dobbie, 2009). Critical illness for an individual usually comes as a crisis to families, but social workers provide the interventions to help patients, families, and staff cope (Hartman-Shea, 2011).

In their systematic review of the literature, Hartman-Shea and colleagues (2011) found several themes in social work activities in the ICU such as counseling professional, facilitator of communication and resource agent. Providing psychosocial counseling and support was identified as the most frequent activity and was an indicator of family satisfaction. The social worker’s assessment of the family’s response to crisis and understanding their communication was found to support effective and empathetic interactions between the staff and family. The researchers determined that social workers are distinctively qualified to provide practice in critical care units and require an understanding of family dynamics, team functioning, crisis response and end-of-life care (Gwyther et al., 2005; Hartman-Shea et al., 2011). The role of the social worker in providing end-of-life care in the ICU is becoming increasingly complex.

Holliman, Dziegielews, and Teare (2003) indicated that among social workers and nurses, both disciplines agree that social workers are better qualified to provide concrete services

such as assisting patients in understanding insurance and financial planning, setting up home health aides, and connecting patients with in-community support. On the other hand, both social workers and nurses felt they were competent and qualified enough to provide counseling support to patients and their families. There is dissonance in health care practice that acknowledges that social workers are essential for assessing patient social supportive needs and discharge facilitation, yet they are also expendable when funding is a concern (Auerbach, Mason & Heft LaPorte, 2007). More recently, other health professionals have recognized that social workers utilize strong assessment skills that incorporate systems and community knowledge to solve problems (Craig, Betancourt, & Muskat, 2015).

Hospice and Palliative Care Models

When medical care options become futile and the suffering of the infant is greater than the possibilities with treatment, staff must also delicately and empathetically facilitate that discussion. Studies show that physicians have difficulty with communication about end-of-life decisions (Curtis & Vincent, 2010). The manner in which parents are approached with the information is important for how they respond and establish trust for medical staff. Helping parents understand that withdrawal of treatment and promoting comfort care (not abandonment) can be difficult for parents to understand (Kitchen & Brook, 2005). Social workers, on the other hand, have demonstrated intentionality in involving family members in life-sustaining treatment and spending time with the families to process their emotions than nurses and physicians (Werner et al., 2004). It then becomes the responsibility of social workers to demonstrate their skills in not only conducting thorough assessments, but effective communication with parents and coordination of services. Furthermore, social workers need to emphasize their role as change

agents and key participants of interdisciplinary teams by focusing on ethical activism and development of community partnerships (Judd & Sheffield, 2010).

In adult medicine, the current treatment models to address care for severely chronic and/or terminally ill patients are hospice care and palliative care. Hospice care (HC) and Palliative care (PC) are often used interchangeably; however, this is a misconception and they have distinct meanings and purposes. Hospice care, also called end-of-life care (EOL), is the organized provision of services to address the needs of a dying individual and their family (World Health Organization, 2004). The quantifying factor is that hospice care requires that the patient has a prognosis of living six months or less and does not allow for curative treatment. Hospice providers are also required to have a bereavement program that minimally consists of memorial services, office or in-home individual and group counseling services. The program is designed to assist the family up to one year following the death of a patient (Hutcheson, 2005). Conversely, PC permits both curative treatment and comfort care (pain management). Palliative care is considered a comprehensive approach that improves patient and family quality of life, and pain/suffering when facing a life-threatening illness (WHO, 2017).

Pediatric palliative care addresses the needs of children between infancy through young adult (under 21) by providing treatments that aim to relieve suffering, improve the child's quality of life, facilitate informed decision-making by patients, family members, and health professionals, and assist with on-going coordination of care among clinicians across various sites of care (AAP, 2013). While the coverage is not the same, both Medicare and Medicaid insurance cover hospice and palliative medical services. According to the Patient Protection and Affordable Health Care Act, children (including infants) are permitted to receive concurrent hospice and curative treatment Kang & Feudtner (2012). Unfortunately, while legislative policy and funding guide practice, they

do not guarantee that all populations will receive the appropriate benefits. There have been few hospitals that provide palliative or hospice care to neonates.

Given the fragility of the premature infants, medical staff must consider the ethical obligations of continuing curative treatment versus changing its focus to accepting that death is eminent and providing comfort care that is essential for the infant and family. Although it is not customary practice to provide EOL services in the NICU, I propose that they should be an extension of standard treatment. Prematurity predisposes the infant to various types of deficits and abnormalities. The short time between birth and diagnosis of a life-limiting illness does not give parents adequate time to prepare for death. If hospice care, palliative care, and bereavement care were designed to be a part of continuum of care under the Family-Centered Care, the NICU would be more comprehensive and inclusive of a population (bereaved parents) that has been silenced for too long. Neonatology and perinatal practice must reference medical structures that currently exist for EOL care and bereavement support.

Bereaved Parents

In the weeks following a newborn death, parents experience shock, sadness, and difficulty completing “normal” daily tasks (Badenhorst & Hughes, 2007). It is unreasonable to expect that they would be coherent and or functioning well enough to follow-up on resources provided at the time of the loss. Since clinical practice is heavily driven by policies supported by funding, policy directives should be informed by current practice, examination of curriculum design of academic programs, institutional capacity, engagement of stakeholders (families and staff) and ethical obligation to the critically ill neonates (Kain & Wilkinson, 2013).

Recommendations for care clearly outline and define the work of physicians and nurses, but the

expertise of the social worker appears to be overlooked in NICU, hospice care/end-of-life, and palliative care literature.

Discussion/Practice Implications

As evidenced by the work of neonatal and perinatal advocates, significant research and policy development have been introduced over the past fifteen years. Much of the work has focused on the treatment of the child and the experience of the family while the child is in the NICU. This work is unequivocally essential, however, should not supersede research of the social supports, policies, and best practices for bereaved parents of the NICU. Given the medical fragility of the premature infants and the rate at which neonates die, considerations should be made simultaneously to support these traumatized parents.

The literature review revealed several factors that contribute to the role that social workers currently play in providing services to parents in the NICU and after death of a child. The social worker's ambiguous role, overlapping responsibilities with nurses, insurance regulations, and identified parental needs have influenced social workers practice (Auerbach, Mason & Heft LaPorte, 2007; Reisch, 2012). One of the most persuasive factors is the lack of clarity in the perception of social workers' role, despite their demonstrated expertise in conducting biopsychosocial assessments, skilled case management and provision of clinical mental health services. While social workers are an integral component of the interdisciplinary team, there is limited literature that discuss their specific role and purpose (Craig et al., 2015). As a result, when social workers are compared to other professionals, they have not fared well in resource allocation. Considering limited coverage of social services by insurance companies, erosion of government funding, and inadequate evidence of social work contribution to

healthcare (Maramaldi et al., 2014), social workers must be intentional and proactive about demonstrating their level of expertise to be less expendable.

By virtue of their training, social workers are uniquely positioned to address not only the death of the loved one, but bring a holistic perspective to end-of-life care and major life transitions for vulnerable populations (Paul, 2013). The MSW programs are designed to educate and develop practitioners that can work with disadvantaged and marginalized populations. Some of the theoretical frameworks that make social work training distinctive from other professionals are that topics on oppression (including racism, classism, sexism, etc.), privilege, and resilience are integrated in core content classes (Shulman, 2016). It is essential that social work institutions intentionally remain true to its core values in promoting social justice to vulnerable populations. The preparation of social work students, their willingness to engage in critical dialog about their own biases, and how they influence practice contribute to effective social work practice (Edmonds-Cady & Wingfield, 2017). Their coursework is inclusive of concepts like strengths-based perspective, unconditional positive regard, and client's right to determination prepare social workers to be clinicians, advocates and a source of resilience for the clients they serve (Shulman, 2016).

Based on a thorough review of the literature, there were no identified articles specifically from the NICU social worker's perspective. In spite of this, there were several articles that justified the significance of a medical social worker (Auerbach, Mason, & Laporte, 2007; Judd & Sheffield, 2010). Although discharge planning is identified as a core activity, administrative tasks requiring more complex skills are being required (Cleak & Turczynski, 2014). Social workers not only assist with connecting the family to resources and discharge planning, but also serve as a counselor and advocate, educating the medical team about the needs and wishes of the

family (Mizrahi & Abramson, 2000; Mizrahi & Berger, 2005; Smith, 1987). Additionally, social workers develop coping strategies with families to deal with the stressful environment of the intensive care unit, clarify medical information regarding prognosis, and assist with decision making options (do not resuscitate, artificial hydration/nutrition, mechanical ventilation, antibiotics, renal dialysis, etc.) (McCormick et al., 2010). Additionally, much of the research involving communication with parents focus on the dynamics between the nurses and doctors, rather than social workers (Green, 2015). In spite of this, social workers are the professionals that have the training to effectively communicate to clients and family members in crisis situations. The National Association of Perinatal Social Workers (NAPSW) is the only organization identified geared toward the subspecialty of the NICU. Incorporated in 1980, its mission is “to promote, expand and enhance the interests and role of social work in perinatal health care” (NAPSW, 2016, para.4). Given the expansions of neonatal intensive care units nationwide, there should be more resources available to social workers in this field. Organizations like NAPSW are conduits by which social workers can explicitly advocate for the work. Other disciplines like nursing and medical journals are talking about the gaps in service for working with bereaved parents, but the social work perspective is missing in the discourse. I propose that social workers can advocate for regulations that enforce implementation of the FCC model and that they are the solution to this identified need. Social workers have the skills necessary to implement an effective, coordinated bereavement program for parents in the NICU.

Recommendations for future research

The limited scope of this article was not able to capture all of the key components to why social workers are an untapped resource in the NICU for bereaved parents. There is a significant amount of literature from the nursing and medical disciplines and it is unclear what barriers exist

for academic social work publications. Medical social workers have been expendable over the past decades and have endured competition and sometimes negative interaction with nurses and physicians. These and other factors like lower salary and limited assessment instruments can make social workers feel incompetent, inadequate, inferior, and oppressed in comparison to nurses and physicians. The imposter phenomenon coined by Clance and Imes (1978), references a feeling of incompetence despite professional successes (as cited in Lane, 2012). Exploration about the imposter phenomenon among medical social workers compared to other disciplines may provide some insight to whether they feel inferior and thus limiting how they function in the medical setting.

There are limitations with the ability to generalize work with bereaved parents primarily because of the homogeneity of most samples. Four in every 1,000 births will result in neonatal death annually in the US. Non-Hispanic Black women are more likely to have a baby die than women of any other race or ethnicity (March of Dimes, 2017). Given these statistics, it is questionable why most of the published research on this population targets middle-aged, educated, married Caucasian women. Future research might explore methods of recruitment and region of sample population.

Conclusion

Over the past century, social workers have made a crucial mark in medicine. The graduate level training provides exposure to theories and evidenced-based practice that informs the work they do in the field and clinical practice. The research and technology advancements in the NICU have sustained the lives of newborns that would have otherwise died. Unfortunately, even with all of the technology, some babies will die in the NICU. Similar to the intentionality of advancement of treatment, hospice and palliative care (including bereavement services) should

be equally advocated for. Social workers are identified as essential members of the NICU interdisciplinary team and with the proper tools and resources can be the advocates and service provider for bereaved parents.

For parents who are having a challenging time with perinatal loss, grief counseling can assist them in their journey to healing. The social worker who is guided by grief theory has the framework to provide a safe space for the bereft to explore a new narrative. Just because the infant is deceased does not negate his/her value as a member of the family. Klass, Silverman, and Nickman's continuing bonds theory sheds light on the ability to continue a relationship with the infant in a different manner. Sometimes parents "need help affirming the ongoing relationship to the baby they dreamed of having (and lost) and differentiating it from a new pregnancy and/or baby" (Walter & McCoyd, 2009, p. 330). After experiencing such a traumatic loss, Neimeyer's meaning-making theory can help the bereaved parent construct a coherent experience that accounts for their presumptive worldview, while integrating the death of his/her loved one.

Specific plans for publication

It is evident that there are gaps in the educational training and the empirical research for NICU social workers. Publication is one method for creating awareness of the significance of this topic. Upon completion of the dissertation process, peer-reviewed social work journals will be explored to contribute knowledge to clinical practice. Development of a continuing education course or a master's level course curriculum are other opportunities to bolster social work content expertise. Mandating courses on "grief and loss" or "trauma" as core content may be a long-term goal, however, masters of social work programs are ever changing to meet the clinical demands of practice. Inclusion of more elective courses with this may be a more realistic option

and can further qualify social workers as “content experts” in working with bereaved parents of the NICU. Additionally, designing a comprehensive FCC program that includes neonatal hospice/palliative care programs and a full bereavement program for the NICU will provide opportunities for hospitals to provide necessary services for bereaved parents.

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Appendix

Sample Prospectus NICU Bereavement Program

Ideally, advocacy work that supports the recommendations of the American Academy of Pediatrics (2008, 2013) would require that neonates have access to both palliative and hospice care upon admission into the Neonatal Intensive Care Unit (NICU). The provision of psychoeducation to all parents would include topics like: expectations in the NICU, prematurity, breastfeeding, communication with medical staff, parenting/bonding in the NICU, life after the NICU. For parents who experience the death of their child in the NICU, the following bereavement services would be immediately available.

Name: Elise Mone' Memorial Benefits Services

Purpose: To provide research based, theory driven, comprehensive Family-Centered Care and Bereavement services for those who may experience perinatal loss in the NICU.

Description: This program is an extension of the Family-Centered Care design proven to increase favorable outcome for NICU neonates. Upon admission into the NICU, all neonates are enrolled into palliative and hospice care services. Should the infant become terminally ill, hospice care would become primary and the family are connected to the bereavement services.

The four major components include: connection, experience, follow-up, and education.

“Connection” encompasses contacting the bereaved parents/family within 24 hours. Provision will be made for the family to privately spend time holding and seeing the baby once it is determined that death is eminent and after the infant dies. In alignment with current practice, space will be provided for the family’s spiritual advisor, creating memoirs e.g. hand/foot prints,

dressing the baby, etc. After leaving the hospital, a phone call will be made to inquire about any needs or if questions have surfaced since leaving the hospital. Within the first month of the loss, a visiting social worker will schedule a minimum of two home visits to assess family's needs, status, and resources available to the parents and family. After the first month post loss, the option will be provided for the family to continue participating in bereavement services by obtaining a parent mentor. Within the first year, condolence cards will be sent on holidays, time interval periods, and the one-year anniversary.

“Experience” – focuses on grief counseling facilitated by a licensed social worker either in a group setting and/or individually up to a year. The groups are held at a parent friendly space in the hospital. Individual sessions are provided in the home or in office space.

“Follow-up” – after one year of services, another assessment will be conducted to determine if additional services are necessary to make appropriate community-based referrals.

“Education” – recruitment of bereaved parents who have participated in the service and are willing to be trained in the model. Parent/Staff development and continuing education will be provided through the trauma-informed lens and grief theory perspective, addressing issues of grief, trauma and perinatal loss, and effective communication. This component will also include advocacy work that makes connections with groups like National Association of Perinatal Social Workers.