Doing, Being, and Becoming: A Family’s Journey Through Perinatal Loss

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• family relations
• grief
• human activities
• life change events
• narration
• perinatal mortality

Occupational therapists are encouraged to reflect on doing, being, and becoming not only as it relates to the development of their profession but also in their own lives (Wilcock 1999). This article is a description of that process for me and my family in our journey through perinatal loss. This autoethnography uses a personally situated account of perinatal death. This article is a form of self-narrative that places me and my family in social context through the lens of an occupational therapist. This article aims to convey the meanings attached to the experience of grief and loss in the context of participation in everyday occupations. By sharing a perspective on the lived experience and connecting it to the literature on grief and occupation, readers will be able to decide if the connection holds as valid from a theoretical and clinical perspective.


Perinatal loss was a term unfamiliar to me until my son Quinn was stillborn at 37 weeks on May 11, 2005. My world was forever changed in ways that I could never have imagined before that date.

Ethnography has traditionally been situated in anthropological studies. However, more recently, it has been used in applied sciences in an effort to better understand the beliefs, motivation, and behaviors of populations of interest (Tedlock, 2000). A narrative account that includes the reference to one’s own experience and the cultural reference in which the experience takes place is referred to as an autoethnography (Reed-Danahay, 1997). Autoethnography is a methodology for introspection with a goal of critiquing the practices of everyday life (Reed-Danahay, 1997). In my case, it is a subjective description of the experience of grief and loss within the culture of my family and through the lens of an occupational therapist. Occupational therapists have used the methodology of autoethnography in relaying their stories of chronic pain, mental illness, and caring for parents with dementia and at the end of their lives (Hasselkus, 1993; Hatchard & Missiuna, 2003; Hoppes, 2005a; Neville-Jan, 2003; Thibault, 1997). These explorations of the lived experience fit well within the occupational therapy profession’s conceptual framework of doing, being, and becoming (Wilcock, 1999).

Conceptual Perspective

Wilcock (1999) encouraged occupational therapists to reflect on doing, being, and becoming not only as it relates to the development of our profession but also in our own lives. Occupational therapy is based on the belief that participation in occupation contributes to the health and well-being of people (Wilcock, 2006). Wilcock (1999)
proposed that the realization of who we are is achieved through a balanced interaction of being and doing. This concept is grounded in part by the philosophical perspective of being that occurs as the result of time to think and reflect (Wilcock, 1999). It is this perspective of being that I refer to in this article. *Doing* is the participation in occupations that include activities of work, school, self-care, and leisure. *Becoming* is the realization of who you are as a result of the values, skills, and abilities attributed to occupations (Wilcock, 1999).

To keep with the tradition of autoethnography (Reed-Danahay, 1997), this article is written in first-person voice. This article is also written in layered text by using narratives directly from my journal followed by information from the literature about grief and occupation. Reflections on the meaning of the events at each transition are also discussed. The findings are reported under headings that represent sequential transitions along the journey that my family and I traveled during the year after the stillbirth of Quinn. This method of reporting results is traditional for use in narrative accounts that aim to create a better understanding of the beliefs, motivation, and behaviors of a population of interest (Tedlock, 2000).

After reflecting on my own and my family’s experience, four naturally occurring transitions emerged. Similar transitions have been identified in the occupational therapy literature in the context of occupation (Hoppes, 2005b). Hoppes wrote about his experience after the loss of his nephew. In his article, Hoppes proposed four phases of occupation after loss. The phases of occupation proposed by Hoppes are not intended as a fixed progression; rather, they are possible responses to loss in the context of occupation. The occupational phases in response to loss proposed by Hoppes (2005b) were instrumental in organizing my experiences and those of my family that made sense to me as an occupational therapist and normalized the experience for my family.

The *occupational maintenance phase* occurs while the reality of the loss is in question. It is during this phase that daily, familiar occupations are continued. The occupations serve to buffer the emerging reality of the loss.

The *occupational dissolution phase* occurs during the time that the reality of the loss is acknowledged as the shock of the situation weakens. It is during this phase that familiar, everyday occupations may lose their meaning, become devalued, or be discarded.

The *occupational ambivalence phase* occurs as the reintegration of occupation takes place. Familiar and meaningful occupations return; however, they are met with feelings of guilt and ambivalence about their importance.

The *occupational restoration and adaptation phase* occurs when occupations that were familiar are restored or adapted and new occupations may be added.

**Method**

*Autoethnography* is defined as “a form of self-narrative that places the self within a social context. It is both a method and a text” (Reed-Danahay, 1997, p. 9). Narratives of loss and the experience of grief have used the methodology of autoethnography (Ellis, 1993; Hoppes, 2005b). These stories are told in an effort to make sense of traumatic events. The methods I used in this article include a review of notes I kept in a journal for 1 year, artifacts, discussions, emotional recall, and reflection.

Within 1 day after the stillbirth of my son, I started writing in a journal that I kept as an electronic document. For the first 6 weeks after Quinn died, daily entries varied from 1 page to 10 pages. The frequency of entries fell to an average of one per week for a period of 1 year.

More than 100 journal entries were reviewed.

While I was in the hospital, the nurses put together a memory box that included a picture of my son, an ink print of his feet, a lock of his hair, and statistics of his weight and height. Included in the box were some items donated by other families in memory of their babies who had died. These included an angel figurine and an infant sleeper and hat. During the 1st year, other items have been placed into the memory box, including a recording of the funeral service, sympathy cards, and a pencil drawing that includes Quinn. These items were used to facilitate discussions, emotional recall, and reflectivity.

I discussed the experiences of living day to day after the death of my son with my husband, my children, my parents, and my friends. My husband and some friends familiar with academic writing read drafts of the manuscript and offered feedback. I discussed the content of the manuscript related to the experience of my children, including the interpretation of artifacts, with my children, who also offered feedback. *Emotional recall* involves remembering conversations and contexts of important events in as much detail as possible (Ellis & Bochner, 2000). This recall was enhanced by the detailed notes in my journal and caused the reliving of emotions that were as intense as if the events had just occurred. I read and revised this manuscript over a period of 3 years, during which time I was able to add details about what it is like for a family to participate in day-to-day activities immediately after the death of a family member and years later.

Reflectivity is an important criterion for evaluating autoethnographic projects (Ellis, 2004). When I was writing the sequential narrative of my experience, I paused at each natural transition in the story to consider what the events just before the transition meant to me and to my family. I also considered what my emotions were at the time and how I felt as I reread my journal and discussed the events with...
others. I wondered about the choices made at the time and what I would do if ever in that situation again. Foremost in my mind as I wrote the manuscript was how the events during that time of my life have shaped who I am and who my family is today. This type of reflection is painful, even years after the event, and is met with concern about revealing so much about the self. However, it leads to a deeper understanding of the beliefs, behaviors, and motivation of a bereaved family that could help others who may experience similar events.

This autoethnography is based on the assumption that the experience of a phenomenon such as perinatal death is highly contextualized (Portney & Watkins, 2000). It is my hope that readers will be able to think about occupation through the description of my story and not dwell on my story. The intent of this article is to engage the readers in such a way that they are able to imagine what their own and their clients' lives would be like under similar circumstances and that by sharing my story and connecting it to the literature on grief and occupation, readers will be able to decide whether the connection holds as valid from a theoretical and clinical perspective.

The people identified in this article include me, my husband Jeff, and my son Benjamin and my daughter Jessica, who were 6 and 9 years old at the time of the death of their sibling, Quinn. Quinn was stillborn at 37 weeks of gestation. The extended family members mentioned in this article include two sets of grandparents. Before and during my pregnancy, I was practicing as an occupational therapist and as a clinical faculty member at a Canadian university. Currently, I am enrolled as a graduate student in a rehabilitation science doctoral research program. The experience of losing an infant was new to each member of my family.

Transition 1: The Journey Begins

May 10, 2005

There has been an eerie calmness since Saturday afternoon that is concerning. I had considered going to the hospital to check things out but was afraid to hear what I already thought I knew to be true. All weekend, everyone assured me that it was quite normal for the baby to become quieter as the delivery date approaches. The good news from the ultrasound 4 days earlier was reassuring to me . . . . He was fine then. Could things really change that much?

1:00 p.m.: I sit calmly waiting in the doctors' waiting area. I enter the office and collapse in tears and verbal purge on the examining table. “Something is terribly wrong, the baby is so quiet and I think I have lost him.”

1:30 p.m.: I enter the labor and delivery wing of the hospital. I can't find the nurses' station, I am shaking, and my heart is pounding. There is a woman in labor, the room I recall having my daughter in 9 years earlier. I hope all is well. I am whisked off to a room where a very gentle, soft-spoken nurse begins to place the heart monitor on my round, motionless belly. Nothing. More gel, a new position . . . Nothing . . . more gel, more nurses in the room . . . a very strong heart beat . . . . my own. The specialist has come in. The ultrasound is being done, I can't look, I know the news. “Mary, I'm so very sorry, the news is not good.”

A shriek comes out of me but it does not sound like me. Who is this woman with shrieks of grief? I've heard them before but not thought myself capable of such emotion or breakdown. Jeff has come in now and grabs me, holds me, and cries with me. His face is white, his eyes are wide with disbelief, and he tells me he loves me.

Enough of these hysterics. Let's get it together and let these people do their job. I look around the room and all the nurses are crying with us. I need to make this easier for them; after all, I am the one who works in mental health.

I have clients and meetings booked for the rest of the week. I methodically and stoically call my places of work to cancel my week, arrange for my two living children to be picked up from school and be met at home by my parents. I am calm and reassuring to everyone I speak to.

Tons of blood tests to be done, admitting questions to answer. The nurse is so patient and calm. So apologizing for the intrusion of questions and blood taking. I assure her I understand the need and pull myself together. I can't let this be too hard on her. She must have pulled the short straw to get the lady with the dead baby in the room. . . . I ask to talk to a social worker and the chaplain. Jeff and I don't know what the protocol is, and we want to make sure that we don't make any mistakes that will affect how we deal with things later. What are the rules to arrange a funeral?

My family doctor has arrived; she runs to me, hugs me, and cries with me, “I just could not tell you at the office, I am so sorry you have to go through this. It's not fair, you did everything right." I ask her all the medical questions and ask her to explain how I could have had an ultrasound Friday and likely lost him on Saturday. She and the specialist have reviewed the ultrasound and can't find anything that could have predicted this. We all know that there was a cyst growing on the umbilical cord. We've known and followed this since January. The baby was growing, appeared healthy.

The social worker comes in. She has a look of concern, pity, and sadness. I know the feeling she has, I am usually on the other side of this relationship, and I see the strategies in place and the need for her to come across empathetic yet strong and professional. She is doing very well. This is not her unit; she was on call and usually works in rehab. It feels good to ask someone else for help. The social worker shares with me that she lost a
child hours after birth. She has gone on to have more children. She still mourns the loss, but I can see she is functioning. HOPE.

5:00 pm: It’s time to induce. I am switched to another labor room further down the hall. Everyone wants me to have as much privacy as possible. I know they are protecting me from the happy noise of newborns. I thank them for their thoughtfulness.

Labor should be 4 to 6 hr at the most. This is my third child. I wait for things to start. Jeff and I review our lives, our kids, our lost hopes and dreams for this baby. We will name him Quinn. For 2 hr my family doctor, Jeff, and I talk. We waver between talking about how this could have happened and our sadness. We move to other topics, it’s like friends sharing and talking. My family doctor is interested in occupational therapy and mental health. We talk about our respective roles as health care professionals. Boundaries have been crossed, but it feels appropriate. I’m chatty, intellectualizing again, rationalizing, assuring everyone I will get through this. For now I am looking at labor and delivery as a medical procedure. We talk about the ultrasound; I am at peace with it. After all, it is a moment in time.

I could not imagine what I would become as a result of the experience of losing a baby. What was more concerning to me was what would become of my husband and living children. Who were we to become as a family? Having worked in mental health for so many years, I had seen the damage that trauma and stress can do to an individual and to a family. I did not want us to become isolated, separated from each other emotionally, or forgotten. I did not want my children to have parents who were emotionally unavailable. I did not want us all to disperse into our own sorrow to a point that we could not regroup and cope together. As a result, in the first hours and days of finding out that Quinn had died, it became my goal to assure everyone that I was okay, resilient, and not at risk. I took on the role of making sure the nurses who were with us were okay, I reassured my doctor that I did not hold her responsible and that technology was only able to give us reassurance for a moment in time. It appeared that Quinn died a few short hours after my last ultrasound, which showed no reason for immediate concern. I quickly asked for a support network to be mobilized including the social worker on call and the priest from my church. I asked the nurses to keep an eye on my husband, who wandered the halls numb. I made several calls to home to assess my parents’ state and reassure them all would be well. I had completely separated myself from being Quinn’s mother to being the organizer of all that needed to be done and to establish a strong network around me. I had no idea when I was going to crash, although certainly I would. At the moment I was in a medical crisis, I wanted to be the perfect patient. Compliant, easy to manage, and well informed. I could not just “be,” I had to “do.” “Being” created too much time for thinking, and the reality of what was happening became too overwhelming. From my experience as an occupational therapist, I knew how to “do” in a time of crisis, so that’s what I did from my bedside for the next 7.5 hr of labor.

Transition 2: The Reality of the Loss

Quinn, born at 12:20 a.m. Wednesday, May 11, 2005, weighing 5 lbs, 10 oz.

Jeff holds his son and rocks and weeps. I am shaking so much that I cannot hold Quinn but watch from afar. I admire Jeff's show of emotion, his strength to hold our son. We tell Quinn that he is loved. We tell him that his siblings love him and will miss him. We request a priest for baptism. There is some peace in knowing that he is now baptized. I sense Quinn is gone in spirit and that spirit is pure. We kiss Quinn goodbye. Two nurses have put together a memory box, pictures, hair, and footprints. I think that is morbid and cannot imagine wanting such a thing. How can this help me or my family? They carefully put the box on the windowsill and say it is mine to do with what I want; I don’t need to decide now.

Crisis models that include respect, validation, and support are often followed in response to perinatal loss. In these models, a multidisciplinary team responds to the immediate needs of the mother, father, and family. Providing information about what to expect over the next few hours and days and how to arrange religious or ceremonial services and being available to the family are all essential duties. Hunfeld, Wladimiroff, and Passchier (1997), in their study on grief in late pregnancy loss, found that parents wanted information and support immediately after notification of a death. Equally important are actions that validate the existence of the baby in the family’s life. Gathering mementos such as pictures, locks of hair, and footprints and offering them to the family help to establish memories of their baby. Opportunities to hold and spend time with the baby also respect the family’s connection and bond that was developed during the gestation period. There is also evidence that holding the baby is related to a positive outcome or lessens the risk of depression (Nicol, Tompkins, Campbell, & Syme, 1986). Naming the baby helps to provide an identity that the family needs later on (Hammersley & Drinkwater, 1997).

Reflecting back on the activities during this transition, I realize that they were important to me and my family. The memory box is validating that our experience was real and that my son’s existence was acknowledged. There is no birth or death certificate issued for a baby that is stillborn. The contents of the memory box are all that we have.
Transition 3: Moving Forward

After 24 hr in the hospital, I am discharged home. It seems so wrong to be packing up and leaving without a baby in my arms. This is the longest, most difficult walk I have ever taken. As we enter the parking lot, the tears come flooding. I want to run into the hospital morgue, find Quinn, and bring him home. How can we leave him here, what if the funeral home doesn’t pick him up? I hope they drive carefully with him in the car.

I arrive home to see neighbors talking in the street. They scatter as they see us pull up. No one knows what to say. I cry myself to sleep, thinking that the last time I was in my bed, Quinn was with me. The dresser I had set up with diapers, clothes, and blankets is at the end of my bed. I look to the part of the room where a crib was to be. Now there is a memory box.

Thursday, May 12, 2005: Jeff’s parents are coming to watch our children while Jeff and I make funeral arrangements for Quinn. Flowers are arriving at our home. We cry with each delivery but know that people just don’t know what to do. Our children enjoyed a morning with their grandparents shopping. Jeff’s mom gives me a gift. I am confused; why a gift? She tells me that it is a birthday gift for me, something positive to think about. I had forgotten that my birthday is in a few days. It does not seem important.

Friday, May 13, 2005: Food is arriving from colleagues at work. Much needed and most welcome. We continue to be overwhelmed by the calls, food deliveries, and support by so many people. We truly feel blessed with support.

Saturday, May 14, 2005: Our two children have tennis lessons. I need to go and face people. It will be hard, but I need to keep some normalcy for them. Jeff wants to stay home and clean the house. I get through the tennis lessons okay; I hide behind my sunglasses and baggy sweatshirt.

Sunday, May 15, 2005: Our neighbors knock on our door. There are at least 12 people standing outside holding a plant, a gift bag, and wet tissues. They all express how sad they are for us and want us to know they are here for us. [They give us a] gift certificate for dinner as a family outing. How thoughtful. It feels strange to me that other people would think it is okay for us to go out and enjoy a meal together—reassuring that others believe that we should and can function as a family.

Monday, May 16, 2005: Today is Quinn’s funeral. I wake up feeling emotionally and physically stronger than ever. I am a mother saying goodbye to her son. I will be there for him. I squeeze into my black skirt and jacket. I want to look nice for Quinn and also to reassure my parents that I am okay. I pull together some flowers from all of the arrangements to make one large arrangement to take to the funeral home. I hear every word that the priest and sister say. Comforting. I sense that Quinn’s spirit is in the room. I am at peace but so sad. I am glad that we decided to have a small service. Personal. Meaningful. I will recall this day as a sad, but necessary, day in my life. We go back to my home, half torn up with renovations, to eat on my grandmother’s china among the sawdust, boxes, and construction workers. I don’t mind; I don’t have any energy or desire to complain about petty things anymore.

May 17, 2005: Today is my birthday. I had forgotten until Jeff told me he was staying home from work again today to be with me. I am glad he did; this has been a very difficult day. I had pictured me holding a new baby in my arms for this day, not struggling to get up out of bed and open up more sympathy cards than birthday wishes. We plan outings to look at light fixtures; we return the unopened stroller and car seat. There are newborn babies everywhere. We hold hands supporting each other in silence as we go about these sad tasks. With each item we return, I say a silent prayer that the next person to purchase these items will get to use them as they are intended. We go out to a Thai restaurant for lunch to try and celebrate my birthday. This is a treat for us to spend such quiet time alone together. We try to talk about summer vacation plans. We go through the motions, but neither of us feels like going anywhere or doing anything without Quinn. We know we need to make some plans and try to move forward for us, Jessica, and Benjamin.

May 18, 2005: My first day on my own. Jeff has gone to work. It was hard for him to leave this morning. I walk Jessica and Benjamin to and from school today. Parents who know what happened look at me with sad eyes, some look at the ground as I pass by, and others act as if nothing has changed. I knew this day would be hard and it is. The walk home alone is good. I see a neighbor and friend walking toward me. She is pushing a baby in a stroller . . . a friend’s baby she is watching for the day. I am able to interact with her and the baby. I am pleased to see life going on but sad that Quinn is not here in body to share the moment. What a beautiful morning to walk.

May 28, 2005: This was Quinn’s due date. It is a Saturday, and Jessica and Benjamin have tennis lessons. Jeff and I go and sit in the sunshine watching them play. We are trying so hard to focus on them, but our minds are always thinking “if only Quinn were here.”

May 31, 2005: I have been making contact with colleagues and students at the university. There are students [whom] I need to connect with and support for their research projects due in 2 weeks. I find the connection helpful and meaningful. I have been reaching out to support services looking for a perinatal support group. Jeff and I both want to attend. I have made an appointment with a grief counselor at the funeral home for later this week. Jeff would like more support, and I hope this will be an outlet for him.

June 6, 2005: Jeff and I went to our first support group by the Perinatal Bereavement Support Services of Ontario. The group was everything I had hoped it would be. Everyone there had a story, so different yet so much of the same pain and loss.
The facilitator was male, which I think helped Jeff feel more comfortable. Jeff did not say a word until we met informally after the group. He said he was afraid he would cry in front of everyone and did not want to do that. Everyone else did. . . . We will go back.

We attended the support group biweekly for the rest of the summer. During each session, we reconnected with members from the meeting before and met new members who joined. The sessions provided an opportunity to share our story and to listen to the stories of others who had lost a baby. Solutions to grief were not sought. Validation for the losses and strategies to incorporate deceased babies into our lives were the focus.

Narrative models have been published in the bereavement literature (Shear, Frank, Houck, & Reynolds, 2005; Wheeler, 2001). Such models help parents to find meaning in perinatal loss. In my narrative, there is no final ending; rather, it is a story that will be told again and again. I do not find it important to have final resolution. It is when I realized that there would not be resolution that I was able to build my future hopes and dreams with the belief that my story could grow with me. We are not seeking to integrate experiences with our lost baby into our stories. We have no experiences. What we are seeking is how to put hopes and dreams of what would or could have been into our memories that create meaning for the existence of our babies. This is why the mementos from the hospital have come to mean so much to me and my family. This is the validation that our child was real. Making sense of the impact that the loss has had on our lives has created a place for Quinn in our family. We are not the same, nor should we be. What we have discovered is how resilient and caring we are as a family and how our social circles and beliefs were important. The everyday social and cultural aspects of our family were demonstrated in the narrative of our journey. Listening to other people’s stories and sharing our own has also given us the opportunity to reflect and become aware of our strengths as individuals and as a family.

**Transition 4: Resumption**

June 28, 2005: Jessica and Benjamin often refer to Quinn in daily conversations. Jessica has told me that she talks to Quinn every night. She has also told me that she has asked Quinn to talk to me and comfort me. She knows I cry for him daily. Benjamin came to me one night out of his bed after he heard me crying on the couch and gave me a big hug. He said, “Mom, I know a piece of your heart is missing, but I want you to know that I will help keep the rest of it together. Jessica and I love you and Quinn.” He often asks me for confirmation that he has a little brother and that nothing will change that. I smile and tell him . . . absolutely. I wonder if all children who have had this experience are so mature and spiritual about their loss.

A search of the literature revealed limited information on the impact of loss on the entire family (Wilson, 2001). Most literature is targeted to the bereaved parents, particularly the mother, with little reference and only one research article on the effects of perinatal loss on older siblings (Wilson, 2001). As a mother, I was supported by my doctor, colleagues, family, and other resources. I was home to receive the calls from well wishers and bereavement counselors. A group was available for my husband and me to attend but not with the children.

Our living son was 6 years old when he lost his brother. The loss of a family member was not new to him with the loss of his great-grandmother 1 year earlier. However, the death of an older relative made sense to him as the natural order of life. The experience of losing a younger brother brought floods of fears and anger. He began to question the safety of our world and the inability of his parents to protect their children from harm. He was afraid to go to sleep at night for fear that he too would not wake up. He no longer said, “Good night, I will see you in the morning.” Rather he would say, “Good night, I hope we will all be here tomorrow.” According to Christ (2000), children between the ages of 6 and 8 understand the permanence of death. They may exhibit anxiety, sadness, and dejection. Although Benjamin was only 6, he had a strong connection to his spirituality and a strong belief that there is life after death and that his brother is now an angel. This angel was incorporated into all of his drawings (Figure 1). We are grateful that his teachers did not question this need for him to include his brother in family pictures and drawings of him playing with his friends. He continues to bring up his brother’s name in conversations.

Our daughter was 9 years old at the time she lost her brother. The anger and sadness of unmet dreams came flooding from her. She had planned a summer of walking her baby

Figure 1. A drawing that my 6-year-old son did 1 month after the death of his brother showing his brother as an angel.
brother in the stroller, reading him stories, and helping to bathe him. She collected some of the baby clothes that we had bought for Quinn and dressed her prized stuffed animals with them. According to Christ (2000), children ages 9 to 11 are characterized by a need for detailed facts about death to gain a sense of control. School, peer, and after-school activities become important. Our daughter was most upset that he would never know how much she loved him. My daughter is very spiritual and found comfort in prayer and quiet reflection. She continues to pray each night and talks to her brother regularly. Once in a while, she will hug me and ask how I am. Conversations are starting to reflect who we have become.

Developmental stages of mourning have been outlined in the literature. The impact of a loss of a parent on children at different ages has been studied (Christ, 2000; Wilson 2001). A study by Wilson (2001) also described the experiences of siblings with the death of an infant. Integrating the deceased into the family was reported as being important to children and adults. Wilson (2001) reported that one child, age 7, always included the name of his deceased infant brother when filling in forms about the family at school. Both of my children do the same and include him in drawings.

To this day, we all struggle with how to respond to common questions such as how many children do you have or how many siblings do you have? Balancing the need to acknowledge Quinn’s existence and not wanting to upset others or repeat our story to strangers remains a challenge.

April 11, 2006: The faith that others have in my ability remains astounding to me. I am so concerned that I am going to crash emotionally and become useless in my ability not only as a parent but also a professional. In looking back over the past 11 months, I am aware of how surprised I have been that others around me continue to expect or demand performance from me. This is not a bad thing at all. The fact that others around me have not just assumed that I would not want to do things or would not be capable of doing is important and has helped me. Things like neighbors asking us to watch their house for several weeks while they were away, family asking what we are planning for holidays and celebrations, teachers asking us for involvement in the school and expecting the kids to do all the work they need to do . . . no excuses. I know that if I asked for some slack I could get it. How nice that people acknowledge our loss but don’t let us get away with slinking away and doing nothing.

Discussion

Four transitional phases my family and I experienced have been identified: (1) beginning the journey, (2) realizing the loss, (3) moving forward, and (4) resumption. Throughout each phase, the occupations of daily life took on various meanings, values, and purpose. The conceptual framework of occupational phases in response to loss proposed by Hoppes (2005b) is useful to guide the organization of the occupations described in my story of perinatal loss. The first phase of occupation identified by Hoppes (2005b) is occupational maintenance, in which “occupation is maintained while in denial of the gravity of a loss” (p. 80). At the beginning of the journey, I was more focused on my job and responsibilities as a health care professional. I continued to perform professional and personal tasks inherent to my role as an occupational therapist, prenatal patient, spouse, and parent. Later entries demonstrate efforts at occupational maintenance such as my other children taking tennis lessons, eating meals together, and playing with grandparents. Participating and maintaining these occupations served a therapeutic purpose of keeping a routine and continuing with a life that was planned, intended, and enjoyed.

Occupational dissolution is the second occupational phase during which familiar, everyday occupations become devalued and may lose meaning (Hoppes, 2005b). The second transition in our journey came the moment Quinn was delivered, during which the reality of the situation was evident. Rituals and ceremony to create memories and meaning took place. At this point, there was a significant time of just “being.” We spent 3 hr with our son absorbing every memory and feeling. Time stood still for us—it was incredibly special and, in reflection, critically important in our becoming who we are as a family and individuals now.

It was also in this phase that we began to share our story by telling our children and our parents the news and helping to support them through the initial crisis. This phase continued from my hospital bed as I called places of work and extended family members. The task of continuing to tell our story occurred repeatedly as we encountered people who knew we were expecting a baby. During each phone call, the story was told and developed as I discovered meaning in events as they unfolded. The strength I gathered from supporting others in responding to the news built with each call and words of support from others.

We left the hospital 27 hr after I was admitted. I was faced with the reality of the situation as I entered my home with reminders of our hopes and plans, such as ultrasound photos scattered throughout the house, baby clothes laid out on a dresser, and home renovations to make room for our expanding family. Evidence of this phase is also found in my decision to spend 4 months at home with my children and to let go of my clinical and teaching roles that seemed less valuable and important to me. The day-to-day tasks of organizing appointments and planning meetings and treatment sessions appeared trivial. It was during this time that I questioned my interest and ability to ever return to work.
The third phase identified by Hoppes (2005b) is occupational ambivalence. My family and I forced ourselves to participate in familiar and previously planned activities, including tennis, a camping trip, and birthday celebrations. However, we felt guilty—an emotion associated with the phase of occupational ambivalence (Hoppes, 2005b). The activities were thought to be frivolous and were experienced as a stark contrast to the gravity of the loss experienced only a few short weeks before. I also experienced thoughts of never being able to return to work. I was feeling so angry about the loss of Quinn that I did not think it possible for me to be empathic to my clients. Nothing seemed important.

Occupational restoration and adaptation, the fourth phase identified by Hoppes (2005b), was the point in our transition with which we struggled the most. The most challenging events during this time occurred as a result of free gifts and businesses calling our home for services for a new baby. I had registered my name in a few locations to receive product information. Samples of infant formula and diapers arrived at my door as my due date arrived along with calls from photographers. These events stopped me cold in my efforts to cope, sometimes for hours at a time. Occupational maintenance (Hoppes, 2005b) occurred in this phase as my children, parents, husband, and I participated in everyday activities that included eating meals together, walking to school, playing sports, or watching television. I began putting baby items away in boxes and returning larger items to stores. Participating in these activities proved to be therapeutic. We had structure and purpose. “Doing” was the experience we needed to be able to handle and benefit from quiet, reflective time. Occupational restoration and adaptation (Hoppes, 2005b) is demonstrated by my return to work, which adjusted to fit with my new perspective on balance and priorities in my life, my two living children’s return to school and extracurricular activities, and my husband’s continued participation in work.

We made a deliberate effort in this phase to include Quinn in our memories and family life. A shadow box with his footprints hangs in our family room; his name is mentioned in everyday conversation. It is at this transition that we are “doing,” as individuals and a family, and that we are continuing to discover who we have “become.” We now believe in our strengths and in our ability to function in spite of this tragic loss in our lives. The challenge of integrating our new experience into everyday living began and continues to this day, especially as we endeavor to acknowledge Quinn’s existence to others who are not aware of our loss. The journey is not complete. It continues as long as our family participates in life. The loss of our son is integrated into each new phase of our family development. Meaning of the loss changes over time and is woven into all celebrations and acknowledgments of who we have become.

Once the medical crisis was over, we were left to seek services on our own that best met our needs. This was not a difficult task for me because I had experience as an occupational therapist who for many years had helped clients identify and seek resources. I also understood the need for support and accepted that reaching out for help was appropriate. I was fortunate to be surrounded by colleagues and friends who were experienced in the areas of mental health and coping.

My husband and I noticed a significant gap in knowledge and comfort level with perinatal loss and bereavement by health care professionals outside of the labor and delivery program. A gap exists between the health care professions and the self-help associations. Brownlee and Oikonen (2004), in their review of the literature on perinatal loss, proposed that a theoretical framework needs to be established. This framework would be used by professionals to better support and understand perinatal loss with their clients.

Occupational therapy practice models require a focus on assessment and interventions that consider the context of occupation and consider the strengths and resources of the client (Craik, Davis, & Polatajko, 2007; Law et al., 1996). Models used in occupational therapy have the potential to contribute to a framework that allows for the (1) needs of individual family members to express their grief in a way that offers validation of the existence of their child, along with (2) respect for cultural and religious beliefs, and (3) consideration for the developmental needs of each family member. This type of framework will serve the bereaved family well. Respect for each family member’s way of coping with the loss is also important. I feel fortunate that my husband found it helpful to attend a support group and was comfortable including Quinn in our lives by mentioning his name in conversations and looking at his footprints displayed in a frame. If we had needed to cope in different ways, however, we would have needed to find a way to respect our differences in grieving just as we had respect for the coping strategies of grandparents. The material that I read in the weeks after Quinn’s loss also helped me find meaning of my own. No one else in the family could relate to the bond and sense of personal responsibility for Quinn that I had developed during the pregnancy and the constant reminders of the pregnancy from my postnatal body. Reading about the stories of other women who experienced stillbirth helped normalize the feelings of guilt and anger that I had. It also provided assurance that all people have the right to express their grief in ways that makes sense for them.

The critical inquiry of my family’s experience with perinatal loss was guided by recognized methods used in qualitative research. However, despite this rigor, there are limitations to this article. This single autoethnographic analysis
cannot be generalized and therefore accepted as the experience of all bereaved families. This article serves to stimulate discussions about occupation and bereavement.

Conclusion

Experiences are shaped by the beliefs and values of those around us and by past experiences. A sudden and traumatic event, such as perinatal loss, is a catalyst for a process in which the experience changes and a process that influences individuals and groups over time. “Experience is intersubjective and embodied, not individual and fixed, but social and processual” (Tedlock, 2000, p. 471). The experience of being a bereaved parent, sibling, or grandparent is dependent on a multiplicity of locations and positions that are socially constructed. Therefore, the experience of each member of my family was influenced by the different positions we have as women, men, children, spouses, and parents. Little is known about what it is like to grow and develop as a family after perinatal loss and the meaning of that loss in the future. I realize that from my own experience, and those of my husband and children, that memories of Quinn include him aging with us as a family. He is no longer an infant in our discussions; rather, he is positioned as a toddler in the family and, no doubt, in the future the memories will revolve around him as an adolescent, young adult, and onward.

Who we have become as a family remains a question for which answers continue to emerge. The issue that is most meaningful to us at this point is the value that we place on maintaining our focus on growth and development as a family despite the pull to dwell on what might have been. As parents, my husband and I are challenged to support opportunities for our children to become independent, which includes time away from family and less adult supervision. Our ability to make decisions that support individualization and autonomy is enabled by the skills and resources we have to talk openly about our experience and the impact it has on everyday living.

Writing about my own experience was a challenge. I started a journal as a diversion, a way to have some structure and method of hiding from the chaos that surrounded me emotionally (grief) and physically (the construction of a new floor of my home that included a nursery). The journal was a way to make sense of the ebb and flow of daily life that was new and unexpected for me and my family. In time, I saw this as a way to become more aware of my daily existence.

Working on this article has been a therapeutic experience for me, as well as an academic exercise. Several colleagues and fellow bereaved parents have asked me to write about my experience so that it would be available in a useful format for others. There is truth in the therapeutic value of telling one’s story repeatedly with a deeper understanding of the experience that occurs each time. My current role as a graduate student and having the opportunity to learn about and explore qualitative methodologies, including autoethnography, helped to shape my story into a study of grief and loss that is meaningful to me as an occupational therapist. The crossroads of my personal and professional experience was a tension throughout my experience, and this article was a way to ease that tension.

Future research is needed to better understand the impact of perinatal death on the participation in activities of daily living for parents and family members. Research that explores the role of occupations in coping with grief and loss is also needed. I was searching for information that would help to inform me about the experience of my living children and also for the grandparents. The stories exist within the confines of support groups; however, these are not accessible to outsiders or to people who may not have access to such groups. There is a gap in knowledge about the experience of the death of a sibling for children and adolescents. This information has the potential to inform occupational therapists about the meaning of occupation in the context of grief and loss and to guide the development of occupation-based services for bereaved families within family-centered care models. Family-centered care that is occupation based is discussed in the literature (DeGrace, 2003) and could be applied to bereavement. Occupational therapy services provided in primary care settings, mental health centers, or community-based programs have the potential to contribute to enabling occupation for bereaved families. This could be done through the integration of values and beliefs associated with bereavement into areas of work, school, self-care, and leisure. An evaluation of the effect of existing occupational therapy interventions that aim to promote participation in meaningful occupations through the development of effective coping strategies will contribute to the knowledge of occupation-based interventions and bereavement.

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References


