PERINATAL AND PEDIATRIC BEREAVEMENT IN NURSING AND OTHER HEALTH PROFESSIONS
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In memory of my beloved husband Tal, who graced my life with his joyful spirit. —BPB

To my family, with gratitude, for their steadfast love and support. —PMW

In loving memory of my parents, who taught me at an early age to not fear grief. —RKL
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Foreword

The idea of losing a child is so overwhelming to all involved—parents, families, professionals, and society—that our natural instinct is avoidance. We wish not to speak of the possibility that a child could die, as if this avoidance would mean it could not happen. But children die. And we now know that the conspiracy of silence only adds to the pain and also keeps health professionals from creating better ways to support children and families.

We have learned over the past 30 years that we must talk about the unspeakable and share stories that make our hearts break with the conviction that, in the telling, we can create a new story. This book on perinatal and pediatric bereavement is really a chapter in a larger “book”; the story the authors will leave for our colleagues and future generations. It is a story of love, hope, and healing. There are 18 chapters in this book covering intimate aspects of a young life ending and how those who remain behind can grieve in such a way that they can go on living. The collective message of these chapters is that there is a better way.

One of the highlights of my professional life has been to be involved in the End-of-Life Nursing Education Consortium (ELNEC) project. ELNEC began in the year 2000 as an educational program to prepare nurses to care for the seriously ill and dying. Soon after, in 2001, we realized the need to create a separate pediatric curriculum to prepare nurses for perinatal and pediatric illness and death. Through the ELNEC pediatric program I have had the honor of learning from pediatric nurses all that can be done to transform the care of children and families.

My commitment to pediatric bereavement goes beyond my profession; it is personal. I have lived it. In 1982, I had a beautiful son, Andrew, who died after 3 months in a neonatal intensive care unit (NICU). He was cared for by wonderful nurses, physicians, and other professionals but very much within a culture of avoidance. There was no discussion about the care of my son relating to any topic written in the pages of this book. My son had been improving and, as we were eagerly preparing for his discharge home, he developed a viral endocarditis and had an acute myocardial infarction. Arriving to the NICU expecting to finalize discharge plans, instead
I witnessed futile resuscitation attempts on my son. When I asked for these efforts to stop, I was told there was no other way, no hospital policy to support my wish that he die in my arms. With my insistence the NICU staff stopped their efforts and many professionals, who had gathered to do all they knew how to do, quickly disappeared. I then stood alone and removed all the tubes, lines, and other equipment from my son’s body and held him in my arms until he died. I stood alone with my son in the middle of 30 infants as other parents were guided away. I could sense the sincere angst of the NICU staff but also their intense need for this scene to end. Within moments, my family, including my son’s 2-year-old sister, left the hospital with no support, no plan, and certainly no thought of bereavement.

In our ELNEC project we have a mantra: “Nurses can’t practice what they don’t know.” The professionals who cared for my son were some of the smartest, kindest, most dedicated and compassionate people I have known. But they did not know what to do when a child died.

This book is a tribute to all those families like mine, who have sailed on unchartered waters with no map, no guide, and no support through the storm. From these families, the field of pediatric palliative care has been born and now the stories are being transformed.

We know now that, while the pain of losing a child remains, much can be done. We now tell stories of families who are prepared for the death, of siblings who are involved, and of bereavement support that honors the precious life of the child and offers hope for healing for the bereaved. This book is a collection of clinical wisdom, theoretical knowledge, and models of care that can continue to tell the story and change cultures of care. There will soon be a time when the care I experienced when my son died, which was, unfortunately, standard care at that time, would not happen any longer because professionals and families will know there is a better way.

As a palliative care nurse I am honored to write this Foreword and to be included in these pages with the authors who are truly pioneers in perinatal and pediatric bereavement. As a bereaved mother, I am grateful to my colleagues who wrote this book because the memories of the care of a child last a lifetime.

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In the past few years, the focus of health care has been the development of evidence-based practice; a three-pronged approach to the delivery of the best care possible to our patients or clients. Evidence-based practice requires that interventions be grounded in the best research evidence possible; that patients or clients find the intervention acceptable; and that clinicians have the expertise to carry out interventions appropriately and effectively. In this text, we offer you—providers of care to bereaved families experiencing a perinatal loss or the death of a child—a means of enhancing your practice. First, we offer evidence from research on effective interventions. Second, we provide evidence from the perspective of families regarding what care they need and find acceptable. And third, we provide information to increase your own expertise in caring for families experiencing tragic losses.

In this book, experts in the fields of perinatal and pediatric bereavement contribute their knowledge about the current state of practice and inquiry in their respective fields. Our contributors coalesce findings from research and practice into 18 chapters that we think you will find useful and meaningful. We present theoretical underpinnings of perinatal and pediatric bereavement, chapters on dimensions of perinatal and pediatric loss that have been of interest recently, and clinical interventions derived from research.

We are grateful for Betty R. Ferrell’s commitment to bereavement care as her life’s work and honored by her generous, thoughtful words in the Foreword. The book is divided into two sections. The first section, “Perinatal Bereavement,” has 10 chapters focusing on aspects of perinatal loss. Kristen M. Swanson introduces this section with her perspective on the painful nature of perinatal loss. The second section, “Pediatric Bereavement,” has eight chapters focusing on various aspects of caring for families whose children are dying or who have died, and caring for children who are grieving. Mary Muscari introduces this section by describing how this text is “a breath of fresh air that tackles a taboo topic,” transforming the discourse around the painful reality of pediatric death.

In the first chapter, Patricia Moyle Wright, Rana Limbo, and Beth Perry Black present background content on various grief theories developed in the past five decades. These theories have expanded our understanding of
the processes of death, dying, and bereavement. Although we recognize the widespread acceptance of stage theories of grief, such as that developed by Elisabeth Kübler-Ross, the goal of this chapter is to introduce our readers to other theorists and frameworks to explain grief and bereavement and how these theories may be used in understanding responses to death in perinatal and pediatric settings.

Chapter 2 offers a primer for those seeking to apply theories to empirical work. Authors Sarah Kye Price and Dalia El-Khoury extend the conversation on theory by presenting a review of theories that have been applied to grief studies and offer readers insights into how each theory can be used to frame empirical work. Continuing the focus on theoretical perspectives, Rana Limbo, Anthony Lathrop, and Jane Heustis present an overview of caregiving as a theoretical framework in perinatal palliative care in Chapter 3, beginning with a brief history of social movements that supported the development of perinatal palliative care services in the United States. Chapter 3 contains a review of the current body of literature regarding perinatal palliative care, relates extant research to the theory of caregiving, and ends with a comprehensive overview of clinical guidelines important for the provision of effective perinatal palliative care.

In Chapter 4, Beth Perry Black presents the history of efforts to promote the relationship of mother and infant, first through bonding practices of the 1970s, to the use of ultrasound in the 1980s, and forward. Measures of maternal–fetal attachment are presented and critiqued, and examples from research underscore expectant parents’ connections with their babies who are likely to die before or at birth. In Chapter 5, Patricia Moyle Wright presents her Pushing On theory, developed from research interviews with women who have experienced perinatal loss; from finding out about the pregnancy to living with the loss. Wright has recently updated her theory, based on recent research, and describes how to apply Pushing On theory to practice. In Chapter 6, Joanne Cacciatore describes an approach to supporting bereaved parents, noting that normal grief after perinatal loss can be emotionally distressing for parents. She explains mindfulness-based interventions, such as meditation, which are easy to use, low cost, noninvasive, and have no apparent associated negative effect.

Grief reactions in perinatal loss can be quite intense and require special consideration and support. In Chapter 7, Patricia Moyle Wright presents a discussion of the evolving concept of complicated grief, a concept of interest for a few decades that has garnered significant attention. Wright notes the controversy related to whether complicated grief is simply a manifestation of normal grief, presents the literature on what is known about complicated grief in relation to pregnancy loss, and reviews supportive interventions from the literature.
Grief after pregnancy loss can be more complicated for certain groups. In Chapter 8, Danuta M. Wojnar provides a comprehensive overview of perinatal grief among lesbian couples. This topic has yet to be widely explored, despite the circumstances of same-sex childbearing that vary significantly, biologically and socially, from heterosexual couples. Wojnar addresses specific challenges faced by lesbian couples, such as negotiating parenting roles. In Chapter 9, Sara Rich Wheeler and Marlene G. S. Sefton provide an overview of perinatal loss in adolescents, discussing normal adolescent growth and development, and using Sanders’s integrated theory of bereavement to discuss the common physical, emotional, social, and cognitive reactions to loss.

Another special circumstance—pregnancy after loss—is addressed in Chapter 10 by Denise Côté-Arsenault and Joann O’Leary, who present theoretical perspectives that underpin understandings of the experience of pregnancy after loss. The authors also discuss parental attachment, and the characteristics of pregnancy after loss in both expectant women and men, offering beneficial interventions for bereaved couples who are experiencing pregnancy after loss.

Section II, “Pediatric Bereavement,” begins with Chapter 11 in which Margaret Shandor Miles provides a scholarly review of parental grief, placing it in the context of what is known about grief from a historical perspective. She also reviews psychoanalytic and psychobiological models, crisis models, attachment models, and integrative models, among others. Miles then specifically focuses on parental grief models, with an emphasis on the psychosocial, cognitive, and physical aspects of parental loss and the effects on the family system.

In Chapter 12, Rose Steele and Kimberley Widger address pediatric palliative care, discussing its historical evolution and the development of standards for this specialty. The authors present a comprehensive discourse on various models of pediatric palliative care used in the United States and Canada, ending with a focus on the specialization of pediatric care and support for professionals. Douglas L. Hill and Chris Feudtner offer an excellent discourse in Chapter 13 on the concept of hope and the role of hopeful patterns of thinking in the context of serious pediatric illness and death. They address clinical concerns, such as offering false hope, and present “regoaling” to help parents cope with their child’s declining condition. Hope and regoaling provide the platform for parents to cope with the progression of numerous losses that accumulate during a child’s illness and eventual death.

Sometimes, the death of a child can occur under traumatic circumstances, setting the stage for very intense psychological responses. In Chapter 14, Wendy G. Lichtenthal, Geoffrey W. Corner, Corinne Sweeney, and Kailey E. Roberts present a comprehensive overview of grief following the traumatic
death of a child and review the importance of time in the grief trajectory. The authors then focus on the impact of the cause of the death on posttraumatic stress responses and overall parental health after the traumatic loss of a child and describe supportive interventions for bereaved parents. Suicide is one of the most traumatic losses a family can experience. In Chapter 15, Rebecca Kabatchnick and Beth Perry Black review the literature on sibling survivors after the completed suicide by their brothers or sisters. Little has been written on the “forgotten bereaved”—siblings left behind who are troubled by deep grief made worse by feelings of regret, anger, guilt, and a sense of need to take care of their parents.

The grief of children is the focus of the next two chapters. In Chapter 16, Betty Davies, Camara van Breemen, Susan Poitras, and Eric Stephanson discuss bereavement in young children in pediatric palliative care, providing an overview of theoretical perspectives to frame health care professionals’ understanding of bereavement in children. Davies’s Shadows in the Sun model is the chapter’s centerpiece and provides a platform for understanding responses of bereaved siblings and how to support families effectively. In Chapter 17, Andy McNiel and Donna L. Schuurman discuss how children process death and how the experience of loss affects their mental, social, and emotional well-being. How children make sense out of the death of a loved one and how they express grief are presented, including resources for professionals working with grieving children.

In the final chapter, Rana Limbo and Kathie Kobler present the importance of creating and capturing meaningful moments in the time leading up to and after the death of a child, focusing on the importance of relationships among families and professionals as they prepare for the child’s death. Limbo and Kobler describe ritual, photography, creation of keepsakes, and other important ways of creating meaningful moments and, ultimately, creating “ties that bind.”

We hope that you find this book to be useful as you seek to improve your practice with bereaved families. We honor your work and are grateful that you have chosen to enter the most vulnerable of spaces in the human experience—those spaces occupied by mothers, fathers, sisters, brothers, grandparents, friends, and others bereft of a child they loved.

Beth Perry Black
Patricia Moyle Wright
Rana Limbo
Over the past four decades, I have witnessed considerable progress in our understanding of the difficult, sometimes tragic, circumstances that surround the experience of loss during pregnancy and the first year of life. The death of one’s longed for daughter or son yields heartache, emptiness, and a lifetime of bittersweet memories. Over time, health care providers have come to recognize that even the earliest miscarriage of the most privately acknowledged pregnancy may hold great significance to the frightened woman who arrives at the emergency department, bleeding and cramping, accompanied by a beleaguered partner clutching a Tupperware container with still warm “scooped up” bloody clots. For some families, loss begins with a prenatally detected serious, life-limiting defect, made all the more unreal by the life-affirming movements of their yet-to-be-born baby. For others, the unexplainable stillbirth of their baby ushers in relentless yearning for answers. Some share their newborn infants with those able to get to the hospital quick enough to say hello and good-bye as they offer witness to a precious short life.

Caring for women and families whose pregnancies end in death challenges providers. They, too, wonder “Why?” “What could I have done differently?” Somewhere in the back of their mind or in the depth of their heart, they know that this pregnancy outcome could have happened to them or to their loved ones. The fear of pregnancy loss looms greater than does the actual threat; however, the very human act of producing our children creates vulnerability as we accept whatever is at stake with each child conceived. Caring—really caring—for women and families experiencing pregnancy loss takes courage, competence, and compassion. It starts with knowing, intentional continuous engagement with the other person in order to understand the meaning of what she is going through.

Enhancing practice by seeking out, knowing, and acting on the best evidence available is another form of caring. A nurse, social worker, physician, or another provider whose practice is current and based in evidence is better
positioned to provide effective care, to elicit the meaning of the loss for the woman and family, and to create an environment for healing. This text provides the theoretical basis for effective care. It is rooted in years of expertise, research, and the wisdom of the editors and multidisciplined contributors who bring many perspectives to their commitment to caring for families whose lives are touched by perinatal loss. Their words illuminate the dark spaces occupied by families whose babies or children have died, shed light on their experiences, and offer hope for healing.
CHAPTER 1

My Absent Child: Cultural and Theoretical Considerations of Bereavement When a Child Dies

Patricia Moyle Wright, Rana Limbo, and Beth Perry Black

Grief fills the room up of my absent child,
Lies in his bed, walks up and down with me,
Puts on his pretty looks, repeats his words,
Remembers me of all his gracious parts,
Stuffs out his vacant garments with his form;
Then, have I reason to be fond of grief?
Fare you well: had you such a loss as I,
I could give better comfort than you do.

(Shakespeare, King John, Act III, Scene IV)

Shakespeare wrote in the language of maternal bereavement in his play King John. In Act III, Lady Constance, mother of Arthur, is so anguished upon learning of his death that Cardinal Pandulph tells her she holds “too heinous a respect of grief,” to which Constance responds, “He talks to me that never had a son.” King Phillip suggests that she was as fond of grief “as of your child.” Constance’s response began: Grief fills the room up of my absent child.

Secular and sacred texts and musical works alike give witness to the sorrows of bereaved mothers, fathers, sisters, brothers, and friends of children who have died. German poet Friedrich Rückert (1788–1866) penned more than 400 poems in 2 years after the deaths of two of his children to scarlet fever. Austrian composer Gustav Mahler (1860–1911) later set five of these poems, Kindertotenlieder (Songs on the Death of Children), to music in an exquisite musical exploration of the grief of a father. In a tragic twist of fate, Mahler’s daughter, born about the time he composed the Kindertotenlieder,
died at age 4 of scarlet fever. Czech composer Antonín Dvořák (1841–1904), best known for his New World Symphony, began to compose a cantata based on the ancient Latin hymn Stabat Mater Dolorosa (referring to Jesus’s mother Mary at his crucifixion) in the aftermath of the death of his infant daughter, who died within days after her birth. Moved by the account of Mary’s grief, he recognized his own suffering reflected in the words of the Stabat Mater Dolorosa. Dvořák set the work aside, his pain too great to finish it at the time. Two years later, however, he completed it in the aftermath of the deaths of his remaining two young children, a toddler daughter who drank poison and his 3-year-old son who died of smallpox.

These works are among countless in literature and music that remind us of the vulnerability of children historically, and also underscore the universality of profound suffering of parents when their children die. In the developed world today, children are spared deaths by infectious diseases such as scarlet fever and smallpox; stringent attention to safety has reduced their risk of death by poisoning and other accidents. But despite all efforts to make the world safe, children die, rendering their parents, their families, their friends, and their communities heartbroken. For health care providers, scenes surrounding the deaths of children are burned into their memories, even as they struggle to find the professional space to provide consolation to the inconsolable.

Texts on death, dying, and bereavement for health care providers often begin by noting that the death of a child is one of the most traumatic events a person can experience. This text is no different. We honor and respect your work with children and families when death has invaded their lives, acknowledging that persons reading this have scenes of childhood deaths stored among their memories or are willing to enter the tragic spaces where children encounter death. Knowing how to comfort those bereft of any loved one is difficult. Comforting those mourning the death of a child poses a challenge to even the most sensitive and caring clinicians. We also know that being sensitive and caring is not enough, although these are crucial personal and professional attributes in helping families bereft of a child.

Clinical education and training regarding care of the dying and bereaved is often insufficient and may be based on outdated or debunked theoretical understanding of the process of grief. Despite nurses’ frequent proximity to dying patients and their families, death and bereavement education in nursing is typically inadequate in both quantity and quality, although nurse educators are increasingly incorporating this content into their curricula (Barrere, Durkin, & LaCoursiere, 2008). In a systematic evaluation of 23 psychiatric nursing textbooks frequently used in undergraduate education, Holman, Perisho, Edwards, and Mlakar (2010) found that 100% contained at least one unsupported myth about grief and 78% had four or more myths
and only one finding about coping with loss that was evidence-based. This means that many nurses are inadequately acquainted with evidence that challenges commonly held assumptions about loss and grief. Medicine has similar deficits, with the ongoing—albeit improving—view of hospice and palliative medicine as a “soft specialty” requiring training in advanced communication skills and symptom management, content that lacks importance relative to other specialties (Case, Orrange, & Weissman, 2013).

Throughout this book, various authors expand on theories and concepts that we present in this chapter as fundamental to understanding the development of practice and inquiry related to bereavement. We use the word bereavement broadly, recognizing that grief associated with death includes losses in addition to the actual physical death, such as loss of hope, companionship, a future, and a legacy. We first acknowledge that caring for the bereaved occurs within the cultural contexts of the dying person, the family, and the health care providers. Understanding that cultures intersect when a death is near enhances the likelihood of effective care.

**ADDRESSING CULTURE: A FIRST STEP IN BEREAVEMENT CARE**

Care of the dying and their families occurs within cultural contexts that, unless recognized, may impede sensitive and effective care. Although an extended treatise on culture is beyond the scope of this text, we recognize that any discussion of bereavement must be accompanied by acknowledgment of deeply ingrained cultural aspects of death.

From a macrocultural perspective, there are certain universal elements to the human experience, such as drives to procreate, find food, establish safe shelter, and create social networks. Births are celebrated, deaths are mourned, and the deaths of children are recognized as particularly tragic in light of the universal assumption that children will outlive their parents. One’s microculture, however, determines how these events evolve and are lived out. Microculture refers to patterns of shared behaviors and ways of thinking learned in groups by locale, ethnicity, gender, age, religion, nationality, and profession, among many others. In common usage, the word culture refers to elements of microculture.

Death practices vary widely across and among microcultures. In their text on ethnic variations in dying, death, and grief, Irish, Lunquist, and Nelsen (1993) referred to “diversity in universality,” their description of the variety of death practices that mark the universal human experience of death. Death practices are those rites and rituals that are customary when death is imminent or has occurred. Providers should be aware that cultural practices may influence but not necessarily determine the practices of a family at the time
of death. This awareness means that the provider avoids assumptions that any particular family will or should act in any specific manner as the death of their child approaches.

Effective clinicians recognize that they themselves carry out their work in the context of the culture of their profession. Socialization into a profession includes the development of behaviors valued by the profession. These behaviors may become so deeply engrained that clinicians may no longer recognize these behaviors as a function of the professional culture. Language is a characteristic of culture, a manifestation of the need to communicate as social beings. Health care providers’ language includes words and acronyms that may be poorly understood by patients and families (Corless et al., 2014). Language surrounding death may contain euphemisms meant to soften the effect of bad news, but in fact may obscure the actual meaning. For example, a woman pregnant for the first time, visiting the United States with her husband and for whom English was a second language, went to a local emergency room (ER) with constant abdominal pain, uterine rigidity, and bleeding in her 30th week of gestation. The obstetrician on call suspected a placental abruption, a severe complication of pregnancy. While doing an ultrasound scan, she noted that the fetus had died.

She conveyed this news to the woman as, “Your baby has passed.” In the woman’s confusion, pain, and fear, her understanding of English was almost gone. The obstetrician’s use of the euphemism “passed” was understood by the woman to mean she had in fact given birth. She pulled back the sheets to search for her baby that she mistakenly understood had been born amid her pain and bleeding. An ER nurse who spoke some French recognized what was happening. He took the frantic woman’s hand, established eye contact with her, and explained quietly and in simple words, “Je suis désolé, votre bébé est mort (I am sorry, your baby is dead).” The obstetrician, although attempting to show compassion, did not fully recognize the effect of distress on the ability of the woman to comprehend a euphemism in her limited English fluency. The nurse’s words were simple enough to cut through the confusion; delivered in a compassionate way, the words, though heavy with meaning, helped the woman make sense of a situation in which she was culturally disadvantaged in terms of setting, language, and locale.

Theoretical Orientations for Bereavement Care

As demonstrated in the aforementioned example, clinicians working with perinatal or pediatric patients may expect to encounter death infrequently relative to clinicians in specialties such as oncology and gerontology. The language of grief and bereavement is not embedded in the cultures of perinatal and pediatric providers, whose theoretical understanding of bereavement
care may be limited to outdated and refuted theories of grief. Theories are particularly useful in explaining very complex human experiences such as grief and bereavement. They are a philosophical lens through which providers make sense of phenomena, offering a unifying framework for evidence that allows providers to anchor interventions in models that can guide clinical decision making. In the remainder of this chapter, we present several basic, current theoretical stances regarding bereavement care. These theories are not specific to perinatal or pediatric settings, but are flexible and robust ways to understand end-of-life care across settings.

Grief Theories Then and Now

Freud and Lindemann: Establishing Norms

Although grief had been studied as early as the 1600s, it was not until the publication of Freud’s work “Mourning and Melancholia” (Freud, 1957, as cited in Granek, 2010) in the 20th century that grief was recognized as a legitimate area of scientific inquiry (Granek, 2010). Freud’s work set the stage for identification of adverse sequelae after the loss of a loved one, particularly if the bereaved person failed to sever emotional bonds with the deceased (Freud, 1917/1957; see Chapters 2 and 11). Lindemann (1944/1994; see Chapter 11), among others, studied grief responses and further distinguished “normal” from “abnormal” reactions. Lindemann’s research has been the basis for the development of clinical guidelines (Wright & Hogan, 2008).

Bowlby, Parkes, and Worden: Stages, Phases, and Tasks

Interest arose in delineating how one moves through the process of grief, resulting in the development of several stage and phase theories aimed to explain how grief unfolds. For example, Bowlby (see also Chapter 11) and Parkes (see also Chapters 4 and 11) offered models that depicted bereavement as a series of emotional reactions to the loss that changed over the course of time (Wright & Hogan, 2008). Bowlby and Parkes suggested four phases (Bowlby, 1969/1982): shock and numbness, searching and yearning, disorganization, and reorganization. They posited that the phases were not linear per se, but provided a framework of an individual’s response to the loss of a significant relationship through these four primary categories of experiences. The phases have clinical application; these are used by clinicians to describe for mourners what their grief might be like and provide a framework for follow-up clinical care (Wilke & Limbo, 2012).
The shock and numbness phase is characterized by a sense of unreality, being mentally and emotionally distant from the trauma of the death, and with blunted feelings of disbelief. Most often, searching and yearning, with distinctly different elements of strong emotions (e.g., sobbing, screaming, intense desire for the deceased person’s return), oscillate with shock and numbness, which emphasizes the nonlinearity of a phase model. The third phase, disorganization, refers to a time when the mourner accepts that the death occurred, yet remains bereft, with hope, transformation, and growth seeming impossible or far away. The final phase of reorganization denotes a period of moving forward without forgetting, continuing the relationship with the deceased in meaningful ways. In his dissertation work with 1,200 mourners, Davidson (1984) described the phases as peaking and waning, with overlapping of all four phases at times of particular relevance to the mourner, such as the death date anniversary or holidays.

Worden (2009; see also Chapter 11, this text) noted that bereavement involved a series of adjustments to the loss, which he called tasks of mourning. These tasks involved accepting the reality of the loss, processing the pain of grief, adjusting to a world without the deceased, and finding an enduring connection with the deceased in the midst of embarking on a new life. More recently, the grief process is recognized as less linear and predictable than originally conceptualized. Worden (2009) promoted tasks as useful in understanding the process of mourning, as long as one considered mediators such as how the person died, one’s own self-esteem and self-efficacy, and social variables (e.g., support).

CONTINUING BONDS: RE-EXAMINING HOW ATTACHMENTS ARE MAINTAINED AFTER DEATH

In contrast to some of the work of the past 100 years postulating that emotional separation from the deceased was necessary for recovery, Silverman and Klass (1996) explored the idea that the continuation of bonds of attachment after death is in fact normal. Continuing bonds has gained a foothold in the grief literature. A continuing emotional attachment to a deceased loved one has been identified as a factor in emotional healing and serves as a way to honor the deceased person and reintegrate him or her into the survivor’s life (Bowlby, 1969/1982; Wright & Hogan, 2008). Continuing to maintain an emotional connection with a deceased loved one is now generally considered to be natural and healing. However, some (e.g., Field & Filanosky, 2010) have questioned whether deep, sustained relationships with the deceased might indicate a form of denial. According to Field, it is natural to exhibit protest or denial when faced with a loss. However, prolonged and exaggerated efforts to reject the reality of the loss can indicate maladaptive responses to loss.
Field and Filanosky (2010) described two distinct ways that continuing bonds are expressed: internalized and externalized. Internalized expressions of continuing bonds are based on the bereaved individual’s imagined viewpoint of the deceased. For example, a bereaved mother might say that the baby who died would have loved playgrounds or puppies. Such expressions are based solely on the projections of how the deceased is imagined and “may facilitate integration of the loss” (p. 2).

Conversely, external expressions of continuing bonds can indicate that the loss is as yet unresolved for the bereaved individual. External expressions can include hallucinations and other exaggerated manifestations of grief. Such experiences are more closely associated with traumatic losses for which survivors blame themselves (Field & Filanosky, 2010), as is occasionally the case with perinatal death when an expectant mother questions her role in a pregnancy loss. Importantly, externalized expressions of continuing bonds were more closely associated with complicated grief reactions (Field & Filanosky, 2010). There is, however, a fine line drawn in the literature between adaptive and maladaptive forms of continuing bonds. Researchers caution against the overinterpretation of findings and emphasize that expressions of continuing bonds occur on a spectrum, illustrating ways of coping with loss (Boelen, Stroebe, Schut, & Zijerveld, 2006). While maladjustment to loss should be identified as early as possible, some forms of coping such as cherishing items associated with the deceased have been associated with adaptive grief responses (Boelen et al., 2006).

Research on Continuing Bonds in Bereaved Mothers

Twenty-eight bereaved mothers participated in a study of external and internal expressions of continuing bonds (Field et al., 2013). Researchers studied the effects of continuing bonds in affect regulation—whether continuing bonds experiences were comforting to the bereaved mothers or caused them distress. The study is especially relevant to the understanding of continuing bonds as a framework because 15 were mothers of older children (pediatric) and 13 experienced perinatal death: interruption of pregnancy for medical reasons, stillbirth, and newborn death (i.e., within the first 28 days of life). The time since their child’s death ranged from 1 month to 4.8 years (Field et al., 2013).

Mothers’ narratives demonstrated whether a continuing bonds expression they endorsed was associated with comfort or distress (Field et al., 2013). Significantly more mothers of older children (rather than death in the perinatal period) reported imaginary conversations with their children. Illusions of mistaking sights and sounds for the deceased or hallucinations (e.g., sense of presence through seeing, hearing, smelling, feeling) were endorsed as comforting by some mothers, yet intrusive by others. Otherwise, continuing
bonds expression was equally prominent in both groups, suggesting emotion regulation after the death of a child at any age is associated with ongoing connection. Overall, mothers rated continuing bonds experiences as more comforting than distressing, with no significant difference between the early death group (perinatal) and the later (pediatric) (Field et al., 2013).

The Empty Space Phenomenon (McClowry, Davies, May, Kulenkamp, & Martinson, 1987), a concept developed through grounded theory research, provided one of the earliest examples of what is now called continuing bonds. The researchers used grounded theory methodology to analyze interview data from members of 49 families whose child or sibling died 7 to 9 years previously. Most family members spoke of an ever-present emptiness resulting from the child being physically absent from the family. The empty space was primarily described in two ways: “filling the emptiness” (p. 365) and “keeping the connection” (p. 367). Those who spoke of “getting over it” (p. 365) did not have an intense grief response; rather, their memories were less vivid and the experience of the child’s death less present than those in the two “emptiness” categories. Family members filled the empty space by keeping busy. At times, keeping busy meant filling the space with other tasks or relationships that required energy, in essence, refocusing away from the child’s death and toward other events or situations. The researchers cited building a new house, adopting a child, and developing marital distress as examples. The second way family members filled the emptiness was through altruism such as becoming active in bereaved parent groups. Interestingly, most who filled the emptiness with altruism reported a shift in focus at some point, a “need to go beyond where they were as if the emptiness was for the most part filled” (McClowry et al., 1987, p. 366).

The researchers (McClowry et al., 1987) described those who kept the connection as never forgetting, but at the same time, being able to continue the connection with the child who died by remembering and cherishing the relationship. The grief of family members lessened in intensity because they were able to integrate the pain and suffering into their lives in the present. They reserved “a small part of themselves for the loss of a special relationship which they view as irreplaceable” (p. 368). The idea of keeping the connection fits well with the current understanding of continuing bonds.

**POSTTRAUMATIC GROWTH IN RESPONSE TO LOSS**

Reconstituting a life without the deceased loved one is certainly the most daunting aspect of loss; yet in the midst of profound loss and bereavement, personal growth can occur. Posttraumatic growth (PTG) has been identified, described, and measured most thoroughly by Tedeschi and Calhoun (1996, 2004, 2008). PTG as a result of bereavement has been identified through
empiric inquiry in several populations (Schoulte et al., 2012), including bereaved siblings (Hogan & DeSantis, 1992), perinatally bereaved families (Black & Wright, 2012), and bereaved spouses (Hogan, Greenfield, & Schmidt, 2001; Kaunonen, Tarkka, Paunonen, & Laippala, 1999). Several studies have demonstrated that PTG involves tendencies to feel more compassionate, more loving, more tolerant, and more grateful than before a loss (Black & Sandelowski, 2010; Black & Wright, 2012; Hogan, Greenfield, & Schmidt, 2001; Wright, 2010). Early conceptualizations of growth after loss described positive and negative aspects of grief as somewhat dichotomous. For example, Hogan, Greenfield, and Schmidt (2001) found that as the most intense negative aspects of grief passed, aspects of personal growth became more prominent. Yet, following pregnancy loss, aspects of PTG surface even as negative responses to loss persist (Black & Wright, 2012; Schoulte et al., 2012). Authors of a review of studies of PTG after a serious pediatric illness called the area “understudied and inadequately understood” (Picoraro, Womer, Kazak, & Feudtner, 2014, p. 209).

Thus, while PTG indicates awareness of positive aspects of loss, it should not be viewed necessarily as a turning point in the grief process after which negative aspects cease. Rather, personal growth has become recognized as an integral part of myriad responses to the multidimensional process of perinatal loss. Further research is needed to determine triggers for personal growth and factors that inhibit movement toward positive grief outcomes. Personal growth after pregnancy loss is discussed as a component of the Pushing On theory in Chapter 5.

Caring Theory: From Work With Perinatally Bereaved Couples

Caring is a concept central to nursing and other practice disciplines. Swanson developed her theory of caring from three different phenomenological studies of women who experienced miscarriage, neonatal intensive care caregivers, and at-risk mothers. The theory involves five processes that are useful in clinical practice. The first process—knowing— involves the ability to perceive “an event as it has meaning in the life of the other” (Swanson, 1991, p. 163), in which health care providers strive to understand the event through the eyes of the bereaved. The second process identified is “being with” (p. 163), described by Swanson as “being emotionally present to the other” (p. 163). Health care providers who convey a sense of understanding and are emotionally present to their patients provide comfort at a time when families may feel isolated and misunderstood.

The third and fourth processes of Swanson’s caring theory entail “doing for” (p. 164), wherein the health care provider does for the patient what the patient would otherwise do but cannot because of physical or emotional
distress, and “enabling” (p. 164), which involves efforts to encourage others through difficult life events. Doing for and then enabling self-care is integral in demonstrating professional caring.

The last process in Swanson’s theory is “maintaining belief” (p. 165), which involves “sustaining faith in the others’ capacity to get through an event or transition and face a future with meaning” (p. 165). In this process, providers determine patients’ goals and help them sustain the belief that their goals are achievable despite dire circumstances and may involve support to believe that despite a loss, the future can still hold joy and meaning.

Although Swanson’s theory was derived in part from her research with women who had miscarried, caring theory is broadly applicable. Adoption of this theoretical stance in bereavement care provides a framework for conveying genuine human caring within professional boundaries and clarifies roles and expectations of providers when facing the heartbreak of bereaved parents and families.

**Williams’s Transition Model**

An important function of caring as described by Swanson is to determine meaning of losses. In a study of eight women who had an early miscarriage and their 16 health care providers, Murphy and Merrell (2009) found that the emotional response to miscarriage varies (see Chapter 18). Using interviews, review of key documents, and participant observation, the researchers proposed that grief theory may be suitable for describing many women’s miscarriage experiences, but not all. For example, one health care professional stated, “Check how they’re feeling really. Not everyone is going to be upset after miscarriage” (p. 1587). The researchers suggested that a transitions model may also be a relevant framework for understanding women’s responses to miscarriage, supporting miscarriage as a significant life event and transition (Murphy & Merrell, 2009). Williams’s (1999) transition model is particularly useful and relevant to miscarriage as one assumption is that life events may be perceived as positive or negative. Additionally, the researchers assert that strong emotions such as anxiety, uncertainty, and fear may be associated with the meaning of the event, without the emotions of grief. They remind care providers to offer sensitive, responsive care to all women experiencing miscarriage, staying alert and mindful of each individual woman’s symptoms and behaviors (Murphy & Merrell, 2009).

**CONCEPTS RELATED TO BEREAVEMENT THEORIES**

Theories are fundamentally the organization of concepts (ideas) into a cohesive framework meant to predict outcomes and wholly explain phenomena.
Theories can be difficult to grasp, particularly highly abstract frameworks in which their links to practice may seem obscure. Concepts, however, are often more easily apprehensible and can be used to understand certain dimensions of phenomena. In the following section, we demonstrate how two concepts central to grief studies—being sure and final acts of caregiving—can help explain certain aspects of the experience of pregnancy loss.

Being Sure

Researchers interviewed 23 women who were diagnosed with an inevitable miscarriage (Limbo, Glasser, & Sundaram, 2014). With three treatment choices (surgical intervention, medical intervention, or watch and wait), women identified that they needed to be sure that their pregnancy was not viable. Most women characterized their pregnancy as a baby; several spoke of tissue or, in one case, “It’s for sure there is no life amongst this pregnancy matter” (p. 168). We believe that being sure may be a relevant concept in other decision-making opportunities, one which professionals could engage patients and family members in discussing to determine what decision may best fit their values, goals, and beliefs.

Final Acts of Caregiving

In a study of mothers receiving perinatal hospice care, Limbo and Lathrop (2014) used caregiving theory (Bowlby, 1988) as a framework for analysis of narratives of mothers whose babies were diagnosed prenatally with a life-threatening condition and subsequently died. In addition to nurturing, protecting, and socializing their babies (see Chapter 3, this text; Limbo & Pridham, 2007), the mothers provided numerous examples of the importance of the final tasks of parenting they were able to provide their babies. This frequently meant care given after death, such as choosing just the right flowers for the funeral, bathing the baby, and placing the baby into the casket (Limbo & Lathrop, 2014). Again, we believe that final acts of caregiving may be relevant to all families who are bidding a final farewell to a loved one, whether that be placing a special keepsake in the casket, asking grandchildren to write a special letter, or a sibling to read a book. One woman, who had elected to stop dialysis and prepare for her death, told her daughters she wanted to wear her golden slippers as she passed on to the other side. One of her daughters sensed that death was near, retrieved the slippers from the windowsill, and as she placed them on her mother’s feet, her mother took her last breath. The memory of this final act of caregiving (in this case, child to parent) is a lasting memory to the woman’s family.
CONCLUSION

This chapter has provided you with foundational information about cultural considerations, theories, and concepts germane to grief and bereavement. Providers in perinatal and pediatric settings may encounter death infrequently and, as a result, often feel inadequately prepared to take care of children, their parents, and families when death occurs. From this chapter, you have a basic understanding of the conceptual development of grief and how it does its healing work from a theoretical perspective. The following chapters expand on current grief theories and research and provide specific clinical interventions.

Although clinicians and researchers today are working to formalize identification of concepts related to bereavement, the universality of profound distress related to the death of children is nothing new. Rückert’s poem of his absent children, lost to death, is immortalized by Mahler in the fourth cycle of the Kindertotenlieder (Songs on the Death of Children). His words, borne of tragedy, capture parental grief in an intimate and timeless way:

\[\text{I often think: they have only just gone out,}\\ \text{and now they will be coming back home.}\\ \text{The day is fine, don’t be dismayed,}\\ \text{They have just gone for a long walk.}\\ \text{Yes indeed, they have just gone out,}\\ \text{and now they are making their way home.}\\ \text{Don’t be dismayed, the day is fine,}\\ \text{they have simply made a journey to yonder heights.}\\ \text{They have just gone out ahead of us,}\\ \text{and will not be thinking of coming home.}\\ \text{We go to meet them on yonder heights}\\ \text{In the sunlight, the day is fine}\\ \text{On yonder heights.}\]

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CHAPTER 2

Applying Theoretical Frameworks to Research in Perinatal Bereavement

Sarah Kye Price and Dalia El-Khoury

Perinatal bereavement researchers, and practitioners who utilize research to guide their practice, should be fully aware of the theoretical frameworks that underscore existing and future research studies. In this chapter, we review a range of theoretical frameworks and approaches that have been applied to research in perinatal bereavement, including attachment theory, psychodynamic theory, interpersonal theory, cognitive stress theory, feminist theory, and the emerging perspectives of strengths-based and trauma-informed approaches to research and practice. In this chapter, we present each theory or approach and discuss its applicability to various research methods (quantitative, qualitative, and/or mixed methods) and how it informs research design, selection of measures, framing of questions, analysis, and implications. At the conclusion of the chapter, the reader should be able to describe the implicit and explicit benefits and challenges of research conducted by applying various theoretical frameworks, and to critically evaluate and/or design research studies that meaningfully inform knowledge of perinatal loss and bereavement.

ATTACHMENT THEORY

Attachment theory (Bowlby, 1980) emphasizes the interrelationships between attachment, affectional bonds, separation, and loss in human relationships. Historically, attachment theory has most often studied the relationship between mother and child (Bowlby, 1977). However, attachment theory is applicable across multiple relationship contexts, such as those among spouses and intimate partners, between parents, and with children (Bowlby, 1977). Attachment theory posits four archetypal attachment styles: secure, avoidant, anxious/ambivalent, and disorganized/disoriented; the latter three collectively may be described as insecure attachment (Bowlby,
Attachment theory can provide a framework for understanding the patterns people elicit when experiencing both grief and bereavement, and how these extend from the pre-existing relational bonds (Stroebe, Schut, & Stroebe, 2005). People exhibiting different attachment patterns or styles have been identified as handling emotions related to loss differently (Fraley & Bonanno, 2004; Parkes, 2001; Shaver & Tancredy, 2001; Wayment & Vierthaler, 2002). Since attachments form differently throughout life, individuals may enlist generalized attachment styles that guide expectations of potential relationships, and also develop specific models of attachment that are unique to each attachment figure (Shear & Shair, 2005).

Understanding Loss and Grief as a Function of Attachment

Broadly speaking, attachment theory is a way to understand how individuals react to loss and grief, whether that is loss due to death, separation, or distance. When a loss is experienced, the individual is theorized to react in a specific manner (based on his or her own attachment style) in order to ameliorate the intensity and pain of that loss, and in order to try to recover a sense of proximity to the attachment figure. When the loss is due to death, the recovery of attachment may prove more challenging, resulting in emotional disequilibrium (Stroebe & Schut, 2001). This attachment-based disequilibrium offers one lens for understanding the internal processes that take place during both normal and complicated grief.

Expanding Bowlby’s (1977, 1980) initial conception of attachment theory to perinatal loss, attachment may begin during pregnancy, reflecting a bond between mother and fetus. Therefore, if a pregnancy ends before those bonds of affection are fully actualized, the result can be intense longing and disequilibrium from having to “let go” before full and complete attachment could occur. Medical advances, including certain prenatal diagnostic procedures that allow parents to monitor fetal development, contribute to the growing attachment between mother and fetus (Robinson, Baker, & Nackerud, 1999). Research indicates that attachment can begin as early as the planning and learning of the pregnancy, and is often heightened when fetal movement is felt, which is hypothesized to be related to the mother’s ability to conceptualize the infant (Robinson et al., 1999). While prenatal attachment is associated with this awareness of gestational and relational development, the degree of prenatal attachment (and subsequent grieving and bereavement if a loss occurs) cannot be ascertained by gestational age alone (Moulder, 1994; Robinson et al., 1999). Prenatal attachment, just like adult attachment, is highly dependent on life context.

Attachment theory may be applied in research to understand the impact of perinatal loss on the parent’s grief, as well as on subsequent pregnancies.
and parenting. Uren and Wastell (2002) found that mothers who have experienced a perinatal loss continue to have an emotional relationship with the deceased baby; this parallels research conducted on the development of continuing bonds (Stroebe, Schut, & Boerner, 2010). Grief and meaning making with respect for a baby who has died are essential in order to develop a healthy attachment to a future baby (O’Leary, 2004). Research asserts that prior perinatal loss has been associated with higher levels of anxiety with ensuing pregnancies (Côté-Arsenault & Donato, 2007), decreased prenatal attachment to the current baby (Armstrong & Hutti, 1998), and higher levels of depressive symptoms (Armstrong, 2002). Additionally, the unresolved grief parents may exhibit has been shown to predict the development of disorganized attachment patterns in their subsequent children (O’Leary, 2004).

**Measures in Attachment and Grief Research**

Attachment theory informs much of the research design and measurement instrumentation in studies pertaining to subsequent pregnancy after perinatal loss. There is an inherent assumption in attachment theory that some degree of disequilibrium is normative in bereavement, and that greater emotional stability should begin to take shape over time if one is attentive to the energy it takes to work through a state of grief-induced disequilibrium and emerge into a “new normal” as a result of the grief process. Attachment theory posits that grief resolution is not simply better for the individual griever, but for those who will continue or develop new relationships following the grief event. Therefore, measurement of grief symptoms and impact may need to be longitudinal, or at a minimum, research designs may consider including the length of time since the grief occurred as a part of research models. Research related to subsequent pregnancy in particular often relies on measurement of grief and attachment response in the parent and subsequent child, in order to consider the impact of grieving (and resolution of the intensity of grief) on the development of attachment patterns over time. Applications of attachment theory also seek to identify long-term, generational patterns that exemplify adaptive or complicated bereavement patterns that may impact the family system over time.

In quantitative research solely involving the griever, attachment theory suggests that it is important to consider the differential severity of symptoms present in the time since loss occurred as a part of the analytic plan, and to include variables such as the degree to which parents perceive themselves to have played out roles that may foster attachment (i.e., holding, seeing, bathing, caring for the infant including postmortem care) as adaptive to moving through the disequilibrium of grief. These variables, measured appropriately, reflect an understanding of the intersecting roles that
attachment, separation, and loss may play in grief response. Expanding questions in research protocols that include items reflecting parental perceptions of choice in their level of tactile involvement in perinatal end-of-life care will allow for a rich research design that integrates an understanding of the dynamics of the grief process rather than merely the observed outcome or symptoms devoid of the attachment context.

In terms of analysis and interpretation of findings, attachment theory may also help explain why the intensity of emotional expression (or symptoms of grief) during and after a subsequent pregnancy may be heightened. Specifically, attachment theory would suggest that disequilibrium may lessen over time when these affective bonds are able to be adequately expressed at the time of loss. This theoretical underpinning may be important to interpretation of findings and implications for client-centered companioning and choice making throughout the grief process.

PSYCHODYNAMIC THEORY

Psychodynamic (or psychoanalytic) theory, particularly advanced by the work of Freud’s “Mourning and Melancholia” (1917/1957), provides an introspective perspective on the process of coping with any loss in an adaptive manner. Freud argued that grief following loss serves a functional purpose in that it allows the individual to detach from the deceased (Stroebe & Schut, 2001). Psychodynamic theories of bereavement conceptualize that the duration and intensity of the grieving process force a psychological restructuring of self. This model indicates that relief will follow as a result of detachment that ensues from the adaptive process of grieving (Shapiro, 2001). In addition, objects relations theory, a subset of psychodynamic theory, conceptualizes one’s life as an amalgamation of internalized representations of actual relationships with childhood caretakers (Shapiro, 2001). As a result of a loss, an intrapsychic reorganization takes place in which one’s internal object universe is changed.

Psychodynamic Frameworks

Psychodynamic theory posits that intrapsychic meanings attributed to pregnancy, parenting, and death impact the resolution of the grieving process and the ensuing restructuring of one’s inner self. Leon (1992) presents four psychodynamic frameworks within which to understand pregnancy, and the personal meaning behind pregnancy as well as perinatal and reproductive loss: developmental, conflictual, object-oriented, and narcissistic frameworks (Leon, 1996). The developmental framework presents perinatal loss as interference within a normal developmental process of adulthood and
parenthood. In the conflictual framework, perinatal loss may intensify intrapsychic conflicts, particularly related to the female drive to reproduce that may or may not be realized. The object-oriented framework focuses on the importance of the detachment process of grief following a perinatal loss as essential to a reconceptualization of self. The narcissistic framework presupposes that perinatal loss may result in feelings of narcissistic injury and rage, as the unborn child is seen as an extension of the mother and is therefore tied to her sense of self and self-esteem (Leon, 1992). Perinatal loss may also impact the feeling of immortality and omnipotence associated with continuing a biological or genetic line (Leon, 1996). Upon experiencing a perinatal loss, individuals may react with guilt and self-blame, which may be associated with feelings of helplessness and lack of control over one’s own body (Leon, 1996).

Psychodynamic theory may be an important consideration in research that emphasizes the meaning, personal significance, and intrapsychic conflicts of perinatal loss. In both qualitative and quantitative methods, the exploration of personal meaning associated with grief following perinatal bereavement may mirror, or challenge, the lens offered through psychodynamic theory. Research designs that integrate a psychodynamic perspective are often individualized, and frame research questions and exploratory dialogue on the way in which the experience of loss impacts identity, self-worth, and/or conflicts within the person’s self-conceptualization. Psychodynamic theory also provides theoretical foundations for interventions such as interpersonal psychotherapy (IPT) that have been applied to perinatal bereavement. In keeping with this theoretical perspective, process and outcome measures used in intervention research using a psychodynamic framework should focus on the individual changes in meaning associated with the loss, as well as resolution of both internal and interpersonal conflicts that may have emerged as a result of the grief process.

INTERPERSONAL THEORY

Interpersonal theory offers a lens to understand the impact prolonged depression (or events that contribute to similar symptomatology) can have on interpersonal relationships, as well as social relations in general (Weissman, Markowitz, & Klerman, 2000). In practice, interpersonal theory (as IPT) advocates for individual change, rather than the mere development of insight. It focuses on addressing the experience of symptoms, as well as social adjustment and interpersonal relations. IPT utilizes time limited and focused treatments that concentrate on current interpersonal relationships (Weissman et al., 2000). Interpersonal theory can be applied to the process of grief (or complicated bereavement), particularly accompanying
difficulties associated with the mourning process following the death of a loved one, resulting in experiences of depression (Weissman et al., 2000). The goals of IPT in this situation are to assist the individual through the mourning process, as well as re-establish interpersonal relationships and interests that can begin to take the place of the loss (Weissman et al., 2000). Interpersonal relationships provide a link between one’s individual grief experience and bereavement outcomes (Shapiro, 2001). Interventions utilizing the interpersonal theory base of IPT have been shown to be effective in the treatment of postpartum depression (Pearlstein et al., 2006), major depression (Johnson & Zlotnick, 2012), as well as bereavement and mild depression following miscarriage (Neugebauer et al., 2007).

Interpersonal Dynamics of Grief

The interpersonal dynamics of grief impact the parent–child as well as partner and social system dynamics of perinatal bereavement. Interpersonal theory is often combined with psychodynamic and attachment theories as it takes shape in practice. The ensuing perspective takes into account the importance of attachment, and focuses on the resolution of loss through enhancing the interpersonal dynamic surrounding grief. Interpersonal theory views personality as an amalgamation of patterns representing interpersonal relationships, and argues that healthy attachments can serve an adaptive purpose. Interventions utilizing both an interpersonal and psychodynamic perspective assume that the death of a loved one disrupts the unique individual strategies used to self-define interpersonally and to retain control over emotions (Shapiro, 2001). In reproductive loss, as well as the personal, marital, and social stress associated with infertility, the intensity of the grief response may be ameliorated by perceptions of interpersonal and social support (Martins et al., 2013).

Gender Differences in Grief

The grieving process may also reflect gender differences, particularly related to communication styles, incongruent coping strategies, and a propagation of misunderstandings (Wing, Clance, Burge-Callaway, & Armistead, 2001). The experience of men coping with perinatal and reproductive loss is particularly important to consider when applying interpersonal theory, in part because men may play an integral role in the provision of interpersonal and social support (Rinehart & Kiselica, 2010). Men also go through the grieving process following a perinatal or reproductive loss, although the intensity and duration of their grief may differ from that of women (Abboud & Liamputtong, 2003; Rinehart & Kiselica, 2010). Gender-based incongruence,
real or perceived, can be challenging to the interpersonal dynamic that implicitly exists within a couple or family.

**Sampling and Intervention in Research**

In designing perinatal loss research, interpersonal theory may inform the choice of intervention, as well as influence sampling. Most importantly, to fully understand the interpersonal impact of grief and loss requires data gathering from all those who interact with each other in the interpersonal context. Measuring relationship quality and stressors or comparing differential grief expression and responses in a partner dyad requires sampling that includes accessibility to both partners, and therefore requires heightened attention to research ethics, confidentiality, and informed consent both in the conduct of research and in the dissemination of results. This lens of interpersonal theory offers an important manifestation of our value of human relationships and acknowledges that our ability to fully understand and appreciate the impact of grief requires a theoretical and empirical acknowledgement of its relational impact.

**COGNITIVE STRESS THEORY**

Cognitive stress theory (Lazarus & Folkman, 1984) asserts that any stress-inducing situation warrants a need for cognitive processing and restructuring. Individuals utilize “cognitive schemas” to help make sense of the world, particularly in situations eliciting stress, discomfort, or pain. These schemas guide thoughts, beliefs, and assumptions about the origin and outlook of particular events, and may be either adaptive or maladaptive. Some common schemas we carry, such as “good things happen to good people” or “pregnancy is a time of joyful expectation,” can become deeply challenged by perinatal loss. The primary role of cognitive adaptation to a stressful event or situation is a hallmark of this theoretical orientation.

**Three Types of Human Responses to Stress**

Lazarus (2000) identified three types of human responses to stress: one’s appraisal of said event; one’s choice of responses (coping strategies); and the ensuing emotions. Coping strategies are cognitive or behavioral responses intended to assist one’s external and internal adaptation to a stressful event. The coping strategies chosen, if effective, are hypothesized to be used consistently over time (Lazarus & Folkman, 1984). When applied to bereavement, this theory is predicated on the assumption that coping makes a difference
in adjustment and recovery from loss (Folkman, 2001). In addition, Folkman (2001) proposed the inclusion of the personality trait of positive affect to the coping process, particularly related to personal growth within the bereavement experience.

**Dual Stresses of Pregnancy and Loss During Pregnancy**

The biological and psychological experience of pregnancy is generally considered to be stressful, and a loss within that time period can be perceived as a stress within a stress (Price, 2008). Regarding perinatal and reproductive loss, cognitive stress theory argues that this loss must be processed, a new role must be identified and adapted to (for example, from “expectant” to “grieving”), and the future impact of this loss must be examined for its continuing and changed life expectations (Price, 2008). For example, women experiencing pregnancy after a perinatal loss may view that entire pregnancy as threatening, stressful, and anxiety-inducing (Côté-Arsenault, 2003, 2007), which likely differs from the experience of mothers who have not experienced a perinatal loss.

An individual’s response to loss may be polarized: at the same time profoundly sad, but perhaps relieved, which may then be followed by guilt. Additionally, infertility-related stress can be ameliorated through the presence of social support, as well as the use of successful coping strategies (Martins, Peterson, Almeida, & Costa, 2011). One’s cognitive schema will guide the way in which he or she processes through a perinatal or reproductive loss. Being able to authentically identify and confront one’s thoughts is a key element of this theory, even if those thoughts and beliefs are at times disturbing or differ from one’s perception of the norm.

**Instrumentation in Perinatal Bereavement Research**

In designing perinatal bereavement research, cognitive stress theory guides the selection of instrumentation as well as the inclusion of items and descriptions that are cognitive in nature in addition to typical emotional components of grief response. For example, including stress appraisal measures, coping inventories, and questionnaires that suggest patterns of thought and reflect cognitive schemas may assess coping style in addition to emotional symptomatology of grief. Stress and coping may be measured in cross-sectional as well as longitudinal studies; this offers flexibility in research design. Finally, the integration of cognitive stress measures can occur simultaneously with other relational and emotional measures. Introducing cognitive components into research design and measurement may allow for richer comparisons.
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and theory testing regarding the interface of cognitive, emotional, and relational aspects of grief related to perinatal and pediatric bereavement.

FEMINIST THEORY

Feminist theory is reflective of the diversity of women’s perspectives and experiences, and takes into account issues that affect women in a unique manner, including pregnancy and reproductive loss. An inherent assumption within feminist frameworks is that women have historically been suppressed and served in subordinate roles, and that this is no longer acceptable (Valentich, 2011). Feminist theory encompasses a commitment to social justice issues, social change and activism, gender equality, multicultural perspectives, diversity issues, and culturally competent practice (Valentich, 2011). The role of feminist practice is to free women from oppression that has been propagated through societal norms, role expectations, and mores. Feminist theory accounts for and undergirds the complexity and diversity of factors that have an impact on the functioning of women all over the world.

Constructions of Meanings of Perinatal and Reproductive Loss

Perinatal and reproductive loss is an experience that impacts women in a unique manner. Historically, social norms perpetuated silence around experiences of miscarriage and loss, which contributed to a sense of secrecy and shame (Price, 2008). However, in the past few decades, it has become more acceptable for women to speak out about their grief and emotions following experiences of perinatal loss (Reagan, 2003). Women’s experiences of perinatal and reproductive loss are neither unique nor universal—they are socially, historically, and culturally constructed (Reagan, 2003). For example, the meaning that women ascribe to miscarriage will depend upon the era in which they live. An emphasis on the notion of “happy endings” related to pregnancy and motherhood renders a negative judgment or social taboo on those pregnancies that end in loss (Layne, 2003). When a pregnancy does not result in the “happy ending” society leads women to expect, the self-blame burgeons, particularly among women (Layne, 2003). Women have historically borne an unequal share of the burden associated with pregnancy loss, including medical risk, shifts in identity, placement of blame, and invalidation of the experience of loss (Layne, 2006). Additionally, within a woman’s own lifetime, the meaning she ascribes to a perinatal or reproductive loss may shift. Currently, with feminist theories and frameworks calling for the voices of women to be heard, women have begun to break the silence around perinatal and reproductive loss. An example of the leadership role
that women have begun to undertake is the pregnancy and infant loss support movement in the United States, which has been initiated, organized, and led by women (Layne, 2006).

**Effects of Research Design on Women’s Bereavement Experiences**

In designing research around perinatal bereavement, it is important to realize that choices around design, instrumentation, language, and sample all have the potential to affect women’s experiences of perinatal bereavement in both explicit and implicit ways. Research that fails to objectively measure capacity as well as challenges or that overlooks social stigma or norms that may impact a woman’s sense of self may perpetuate negative stereotypes or reinforce a need for secrecy and silence. Research that attends to the variety of women’s experiences using nonjudgmental language and gender attentive descriptors of people and events is the first step to integrating a feminist perspective into research design.

Additionally, attention to selection of instrumentation that has been appropriately applied to women in other studies, and has been validated based on women’s grief experiences, avoids a common research pitfall of pathologizing emotional responses, which may be quite normative from a feminist standpoint. Additionally, the prospect of adding open-ended response items to elicit participant’s view (which may be possible, even in quantitatively oriented studies) allows for greater participant voice and the possibility of raising an alternative experience or point of view. This, in turn, may widen the lens with which we come to know the range of response to perinatal and pediatric bereavement, furthering our awareness of lived experiences of all people who experience perinatal and pediatric bereavement.

**EMERGING PERSPECTIVES: TRAUMA-INFORMED AND STRENGTHS-BASED APPROACHES TO RESEARCH**

There are a number of emerging perspectives in recent literature, including several chapters of this text, that can inform approaches to research and practice with perinatal and reproductive loss. Most significantly, these include trauma-informed perspectives and strengths-based approaches to research and practice.

**Trauma-Informed Perspective**

A trauma-informed perspective endeavors to identify and explain patterns of responses to traumatic events such as the bereavement associated with a perinatal or reproductive loss (Stroebe & Schut, 2001). While the process
of bereavement shares some commonalities with general traumas, there are singular differences as well, particularly in that bereavement models do not commonly include a confrontation–avoidance pattern of behavior that may be exhibited consequent to a general trauma (Stroebe & Schut, 2001). A trauma-informed perspective leads with the assumption that an individual has been impacted by a trauma, and the selection of questions, interventions, and exploratory research must attend to its potential to impact the trauma experience. This leads to heightened sensitivity regarding the ethical conduct of research, as well as to considering the potential therapeutic benefit of participation in research as a component of recovery.

The experience of miscarriage has been viewed as a traumatic event, which has implications for interventions aimed at easing emotional adjustment and providing appropriate long-term follow-up care to address any future negative responses that arise (Lee & Slade, 1996). In addition, some of the symptoms women experience following a miscarriage may be ascribed to the trauma. Individuals experiencing trauma tend to show a characteristic set of symptoms, including restlessness, irritability, fatigue, disturbance with sleep, heightened anxiety and startle responses, depression, difficulty concentrating, and denial of the event (Lee & Slade, 1996). Many of these symptoms are present for women who have experienced a perinatal or reproductive loss, strengthening the argument that this experience is in fact a traumatic experience, warranting the use of different interventions.

**Strengths-Based Perspective**

Given the experience of trauma associated with perinatal and reproductive loss, what characteristics differentiate those individuals who adapt and survive the traumatic experience from those who do not? It is important to note that not all traumas are experienced equally; as such, the nature and duration of the intensity of the reaction will differ, although similarities and patterns in symptom profiles exist (Norman, 2000). One of the factors that has been acknowledged in survival from trauma is personal strength (Norman, 2000).

Specific to the process of bereavement following perinatal loss, Lang, Goulet, Aita, Giguere, Lamarre, and Perreault (2001) argue that the personal characteristic of hardiness will allow individuals to survive, transcend, and grow as a result of the experience of perinatal loss. Hardiness is a personal resource that contributes to one’s ability to remain proactive and retain a sense of control during the experience of a trauma, such as a perinatal or reproductive loss, as well as make sense of the experience (Lang et al., 2001). Hardiness implies more than just resilience; hardiness implies the individual...
grows beyond what he or she would previously have been capable of doing as a result of the experience. This perspective emphasizes the strengths inherent in the individual and the family, rather than focusing solely on the negative consequences or reactions to the perinatal or reproductive loss (Lang & Carr, 2013). Implications of strengths-based research for practice include a goal of fostering the personal characteristic of hardiness among those who have experienced a perinatal loss, concomitantly with reducing the psychosocial distress that so often accompanies bereavement (Lang & Carr, 2013). From a strengths-based framework, grief becomes an opportunity for growth.

Perinatal bereavement research has focused predominantly on the identification and reduction of negative symptoms associated with grief and its psychological sequelae. Inadvertently, this emphasizes the pathological aspects of grief and may even mean that those without a clinically significant level of “symptoms” are not included in research samples. A strengths-based approach could equally include items of personal growth, as well as psychosocial challenge and open research to those with a range of responses to perinatal bereavement. An analysis of secondary data recently suggested that women experiencing both perinatal loss and fertility barriers demonstrated personal growth with more similarity with each other than in the nonbereaved population (Price & McLeod, 2012).

The emotional, cognitive, and relational challenges accompanying the experience of perinatal and pediatric bereavement simultaneously create the opportunity for growth. Attention to inclusion of strengths in quantitative measurement and qualitative interviewing is essential to understanding the wider picture of how perinatal and pediatric bereavement impact the lives of individuals, families, and communities both as a challenge, and as an opportunity for growth.

CONCLUSION

This chapter covered a range of theoretical perspectives on perinatal and pediatric bereavement, and has offered information for the conduct and interpretation of research in the field. To summarize these perspectives, we have included in Table 2.1 the theories and perspectives reviewed with the key points related to research design. In order to advance knowledge of perinatal and pediatric bereavement, attention to the theories that inform research and practice is essential to sensemaking of the data that emerges and the way that data is applied to understanding the grief and growth experiences of individuals, families, and communities.
**CASE STUDY**

Mora is a 24-year-old patient who is 28 weeks pregnant. She is seeking care for vaginal bleeding that began a few hours ago. Her partner is present but states that he is not the father of the baby. Mora explains that she met her partner after she became pregnant but wishes he were the father of her baby. The provider advises Mora to be admitted to the hospital for care. Mora agrees, and her partner will drive her to the hospital. Her mother and sister will meet her there. Mora states that her mother is her “rock” and her sister is her “best friend.”
FOCUS QUESTIONS

1. Describe the key concepts of each of the theories described in the chapter.
2. Which of the theories or concepts described in the chapter would be most applicable to the case study? Why?
3. Using one of the theoretical frameworks from the chapter, describe how care should be structured for Mora.
4. If you were designing a research study using one of the theories in the chapter, which one would you choose? Why?

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