Meanings and Purposes of Caring for a Family Member: An Autoethnography

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Engagement in two interlinked areas of occupation, familial social participation and caring for my father at the end of his life, led to a journey of self-discovery. A qualitative research methodology, autoethnography, is used to develop a narrative that examines engagement in these two occupations before, during, and after my father’s illness and death. I discuss meanings and purposes of familial social participation and caregiving, suggesting that transforming fear of death to awareness of death is a central purpose of caregiving. Implications for therapists and caregivers include considerations about the value of occupation, discussion of a continuum of caregiving, examination of boundaries when caring for a parent, thoughts about the roles of altruism, love, anger, and “bad faith” in caregiving, and analysis of sons as caregivers for fathers. Further research on meanings and purposes of caregiving is proposed.


Have patience with everything that remains unsolved in your heart. Try to love the questions themselves, like locked rooms and like books written in a foreign language. Do not now look for the answers. They cannot now be given to you because you could not live them. It is a question of experiencing everything. At present you need to live the question. Perhaps you will gradually, without even noticing it, find yourself experiencing the answer, some distant day.

—Rainer Maria Rilke, Letters to a Young Poet

People say I look just like my father. I search the mirror and photos to find what others see, but I recognize nothing more than a faint resemblance and usually not even that. I think our values, beliefs, and personalities were worlds apart; more objective observers may differ. As a boy, I wanted to be just like the strong, effective man who knew how everything worked and could do anything. As an adolescent and young adult, we disagreed on all that mattered and I wanted to be as unlike my father as possible. Now that he’s gone, I’m sorting through a pile of memories, misperceptions, and conflicted feelings, and buried in the pile are keys to who I am.

Autoethnography as a Research Tool

Autoethnography is “a postmodern form of ethnography” (Neville-Jan, 2003) and “an autobiographical genre of writing and research that displays multiple layers of consciousness, connecting the personal to the cultural” (Ellis & Bochner, 2000, p. 739). The anthropologist David Hayano (1979) first used the term to describe ethnographic research done on one’s “own people” through an insider’s perspective. A second definition of autoethnography has evolved to include “autobiographical writing that has ethnographic interest” (Reed-Danahay, 1997, p. 2). Although methods vary, an autoethnographer generally engages in note taking, identifying...
categories and themes, emotional recall, discussion, and reflection to yield a narrative that affords both the inside view of a research participant and the outside view of a researcher (Ellis, 1998; Ellis & Bochner).

In occupational therapy, Neville-Jan (2003) employed autoethnography to analyze her experience of chronic pain and explore ways therapists can more effectively work with individuals with this problem. Although not called “autoethnography” by Dickie (1997), Thibeault (1997), and Hasselkus (1993), their autobiographical accounts examined the occupations of making crafts, caring for a father with dementia, and caring for a mother at the end of her life, respectively. While still limited in its use in occupational therapy, autoethnography fits well with the profession’s valuing of narrative reasoning (Mattingly, 1994; Schell, 2003).

Many autoethnographies are narratives of loss, told to make sense of existential crises (Ellis, 1998; Hoppes, 2005), and this autoethnography fits that model. Although I took a few notes immediately before and after my father’s death that were later integrated into this manuscript, the primary methods I used, consistent with autoethnographic research, were discussion, emotional recall, and systematic reflection.

I discussed these events with other family members, including my wife, mother, brother, and sisters, and they read drafts of the manuscript and offered feedback. Emotional recall involves remembering conversations, contexts, and emotions of important events in as much detail as possible (Ellis, 1998; Ellis & Bochner, 2000). I wrote initial drafts within the first weeks after my father died in order to capture an “inside” view of the emotional experience. I repeatedly read and revised these drafts in following months with conscious effort to add an emotionally detached, “outside” view of the events to yield a cultural perspective of what it’s like to participate within a family before, during, and after illness and to care for a father at the end of his life.

Systematic reflection was also integral to the research process. When writing about significant events, I paused for lengthy consideration: “What did that event really mean to me?” “How do I feel at the time?” “How do I feel about it now?” “Why did I make the choices I made?” “Why did others make the choices they made?” “What other choices were possible?” “How was that event influenced by my past and how has it shaped who I am today?” The goal of this reflection was honest discovery, regardless of how painful, self-revealing, or humbling that might be.

This autoethnography is not seeking one “correct” interpretation of meanings and purposes of caring for a dying family member. Instead, like other qualitative research, it is based on an assumption that phenomena are highly contextualized (DePoy & Gitlin, 1994; Portney & Watkins, 2000). Mertens (1998) wrote that in qualitative research, “The burden of transferability is on the reader to determine the degree of similarity between the study site and the receiving context. The researcher’s responsibility is to provide sufficient detail to enable the reader to make such a judgment” (p. 183). I’ve sought to describe my cultural, social, personal, spiritual, and temporal contexts (American Occupational Therapy Association [AOTA], 2002) clearly enough so that readers can, in fact, make these judgments.

Social Participation, Providing Care, and Meaning

The Occupational Therapy Practice Framework: Domain and Process (AOTA, 2002) categorizes social participation within the family as an area of occupation, and clearly defines it as, “Activities that result in successful interaction in specific required and/or desired familial roles” (p. 621). Care of others, another area of occupation, is defined simply as “arranging, supervising, or providing the care for others” (p. 620). Anyone who has participated in a family during illness, or provided care for a family member, knows that these areas of occupation are anything but clear and simple. Although these bare-bones descriptions are accurate enough, they don’t even hint at the enormously gratifying, challenging, heartbreaking, puzzling, rewarding, meaningful, and purposeful potentials of these occupations.

When I accepted caregiving responsibilities during my father’s last years, I thought my background as an occupational therapist with experience in geriatrics gave me all that I needed. Instead, I had a great deal to learn. I thought I had a firm grasp on my valued occupations and couldn’t lose them. But I did. I believed that I was acting out of love and altruism and wouldn’t have dreamed that resentment, frustration, and anger would emerge. But they did. And I didn’t anticipate that I wouldn’t be able to see my father and his health issues clearly, that we would clash over boundary issues, or that old ghosts would haunt us as we negotiated a caregiving relationship. But all of that happened. Even so, I imagine that in years to come I’ll look back on caring for my father as one of the most meaningful and rewarding passages of my life.

This autoethnography explores meanings and purposes of socially participating with my family and providing care for my father at the end of his life. “Meaning,” according to David Nelson (1988), “is constituted by the interaction between occupational form and the individual’s developmental history (a looking back).” “Meaning,” he continued, “involves reflection” (p. 636). So, to understand what socially participating with my family and taking care of my...
father meant to me, looking back and reflecting seems like a good place to start.

The Long and Winding Road

I clearly remember the day in 1964, at age 13, when I wandered off the path my father had worked so hard to clear and pave for me. A friend showed me a new album called “Meet the Beatles” and played a few cuts. The record introduced me to a world where it was right to revel in your youth and openly express yourself and I immediately knew I belonged in a way I could not belong in my father’s world. Within weeks, most of my friends wanted to grow their hair longer than their fathers and school principals liked. This tiny rift, over something seemingly as insignificant as hair length and musical preferences, widened into a vast chasm when the Vietnam War exploded into the cultural mix a few years later. My father and I couldn’t bridge it.

Sons ache for the respect of their fathers and despite our constant disagreements and misunderstandings, his respect remained as important to me as it was unattainable. Nothing I did in my personal or professional life ever won his respect, or, if it did, he never let me know. He never hesitated to let me know when I disappointed him with my decisions or didn’t do things the way he would have. He never needed me in any way that I could discern. The idea of helping my father, in any way whatsoever, seemed totally incongruous. He never seemed to need much help from anyone, but if he did, I might be the last person on the face of the earth he would turn to. Little did I know that, in the end, it would fall to me to help my father die.

Leaving Home To Find Home

In 1970, I left my hometown to go to the University of Texas. My father and I weren’t communicating well but we thought this transition might remedy some of our problems. He hoped the university might instill discipline and purpose he believed I lacked. Texas has a great engineering school and perhaps he dreamed I could become an engineer like him. My agenda wasn’t much better defined than moving 500 miles away and being on my own.

From my first hours in Austin, I felt at home in a way I’d never felt anywhere else. The campus and city buzzed with artistic and political energy I’d never witnessed. The previous spring tens of thousands of students and faculty marched on the state capitol to protest the Vietnam War and the killings at Kent State. The student-body president had hair down his back and, at an orientation assembly my second day on campus, he told new students that the university administrators were all liars and, if we wanted an education, these were the men, sitting on the stage behind him, who would stand in our way. I was ineluctably pulled into this bold new place and time and I knew there could be no turning back.

My father sent me to college to learn the equation that had paid off so well for him: Education multiplied by Hard Work plus Belief in the American Way equals Prosperity. Like so many sons of the ’70s, I arrived at a different formula: Education multiplied by equal parts of Work and Play plus Good Friends (multiplied by Beer, Marijuana, and Great Music) divided by a Healthy Disrespect for Authority equals Self-Actualization. What I would do with self-actualization or how I would know if I achieved it, I didn’t know, but I assumed it would work itself out.

My father realized that my enrollment at the University of Texas wasn’t going as he’d planned when I returned as an English major with a beard and ponytail. I thought I looked pretty cool and let’s just say that he didn’t. So we drifted further apart, and I imagined that his influence in my life was becoming negligible. We gave up on each other and I found mentors and friends who could provide the respect and support that my father could not.

Few fathers and sons were exempt from conflict fanned by these cultural crosswinds. Our fathers served in World War II and believed that when the country calls you to service, you go without question. They were justifiably proud of their bravery and sacrifices that changed the world for the better. But my generation couldn’t comprehend why our fathers were so anxious for us to participate in Vietnam. The reasons and costs still don’t add up 35 years later. We believed that we could change the world for the better by loudly telling our fathers that they were wrong and refusing service. Student deferments and a good-enough lottery number kept me out of the military, but there was no easy fix for the deepening estrangement with my father and that war raged on long after the one in Vietnam was over. My father hated my long hair and the logic that led me to question the war and Richard Nixon. We settled into a decade-long standoff and silence was broken only by clashes over hair, religion, and politics. We became experts at baiting each other into arguments and ignoring each other’s feelings.

In the mid-1980s, I finished my doctoral work, got married, and left Austin for a bottom-rung-of-the-ladder college teaching job. Around the same time, my father had a heart attack. The strong, effective man became mortal and vulnerable. Slowly, my father and I realized that we didn’t have forever to reconcile and begrudgingly took baby steps toward understanding each other. Over the next few years, I became more secure in adult roles while he experienced another heart attack, a stroke, and a series of transient ischemic attacks. A quadruple bypass gave him a new lease
on life and his health crises motivated us to quit fighting and start figuring out how to care for each other. We had little idea of how to do this but we were willing to try from time to time.

Family History Lesson

_The past isn't dead. It isn't even past._ —William Faulkner

Around this time, I wondered if researching my family history might hold some keys to finding peace in my troubled relationship with my father. My grandfather died before I was born, so I knew him only through old photographs. When I asked my father about his dad, he said, “We just never got along,” and that was all he would offer. Shortly afterwards, I interviewed my aunt about the family’s history.

My father’s formative years weren’t easy, my aunt told me. Then, fathers believed their children, particularly sons, needed discipline, and sometimes the discipline became pretty physical, abusive by today’s standards. My grandfather was very hard on my dad when he was a boy. During the depression, my grandfather was a banker and his bank failed. He bought a lot of his frustration and unhappiness home and took it out on his children. My father won academic and athletic awards and my aunt thought my grandfather was proud of him but never expressed that. My dad thought his father tried to control his life and as soon as he finished high school, he joined the Navy to see the world and get as far away from his father as possible. At age 17, in 1941, he signed on for a 2-year enlistment against his father’s wishes.

My grandfather died of a heart attack at 59 years of age while my dad was in basic training. He came back for the funeral, but any chance to reconcile with his father was gone. World War II extended his 2-year enlistment and took him into the Battle of Iwo Jima in 1945, where, in 36 days of fighting, over 6,800 American boys died and another 19,000 were wounded. My father made it through the war and came home and proposed to my mother on their first date. My older brother arrived a few years later, I came next, and then three sisters.

Like his own father, my father never enjoyed the emotional work of being a parent. He preferred long hours at his job, including traveling for weeks at a time. But when I can push aside old resentments and anger because he didn’t try very hard to understand me in the way I wanted to be understood, I remember family picnics with roasted hot dogs and marshmallows and Christmas trees surrounded by deep stacks of gifts. I remember that he patiently taught me to catch a fish, ride a bicycle, and hit a baseball. He bought a car I thought I needed as a teenager and covered college expenses for his five children. He made countless sacrifices I seldom acknowledged.

My research and exhumation of old memories helped me realize that he’d done a better job of fathering than my grandfather had done and he deserved a lot of credit for that. Appreciating this, I could at last begin to forgive my father for old injustices, real and imagined, and stop leveraging old resentments to become my own person. Looking at my father in this new light illuminated a paradox: The people I really cared about, and the type of person I wanted to be, believed deeply in themselves in a quiet way while remaining thoroughly down-to-earth and unpretentious. Well, that was my dad, the man I thought I wanted to be so unlike. Perhaps I didn’t have to run from my father to be myself. Our paths would never coincide but perhaps they could run parallel. With this vision, I hoped my father and I could write a happier ending to our story than the sad history composed by my grandfather and father.

Second Chances

After a career change to become an occupational therapist and clinical jobs in Nevada and Georgia, a move back into academia put me 250 miles away from my old hometown and my parents. That seemed about right. But I became embroiled in a losing battle with a dean at the university where I taught. My deep-seated skepticism of authority, fostered during the Vietnam years and battles with my father, coupled with the dean’s narcissism, created a combustible mixture. Predictably enough, I was fired.

Y2K dawned with power grids intact but my professional life had crashed. I needed a new start. I applied for several attractive academic jobs and interviewed at a few campuses. In exploring options, I inquired about a possible opening on a new campus a mile from the house where I grew up and my parents still lived. I interviewed and received a job offer. When I left my hometown 30 years before, I would have bet my life that I’d never return there to live. The city was too conservative and culturally limited for my tastes and I never felt particularly at home there.

My mother increasingly needed support to manage my father’s health problems and she was excited by the prospect of my return. My father, with his usual stoicism, said that if I wanted to return it would be fine with him but if I wanted to take one of the other jobs I was considering, that was fine, too. Another job offer, in many ways, fit better, in a more appealing college town with a big-time sports program I would have enjoyed immensely. I liked the job description and faculty and they seemed anxious for me to join them. But my mother’s happiness meant a lot and
because of that and other reasons I couldn't fully articulate, I returned to the city where I grew up. Although neither my parents nor I said anything about it, we knew I was coming home to help care for my father during the last phase of his life. I hoped I was up to that challenge, whatever shape it might take.

Role Reversal

During the next 3 years, I settled into a job I enjoyed, working with colleagues and students I loved. My father's doctors and pharmacists stayed one step ahead of his congestive heart failure and he seemed to adapt to a quieter, more sedentary lifestyle. My father had always enjoyed working in the yard and going for walks but his waning energy and frequent falls curtailed most physical exertion. Instead, he watched television, followed his stocks, napped, and listened to books on tape.

Taking on a role of providing care and participating in “required and/or desired familial roles” was delicate and I sometimes noticed unspoken, mutual resentments between my father and me. When I offered to drive him to a doctor's appointment, work in his yard, or pick up groceries, he impatiently assured me that he could do these things for himself. Abdicating his independence was one thing, but allowing me to do things that he once easily did for himself was particularly galling, I suspect. I tried to make peace with my old hometown and although I found things I liked, it still didn't feel like home. I dreamed of searching for a place that fit my wife and me better, but obligations to my parents kept me tethered to a place I thought I'd left for good 30 years earlier. I kept my resentment tamped down and my father did, too.

My wife and I took my parents out for lunch every Sunday and as time went on, my father had less and less to say during these outings. We generally steered our Sunday conversations clear of politics, but when the war in Iraq or the president’s handling of the economy came up, I couldn't resist expressing my opinions. My father, never one to back down from a good argument, wasn't up for these fights. As an adolescent and young adult, I longed for the last word in our disputes. Now, when he declined to fight, his silence was sad and puzzling.

We found other battlegrounds. His driving deeply worried me as his physical abilities, vision, and cognition slipped. After riding with him on a short errand, I vowed never to ride with him again because his errors would have caused a couple of collisions if not for other drivers' skills to avoid us. My father seemed oblivious to dangers he created. After he had a minor accident, I urged my mother to take the car keys from him. Instead, he bought a new car. I told both of them to call whenever he needed to go out and I would drop whatever I was doing to take him. But my father wasn't interested in this plan. I called his doctor before his next appointment, told him of my concerns, and asked him to intercede. If he talked to my father, it made no difference. After much agonizing, I decided that I'd done everything I could about his driving and for the sake of our relationship needed to drop the topic. This wasn't a satisfactory resolution for me and I knew I'd feel deeply guilty for not being more forceful if he had an accident.

Later I learned that he'd drive to church or the store, both within 5 minutes of his house, and get lost. He'd call my mother and she'd explain how to return home. This became so frustrating that he voluntarily gave up driving, a huge relief to me.

I imagine 35 years earlier my father was uneasy every time I backed his car out of the same driveway and left his oversight. He knew that my experience and judgment were limited in ways that I didn't understand and that I'd have to learn for myself. I had a few fender benders and survived on the skills of other drivers to avoid my mistakes. Now the roles were reversed. Luck was on our side both during my teenage years and during my father's last years and no one was hurt.

Understanding boundaries of the role of family-care provider is tricky business. Fortunately, my experience as a clinical occupational therapist informed me. Repeatedly, I told clients’ families that I believed it was best if they permitted their loved ones to be as independent as possible. I knew this also served as the best policy for my father. I also knew I had an ethical obligation to voice concerns about safety. As a therapist, after making recommendations I stepped back and let clients and families make their own informed decisions. Walking this tightrope and biting my tongue when I believed poor decisions resulted never came easily as an occupational therapist and proved much tougher as a family-care provider.

Blind Spots

We don't see things as they are, we see things as we are.

—Anais Nin

For 3 years, caring for my father ran smoothly. I checked in a couple of times a week, remained on-call for any required help or support, and my wife and I joined my parents for Sunday lunches. We quietly celebrated birthdays, Father's and Mother's Days, Thanksgivings, and Christmases together.

Familiarity plays tricks with perception and creates problems for family caregivers. It brings some things into
sharper focus—too sharp sometimes—and at other times causes blind spots. I noticed this when I tried to apply my knowledge and experience as an occupational therapist to my father’s “case.” After my father fell a few times, I rerouted electrical cords in his office and recommended use of a cane and bathroom grab bars. My father knew me too well to accept my advice without huge reservations. He had changed my diapers and saw grounders go between my legs in Little League baseball games. He remembered the dents I put in the family car. He was there when I returned home from Austin with my hair in a ponytail and a pierced ear, spouting radical nonsense. Even though my act has toned down a great deal as I’ve settled into middle age, I still didn’t look anything like a professional to him. Grumbling, he eventually accepted modifications I suggested.

Suspecting that I had something of a blind eye to the home where I grew up, I asked an occupational therapy colleague to further assess the house. She recommended installing a half-step between the den and kitchen where he’d fallen, something I’d missed. My colleague looked and sounded like a professional to him. He readily accepted her recommendations and proudly showed visitors the extra step when it was completed.

I’d gone up and down that step for almost 50 years, but didn’t see that it was too high, and a fall hazard, before my colleague pointed it out to me. If I couldn’t see that step clearly, I wondered, how clearly could I see my father after all this time?

If only, somehow, we could wipe our lenses clean so we could see each other without old nicks, blemishes, and clouding. Our pictures of each other were blurred and dated and we didn’t know how to bring them into focus. If we could have seen each other clearly, perhaps we could have loved and respected each other with more overt affection than we could manage in the real world, in real time.

Taking What Comes

Every other week, I drove my father to the hospital for an infusion treatment for his congestive heart failure. During the short drive, I initiated safe, impersonal conversations about the weather, baseball, and how his stock portfolio performed that week. On these trips, I felt like a taxi driver and wanted to connect on deeper levels but I struggled to articulate the right questions. Introspection was never his strong suit and any probing made him uncomfortable. Experience taught us to keep our guards up with each other so mostly we drove in silence. When I dropped him off at the hospital, he sometimes said, “Thanks a lot,” and I replied, “Sure, Dad.” I think we really meant, “I love you,” but we didn’t know how to say that to each other. As I watched him walk into the hospital, leaning on his cane, we both knew the clock was ticking even if we couldn’t find words to talk about it.

When he began infusion therapy, we were told it would work wonders for several years and then lose effectiveness. The prediction was ruthlessly accurate. Early on, the doses of Primacor® noticeably renewed his energy every 14 days, allowing him to work in his yard, shop for groceries, go to church, join us for lunch, and even take short trips. After 3 years, however, the treatments no longer gave him a boost. He slept most of the day, any exertion taxed him greatly, and he lost his appetite. At a Sunday lunch, I noticed his lips were purple and knew why.

Some bad days followed. He felt unusually weak and struggled to breathe because his heart couldn’t clear fluid from his lungs. I kept in closer touch and gave my brother and sisters a heads-up that his health had dropped to a new low. His doctor adjusted his medications giving limited, temporary relief. On one of our last trips to the doctor, I again wanted a view of his emotional landscape as he neared the end of his life, and asked if his health problems scared him. “No,” he answered, “I’m ready to take what comes.” Afforded a rare glimpse of his inner world, I saw a man at peace.

Two weeks later he didn’t feel well enough for our Sunday lunch. After a particularly bad afternoon, he appeared exhausted, agitated, confused, and uncomfortable. My oldest sister was in town to visit and after agonizing with her and my mother over options, we took him to the hospital emergency room. A young doctor diagnosed toxicity of one of his cardiac drugs, digoxin, along with alarmingly low levels of sodium and my father begrudgingly agreed to hospitalization. Two days later, on his 79th birthday, he looked and felt better. He couldn’t tolerate one more day in the hospital, he told us emphatically, and just needed to go home. His doctor said his health depended on several delicate balances. His father needed more water to wash out the digoxin, but his failing heart might be unable to clear the ensuing increase in blood volume from his lungs. He needed more sodium, but subsequent fluid retention would again strain his heart. And the doctor wasn’t sure why his usual dosage of digoxin caused problems. He okayed my father’s discharge, given his unwillingness to stay in the hospital and because treatment options had been exhausted, but let us know that his health could easily be tipped again. The doctor asked if we’d like to consider skilled nursing or hospice care for my father.

Neither of these alternatives seemed viable to me. Over the past year, my mother and I had feared the possibility that my father would require more care than we could provide and that he would need nursing-home care. We knew,
Serving as a care provider for a family member is a high-stakes craps game. Sometimes I made wise bets, sometimes foolish bets, and sometimes, I didn’t even know I had chips riding when the dice were rolling. The dice rolled more quickly as we approached the end of the game.

And in the End...

Back home, my dad’s health plummeted. After 2 days I suggested to my mother that we contact hospice. I called my brother, sisters, and aunt, urging them to come quickly if they wanted to see my father. I talked with colleagues and they assured me they could cover my classes as long as necessary. My brother and youngest sister flew in the next day and hospice staff swung into action to support us. My doctor came over to say a prayer. After the minister left, we told him we loved him and thanked him for everything he’d done for us. I said, “Dad, if you need to leave us, we understand. We’ll take care of everything here. We’ll take good care of Mom, I promise.” I don’t know if he heard me. My sister, mother, and I attended to him through a restless night.

The next morning he sat on the edge of the bed and felt better. I wanted to interpret this as a rally back to health but my gut told me differently. I’m not sure when it began but his departure was well underway. His strength proved insufficient to sit on the edge of the bed for more than a minute; lying down, his lungs filled and he couldn’t breathe. We moved a recliner into his bedroom and helped him transfer to it. Sitting in his favorite chair provided comfort that had been so elusive.

In the early evening my father died peacefully with his family at his side. There were no tears. Sadness would come later. As he wished, my father’s last days and hours glowed with love in his own home.

What Meanings Did I Find in Caring for My Father?

A few months into the grieving process, meanings and purposes of caring for my father and socially participating with my family have begun to crystallize. In sorting through memories and emotions with hopes of understanding more about the “interaction between occupational form” and my “developmental history,” as Nelson (1988) put it, I’ve uncovered these meanings.

To find my own voice and vision, I had to leave my hometown and my father to explore how I’m unlike the man who created me. My father did the same thing 30 years earlier when he joined the Navy. It is just as true that I had to return to understand our similarities. I imagine I’ll work on this puzzle for the rest of my life, but providing care for my father helped fit some of the pieces into place. Caring for my father resulted in self-discovery and clearer meanings of who I’ve been, who I am, and who I will become.

It bears repeating: Sons ache for the respect of their fathers. Aspirations to earn my father’s validation are so thoroughly enmeshed with my personal dreams that I’m not sure how to untangle them. But I know I didn’t try to hit the baseballs he pitched, bring home good grades from school, or achieve professional goals solely for my own purposes. Accepting responsibilities to provide care at the end of my father’s life, I see now, fits my pattern of working to earn his respect.

I wonder if he respected the fact that I stood beside him through his last moments. Would he have appreciated my eulogy at his funeral? Would he be proud of the ways I’ve supported my mother in his absence? I’d like to think that,
overall, he'd approve, but I don't know. Because he was unable to freely give his respect, or because I just couldn't see it, I learned to live without his appreciation. Even though he's gone, I find myself still trying to earn it. Caring for my father and bearing witness to the end of his life demonstrated my respect for him. I hope I won his respect in return.

What Purposes Did I Find in Caring for My Father?

Nothing in life is more important than the fact of death, and nothing more urgent than learning to overcome it—not in an afterlife, but here and now.

—Eknath Easwaran (1996, p. 9)

David Nelson (1988) wrote, “Purpose is constituted by the interaction between the individual's developmental structure and his or her future occupational performance (a ‘looking forward’). Meaning involves reflection; purpose involves prediction” (p. 636). It’s time to look ahead.

When I decided to care for my father at the end of his life, it didn’t occur to me that it would have a “purpose” or would affect future occupational performance. It was just something I had to do for reasons I didn’t fully understand.

The psychiatrist Irvin Yalom wrote (1980), “The fear of death plays a major role in our internal experience; it haunts as does nothing else; it rumbles continuously under the surface; it is a dark, unsettling presence at the rim of consciousness” (p. 27). Yalom noted that humans seek “symbolic immortality” through children, religious belief, and creative work. Embracing a fiction of immortality may be part of human nature but carries a cost. “A denial of death at any level,” Yalom wrote, “is a denial of one’s basic nature and begets an increasingly pervasive restriction of awareness and experience” (p. 32). But transforming fear of death to awareness of death “shifts one away from trivial preoccupations and provides life with depth and poignancy and an entirely different perspective” (p. 160).

After playing an intimate role in my father’s last days, denial of death will be more difficult than it once was. Deepened awareness that death is an integral part of life will help me live more fully and, when my time comes, perhaps, die more peacefully. Betty Hasselkus (1993) arrived at the same conclusion in a beautiful account of caring for her mother. “Caring for a dying person,” she wrote, “can serve primarily as a means to enter, understand, and share the dying experience. The fulfillment found in the caregiving–care receiving relationship itself can become the ultimate good in the experience, for both the dying person and for the person giving care” (p. 720).

In the past, I often rejected my father’s guidance to find my own, divergent way. But his example of fearlessly “taking what comes,” including death, will serve as a powerful model throughout the rest of my life. Learning this, I believe, constituted the purpose of providing care for my father. Walking side-by-side with my father as he took the last steps of his journey put me within arm’s reach of the awesome mysteries of living and dying. As I continue along that path, walking hand-in-hand with other loved ones, I know that we can complete our passages from this life on our own terms. I know because I helped my father do it.

Implications for Therapists, Family-Care Providers, and Fathers and Sons

Remembering the Value of Occupation

In providing care for my father at the end of his life, I traveled over unexplored and emotionally land-mined terrain. A grief counselor helped me understand emotional dynamics and, most importantly, what I needed. I’d been so absorbed by my parents’ needs before and after my father’s passing, I’d forgotten. Eventually, I remembered that I needed to take time to engage in cherished occupations. I was surprised and amused that, as an occupational therapist, I needed a gentle reminder of the therapeutic value of occupation.

Occupational therapists have unique vision and skills to assess, discuss, and prescribe occupation for those in need. I now deeply appreciate that caregivers, in addition to clients, need our occupational perspectives and guidance. And, although it is most difficult to become one’s own therapist, we can help ourselves by applying our own skills to our own cases when we are in caregiving roles.

Embedded in caring for a family member, given this occupation’s fundamental nexus with one’s developmental history, is potential for profound meaning. As occupational therapists, our ability to apply narrative reasoning to understand caregivers’ meanings and to support the creation of new life stories can make us invaluable in a family’s care (Mattingly, 1994; Schell, 2003).

A Continuum of Caregiving

Caregiving, I came to understand, moves along a continuum from low to high intensity. At the outset, I moved to the same city as my parents and placed myself on-call for infrequent support. I helped with errands, transportation, and routine oversight of my parents’ well-being. During these early phases of caregiving, my father seldom conceded that he needed assistance and only accepted it as a last resort. My
work, leisure, and social participation were not greatly affected. As his health declined, he tentatively allowed me to help more but still preferred to do things for himself, whenever possible. During the last few days, I moved into my parents' home to help with self-care, mobility, and positioning needs. Now, my work, leisure, and social participation were put on hold so I could attend to my father's needs. My ability to provide the intimate, high-intensity caregiving he needed took precedence over his pride and independence. At last, we began working together more smoothly without debate and resistance.

Occupational therapists need to be sensitive to the fact that caregiving is not a uniform experience but instead exists on a continuum. The nature of caregiving changes as it moves along this continuum, often in unexpected ways.

Drawing Boundaries When Caring for a Parent

I suppose many occupational therapists gravitate toward caring for parents. Given our propensity toward caring and advocating for others, our acquired therapeutic skills, our knowledge of medical systems, and our relative comfort with life-threatening illness, this difficult role may be a better fit for us than for others. Hard-won professional skill and insight allow us to help parents in meaningful ways, but parents will likely see us as sons or daughters, not as occupational therapists, and may discount advice and resist care, as my father did.

Psychological literature (Brody, 1964; Peters & Grunebaum, 1977; Yalom, 1995) addresses a “treatment-rejecting patient” who resents dependency on others for care and does everything possible to negate it. “Treatment rejection,” I’d guess, is prevalent when offspring attempt to apply professional skills in the care of parents. Since adolescence, I hadn't accepted dependence on my father grudgingly; it was no surprise that my father found dependence on me to be unnatural and untenable.

For a son or daughter who is a therapist, assuming that role with a parent is tempting because it affords professional detachment from the heartbreaking experience of witnessing a parent die. In her beautiful narrative about caring for her father as he battled dementia and Parkinson's disease, Thibeault (1997) assumed she would be well-prepared, given her professional experience as an occupational therapist. Instead, she found, “my training was never meant to protect me form the pangs of mourning” (p. 108). Her experience as an occupational therapist helped with technical demands of caregiving and she knew where to look for help and how to adapt the environment. But eventually, she decided not to be her father’s therapist. “I lack the necessary objectivity,” she wrote, “and I feel I can assume only one role at a time. So I choose to be his daughter, as always” (p. 111).

Ultimately, I also decided that I had something more valuable to offer my father than professional credentials, expert opinions, and detachment, something only I could provide: a son’s love and unconditional support.

Altruism and Love Mixed With Anger and Bad Faith

Every caregiver has unique reasons for seeking and accepting responsibilities to care for a family member. All, I suspect, are compelled to make essential sacrifices by love and altruism. I think my unalloyed love of my mother and more complicated love of my father were the foremost reasons I chose this role.

I now understand that I also had an agenda to improve my familial social participation; I hoped that caregiving might have the power to bring peace to a long-troubled relationship. Instead, old dynamics and issues were resurrected and left largely unresolved once again. I was dismayed when caring for my father generated resentments, frustrations, and anger. At the time, I thought it best to keep these feelings underground and only now have begun to sort through them.

Therese Rando, a clinical psychologist, has written brilliantly about loss and grief with important implications for caregivers (Rando, 1984, 1993, 2000). Anger, she wrote, is a normal reaction when a family member is dying, “derived not only from the potential death, over which no one has control, but also from the feelings of impotence, frustration, and helplessness generated by the continuing process of loss” (1984, p. 344). “Concern for the patient may cause family members to overextend themselves in numerous ways. This can lead to resentment of the dying person and then to guilt for feeling this way” (1984, pp. 345–346). “Hostile wishes towards sick individuals are human,” Rando wrote, and therapists should assure caregivers that such feelings are “acceptable providing they do not prompt hostile actions” (1984, p. 346). Rando believed that therapists can help family members by identifying and labeling these reactions, giving permission to appropriately express such feelings, and encouraging physical activities to release emotions. When a family member is dying, “A little education about the normality of ambivalence, especially in this situation, can be very therapeutic” (1984, p. 346).

Hard-won independence from my father clashed with a commitment to provide care for him, spinning off anger and
resentment. Caregiving anchored me to a place that didn’t feel like home and to a situation with only one possible, sad conclusion: The death of my father. During his last years, I imagined that the silver lining to losing my father would be the gift of freedom to resume my independent life. But I had made a promise to my father, to my mother, and to myself, and I knew that my caregiving role hadn’t come to an end; it had been transformed into caring for my mother who was now alone for the first time in 56 years. I felt trapped. I complained bitterly about this fate to my grief counselor.

During one of my laments, she used considerable skill to help spring the trap I’d built for myself. We’d often discussed my existential views of meaning, life, and death. Now she gently guided me through an examination of other existential tenets that I claimed to hold. For existentialists, a profound truth is that humans have absolute freedom. We are “doomed to be free,” they say. At times, we’d like someone or something to save us from our world of choices when we’re uncertain about what to do next. It is human nature, existentialists believe, to run from freedom at times because this is easier, less anxiety provoking, than facing unending, complex choices. Pretending not to be free is called bad faith (Baggini & Fosl, 2003; Sartre, 1964).

I had, in fact, been free to make the choice to care or not care for my father and I was now free to make the same choice with my mother. I knew that as painful as it had been, caring for my father put me on a path I needed to be on. Caring for my mother is also something I need and want to care for my father and I was now free to make the same choice with my mother. I knew that as painful as it had been, caring for my father put me on a path I needed to be on. Caring for my mother is also something I need and want to do as long as it is right for her, my wife, and me. Bad faith is the only thing that can turn caregiving into a trap.

My father has shown me how to die. My mother is teaching me how to live with loss. I’m busy taking notes. “Repeatedly,” Rando wrote, “human beings are mourners in life” (1993, p. 26). The lessons I could only learn through caregiving will, I believe, repeatedly prove to be precious.

Fathers, Sons, and Ghosts
For thousands of years, father and son have stretched wistful hands across the canyon of time, each eager to help the other to his side but neither quite able to desert the loyalties of his contemporaries. The relationship is always changing and hence always fragile; nothing endures except the sense of difference.

—Alan Valentine, From Fathers to Sons: Advice Without Consent

The deck is stacked against fathers and sons who enter into caregiving relationships. My father and I had no blueprint or role models. Cultural norms worked against us: Women are supposed to nurture, not men; a father takes care of a son, not vice versa; and dependence has no place in a father–son relationship after the son becomes an adult. My father and I were haunted by old ghosts, too numerous to count, but included his father who died too soon while they were at odds, boys his age who died in Iwo Jima, and boys my age who died in Vietnam. It seems unfair that they should interfere in caregiving, but since they had become part of us, surely they did. Independence and difference were volatile, cherished principles in my relationship with my father, inevitably undermining caregiving. Now that he’s gone, these principles that shaped my life appear heartless and hollow.

In spite of these barriers and values that often worked against my father and me, I learned that the occupation of caregiving carries extraordinary therapeutic power. Because I cared for my father at the end of his life, imperfectly but as well as I knew how, I am at peace.

Further Research
Work on this autoethnography has helped me understand my experience and now I’m ready to hear others’ stories of caregiving. I’m planning a study, using grounded theory methods, to interview family caregivers. I want to know more about why they’ve chosen to care for a family member, what they’ve learned in the process, how caregiving has impacted their occupational lives, how they’ve dealt with anger and “bad faith,” and what they perceive as costs, benefits, meanings, and purposes of this occupational activity. I’d like to better understand the connection between two related areas of occupation, caregiving and familial social participation. The Occupational Therapy Practice Framework (AOTA, 2002) doesn’t distinguish between low-intensity and high-intensity caregiving. Further research is needed to appreciate similarities and differences in meaning and purpose along this continuum of caregiving. I would also like to compare father–son caregiving with father–daughter, mother–son, and mother–daughter caregiving. This information has potential to inform occupational therapists’ work with families as well as help therapists who, like me, decide to offer their insight, experience, and caring to their own family members.▲

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References


