When a Child Dies the World Should Stop Spinning: An Autoethnography Exploring the Impact of Family Loss on Occupation

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The death of a loved one disrupts family-members’ occupational lives. This paper explores the role and course of occupation during a time when my nephew died. A qualitative research methodology, autoethnography, is used to develop the narrative. I found that familiar occupations lost meaning during this time and even seemed absurd. Paradoxically, occupation helped forge a vital pathway back to health and reconstruction of meaning. Four stages of occupation during a family crisis are proposed: maintenance, dissolution, ambivalence, and restoration and adaptation. Reflections on occupational therapists’ role during family crises are discussed, as are implications for further research.


Something was wrong. A phone rang, awakening me in a strange bed. By the third ring, I knew that I was in a hotel room, but in my sleepy fog, I couldn’t name the city. I was comforted by the realization that my wife slept beside me in the dark. With this scant information, I picked up the phone and said, “Hello.” I heard my father’s voice, soft and quivering, saying something about my nephew, Marc, and something about cardiac arrest and cardiopulmonary resuscitation (CPR) in Reno. This didn’t sound right. Marc had no business being in Reno, as far as I knew. He was 13 years old, and even though he had some health issues, 13-year-olds don’t have heart attacks, do they?

After a series of strokes and TIAs (transient ischemic attacks), my father sometimes has difficulty explaining things. But my mother spoke up on the other line to confirm the story. I assured them I would follow up with one of my sisters in the morning and do whatever I could to help. For years, I’ve been more-or-less expecting a late-night call about my father, but I couldn’t make sense of this call from my father.

“Who was that?” my wife asked sleepily.

“My dad. He says Marc has some sort of problem. Said he had a heart attack, but I don’t think he has the story right. Don’t know why it couldn’t have waited until the morning,” I grumbled.

By this time, I knew I was in Washington, DC, for the 2003 American Occupational Therapy Association (AOTA) Annual Conference. After a long day of walking the Capitol Mall we were exhausted. I was presenting a short course the next day and needed sleep. Things couldn’t be as dire as my father seemed to think. I quickly fell asleep.

The next morning I put the late-night call to the back of my mind so I could review my part of the short course. The presentation, focused on the design of a community-service class I teach at the University of Oklahoma, went well, and I was particularly pleased and impressed with my students’ skills in presenting what
they'd learned in the class. With the short course behind me, my thoughts turned to Marc and his family.

Telling a Story Through Autoethnography

Autoethnography is a postmodern research genre that connects self-narrative with ethnographic investigation of a cultural phenomenon (Ellis & Bochner, 2000; Hayano, 1979; Neumann, 1996). The autoethnographer has been described as a “boundary-crosser” with a dual identity of researcher and research participant (Reed-Danahay, 1997). Autoethnography builds on the assumption that examining one's own life is an important step in understanding a way of life (Ellis & Bochner).

The anthropologist David Hayano (1979) is often credited with coining the term autoethnography to describe research done on one's “own people” through an insider’s perspective. Over the past 25 years, this research technique has evolved to include a wide range of “autobiographical writing that has ethnographic interest” (Reed-Danahay, 1997, p. 2). Ellis and Bochner (2000) wrote that autoethnography, personal narratives, autobiography, reflexive ethnography, and memoirs have become “blurred genres” (p. 742). But the goal of autoethnography remains clear: to write a meaningful and evocative narrative about a topic that matters, connecting the personal to the cultural, and affording both the inside views of a participant and the outside views of a researcher (Ellis, 1998, Ellis & Bochner, 2000). Many autoethnographies are narratives of loss that help the writer and readers “understand and cope with our own losses, heal wounds, create meaning, and move ahead with our lives” (Ellis, 1998, p. 50).

In occupational therapy, Neville-Jan (2003) wrote an autoethnography describing personal experiences of chronic pain and her encounters with medical professionals and systems. Her first-person narrative helps readers understand realities for individuals with chronic pain in ways that other types of qualitative and quantitative research cannot. Dickie (1997) wrote a “focused autobiography” exploring her experience as a crafts person in order to understand a community of individuals who made crafts. Hasselkus (1993) wrote a personal “journey of caregiving” to describe the events and meanings of the death of her mother.

Autoethnographers use various methods in their writing including note taking, reflection, and discussion with others involved in phenomena of interest. For this autoethnography, I took detailed “field notes” to use while writing about the impact of death and loss on occupations of my family. While writing the narrative, the notes triggered recall of circumstances, conversations, and emotions that comprised the experience. I discussed rough drafts of the manuscript with family members and professional colleagues and rewrote drafts until I was satisfied that I had described events, implications, and meanings accurately. Now that I had found the appropriate research format, my next task was to articulate my frame of reference.

Irvin Yalom, Victor Frankl, Albert Camus, Meaning, and Occupation

I find the existential views of Irvin Yalom (1980, 2000), Victor Frankl (1969, 1984), and Albert Camus (1991) thoroughly persuasive and a precise fit with occupational therapy. Yalom (2000) sees humans as “meaning-seeking creatures . . . hurled into a universe that intrinsically has no meaning.” The only viable solution to this problem, according to Yalom, is to invent a “life-meaning project sturdy enough to support a life” (pp. 5–6). To escape meaninglessness, Yalom wrote, “It is good and right to immerse oneself in the stream of life” (1980, p. 431).

Frankl (1969) identified three ways to find meaning: creating something to give to the world, immersing oneself in the experiences that life offers, and developing positive attitudes about the fate of living in a world without inherent meaning.

Camus (1991) told the story of Sisyphus, an “absurd hero,” whom the gods condemned to roll a huge rock to the top of a mountain. Once he reached the summit, the rock rolled to the bottom, and Sisyphus’ fate was to repeat the task forever. “The workman of today works everyday in his life at the same tasks,” Camus wrote, “and his fate is no less absurd” (p. 121). Gradually, as he trudged up and down the mountain, Sisyphus transformed the pain and sorrow of his imposed fate to real joy of a destiny he accepted as his own: to be on the move and keep the rock rolling. At the end of the story, Sisyphus concluded that all is well and that struggle itself can be a source of purpose and happiness.

The views and assumptions of Yalom, Frankl, and Camus informed me at a time when meaning was blindsided. My nephew’s life-threatening illness shattered the safe, meaningful, and positive worlds my family and I had created for ourselves. Although these comfortable world views supported our psychological stability during “normal” day-to-day life, they were exposed as flimsy illusions during this crisis. Life began to look meaningless and malevolent (Janoff-Bulman & Berg, 1998). With our world views turned upside down, we badly needed to hold onto a semblance of meaning and balance based on who we were before this sorrow and pain exploded into our lives and who we might become in uncertain days ahead.
Although occupation isn’t in the vocabularies of Yalom, Frankl, or Camus, the clear inference from their writing is that occupation is an indispensable tool for constructing meaning. Yalom’s “life-meaning projects” are based on occupation. Occupation is integral to Frankl’s prescription for creative immersion in experience. Camus’ Sisyphus is a story of finding meaning by adapting to an occupational role. Occupations are activities that have “unique meaning and purpose in a person’s life”; they are “central to a person’s identity and competence, and they influence how one spends times and makes decisions” (American Occupational Therapy Association, 2002, p. 610). In the midst of a tragedy, occupation provided my family with the means to begin reinventing our life-meaning projects, to reimmerse ourselves in experience, and to push rocks up mountains that had to be climbed.

A Proposed Course of Occupation After Loss

Rando (1984, 1986a, 1993) wrote of three phases of grief following losses, such as death, divorce, amputation, or natural disaster. She cautioned that these phases are not to be seen as a fixed sequence. Instead, a griever tends to move back and forth among the phases.

The Avoidance Phase commences when news of death is first received and continues for a short time after. It is marked by denial, bewilderment, and numbness. Rando (1984) compared this grief reaction to “emotional anesthesia” for a psyche shocked by an important loss. Resulting confusion and denial may appear unhealthy but in fact are therapeutic. This phase “functions as a buffer by allowing the individual to absorb the reality of the loss a little at a time, preventing her from being completely overwhelmed by it” (1984, p. 29).

Grief is experienced most intensely during the Confrontational Phase of anger, guilt, and sadness. As shock dissipates, a griever begins to understand the gravity of loss and considers implications for his own life.

Emotional and social reentry into the everyday world is attempted during the Accommodation Phase (Rando, 1993). During this time, the loss is not forgotten, but the griever makes necessary internal and external adjustments to allow for new relationships and ideas. Guilt may be elicited during this phase as one moves forward in spite of a loss.

Although not addressed by bereavement researchers, I know, firsthand, the death of a loved one, particularly a child, greatly disrupts a family’s occupational life. I propose four phases of occupation following loss that are consistent with and overlap Rando’s phases. Like Rando’s phases, these are not to be seen as a rigid progression. Instead, these are possible occupational responses to loss. Grievers may not experience all occupational phases and probably move back and forth among them.

Occupational Maintenance. Occupation is maintained during Rando’s Avoidance Phase while in denial of the gravity of a loss. Occupation buffers loss, allowing an individual to slowly come to terms with an emerging reality. In my case, I now understand that I used the AOTA presentation in this manner. Later, my family dined together, read books, played computer games, went boating, and attended baseball games while my nephew was dying. Maintaining these occupations served a therapeutic purpose as illustrated in the story that follows.

Occupational Dissolution. As shock wears off and reality is at least partially accepted, everyday occupation can lose meaning and become greatly devalued or discarded. This occupational phase runs concurrently with Rando’s Confrontational Phase. In the story that follows, I experienced occupational dissolution when I returned to work from Washington, DC, I quickly dropped familiar professional and personal occupations to attend to the crisis surrounding my nephew.

Occupational Ambivalence. Occupation gradually returns infused with ambivalence. My “life-meaning projects” wobbled under the weight of my nephew’s death and family’s pain and once meaningful and cherished occupations (professorial work, watching baseball, riding my bicycle) appeared absurd and induced guilt. This phase coincides with the early part of Rando’s Accommodation Phase.

Occupational Restoration and Adaptation. Occupation comes full circle when it is restored and adapted after loss. During this time, occupation facilitates emotional and social reentry as described in Rando’s Accommodation Phase. Familiar occupations are restored. New occupations and updated versions of old occupations can be adapted as well.

Marc and His Family

My wife and I moved to Atlanta in 1996 where I took a job as a clinical occupational therapist, in part to be in the same city as 6-year-old Marc, his 4-year-old brother Luke, my youngest sister Marilyn, and her husband Gene. We stayed in Atlanta only 11/2 years before I chose an academic position requiring a move, but during that time, we grew close to the family. We baby-sat for the boys to allow Marilyn and Gene rare evenings out and we went to their ballgames and celebrated birthdays and holidays together. My wife and I don’t have children and we enjoyed spending time with such likable, bright, and playful kids.

At 2 years of age, Marc had been diagnosed with juvenile rheumatoid arthritis (JRA). Marilyn practiced nursing before becoming a full-time mom, and analyzing Marc’s
problems, managing medications, dealing with insurance companies, and conversing with doctors had become central to her role as Marc’s mother. Marilyn and Gene homeschooled the boys and Marc developed keen interests in science. In science fairs, he won blue ribbons for an experiment to determine the relationship between water quality and plant growth and a study of the effects of temperature on animals’ activity. At 12 years of age, Marc and two other boys finished second in a national competition for innovative technological design. They devised a model of a hospital gurney with superconducting magnets to cushion a patient being transported. The idea stemmed from Marc’s experiences of bumpy rides through hospitals after JRA flare-ups and a mild, unexplained stroke earlier that year.

As Marc entered early adolescence, he had been unable to live the typically physical life of a young boy, due to JRA, but he adapted and shaped a life based on exploring potentials in other areas. He loved baseball, but JRA prematurely ended his Little League career. Instead, he became an assistant coach for a girls’ soccer team and began the study of karate with his usual enthusiasm for learning something new. He took a computer class for kids at Georgia State University and applied himself in his home-school studies, scoring in the top few percentiles on nationally standardized tests in a wide array of content.

His father, Gene, is a professor of biology and Marc aspired to be a research scientist like his dad. He wanted to become a chemist and develop a remedy for JRA so other kids wouldn’t be subjected, as he had, to the side effects of steroids, the treatment of choice for JRA. Marc acquired a chemistry textbook and began teaching himself the subject.

Marc held an unusually idealistic and mature world view for his age. A devoted pacifist, consistent with his Mennonite upbringing, he traveled to a Washington, DC, peace rally with his father during the spring of 2003 to protest the US invasion of Iraq. He wrote Georgia Senator Zell Miller asking him to support US negotiations with the U.N. in lieu of invasion. Marc’s heroes included Gandhi, Martin Luther King, Jr., Bishop Desmond Tutu, and former president Jimmy Carter. Meeting the latter two at science fairs, he won blue ribbons for an experiment to diagnose and treat the problem. The doctors discussed doing lung biopsies to determine if he had a pneumonia resistant to the antibiotics he’d been receiving. With his parents at his bedside, he was intubated and put on a respirator. The PICU staff gave Marilyn and Gene a pager and directed them to courtesy lodging for patients’ families behind the hospital.

Fifteen minutes later the pager buzzed, and Marilyn and Gene ran back to the unit. Bad news. Marc had a heart attack. That’s not right, is it?”

Marc did have a cardiac arrest. CPR was administered and he’s unconscious right now.”

“Oh my God,” I said. “How did all this happen?”

My sister patiently told the story:

While vacationing in Yosemite National Park and South Lake Tahoe, Marc complained of chest pains during days of hiking. My sister was accustomed to such complaints. After usual methods of dealing with Marc’s pain proved ineffective, she took him to the small hospital in South Lake Tahoe where he stayed overnight. Marilyn called Marsha at that point and made light of it. She’d seen all of this before and it was nothing new. The doctor attributed his respiratory problems to the altitude, but put him on antibiotics just to be safe.

When his condition worsened, the Tahoe doctors recommended transfer, via helicopter, to Washoe Medical Center in Reno. Marilyn, Gene, and Luke, now 10 years old, drove over the mountain pass to Reno, and checked on Marc after admission to Washoe Pediatric Intensive Care Unit (PICU) and talked with doctors and nurses. Although the doctors weren’t quite sure what was going on, Marilyn and Gene believed that Washoe had the facilities, equipment, and expertise to diagnose and treat the problem. The doctors discussed doing lung biopsies to determine if he had a pneumonia resistant to the antibiotics he’d been receiving. With his parents at his bedside, he was intubated and put on a respirator. The PICU staff gave Marilyn and Gene a pager and directed them to courtesy lodging for patients’ families behind the hospital.

I last saw him a year before the late night call to Washington, DC, and he struck me as more withdrawn and guarded than the playful, extroverted kid I’d known earlier. I surmised that he had grown tired of JRA flare-ups and the increasingly frequent and invasive procedures performed to manage his symptoms. Marc was quite aware that “normal” kids, like his brother Luke, didn’t endure painful range of motion exercises, infusion therapies, joint pain, and steroids that caused mood swings and weight gain.

**Family Crisis**

When I returned to the hotel after the AOTA short course, I called my oldest sister, Marsha, in Oklahoma City.

“I got this weird call from Dad last night, saying that Marc had a heart attack. That’s not right, is it?”

“Marc did have a cardiac arrest. CPR was administered and he’s unconscious right now.”

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Fifteen minutes later the pager buzzed, and Marilyn and Gene ran back to the unit. Bad news. Marc had experienced cardiac arrest. CPR had been administered. Doctors estimated that blood flow to his brain had been interrupted for about 2 minutes. They administered drugs to induce a coma. Marilyn and Gene asked many questions, but doctors could not say what caused the cardiac arrest or predict the extent of possible damage.

I felt guilty about discounting my father’s account of this—a clear case of avoidance as described by Rando—and began to understand the gravity of it. Marsha stayed in constant touch with Marilyn, and my middle sister, Betsy, flew.
from Seattle to Reno to support Marilyn, Gene, and Luke. After returning home from AOTA Conference, I would be able to take vacation and fly to Reno to help in whatever ways possible. I told Marsha to keep me posted and began to make contingency plans.

When I returned home from DC, I learned that Marc’s condition had worsened, that antibiotics weren’t proving effective, and that a firm diagnosis still hadn’t been established. The Reno hospital team recommended more specialized treatment for Marc requiring a special ventilator available in only a few places in the county. Beds in the PICU at Stanford were full, but the Children’s Hospital at the University of Washington could accommodate him. Seattle offered a practical advantage because the family could stay with my sister Betsy. She is a Professor of Radiology at the University of Washington and knew pediatric and neurological specialists she could consult. Transporting Marc to Seattle carried some risks, given his coma and dependence on life-support, but staying in Reno seemed riskier, both to the family and treatment team. The treatment team advised Marilyn and Gene that they might say their “good-bys” to Marc prior to the flight, due to Marc’s condition coupled with the risks of the flight. Two PICU nurses and Gene accompanied Marc on the medical flight, while other family members flew commercially. All arrived in Seattle safely. Marc went to the Children’s Hospital, and the family settled in at Betsy’s, hoping the worst was behind them. Betsy relayed information to the family, and when I called and asked to talk to Marilyn, Betsy said she couldn’t talk on the phone. We didn’t talk much about how Marilyn was doing because we knew we couldn’t really understand her pain and sorrow.

After arriving in Seattle, Marilyn told Luke that the scary part of the ordeal was over, and they were safe with a loving place to stay and expertise to solve the riddle of Marc’s illness. Unfortunately, that wasn’t the case and worst-case scenarios began playing out. After about a week at the Children’s Hospital, Marc was transported to the radiology department where magnetic resonance imaging (MRI) revealed massive cerebral damage and an intact brainstem. Gene later explained the results as indicating collapsed ventricles and undifferentiated white and gray matter. As a biologist with expertise in neurology, he knew exactly what this meant. Damage this severe is inconsistent with 2 minutes of oxygen deprivation from cardiac arrest, puzzling the treatment team and complicating the prognosis. Doctors arrived at a diagnosis: macrophage activation syndrome (MAS). We learned through Internet searches that the etiology of MAS is unknown and treatment options are uncertain and limited. MAS involves exaggerated response of a compromised immune system and leads to multiple organ failure. Marc’s immune system had been compromised by years of treatment of his JRA with steroids. Doctors surmised that Marc’s earlier stroke might have been due to MAS. Reported incidence of MAS is one to two for every million children, with an average death rate of 60%. Still, we hung onto hope, and thought his chances might be better than average because he was in the hands of expert neurologists and pediatricians.

Betsy told me over the phone that Marilyn wanted Marsha and me to come to Seattle. She thought I could entertain Luke while Marilyn, Gene, and my sisters consulted with the treatment team and stood vigil at Marc’s bedside. Since Marsha is an MD and Betsy is a professor of radiology, and both are moms, the delegation of roles made sense. I felt lucky to have a less intense role than my sisters’ weighty responsibilities.

All of my clinical experience has been with geriatrics and I’m a volunteer for hospice. Through these experiences, I’ve learned to accept illnesses and deaths of my patients with relative equanimity. But this was so different: Marc was a family member, not a patient, and he was a 13-year-old, not an older adult.

Occupational Dissolution

A counselor later told Marilyn, “When a child dies, the world should stop spinning. But it doesn’t.” Occupationally, my world may not have stopped spinning, but it wasn’t spinning smoothly, either. It lurched as Marc’s illness became perilous.

In DC for AOTA Conference, I balked at letting family concerns interfere with my occupation of presenting a short course. But as I understood the exigency of events, many occupations suddenly lost value. When I returned to work for a couple of days before leaving for Seattle, moving paperwork, meeting deadlines for manuscripts, and attending committee meetings seemed inconsequential. I wondered why I, or anyone, should waste time this way. The meanings of my job, riding my bike, walking my dogs, making dinner for my wife, watching baseball, gardening, reading the paper, and staying in touch with friends quickly dissolved. I hardly thought twice about dropping these occupations so I could go to Seattle.

One of my colleagues, Dr. Beth DeGrace, works with pediatrics and she has impressed me with her vision of family dynamics, pediatric illnesses, and disabilities in courses we co-teach. Before leaving for Seattle, I turned to her for whatever wisdom she could impart.

I told her that my trip to Seattle felt like walking into hell. I wasn’t sure I could keep my emotional balance, let alone be the strong big brother to my sisters and comforting
un Muk for my nephew Luke that I wanted to be. I’d never been through anything remotely similar and she sensed my shaky self-confidence.

Beth gently reminded me that, as an occupational therapist, I had valuable insight into the therapeutic values of occupation. She’d recently published an article in the American Journal of Occupational Therapy entitled, “Occupation-Based and Family-Centered Care: A Challenge for Current Practice” (DeGrace, 2003), where she advocated the importance of occupational therapy’s appreciation of the meaningful occupations of families. Occupation, she wrote, can stabilize a family during stressful times. She wrote beautifully about understanding “family doing” and “family being” as a key to appreciating family occupation. After talking, and finding her article to re-read on the plane, I thought that perhaps I did have a therapeutic lens through which to view hell.

Seattle

Marsha and I flew together to Seattle, rented a car, and drove to Betsy’s house. When we arrived, we spent several minutes hugging Marilyn, Gene, Luke, Betsy, her daughters, and husband. It felt surprisingly warm and joyous to be together in the face of such sad events. At that moment, the vision of the therapeutic power of “family being” made perfect sense.

The following day, neurologists performed a second MRI on Marc and their findings confirmed the bleak results of the first. The University of Washington treatment team told Marilyn and Gene that Marc’s chance of meaningful recovery was remote but uncertain due to the rarity of MAS. Their best guess was that, with years of exposure to therapeutic stimuli and a very high level of medical care, Marc might be able to regain some vague recognition of his parents. But purposeful movement and productive cognition could almost certainly be ruled out. This outcome was not acceptable to Marilyn and Gene and they believed it would have been unacceptable to Marc. But giving up hope was also unacceptable. In the next few days, the looming decision to withdraw Marc’s life-support or continue with aggressive therapies terrified Marilyn and Gene. Tearful conversations with a medical ethicist, a local Mennonite pastor, and family members helped shape the heartbreaking conclusion that the best way to express their love for Marc was to let him go.

Marilyn and Gene told the treatment team of their wishes to discontinue life-support, therapies, and medications. Doctors expected Marc to continue breathing on his own for a while, but predicted it would be “days, not weeks” before he died. Marsha, Betsy, and I accompanied Marilyn and Gene when Marc’s breathing tube was removed and all monitors were turned off. The scene was quite peaceful as the invasive medical equipment no longer came between Marc and his parents. Marilyn and Gene removed Marc’s hospital gown and dressed him in his favorite T-shirt from “Camp JRA” in Pennsylvania. They brought in a few of his favorite books and his “Game Boy,” and laid them beside him on the bed. A nurse brought in an extra hospital bed, so they could make a double bed and lay beside him. With the hospital gown and medical technology removed, Marc appeared more like a regular kid again, not a patient with a rare and fatal illness, and the family was together to celebrate a remarkable life. But we all knew that illusion could not be sustained for long. Marilyn and Gene began taking shifts for a 24-hour vigil.

Occupational Ambivalence

During these days in Seattle, my perspective on events vacillated. Sometimes I saw things as a comforting big brother and sometimes I was a grieving uncle. Gradually, I began to see things as an occupational therapist. The last perspective provided emotional breathing room and put me in a familiar role of analyzing occupation for meaning and purpose. Understanding my family’s occupational life, it seemed to me, held some keys to piecing together a shattered world. I wondered why I held so tightly to my short course in DC after hearing the news (occupational maintenance) and conversely, why my work and everyday activities lost meaning (occupational dissolution). In Seattle, occupation helped move my family through this crisis.

I wish I could say that during these days, given my experience with the therapeutic power of occupation, I helped engage family members in meaningful and purposeful activities. But I wasn’t seeing that clearly and didn’t know what my grieving family members needed, or even what I needed. Since I’d experienced the recent dissolution of my own occupations, I didn’t suspect that occupation could offer solace.

Hugging each other (“family being”) felt right. When Marilyn cried after a call from the hospital or while trying to sort things out, Betsy calmly led her to the couch, pulled a comforter around them, and said, “Let’s snuggle here for a while.” Soon the rest of us learned how to “be.” My family has never been very physically affectionate, but during this time, old inhibitions didn’t make sense, and the “being” of sitting together and hugging during difficult spells worked perfectly. Beyond that, I wasn’t sure what might comfort us.

I knew I could occupy Luke. He didn’t want to visit his brother in the hospital. Instead, we played a lot of tennis,
soccer, and watched movies. Luke wasn’t overtly grieving as the adults were. One day on a walk, I asked him how he felt about how things were going with his brother and parents. He was sad, he replied, but not as sad as he thought he should be. I assured him that however he felt was okay. His parents communicated Marc’s condition in ways that he could understand. After one of these conferences Luke suggested to Marilyn and Gene, “Let’s not be so sad that we can’t be happy.” One part denial, one part wisdom, I thought.

Occupation seemed effective for Luke. He stayed busy. I noticed the same with Betsy’s daughters, 18 and 12 years old. Their active lives kept them running to swim practice, a Harry Potter party, art lessons, and over to friends’ houses. They seemed more-or-less okay with everything during this time. Later I learned that even though children often do not demonstrate grief and that childhood mourning is a controversial issue, “what is undeniable and incontrovertible is that children, even young infants, will have dramatic and long-lasting reactions to the separation from a loved one” (Rando, 1984, p. 155). Parents, extended family, and therapists must understand, validate, and guide children through the process over time.

My sisters, brothers-in-law, and I did our best to attend to Luke and his cousins, but we were heartbroken and immersed in the developments of Marc’s case. We frequently visited his bedside, consulted with the medical team, and took turns comforting each other and falling apart. As the prognosis and hope grew darker, a tragic reality stared us in the face. At a time like this, occupational diversion wouldn’t work for us, as it seemed to for the kids, would it?

I’m not sure how she knew it, but, fortunately, my sister Betsy intuitively understood that we needed occupation, too, precisely because we were grieving.

During these days, Betsy deftly managed the family’s “doing.” She organized wonderful family dinners featuring comfort food. After dinners, her husband Bob took us boating. On one of these perfect summer evenings as the sun set on Lake Washington, Marilyn, Gene, and Luke sat together in the bow of the boat, smiling, chatting, and holding hands. Things were irrevocably changing on this sadly beautiful evening on the lake as occupation led them through the first halting steps of being together as a family of three instead of four.

I began to see both individual and family occupation as a constant. Several of us played computer games during spare moments. Reading has always been important in our family and these days were no different. We all took solo and group walks. Marilyn, Gene, and Luke rented a canoe. Betsy organized a trip at low tide to gather seashells. This outing was Marilyn’s first significant time away from the hospital and she enjoyed the day. Gene found rare shells of ocean life he lectured about in his biology classes and looked forward to showing them to students when he returned. In the evenings, the family gathered in the den to watch movies. On other evenings, we attended Seattle Mariners baseball games.

My brother-in-law Bob is an executive with the Seattle Mariners and he often arranges box seats at the games when I visit. I love baseball. Watching the game has been an important part of my occupational life since 6 years of age, when I saw the Milwaukee Braves beat the New York Yankees in the 1957 World Series. I’ve been a Braves fan ever since. My childhood dream was to be a major league baseball player (all my buddies had the same dream), but inability to hit a curveball doomed that fantasy. The 1970s spun my religious and political beliefs 180º and during adulthood I’ve changed careers and moved all over the country. But during the journey from childhood to middle-age, my passion for baseball, and the Braves, has been steadfast.

Before I married, I told my wife-to-be, “You need to know that I spend a lot of time watching baseball. I mean, a lot of time. Baseball is part of who I am.” She’s done a remarkable job of understanding that in the 20 years we’ve been married. While planning the trip to Seattle, I peeked at the Mariners’ schedule and was pleased to see the Braves would be in town for an interleague series.

After a day at Marc’s bedside, Marilyn and Gene accompanied Luke and me to a game between the Braves and Mariners. The sights and sounds of a major league stadium often bring back memories of my first major league baseball game, more than 40 years ago, with my father and brother in Kansas City to see the Yankees play Mickey Mantle, Yogi Berra, Roger Maris, Whitey Ford, and their teammates were gods to me, and the stadium was sacred ground. I now view ballplayers in more mortal terms, of course, but walking into a major league stadium is still a spiritual experience.

The writer Roger Angell suggested the spirituality of being a baseball fan is based on belonging, “Belonging anywhere now is terribly difficult,” he wrote, “and the old childhood dream of really belonging will not go away. Nothing comes closer to a band of brothers than a team. We want to know all about ballplayers because . . . then we will belong, too” (1982, p. 200). Baseball fans belong and create a “life-meaning project,” in Yalom’s terms, by following the game and their teams.

But a funny thing happened when we arrived at the Mariner’s stadium for the game on this night. I felt guilty.
An occupation that delivered belonging and meaning over many years wasn’t working. Instead of being therapeutic, this occupation felt wrong.

Marilyn has never been a baseball fan but she came along to spend some time with us. Her thoughts were obviously with Marc, not the game, and she was having a miserable time. Luke, Gene, and I watched the game and talked about the action, but at least for me, it didn’t feel right. I thought Marc would love to be at this game since he is a Braves fan, too, but I knew he would probably never watch baseball again. Was it right for me to enjoy the game while he was dying in a hospital across town? And it seemed absurd to care whether balls were hit or caught, and whether the Braves scored more runs than the Mariners. The meaning of baseball, one of my most durable and trusted life-meaning projects, was exposed as artificial. To be watching a baseball game, at a time like this, seemed trivial and misguided on one level.

On another level, I knew I was where I needed to be: a place where I’ve always belonged, even if I didn’t feel exactly that way on this evening. I could still appreciate the aesthetics of the game. And I knew deep down, however things played out with Marc, I’d continue to be a baseball fan throughout my life.

Ellis (1995) wrote about living a “two-track life” while a family member is dying: “There’s taking care of [a dying family member], and then there’s the part of life that will continue after…and it has to be taken care of too” (p. 75). But nothing was that clear during these days. Engagement in occupation was tinged with guilt and ambivalence.

I began to think about writing a manuscript to sort out details of these contradictions and difficult lessons. Did it make sense to care about a baseball game while Marc was dying? How could I use my family’s tragedy as fodder for research? I wrestled with many difficult questions but I began to understand that occupation was a fundamental answer. Occupation is therapeutic at a time of loss because it connects a more peaceful past with a dark and shattered present and to the future that awaits.

Letting Go

Two days after the doctors removed life-support, Gene called us from Marc’s bedside to let us know that Marc was slipping away. I drove Marilyn to the hospital and Betsy arrived a few minutes later. Marc’s breathing was now labored with increasing intervals between noisy inhalations.

Gene whispered to him, “Marc, it’s okay. We love you. You don’t have to keep fighting. If you want to let go, you can.” And then he was gone.

Atlanta

Two weeks later, family and friends assembled in Atlanta for a funeral and memorial service. Again, continual occupation moved us through these days. The hotel where we stayed had a game room, and we played shuffleboard, pool, cards, and board games. While most of the men and boys attended an Atlanta Braves baseball game the night before the funeral, the women took Marilyn to the hotel to “snuggle” and watch a movie, and then go on a walk for ice cream.

The next morning, through our tears, we placed flowers on Marc’s casket. Later in the day, we walked into the Cannon Chapel on the Emory University campus, overflowing with 300 people, to the sounds of a bluegrass band from the family’s church. Singing and fond remembrances of Marc were followed by a warm reception. Since we couldn’t stop the world from spinning, we held on tightly to each other, and said good-bye to Marc.

Occupational Restoration and Adaptation

My professorial occupations, which seemed virtually meaningless a short time before, slowly awakened. Beginning work on this manuscript initiated the Restoration and Adaptation phase for me. Writing became more than professional work; it served as a primary, occupational tool to rebuild meaning, purpose, and understanding after the saddest days of my life. My cycling gradually regained its importance, as did gardening, walking my dogs, and other familiar activities.

Looking back, I marvel that my family found needed strength and direction. I know that individual and family occupations helped move us through this crisis, taking each small step, absorbing each bit of bad news, and answering each impossible question, one at a time. Occupations, as simple as a family dinner, boating, or watching a baseball game together were much more than simple diversions. Occupations served as powerful statements that life is worth living at a time when that had been called into question.

Through occupation, we found that we could still, incredibly enough, enjoy each other and ourselves, if only for brief periods between our tears. We held tightly to familiar meanings, embedded in occupation, while waging a losing battle to hold onto a precious source of meaning and purpose, our relationship with Marc. We began to understand that, even though our lives could never be the same, it might be possible to learn to live with this most profound loss, just as we were doing in these days before and after his death.
Implications for Research and Practice: What Can an Occupational Therapist Offer a Family in Crisis?

Rando (1986b) wrote, “The constellation of factors inherent in child loss makes the experience totally unlike any other bereavement” (p. 46). Does “high-grief loss” (Despelder & Strickland, 1999) impact occupation differently than an anticipated death of an older adult? Does the course of occupation following loss differ for men and women? Does it differ for children, adolescents, and adults? Further research is needed to address these questions.

Work on this autoethnography has helped me understand my own experience with occupation during and after loss of a family member and now I’m ready to hear others’ stories. I’m conducting a study, based in grounded theory, to explore the impact of loss on others’ occupational lives. Early data suggest that loss of a family member affects work, leisure, and social participation in some predictable ways. I’ve heard participants in this study describe patterns of occupational maintenance, dissolution, ambivalence, and restoration and adaptation.

Perhaps no force can decimate one’s sense of meaning more profoundly than loss of a family member, particularly a child. A “search for meaning” is an essential component of the grief process (Rando, 1984). “Reasons that cannot be understood,” Rando wrote (1984), “have to be assimilated as that—something that cannot be comprehended but must be accepted” in order to “cope with the unfathomable” (p. 130).

As occupational therapists, we hold a powerful compass that can assist family members in a search for meaning after loss. That compass—occupation—points directly to vital pathways to health and reconstruction of meaning and purpose. Occupation, I’ve learned, can be terribly confusing, like so much else, at a time of loss. Our vision, as occupational therapists, enables us to help as no other profession can. By standing beside family members during and after loss, we can help strengthen their hold on life through occupation. This task will test our clinical reasoning, compassion, and wisdom unlike any other. I propose that this is one of our highest callings as occupational therapists.

Epilogue

Five months after Marc’s death, my father died from complications of congestive heart failure, and for a second time, my family came together to witness the last moments of someone we loved. I’d anticipated my father’s death since his first heart attack 20 years earlier, so my reaction was different, in some ways, than the shock of losing Marc, but occupationally, a familiar pattern repeated itself. The ride was smoother this time, perhaps because it was anticipated or perhaps because it was across terrain I recognized:

- Occupational Maintenance. I again held onto my occupations, including teaching classes and riding my bike right up until 2 days before my father died. To some extent, I understood what was happening: to some extent I again avoided it and didn’t want to give up my comfortable occupational life.
- Occupational Dissolution. Two days before my father died, I let go of everyday occupations to move into my parents’ home and became a frontline caregiver, dusting off my geriatric occupational therapy skills of bed positioning, activities of daily living, and functional mobility. While engaged in caregiving for my father, the occupations I relinquished hours before again seemed trivial in comparison.
- Occupational Ambivalence. After the funeral, I needed a few extra days before returning to work and normal occupational life. I knew I wasn’t ready to step back into the spotlight of teaching.
- Occupational Restoration and Adaptation. Eight days after my father died, I found myself in front of an unusually quiet and attentive class. The students gave me sympathy cards they’d signed and I thanked them. After several deep breaths, I told my students how grateful I’d been for my occupational therapy skills that brought comfort to my father’s last days. I said I had an invaluable tool, occupation, which would help me through this difficult time. After a pause to get a tissue from a student to dry my eyes, I heard my shaky voice strengthen as I launched into a favorite lecture and saw students settle into note taking. Occupation was working its extraordinary and common magic again and, I knew, I’d be okay.

Acknowledgment

This paper is dedicated to the memory of Marc McGinnis. We will never forget you.

References


Epilogue

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