

Navigating Infant Death from Life-Limiting Congenital Anomaly: A Classic Grounded Theory Study

Susan Bush Welch, PhD, RN

Abstract

The purpose of this classic grounded theory study was to explore how parents experience the expected death of an infant from a life-limiting congenital anomaly. These anomalies are the leading cause of death of infants in the United States. Death typically occurs in intensive care units with limited access to adequate palliative/end-of-life care. An extensive knowledge gap about the experience of these parents exists. The grounded theory *Navigating Infant Death from Life-Limiting Congenital Anomaly* contains three stages and two cutting points. The first stage is *living in innocence* which ends with the first cutting point of *getting the bad news*. The second stage is *parenting in the new reality* which ends with the second cutting point, *death of the baby*. The final stage of the theory is *going on*. This new theory has implications for nursing/health care professionals in practice and research. This study was conducted as the dissertation while the author was a student in the doctoral program at West Virginia University.

Keywords: classic grounded theory, infant death, congenital, parenting, anomaly

Introduction

Birth and death are two end-points on the continuum of life. For some infants, the space separating birth and death is very close with death occurring just minutes after birth. Many of these children are infants born with life-limiting congenital anomalies. In 2016, 23,000 infants died in the United States with congenital anomalies the leading cause of death (20%, n=4816) (Xu, Murphy, Kochanek, Batian & Arias, 2018). Worldwide the percentage of deaths from congenital anomalies is 11.3% for neonates, and 6.5% for 1-59 month old infants/children (World Health Organization [WHO], 2018).

There is much literature about the impact of infant loss on parents. However most of it focuses on death through sudden and unexpected means such as Sudden Infant Death syndrome (SIDS), stillbirth, extreme prematurity, or miscarriage. The experience of parents whose infant has a life-limiting congenital anomaly is different. These parents know their baby will die. Scant research exists in which authors explored the experience of parents who had an infant die from life-limiting congenital anomalies.

Recent authors have focused on adequate palliative and end-of-life care for infants with life-limiting congenital anomalies and the families (American Academy of Pediatrics, 2013; Dahlen, 2013; National Association of Neonatal Nurses, 2015). Unfortunately, little

empirical evidence defines and describes adequate palliative and end-of-life care. Of special note is the scarcity of evidence describing parents' experiences. Classic grounded theory was used to explore the process parents experienced during the birth, life, and death of an infant with a life-limiting congenital anomaly. The development of a substantive theory using classic grounded theory methodology will assist health care professionals to understand and address parental needs through this process.

Method, Data Collection and Analysis

The dearth of literature specific to this population supported the use of qualitative methods. Health care professionals cannot develop appropriate interventions when so little is known about the experience of these parents. Classic grounded theory was chosen because it is a powerful method to understand unfolding processes. The parents' experience from birth to death was an unfolding process.

The study was approved by the Institutional Review Board to ensure the protection of participants. Data collection, sampling and data analysis/interpretation occurred iteratively. Almost all sampling was purposive. To qualify for the study, each participant was (a) the biological mother or father of an infant who died of a life-limiting congenital anomaly within the first 15 months of life, (b) over 18, and (c) understood/spoke English. The baby had to meet the following criteria: (a) lived at least 48 hours and no more than 15 months, (b) had a prenatal or post-delivery diagnosis of a life-limiting congenital anomaly, and (c) died within the last 10 years. A healthy pregnant woman was interviewed for theoretical sampling to illuminate the experience of hope and expectation of pregnancy that was no longer real to the other participants. Sampling took place until saturation occurred. There were a total of 12 participants, eleven females and one male. All but one participant lived in West Virginia. The babies suffered from a variety of congenital anomalies. Diagnosis of the anomaly occurred prenatally (n= 4), at delivery (n=4), in the first day or two of life (n=1) and after 30 days (n=2). The life span of the deceased babies ranged from three days to nine months of age. Six of the babies died within the first two weeks of life, the rest between three months to nine months of age.

The participants were first contacted by a third party about willingness to participate in the study. The participant chose where, when, and how the non-structured interview happened. Interviews were not recorded, as suggested by Glaser (1998). The writing of field notes on a password-protected computer occurred within minutes of completion of the interviews. Data analysis started after the first interview. Constant comparison was used throughout the process to code and classify data. Memos were generated and sorted. The outcome of the study was the grounded theory *navigating infant death from life-limiting congenital anomaly (navigating infant death)*.

Navigating Infant Death from Life-Limiting Congenital Anomaly

The theory of *navigating infant death* has three stages with two cutting points. In the first stage, the parent-to-be/parent is *living in innocence*. *Living in innocence* abruptly ends with the cutting point of *getting the bad news*. *Getting the bad news* occurs when the parent learns that there is a major health issue with the fetus/baby. This cutting point may happen

prenatally or after birth. The second stage of *parenting in the new reality* starts after *getting the bad news*. During the stage of *parenting in the new reality*, the following processes occur: *seeking answers, squeezing a lifetime into a moment, and letting go*. A second cutting point occurs at the *death of the baby*. The third stage that follows the death of the baby is *going on*. *Going on* includes four processes: *saying goodbye, seeking meaning in the baby's life, keeping his/her memory alive, and living life*.

Stage 1: Living in Innocence

Living in innocence is the first stage of the theory. During this stage, the expecting parent awaits the birth of a healthy baby or the new parent enjoys a seemingly healthy baby. The physical discomfort related to pregnancy or childbirth are minimized or tolerated because the outcome, a healthy baby, is worth it. The parent feels optimistic and plans for a future that includes the new baby. This time is full of hopes and dreams. However, this stage ends abruptly with the diagnosis of a life-limiting congenital anomaly or *getting the bad news*. The participants talked briefly about this time, but focused instead on the rest of the story.

Cutting Point #1: Getting the Bad News

The stage of *living in innocence* ends abruptly with *getting the bad news*. *Getting the bad news* is a significant event and occurs when the parent learns that there is a major health issue. This cutting point may happen during pregnancy or after the birth of the baby. At this moment, the ideal of the perfect baby leaves and forces a new reality on the parent. Anticipation becomes anxiety, fear, guilt, and dread. Joy is replaced by sadness and grief. Dreams and plans are forever altered. All participants talked about *getting the bad news*.

Stage 2: Parenting in the New Reality

The stage of *parenting in the new reality* starts after *getting the bad news*. Living in innocence is forever gone. The parent is now left with the new and awful reality that the baby will die. The parent-to-be/new parent must deal with the unique challenges that follow the diagnosis of a life-limiting congenital anomaly in the fetus/baby. The stage may last for minutes, hours, days, or months but always ends with the second cutting point: *the death of the baby*. Three major processes occur within the stage of *parenting in the new reality*: *seeking answers, squeezing a lifetime into a moment, and letting go*.

Seeking answers. The parent starts the process of *seeking answers* to address the issues raised by the bad news. Therefore, *seeking answers* is typically the first process that occurs in the second stage. This process is iterative and happens as long as the baby lives. *Seeking answers* has three properties: *maintaining hope, being separated from the baby, and making decisions*.

Seeking answers may mean trying to find out what is wrong and to save the baby. Transfer and admission to specialized units is another means of *seeking answers*. How to explain the situation to the siblings of the baby and help those children cope is another aspect of this process.

Referral to a high-risk perinatal or neonatal/pediatric specialist is an element of *seeking answers*. These specialists may be local or in locations far from home. The parent goes to the specialist seeking answers about what is wrong with the pregnancy and/or baby. Hope exists that the specialist can make everything all right. All participants received or sought referral to high-risk perinatal or neonatal/pediatric specialists.

Another means of *seeking answers* is transfer and admission to specialized units, high risk antepartum for the still pregnant woman, and neonatal/pediatric intensive care units (NICU/PICU) for the baby. The parent or baby may spend a great deal of time in these units which also may be far from home. Some babies spend the majority or all of their brief life in the NICU. All of the babies, except one, spent a portion of their brief lives in an intensive care unit.

The parent may have concerns about the siblings of the baby. *Seeking answers* may include questions on how and what to tell the baby's sibling(s) about the infant's condition. There may concerns about the logistics of who will take care of the siblings if the parent has to go far away for care. The parent may need assistance in trying to prepare the siblings for the baby's death. Many of the participants had other living children and wrestled with these issues.

A final means of *seeking answers* is finding how to best care for a dying baby. This type of *seeking answers* occurs once the fetus/baby has a diagnosis of a life-limiting anomaly and the parent experiences *letting go*. Options for end-of-life care for the baby may include staying in the NICU/PICU, in-patient or home hospice care, or on the regular mother-baby unit. Many of the participants received hospice care.

Maintaining hope is a property within *seeking answers*. The parent hopes that somehow that something can be done and that the baby will live. Some parents never gave up hoping for a miracle despite a grim prognosis. Others claim to know that the baby will not come home.

Being separated from the baby occurs after admission to a specialized unit and is a consequence of seeking answers. Distances, NICU unit policies, severity of the baby's illness, and/or health complications of the mother are sources of the separation. The separation is a source of stress. Participants talked about seeing the baby only briefly right after birth because the baby was quickly taken to the NICU for care.

Making decisions is the result of the knowledge gained from *seeking answers*. Parents must make many decisions over the course of the pregnancy and/or baby's short life. Some of these decisions are literally life and death ones. Decisions about elective termination or resuscitation efforts at delivery may be made during the pregnancy. Once the baby is born, decisions may include feeding the baby, withdrawal of curative care for comfort care, and staying in the hospital versus taking the baby home to die. One participant upon getting the diagnosis said "I told them to take her off the vent, bathe her, and bring her to me."

Squeezing a Lifetime into a Moment. *Squeezing a lifetime into a moment* is a vital process that occurs during the second stage. During this process, the parent literally

tries to squeeze a lifetime of being with the baby into whatever brief time the baby is alive. No matter the length of this period, there is never enough time. *Squeezing a lifetime into a moment* has three properties: *keeping vigil*, *creating memories*, and *seeking normalcy*. These properties do not occur in any particular order and often occur simultaneously.

Keeping vigil is a hyper-vigilant state of being with the baby. The parent rarely, if ever, allows the baby out of sight and includes closely watching the baby breathe or holding the baby all the time. This differs from what an anxious new mom of a healthy baby exhibits. The anxious mom is still *living in innocence* and assumes there will be a lifetime with the baby. Whereas the parent in the process of *squeezing a lifetime into a moment* knows there is a future without the baby. The parent *keeping vigil* watches for any sign that there is improvement or worsening of the baby's condition. Reinforcement of *maintaining hope* occurs if the baby demonstrates any improvement or remains stable. Conversely, as the parent sees the baby's condition worsening, the process of *letting go* begins. Any changes seen during *keeping vigil* may require the parent to revisit *making decisions*. All participants talked about *keeping vigil*. Some participants talked about sitting at the baby's bedside in the NICU/PICU for hours, only leaving to get some sleep.

Creating memories is another property in *squeezing a lifetime into a moment*. Since the parent has an unknown and limited time with the baby, there is an urgent need for *creating memories* that will last a lifetime. Once the baby is gone, the parent will only have the memories. The parent who is *creating memories* does so by spending time with the baby. The baby's siblings, grandparents, other extended family and friends may also spend time with the baby. During this time, the parent may hold, dress, feed, and/or provide other types of care for the baby. Others may hold the baby, but not too long as the parent wants all the time possible with the baby. The creation of mementos is also a means of *creating memories*. Taking pictures, making a casting of the baby's hands or feet or putting hand or footprints on a card or other items are types of mementos. Items used or worn by the baby may also become mementos later. *Creating memories* was done by all participants. All participants showed the author at least one memento of the baby.

Seeking normalcy is the third property within *squeezing a lifetime into a moment*. As with the other two processes, this may occur anytime in the process of *squeezing a lifetime into a moment*. *Seeking normalcy* is the attempt by the parent to find or create a sense of order in an out-of-control situation. During *seeking normalcy* the parent will look for familial physical traits and/or may overlook obvious outward signs of the baby's problems. *Seeking normalcy* may include creating an environment that is more home-like than the highly technical intensive care unit. The parent wants the time spent with the baby to be of good quality. To have this quality time, the parent may demand alone time with the baby in the unit. It is a challenge, even a contradiction of terms, for the parent to experience being alone with the baby in the NICU as there are always all types of health care personnel around. The structure of some units may preclude privacy. Many participants talked about being alone with the baby as cherished time, especially those in the hospital NICUs. Taking the baby home to die is another option for seeking normalcy. At home, the parent does not have to share the baby with the nursing and medical staff. Some participants brought the baby home to die. None of the participants who brought the baby home to die voiced regret over the decision.

Letting Go. *Letting go* may occur prenatally with the decision to forgo the initiation of resuscitation measures at birth or after birth with the withdrawal of heroic measures and the initiation of palliative or hospice care. The parent understands that it is futile to initiate or continue heroic medical intervention to save the baby's life. Instead of cure, the focus of care becomes the prevention or ease of suffering. Quality of life becomes primary.

Letting go may not occur just once. Rather, the parent may vacillate between *maintaining hope* and *letting go*. This vacillation may occur if the baby experiences a good hour, day, or week. The parent who vacillates looks for any little sign that the doctors are wrong. The less symptomatic and longer the baby lives, the more likely that this vacillation will occur.

During the process of *letting go* the parent is also *seeking answers* and *making decisions*. The parent seeks answers and makes decisions about how and where to best provide care for the baby who is actively dying or will soon die. Additionally, the process of *squeezing a lifetime into a moment* takes on a sense of urgency as the parent realizes that time left with the baby is very short.

Cutting Point Two: The Death of the Baby

The death of the baby is the second cutting point. The baby takes a final breath, a heart stops beating and death occurs. The stage of *parenting in the new reality* ends. Death is, at times, a paradoxical moment. The parent wants the baby to stay alive but also wants the suffering to stop. So, when death occurs, the parent experiences feelings of grief and sadness. However, the parent may also feel relief that the baby's suffering is over. All participants, except one couple, discussed being with the baby at the moment of death.

Stage 3: The Stage of Going On

The stage of *going on* begins with the death of the baby. *Going on* does not mean getting over the loss of the baby. Rather, *going on* involves doing what needs to be done to live life. The parent goes back to work, a marriage, and being a parent if applicable. However, life is forever changed.

The stage of *going on* has four processes. *Saying goodbye* is the first process that happens in the stage of *going on* and continues throughout the stage. The other three processes, *seeking meaning in the baby's life*, *keeping mementos*, and *living life* occur iteratively after *saying goodbye*.

Saying goodbye. Parents react to the death of the baby and feel the loss. During this time the parents prepare for a physical separation from the baby. A first separation occurs when the baby goes to the morgue or to the funeral home. Leaving the hospital without the baby is a difficult experience for the parent. Participants whose baby died in the hospital talked about how hard it was to leave the hospital with empty arms. For those parents who cared for the dying baby at home, it was hard to surrender the baby to another such as the person from the funeral home. One participant stated, "I felt jealous, they were going to get to be the last people to hold her."

The burial or cremation of the baby's body is a final physical separation from the parent. The parent will not ever be able to hold the baby again. The funeral/memorial service is part of the final physical separation. This service may provide the parent with validation that the baby's life had meaning. The participants appreciated the presence at the service of family, friends, and the health care professionals who cared for the parent and/or baby. This presence seemed to validate that the baby was valued even though here for a short time.

Saying goodbye is a very sensory experience. The parent holds and touches the baby prior to the separations. Some participants dressed the baby in every outfit prior to that first separation. Others bathed, took pictures, and held the baby. One participant shared sniffing the baby from head to toe after death in order to remember the baby's smell.

Saying goodbye is a paradox. The parent goes through the motions of *saying goodbye*; however, the deceased baby never totally leaves. The baby lives forever in the parent's memories and heart. Additionally, parents hang on to and/or display items related to the baby such as pictures, blankets, and plaster footprints. These physical reminders are very present even if the baby is not.

Seeking meaning in the baby's life. During *seeking meaning in the baby's life*, the parent tries to make sense of the loss. The baby was here for a reason. The parents talk about the baby impacting others and making a difference in the world, even if here for a short while. Therefore, the baby's life had a purpose. This effort seems rooted in some faith in the order of the universe. Something good has to come out of something so awful. Properties of seeking meaning in the baby's life are *helping others* and *telling their story*.

Helping others is an element of *seeking meaning in the baby's life*. Through *helping others*, the parent ensures that the baby's life was not meaningless. This helping takes many forms. The parent may volunteer to serve as a personal contact should another person in the area deliver a baby either with the same condition or another one that is life-limiting. Making monetary contributions to hospitals, hospices, or to foundations specific to the disorder that took the baby's life is another means of *helping others*. Participants found that *helping others* helps them to heal.

Keeping the baby's memory alive. *Keeping the baby's memory alive* is done by *telling their story* and *keeping mementos*. These two properties make the baby's life real. Remembering the baby is painful and joyful. Parents smiled and cried while telling their stories and sharing mementos. It was as if the parents were afraid that the baby will be forgotten and that all the pain was for nothing.

Telling their story occurs because the parent wants to share the story of their baby. The baby's life is validated if someone knows the baby's story. *Telling their story* brings pain and joy to the parent. Parents seem willing to experience the pain because the alternative is to forget, which is not possible. In telling the story the parent may resort to presenting elements of their experience in very clinical terms or reciting the facts. This method of sharing seems to protect the parent from painful feelings. Parents want to tell their story. However, factors exist that make sharing a challenging proposition. The death of a baby is,

at best, an uncomfortable subject. Well-meaning family and friends fear that talking about the baby will upset the bereaved parent. Family and friends listen to the story about the baby, but only for so long. The bereaved parent gets the message that others do not want to hear about the baby and feel silenced. Many participants discussed feeling silenced when wanting to talk about their dead baby. One participant who stated "I just love talking about N." also said "No one else wants to hear me talk about her anymore."

The other way to *keep the baby's memory alive* is through *keeping mementos*. The mementos took many forms with pictures of the deceased baby the most common keepsake. The parent may display the photo of the deceased baby in the family home. Family photos shot during *creating memories* may be part of a scrapbook. The scrapbook may also contain hand/foot prints of the baby or a lock of the baby's hair. Other mementos include clothing worn by the baby, blankets, a casting of the baby's hands and feet, hand crafted items made by family and friends, and even medical equipment such as the baby's blood pressure cuff. These mementos symbolize the reality of the baby's existence. *Keeping mementos*, like *saying goodbye*, is a sensory experience. If the parent touches, sees, or smells something that belonged to the baby, the baby existed. Those same mementos also reinforce the fact that the baby cannot use the items because he/she is no longer here. So, mementos are comforting and painful. All participants had something that belonged to the baby. Most participants proudly displayed pictures of the deceased baby along with pictures of the living children on the wall of their homes. A couple of participants reported opening a plastic bag which contained clothing worn by the deceased baby in order to smell the baby.

Living life. The death of a baby does not mean that life stops. Life will never be the same, but the parent must go on *living life*. Children, marriages, relationships, and other elements of life require the attention of the bereaved parent.

The bereaved parent may not want to get out of bed after the death of the baby. Feelings of sadness, guilt, and grief sap the energy of the parent. But the surviving children have needs that must be met. These needs are a powerful force that impels the bereaved parent to get out of bed each day. Several participants described not wanting to get out of bed after the baby died but said the needs of the living children were the impetus to do so.

The baby's illness and subsequent death is a significant stressor which impacts the parents' relationships. However, few of the participants talked about the relationship with the husband or significant other. One participant talked about the anger her husband felt and reminded him of the need to lean on each other. Most of the participants were still in the marriage into which the deceased baby was born.

The other relationships in the parent's life are impacted by the baby's life and death. Family and friends immediately gather to provide help and support to the parent undergoing the birth, brief life, and death of the baby. However, that help and support may have a time limit. New relationships also develop during this time especially if the parent becomes involved with other parents on the private sharing area of websites specific to the baby's condition.

Going back to work may also help the parent get out of bed in the morning. Work may serve to divert attention to something other than the loss. Some participants who worked professionally with children were able to continue their occupation while others had to change.

Part of living life is the decision to have another baby and may be a major risk for these parents. Even a miniscule likelihood of recurrence of the life-limiting anomaly is too much of a risk for some parents. Pregnancy is no longer assumed to result in the birth of a healthy baby. *Living in innocence* is forever lost for these parents. Having another baby for these parents is not replacing the deceased baby. Rather the new baby is a validation that life is good. Participants fell on both sides of this decision. One participant stated "J. brought laughter back into our home."

The death of a baby is a major negative life event. So, it is not surprising that a parent may require professional help to deal with the loss. Concerns about surviving children may also impel the parent to seek the input of a professional. Many participants discussed seeking such care.

Discussion

The new theory, *navigating infant death*, describes the experience of parents whose baby died of a life-limiting congenital anomaly. The theory emerged from the participants' stories. The theory contains three stages with process and properties and two cutting points.

Navigating denotes that the parent is finding a way through the challenging journey of expecting/delivering, caring for and grieving for a baby who died of a life-limiting congenital anomaly. This journey has no roadmap since many of these anomalies are relatively rare and infant death has become the exception rather than the rule in the United States. Navigating this journey never ends. Grief may wane but never goes away.

Limitations

The participants were a homogenous group. There were only 12 participants. However, saturation occurred by the sixth interview. All participants were female, except for one male. Only one participant did not live in same state. Therefore, it is important to research if the grounded theory reflects the experience of fathers of babies with life-limiting congenital anomalies and of parents who live in other locales.

The participants were volunteers willing to talk about their painful experience. The theory may just reflect the experience of parents willing to talk about their experience and not those who still cannot talk about their loss. It is unclear how to include those unwilling or unable to share, but that input could potentially modify the theory.

Many of the participants utilized some form of hospice care (n=7). This statistic is not consistent with the literature in which authors suggested that anywhere from 9-20% of dying infants receive adequate end-of-life care (Feudtner et al, 2002; Friebert & Huff, 2009; Leuthner, Boldt, & Kirby 2004; NHPCO, 2001; Widger, Seow, Rapoport, Chalifoux &

Tanuseputro, 2017; Zwerdling et al, 2000). In this study, more than half of the babies had hospice care. This high percentage reflects the author's participant recruiting source rather than a genuine increase in access to palliative and end-of-life care for babies. Therefore, it would be important in another study to recruit participants whose babies died without hospice care.

This study only included participants whose babies lived 48 hours to 15 months of age. Many of these babies only live a few hours after birth. Thus, it would be important to explore the experience of parents whose babies lived less than 48 hours to see if that experienced mirrored those who babies lived longer.

Comparison to Existing Literature

Research

Brosig, Pierucci, Kupst and Leuthner (2007) examined the parents' experience of the death of an infant with a life-threatening condition of the perinatal period or congenital anomalies. In the semi-structured interviews, bereaved parents identified coping strategies that included seeking support from family and/or a bereavement support groups, focusing on the surviving children, memorializing the dead infant in some manner, turning to God, and giving back. These strategies are similar to the processes and properties in the stage of *going on*.

"Having expectations, continuity of, memory making, having a network of support and altruism" (Tan, Docherty, Barfield & Brandon, 2012, p. 582) were the categories in a content analysis of interviews with bereaved parents of infants who died of complex life-threatening conditions. Memory making and altruism are similar to *creating memories* and *seeking meaning in the baby's life*. Themes within having expectation find congruence in *making decisions*.

Lathrop and VandeVusse (2011) interviewed bereaved mothers who had continued a pregnancy after diagnosis of a lethal fetal anomaly. Themes arose after narrative analysis of the interviews. Continuity, the first theme, refers to the feelings and thoughts still present despite the passage of time such feeling of love and connection for the baby, the pain of loss, and a sense of the baby's ongoing presence in their lives (Lathrop & VandeVusse, 2011). This theme is congruent with many of the processes in *going on*. Another theme, transient phases, characterized transient periods of time when certain feelings or events were predominant, such as at time of diagnosis and the baby's death (Lathrop & VandeVusse, 2011). This theme correlated with the two cutting points.

Theories

Negotiating infant death will briefly be compared to theories from death and dying, grief and bereavement, and parenting. "Awareness of Dying" (Glaser & Strauss, 1965) has limited applicability to this new theory. Open awareness is congruent during and between the two cutting points. The practice of family-centered care where the family is the patient, not just the infant, makes open awareness applicable.

In "Time for Dying," Glaser and Strauss (1968) described perceived trajectories of dying with two properties: time and shape. The new theory is relevant to "Time for Dying" in many ways. The dying trajectories of neonates/infants with life-limiting congenital anomalies vary, so time is critical during *squeezing a lifetime into a moment*. Shape is also a critical element. A rapid decline severely decreases the time in parenting in the new reality; a more insidious course allows for more time. Death expectations exemplify the characteristics of many congenital anomalies that are incompatible with life and have a certain death at a known time. The death expectation impacts on all aspects of *parenting in the new reality*.

The theory of grieving by Parkes (1998) consists of four phases: numbness, pining, disorganization and despair, and reorganization. Parkes (1998) suggested that grieving included the conflicting urges to look back and look forward during the last two phases of grieving. This idea correlates with *saying goodbye/keeping the baby's memory alive* and *living life* in the stage of *going on*. Some aspects of Parkes' reorganization phase bear resemblance to the process of *living life*. The iterative nature of the phases of Parkes theory of grieving is similar to the iterative nature for the processes within the stage of *going on*.

According to Worden (2002), the bereaved have four tasks to complete in a sequential manner. The tasks are (a) accept the reality of the loss, (b) work through and experience the pain of grief, (c) adjust to an environment without the deceased person, and (d) withdraw emotionally from or relocate the deceased and move on. All the tasks are consistent with processes that occur in the stage of *going on*. However, the sequential nature of the tasks differs from the iterative nature of the processes in *going on*.

The constructivist grounded theory of safeguarding precarious survival, parenting children who have life-threatening heart disease, has limited congruence. There are some processes in *navigating infant death* that are similar to strategies discussed by Rempel and Harrison (2007) but other are not. These researchers talked to couples whose baby was still alive, so it is not surprising that the theory has limited applicability.

Implications

Practice

Negotiating infant death has relevance for nurses and other health care professionals in many sites of practice, with NICU and PICU being the most obvious choices. The theory could be utilized as a conceptual framework for practice in the primary or acute care setting when caring for the pregnant patient carrying a fetus with a life-limiting congenital anomaly or a baby diagnosed with a life-limiting congenital anomaly. Since most infants still die in the NICU, most of the discussion focuses on the implications for practice in the NICU. However, many of the principles guiding care for the dying infant in those units can be extrapolated for use in the other settings in which these infants die.

The theory of *negotiating infant death* provides evidence for many of the interventions suggested in the papers, position statements, and protocols about palliative/end-of-life care for an infant. According to Kendall and Guo (2008), most bereavement care that occurs in NICU's has been an "intuitive response to a perceived

need" (p. 131). This author would argue that this statement is true for many of the palliative/end-of-life protocols/documents.

These protocols address issues under the general categories of communication, environment, parental activities, bereavement, withdrawal of life support, pain and symptom control, and prolonged dying process (Carter & Bhatia, 2001; Catlin & Carter, 2002; De Lisle-Porter & Podruchny, 2009; Gale & Brooks, 2006; NANN, 2015). The first four aspects primarily pertain to the parents and find support in this new theory. Honest and sensitive communication with the parents is vital throughout all the stages and cutting points. Most of the protocols addressed the need for creation of an optimal environment for the infant's death. Environment does not just refer to location of care but also the creation of a milieu which meets the parents' needs. The importance of parental activities is supported as parents *create memories* while the baby is alive and *keep the baby's memory alive* after the baby's death. Bereavement care should start *at getting the bad news* and continue on throughout the rest of the stages.

Research

There is a great need for more research related to infants with life-limiting congenital anomalies and their families as evidenced by the dearth of published research. Some suggestions for additional research were already discussed in the limitations. There is some published research in which the authors focused on the bereavement process that occurs after the cutting point of the *death of the baby* in the stage of *going on*. However, as discussed earlier, much of that research lumps all types of perinatal loss together. More research is needed about what helps a parent of baby with a life-limiting congenital anomaly with *going on* after the expected death of a baby.

Researchers need to explore what is happening between the cutting points of *getting the bad news* and *the death of the baby*. More information is needed about the support and care needed by parents from the first breaking point of *getting the bad news* through the stage of *parenting in the new reality*. A great knowledge gap exists between these two periods of time. Research about the process of *seeking answers* could explore models of care that meet the parent's needs and prevent separation. Decision making in ventilator withdrawal in infants has been researched in which infants with life-limiting conditions as well as those born prematurely were discussed. Other aspects of *making decisions* such as those made prenatally about resuscitation or post-delivery about staying in the hospital versus taking the baby home to die are important areas to explore. Related to making decisions would be research on how to support the parent in *letting go*. Perinatal hospice as a model of care from *getting the bad news* through *going on* also needs researched.

Conclusion

Negotiating infant death from congenital anomaly is a new grounded theory that illuminates the experience of parents whose baby died of a life-limiting congenital anomaly. These parents' voices have been missing in the literature on infant loss. Thus, this theory fills a gap in knowledge. The theory provides a conceptual framework to support some interventions already done such as the creation of mementos. However, there is much to

do to ensure that babies dying from life-limiting congenital anomalies have optimal palliative/end-of-life care. It is this author's hope that *negotiating infant death from life-limiting congenital anomaly* will serve as a starting place.

References

- American Academy of Pediatrics (2013). Pediatric palliative care and hospice care commitments, guidelines and recommendations. *Pediatrics*, 132 (5), 966-972. doi:10.1542/peds.2013-2731
- Brosig, C., Pierucci, R., Kupst, M. & Leuthner, S. (2007). Infant end-of-life care: The parents' perspective. *Journal of Perinatology*, 27, 510-516. doi:10.1038/sj.jp7211755
- Caitlin, A. & Carter, B. (2002). State of the art. Creation of a neonatal end-of-life palliative care protocol. *Journal of Perinatology*, 22(3),184-195. doi:10.1038/sj/jp/7210687
- Carter, B. S. & Bhatia, J. (2001). Comfort/palliative care guidelines for neonatal practice: Development and implementation in an academic medical center. *Journal of Perinatology*, 21(5), 279-283. Retrieved from <http://www.nature.com/jp/journal/v21/n5/pdf/7210582a.pdf>
- Catlin, A. Brandon, D, Wool, C., & Mendes, J. (2015). *Palliative and end-of-life care for newborns and infants: Position Statement #3063*. Retrieved from http://nann.org/uploads/About/PositionPDFS/1.4.5_Palliative%20and%20End%20of%20Life%20Care%20for%20Newborns%20and%20Infants.pdf
- Dahlen, C. (Ed.) 2013. *Clinical practice guideline for quality palliative care, 3rd ed.* Pittsburgh, PA. National Consensus Project for Quality Palliative Care. Retrieved from https://www.nationalcoalitionhpc.org/wp-content/uploads/2017/04/NCP_Clinical_Practice_Guidelines_3rd_Edition.pdf
- De Lisle-Porter, M. & Podruchny, A. (2009). The dying neonate: Family-centered end-of-life care. *Neonatal Network*, 28(2), 75-83. doi:10.1891/0730-0832.28.2.75
- Feudtner, C., Christakis, D. A., Zimmerman, F. J., Muldoon, J. H., Neff, J. M., & Koepsell, T. D. (2002). Characteristics of deaths occurring in children's hospitals: Implications for supportive care services. *Pediatrics*, 109(5), 887-893. doi:10.1542/peds.109.5.887
- Friebert, S. & Huff, S. (2009). NHPCO's pediatric standards: A key step in advancing care for America's children. *NewsLine*. Retrieved from http://www.nhpc.org/files/public/quality/Peds-Standards_article_NL-0209.pdf
- Gale, G., & Brooks, A. (2006). Implementing a palliative care program in a newborn intensive care unit. *Advances in Neonatal Care*, 6(1), 37-53. doi:10.1016/j.adnc.2005.11.004

- Glaser, B. (1978). *Theoretical sensitivity: Advances in the methodology of grounded theory*. Mill Valley, CA: The Sociology Press.
- Glaser, B. (1998). *Doing grounded theory: Issues and discussions*. Mill Valley, CA: Sociology Press.
- Glaser, B. & Strauss, A. (1965). *Awareness of dying*. Mill Valley, CA: Sociology Press.
- Glaser, B. & Strauss, A. (1968). *Time for dying*. Mill Valley, CA: Sociology Press.
- Kain, V. (2011). Exploring the barriers to palliative care practice in neonatal nursing: A focus group study. *Neonatal, Paediatric and Child Health Nursing*, 14(1), 9-14. Retrieved from www.npchn.com/
- Kendall, A. & Guo, W. (2008). Evidence-based neonatal bereavement care. *Newborn and Infant Reviews*, 8(3), 131-135. Retrieved from <https://www-sciencedirect-com.marshall.idm.oclc.org/journal/newborn-and-infant-nursing-reviews>
- Lathrop, A. & VandeVusse, L. (2011). Continuity and change in mothers' narrative of perinatal hospice. *Journal of Perinatal & Neonatal Nursing*, 25(1), 21-31.
- Leuthner, S. (2004). Palliative care of the infant with lethal anomalies. *Pediatric Clinics of North America*, 51(3), 747-759. doi:10.1016/j.pcl.2004.01.006
- Leuthner, S., Boldt, A., & Kirby, R. (2004). Where infants die: Examination of place of death and hospice/home health care options in the state of Wisconsin. *Journal of Palliative Medicine*, 7(2), 269-277. doi:10.1089/109662104773709396
- National Association of Neonatal Nurses (NANN). (2015). Palliative and end-of-life care for newborns and infants: Position statement #3063. Retrieved from http://nann.org/uploads/About/PositionPDFS/1.4.5_Palliative%20and%20End%20of%20Life%20Care%20for%20Newborns%20and%20Infants.pdf
- National Hospice and Palliative Care Organization (NHPCO). (2001). *A call for change: Recommendations to improve the care of children living with life-threatening conditions*. Retrieved from www.nhpco.org/files/public/ChIPPSCallforChange.pdf
- Parkes, C. (1998). Bereavement in adult life. *British Medical Journal*, 316 (7134), 1-9. doi:10.1136/bmj.316.7134.856
- Rempel, G. & Harrison, M. (2007). Safeguarding precarious survival: Parenting children who have life-threatening heart disease. *Qualitative Health Research*, 17(6), 824-837. doi:10.1177/1049732307303164
- Tan, J., Docherty, S., Barfield, R., & Brandon, D. (2012). Addressing parental bereavement support needs at the end of life for infants with complex chronic conditions. *Journal of Palliative Medicine*, 15(5), 579-584. doi:10.1089/jpm.2011.0357

- Widger, K., Neow, H., Rapoport, A., Chalifoux, M., & Tanuseputro, P. (2017). Children's end-of-life health care use and cost. *Pediatrics*, *139* (4), 1-9.
doi:10.1542/peds.2016-2956
- Worden, J. (2002). *Grief counseling and grief therapy: A handbook for the mental health practitioner*, 3rd ed. New York, NY: Springer.
- World Health Organization (2018). *Distribution of cause of death among children aged < 5 years: Congenital anomalies*. Retrieved from
<http://apps.who.int/gho/data/view.main.CM3002015WORLD-CH15?lang=en>
- Wright, V., Prasun, M.A., & Hilgenberg, C. (2011). Why is end-of-life care sporadic? A quantitative look at the barriers and facilitators of providing end-of-life care in the neonatal intensive care unit. *Advances in Neonatal Care*, *11*(1), 29-36.
doi:10.1097/ANC.0b013e3182085642
- Xu, I., Murphy, S.L. Kochanek, M.A. Batian, B. & Arias, E. (2018). *Deaths: Final data for 2016. National Vital Statistics Report 67 (5)*. Hyattsville, MD: National Center for Health Statistics. Retrieved from
https://www.cdc.gov/nchs/data/nvsr/nvsr67/nvsr67_05.pdf
- Zwerdling, T., Davies, S., Lazar, L., Crawford, B., Tucker, L., Boughner, A. & Richter-Beck, L. (2000). Unique aspects of caring for dying children and their families. *American Journal of Hospice and Palliative Care*, *17*(5), 305-311.
doi:10.1177/104990910001700507