Occupation Embedded in a Real Life: Interweaving Occupational Science and Occupational Therapy

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This lecture presents an example of research in the genre of interpretive occupational science and demonstrates how occupational science can inform clinical practice. The innovative qualitative methodology used blended elements of the anthropological tradition of life history ethnography, ethnomethodology, the naturalistic methods used by Mattingly and Schön to study practice, and especially narrative analysis as described by Polkinghorne. The bulk of the paper is presented in the form of a narrative analysis that provides an account of a stroke survivor’s personal struggle for recovery, a story that emerged from transcription, coding, and analysis of transcripts from approximately 20 hours of interview time. First, this narrative analysis provides an example of how the occupational science framework can evoke a particular kind of storytelling in which childhood occupation can be related to adult character. Storytelling of this kind is later shown to be therapeutic for the stroke survivor. Next, the narrative illustrates how rehabilitation can be experienced by the survivor as a rite of passage in which a person is moved to disability status and then abandoned. Finally, a picture is given of how occupational story making and occupational storytelling embedded in real life can nurture the human spirit to act and can become the core of clinical practice.

Introduction

I address you with a sense of gratitude to my friends and colleagues in the profession for giving me the honor of joining the ranks of the Eleanor Clarke Slagle lecturers and to my profession for its ethical roots and its recognition of the centrality of occupation in the lives of people, a concept that inspires this lecture. Before I begin, I also wish to express my deep appreciation to Elinor Richardson and Penny Richardson. They were willing to tell their story “so that,” as Penny put it, “something good could come out of all this.” I will now begin with a brief story entitled “The Big A.”

In July 1989, compact, trim, attractive, physically fit Professor Penny Richardson, Chair of the Higher Education Department in the University of Southern California School of Education, having taken a break from the teaching she had been doing in Hawaii, cooked a gourmet evening meal for her new friend Bill. She had just returned from a week-long kayak trip, a great adventure, and was enjoying regaling Bill with tales of mountainous swells and hair-raising experiences on the high seas. She had been with a wonderful group of people; they had been enjoying the stunning Hawaiian waterfalls, sleeping on the sand, having gourmet cookouts, “all that good outdoors Sierra Club stuff.” Penny and Bill enjoyed their lavish meal, but in a sudden twist of events that night, Penny fainted and could not be revived. She was rushed to the hospital. Her head was shaved, holes were drilled...
in her skull, and subsequently she underwent several operations to alleviate the pressure caused by the bursting aneurysm, which she would later call the “Big A.” She was 47 years old at the time, an independent, successful, academic woman, who had many friends and a rich professional life, who traveled widely, who had been a hiker, a skier, and a mountain climber. Nature encompasses not only the natural; in a moment it can disrupt our lives profoundly. Ironically, nature itself can bring about the unnatural.

Penny had been an acquaintance of mine before her trip to Hawaii. When she returned to the states, I decided to pursue a more intense friendship because, as an occupational therapist, I believed I might be able to help, and I was searching for an altruistic project that might distract me from the turmoil of my own life at the time. A second motive was that we were launching the occupational science project at the University of Southern California (USC) and I thought it would be helpful for me to be close to the recovery process of a woman who was dealing with the aftermath of a stroke as I took my place in the development of the new science. That Christmas, I received a Christmas letter from Penny which concluded with the following poem:

1 talk with a rasp
1 walk with a tilt
I’m fed through a tube
I eat applesauce by very small spoonfuls
1 laugh with the best of them
... I love you all, Penny

She was in a skilled nursing facility at the time; it was 6 months after the aneurysm and she embraced a comic vision of her disability. At that time, she had no sense of what was to come when she would reenter the real world of human activity.

I am going to allow you to be privy to a dialogue of experience between Penny and me. The discourse, however, is not simply a conversation between friends, although certainly it was in part that. It emerged through our collaboration as life history ethnographers (Frank, 1979, 1984, 1986), interpreting her experience of disability over time from an occupational science standpoint, and as ethnomethodologists (Garfinkel, 1967) identifying the therapeutic process that emerged as I unexpectedly functioned as her occupational therapist, while engaged in the research process. Research and therapy became intertwined. Was the study an applied scientific inquiry, the purpose of which was to apply the occupational science knowledge base to occupational therapy, or was it basic inquiry describing the relationship of childhood occupation to adult character and eventual recovery from stroke? I think you will agree, after hearing the story, that it was both.

I shall present the findings in the form of a narrative the complex set of events in the story will not be presented as unrelated episodes, but rather as linked by meaning, as a coherent story given plot by human feelings and intentions (Polkinghorne, 1988; Rosaldo, 1989; Sarbin, 1989). The creation of this story involved systematic procedures, the coding and analyzing of over 200 pages of transcriptions, representing approximately 20 hours of interview time. Penny brought to the project her experience of disability, her imagination, her gift with words, her humor, and her energy. I brought the occupational science standpoint and my experience as an occupational therapist. I present the story in what Bruner (1990b) would call broad but carefully selected strokes, without the kind of detail that could appear in a subsequent book. The Czechoslovakian author Milan Kundera (1991), in his book Immortality, stated that “Music taught the European not only a richness of feeling, but also the worship of his feelings and his feeling self.” He then described “the violinist standing on the platform” who closes his eyes and plays the first two long notes. At that moment, Kundera wrote, “the listener also closes his eyes, feels his own instinct, and says to himself, ‘How beautiful!’” (p. 204).

I think of the following story as a kind of musical composition, a symphony with three movements. You have just heard the prelude. The first movement is the Allegro Spirituoso, entitled “Childhood Occupation and the Building of Adult Character.” It demonstrates how the occupational science framework evokes a particular kind of storytelling. Childhood occupation is related to adult character. Later, in the third movement, we find that telling the story this way contributed to Penny’s recovery. The second movement, the Grave, entitled “The Big A—From This to That,” shows that rehabilitation can be experienced by the survivor as a rite of passage in which a person is moved to disability status by experts and therapists and then abandoned. Finally, the last movement, the Grande, called “Nurturing the Human Spirit to Act,” illustrates that storytelling and story making with survivors centered on the theme of occupation embedded in real life can be enormously therapeutic. It may constitute a powerful application of occupational science to occupational therapy. This complex and textured weave may be able to do what former Slagle lecturer Reilly (1962) called nurturing the human spirit to act. So prepare yourself; close your eyes, please; we are about to play the first note.

Allegro Spirituoso: Child Occupation and the Building of Adult Character

In occupational science we are interested in how people become independent, adapt to environmental demands, and achieve competency (Yerxa et al., 1989). I entered this project believing that childhood occupations sow the seeds of adult character. Ruddick and others (Ruddick, 1982) have argued that particular kinds of mindsets are...
shaped through everyday activity. I therefore suggested early in our ethnography that Penny tell me stories of her childhood occupations. What follows is a detailed description of her childhood, the importance of which will be evident in the story of her recovery.

Penny Richardson was born in Los Angeles on December 14, 1941, to Lloyd Richardson (affectionately called Bud) and Elinor Richardson. Later, the Richardsons had another child, her younger brother Steve. In Penny’s view, her parents were very different kinds of people. Her dad “was kind of country style; he liked blue jeans; he was very down-home,” a quiet man. Ultimately his career was in real estate, but Penny did not view him as particularly career-oriented. He cherished being on a farm, close to animals and to the rhythms of nature. Penny described her dad as having been “very low key, a Boy Scout leader,” and “a gentle man.” He had “a profound appreciation of people, whatever their walk of life,” and he valued “keeping your word about things, steadiness, telling the truth, and following through on commitments.” She admired him for having had the strength to do things that men at the time did not do, like cooking.

He used to drive me to school every morning. He used to pick up both me and my girlfriends... And when we were going to Easter Week in Balboa Island, he would always prepare stew for us one night. ... Mr. Richardson’s stew, that was a very favorite night of everybody. Oh great! Time for Mr. Richardson’s stew.

Her mother Elinor continued with her career when her children were young in the 1940s and 1950s, a time when being a working mother was more unusual than it is now. Entering her profession as a teacher, Elinor soon became a school principal and went on to earn her doctorate in education. She was one of a group of educators who first brought educational television to the schools of Southern California. As in the case of her dad, Penny had a strong sense of what her mother valued: “being highly professional but also listening, being sensitive to others, caring, being a good leader.”

At a very young age Penny began to write poems as a way of making sense of her world. For example, in third grade, she wrote the poem “Old Black Bull” which tells the story of a curly-haired city slicker who

... on a farm had her first and worst alarm
She went outside this very day,
When the old black bull came out to play
That city slicker began to scream and cry: If nobody saves me I will die ...

Eventually, the city slicker is rescued by a straight-haired country hick. This poem can be seen as reflecting a child’s effort to deal with two worlds: the rural, down-home world of her father and the urban, professional world of her mother.

In 1949, just 3 years after the house at Chancellor Farm were moved to Chancellor Farm in Whittier, California. Memories of Chancellor Farm are still particularly precious. These are preserved in a book of memorabilia with a bucking horse on the wooden cover that was carved by her grandfather. Penny edited this book as a child, complete with narratives and annotations so detailed they reveal how much the farm meant to her. In a map she made, she included the house, shed, orchard, the big pasture, and the little pasture as well as Sugar the horse, Cuddles the cat, Buck the horse, Valentine the cow, and so on. Her attention to detail was captured in the annotations of the pictures: “The trailer where we lived while the house was being built. Later, the clothesline was there, and west of the tree was pop’s junk pile” (September 1946). Life on Chancellor Farm seemed to be filled with pastoral bliss; Penny celebrated it by writing songs and poems. At the age of 6, she was given her horse, Sugar. Another little girl, Judy Christmas, brought her horse Buck to board at the farm. Judy and Penny developed a deep friendship based on an imaginary world they created as a context for their adventures on their horses. They lived in imagined stories about hideouts and would play out their fantasies on horseback, romping in the meadows, negotiating the rocks in streams, setting out on co-conceived adventures. When I asked Penny what it was about horseback riding that she found so rewarding, she said:

You have a certain independence. You can go places other people can’t go. And it appeared courageous. I really enjoyed that time of my life with Judy creating stories which we read to each other on the phone.

By the time she was 8 years old, Penny had written six tablets full of stories about the “Big Bend Buckaroos,” (BBBs for short), loosely based on a favorite radio show. Each story would have as its protagonist one of the eight Big Bend Buckaroo gang members, each of whom Penny meticulously classified according to his or her nickname, surname, name of horse, breed of horse, color of horse, name of dog, breed of dog, color of dog, and so on, in a 9-in. × 16-in. matrix. The stories reflected Penny’s preoccupation with confrontations between straight-haired country hicks and curly-haired city slickers; the heroic acts of animals who alternately save humans and die in the process; competition in horse shows, in which success must be handled graciously; and natural disasters that threaten the lives of the BBB gang members, who ultimately are survivors. Each book, interestingly, had the same form, 10 or 11 chapters of interlinked stories featuring different BBB members, followed by a neatly drawn and well-organized table of contents, and, at the end, annotated illustrations of story highlights.

Penny gave center stage to others with egalitarian fervor. Her stories celebrated plain people. Animals were major players in Penny’s stories. It occurred to me that this childhood occupation of story making seems to reflect an emerging moral identity: beliefs about such polarities as justice and injustice, wisdom and folly, and honor and dishonor (see Sarbin, 1989).

In 1949, just 3 years after the house at Chancellor
Farm had been completed, the family was forced to move because of an eminent domain seizure so that the Whittier Narrows Dam could be built. Just as Penny had dealt earlier in her childhood with the loss of her dog by writing a poem honoring Sparky, she again resorted to the childhood occupation of writing to cope with her experience of a new loss. One song ended with this chorus, which is sung to the melody of "Home on the Range."

Now Chancellor's no more, no more playing guitar
Never more by the stream shall we roam
It's a memory now and a good one and how
For we still love our Chancellor home.

Memory in this song becomes a way of retrieving loss, but its existence is not quite enough to assuage Penny's pain and anger. The childhood occupation of writing became a way of venting anger when Penny, a desperate 8-year-old, wrote at the end of one of her stories: "P.S. I'll always hate the dam no matter if it saves thousands of lives. I hope it rots on top of the men who built it."

The family moved to East Whittier in 1949, where Penny felt like an outcast in third grade, then back to the country. But the Mill Street Bridge was washed away, and once again the family moved into downtown Whittier. Here, Penny began to rebuild her life, opening herself up to what city life would offer. She joined a Girl Scout troop and made friends, but stayed connected with the country life she still adored by riding her horse in local gym-khanas, where she won several prizes, and by going on camping trips with her family. At 14, upon graduation from Walter F. Dexter Junior High, she gave the graduation speech, entitled "If you make them, your dreams can come true."

From 1955 to 1959, Penny attended Whittier High School, where again occupation marked the memorable events. She did not make the drill team, she was elected to the Girls League Board, and she became editor of her high school newspaper, obviously a natural development of the literary thread in her life. She also joined the CAMYS, a girls' club, some of the members of which became lifelong friends.

She moved on from high school to Pomona College where she finally felt it "was OK to be me, to have a vocabulary of more than two-syllable words, to be literary and excited by ideas." This was also the setting in which she claimed she discovered boys, and they discovered her. Recycling her habit of organization, she kept a calendar of not only the number of dates she had, but also of how many times she had been kissed. She won the freshman creative writing prize at Pomona, earned her bachelor's degree in English Literature, and then went on to Harvard where she earned her master's degree. She taught public school for 5 years, returned to graduate school for a second master's degree in Television and Radio at Syracuse University, and ultimately, at the age of 35, earned her doctoral degree from Syracuse University in Instructional Technology, Educational Policy, and Curriculum. These years of graduate school were also punctuated by a 2-year stint in Lincoln, Nebraska, designing adult telecourses and finding out what the heartland was really about. Next, she took a position as Coordinator of Health, Education, and Welfare's (HEW) Lifelong Learning Project in the Carter Administration. In 1978, she joined the USC faculty of the School of Education; she received tenure in 1985 and became department chair in 1987. As chair she was invested in creating a sense of community, while doing a great deal of campus teaching. Embracing the philosophical stance of adult education, she believed that one should treat students with respect and create a kind of collaborative atmosphere for learning. . . . give them a chance to share experiences, because all adults have experiences. Heaven knows . . . not just the teacher telling, but the learners being equal participants.

She was appointed a residential faculty member in a Dean's Hall at USC and was known for throwing cookie parties. She also did consulting for companies such as Atlantic Richfield Company (ARCO), IBM, Encyclopaedia Britannica, and Polaroid Corporation that involved international travel and adventure. In midlife, Penny rediscovered the out-of-doors and went from being a typical woman "who didn't feel [she] should ever have to lift a hand or break a sweat" to getting "into the exciting new world of fitness" and recapturing the connection to nature that she had enjoyed in childhood occupations. She joined the Sierra Club and became absorbed in sports like skiing, mountain hiking, swimming, and, eventually, kayaking.

Grave: The Big A – From This to That

One evening, a middle-aged woman was admitted to the emergency room of a hospital in Hawaii after fainting. The man who brought her in had tried to revive her, to no avail. Shortly thereafter, she was diagnosed as having suffered a subarachnoid hemorrhage due to an aneurysm from the posterior inferior cerebellar artery. Apparently, prior to the infarct, she had had a fabulous week kayaking on the Na Pali coast of Kauai and had returned to Oahu in time for a gourmet meal with the man who admitted her to the hospital, apparently a friend. Her head was shaved, holes were drilled in her skull, and she later underwent several sessions of brain surgery.

Patients seem to materialize in emergency rooms as if they had no history. In the typical medical model, the work of health care practitioners is to fix patients physically, as a mechanic would a car, so that they can get back to functioning. First, the physicians do their part through surgery, medication, and other protocols. Then the nurses monitor progress, manage unexpected changes in the clinical picture, and generally create a climate of caring (Benner, 1984). At a certain point, the patient is moved on to rehabilitation. According to Kaufman
(1988), the primary goal of all rehabilitation therapists working with stroke patients is “functional independence”—the ability of the patient to care for him or herself as fully as possible with or without assistive devices” (1988, p. 85). Kaufman stated that

to be sure, physicians’ and therapists’ goals are usually relevant and important to the patient, especially in the first few months following a stroke. However, as time passes, patients are ultimately engaged in a personal struggle for recovery. This goal is subjectively perceived and is not within the scope of physicians’ or other providers’ interventions. (p. 85)

Were Yerxa and her colleagues at USC (1989) worried that occupational therapy was heading in this direction when they warned that “acute care” was consuming “more and more resources, leaving less available for” occupational therapists to improve “the life opportunities of people with chronic disease and disability” (p. 2)? They described a health care system that “seems to have adopted an assembly line mentality,” in which “occupational therapists are viewed as treatment machines and patients as products which can be displayed on a balance sheet” (p. 2). Penny remembered being wheeled down long corridors to rehabilitation where she would take her place in line with other victims, aimlessly sitting, until her turn came to be wheeled into the therapy room. She dutifully performed the routines they showed her, the therapy session ended, and she remembered once again being inserted into a line of wheelchairs to reexperience waiting her turn to be wheeled back to her room. She felt passive, disempowered, and not quite human, as therapists rushed around, caught up in their routine with no time to connect with the survivor as a person. She knew they were doing their best, but she felt resentful and angry. She was beginning to recognize that nature, fate, and social structures had intersected in such a way that she was now in a new slot, for, to some extent, identity is contingent on circumstance. Her hospital room walls were covered with cards she had received from friends, family, and loved ones, for which she was extremely grateful.

On the wall also was a schedule of USC Trojan football games, a symbol of her former life situation and a catalyst for connecting her physician to her personhood, as he was an avid Michigan State fan and she was a Trojan fan. Also, the physician and her mother discovered their mutual love of golf, the outcome of which was greater rapport, a line of connectiveness scaffolded by common occupational interests. Yerxa et al. (1989) stated that people are “most true to their humanity when engaged in occupation” (p. 7).

Penny remembered the occupational and physical therapists as very helpful and caring people, although she had difficulty sorting out who was what. She thought everybody saw her as a miracle patient because she should have died, but did not. Overall, she remembered her hospital stay as a happy time, because the staff members were responsive, pleased with her progress, and encouraging. In fact, she truly remembered being the center of attention. At one point, she had a tube inserted through her mouth to her stomach; to communicate she had to write little notes.

Penny could hardly remember what she had done in the early phases of rehabilitation, as if they had been experienced as insignificant episodes, because they seemed to have no purpose. While she was in the hospital, she believed that one day she would be normal again, but she questioned the soundness of the therapeutic procedures. “It was just little stuff. It didn’t make one feel tired, and it wasn’t demanding.”

She recounted an episode toward the end of her rehabilitation in the hospital when she vocally questioned whether she was making sufficient progress and got upset about it. “The therapists really knocked themselves out at that point. They got very positive, and started pushing me to walk on the parallel bars.” Even then, however, she did not experience therapy as sufficiently demanding. What she had hoped for was that she would be able to set goals for herself so that she could have a sense of progress toward something and that the therapists, like personal coaches, would work with her to achieve them. Their obvious kindness, while very much appreciated, was not sufficient for one bent on complete recovery.

As time unfolded, Penny was discharged from inpatient rehabilitation and became an outpatient. Now she and her mother traveled several times a week in Los Angeles traffic so that she could participate in outpatient occupational and physical therapy. To stay committed, according to Martingly (1991), Penny would have had to see how the treatment would move her into a future that she cared to gain. Penny viewed the sessions as disconnected from her project of recovery. If occupational therapy and physical therapy goals had been set by the therapists, she had not been cognizant of them. They would do things in therapy to her, but she was unable to reproduce those things on her own at home. She was unable to practice, to use her own initiative, to get well on her own time. Ultimately, she felt the therapists did not take responsibility for enabling her to do things on her own. They seemed quite happy just to send her off, and have her come back, in a seemingly neverending cycle without a forward-moving plot. At some point she was discharged, which gave her the sense that she had hit a plateau:

I feel they abandoned me, and I feel that they didn’t do their thing . . . but their thing was to do their things, not to help me do the things for myself. And so, in a sense, they kept control of the situation. I was not empowered to do it on my own. They did it with me and in a sense flunked me.

This part of Penny’s story raises the question of the purpose of the concept of the plateau. What really is behind the statement that the survivor no longer can benefit from therapy? Is it a literal statement, or are the words used to
conceal the reality that the patient has psychologically outgrown the rehabilitation context, no longer tolerate it, and feels the urge to move on? Rather than relinquish control, the rehabilitation medical team makes the discharge decision, and the patient is now on her own, and must, at this arbitrary point, fend for herself. Or could the statement be a kind of code that actually serves third-party providers more than survivors?

Taylor (1970) and Crepeau (1993) likened certain hospital practices to ritual. After hearing a talk given by the anthropologist Alexander Moore, I realized that Penny's rehabilitation experience contained elements of a rite of passage as it is classically described in the anthropological literature (A. Moore, 1992). Rites of passage carry persons from one stage of life to the next and are thought of as having three phases: separation, transition, and reincorporation (A. Moore, 1992; van Gennep, 1960). In the separation phase, the participant is separated from her old state. The transition phase is marked by the quality that Turner called "liminality" (1964, 1969). Moore described it as a state in which the participant is reduced to "his lowest common denominator" and most give up all the trappings of their former selves; "one is betwixt and between, neither what one was nor what one shall become" (A. Moore, 1992, p. 133). When this phase is completed, the participant begins the task of reentering the world from which she had been separated. Later, I discovered that Murphy and his colleagues had actually published papers that described not only the rehabilitation process, but the entire experience of disability as a kind of liminal state (Murphy, 1987; Murphy, Scheer, Murphy, & Mack, 1988).

Penny's description of her rehabilitation experience suggested it had had a liminal quality. Her previous identity was not taken into account, except very superficially; she was stripped of her history; and she remained suspended in limbo until she was discharged and on her own. Then she had to focus on trying to reincorporate herself into the world from which she had been separated. The rehabilitation rite of passage seemed to have moved her along into the stage of her life in which she would live as a person with disability. Soon she realized that her disability was a barrier for others. Reincorporation meant going back to work at the university, but no longer being selected for off-campus courses; no longer participating in decision making because her department had been dissolved in her absence; and stoically observing some of her colleagues and friends gradually "wiggle" away.

In this new stage of her life, she felt she was being subjected to a lot of unintentional abuse. People ignored or made an outcast of her. She would sit in her office and nobody would come in, unlike before. People seemed embarrassed to interact with her and were without an etiquette for dealing with a person who had outgrown this kind of transformation. Hardly anyone asked how she was, and if someone did, the answer was supposed to be "just fine." She stated: "Nobody really wanted to know. So the thing about 'laugh and world laughs with you, cry and you cry alone,' I really know what that means."

One day she went to shop for a bathing suit at an outdoor equipment store she used to frequent and she had an important insight, "that occupations were important because they marked the new you versus the old you." There she was, poking through the racks of swimsuits, surrounded by ski and hiking equipment. Three years had transpired since the Big A. For a moment she flashed back to an earlier time when she had rented her skis for a ski weekend and backpacks for a mountain hike from this store. She thought, "Gosh, that used to be me. . . Now my outdoor experience is lacking to take the trash out. I enjoy it, but it's all that I do." It was an emotion-ridden moment, and she began to cry wildly. The reaction presented itself suddenly: "There I was, sobbing my little heart out because I was in [the store] and I couldn't ski anymore." She had liked her old self just fine; but now she was struggling with "trying to be whatever I could of the old me, but becoming this new me if I had to."

Grande: Nurturing the Human Spirit to Act

At the time of the Big A, Elinor Richardson flew to Hawaii to be at her daughter's side; she had been living alone since 1970, when her husband Bud had died. Having had a successful career as an educator, she was now retired and had become a consultant in educational television. She also enjoyed a rich array of avocations and social activities. Among these, golf was her favorite. In one night's time, Elinor's life was radically changed. She worried that she would lose her daughter. Thomas Moore wrote that "all mothering. . . is made up of both affectionate caring and bitter emotional pain" (1992, p. 43). In Greek mythology, Demeter, the mother of Persephone who descends into darkness, symbolizes survival, the profound maternal feeling in us for life, continuity, and fruitfulness" (T. Moore, 1992, p. 48). Nature and fate combined to reunite Penny and Elinor, and Elinor realized she would be taking on a new assignment: helping her daughter get well. She was the enduring presence who had known her daughter as an adventurous horseback rider and a member of an imaginary gang, the Big Bend Buckaroos. For 40 years, Elinor had saved the poems, stories, songs, and drawings that her literary and artistic child had produced, and had taken pride and delight in Penny's academic accomplishments as a mature woman. She, more than anyone else at the hospital that day, grasped the significance of what had happened, of the extent of damage and disruption. For the next 4 years, she would be with her daughter virtually every day. Inside, she knew her daughter had the spirit, if Penny could muster it, to move forward.
Elinor remembers the moment when Penny first wiggled a toe and when she choked on a piece of broccoli during a feeding session, an indicator that therapy should have begun with applesauce. By December 1989, Elinor had moved in with Penny, becoming her full-time caregiver. "It was very slow . . . steps backward instead of steps forward," Elinor said. One year later, Penny was eating whatever she wanted, was back to teaching, and was using a motorized scooter. A year after that, she could have begun with applesauce. By December 1989, Elinor was using a motorized scooter. A year after that, she could assemble in her world people who were committed to her recovery. Throughout this 2½-year period, Elinor also drove Penny to medical appointments and therapy sessions.

"The individuals made an impression on me, but not the therapy that much." 

Before her stroke, Penny would often have students over for cookie parties. Now Elinor assisted Penny in continuing this tradition. Penny said the following about these occasions, "We had afternoon cookie parties; we had evening cookie parties; we had out-in-the-lobby cookie parties; and it didn't matter; it always worked because there is something about sharing food in a home environment that works." This statement echoed the motif of Mr. Richardson's stew.

In the fall of 1992, Elinor and Penny bought and moved to a new townhome several blocks from campus. Just before that, in the spring of 1992, I was named the Eleanor Clarke Slagle Lecturer. In the fall I visited Penny at the new condo and invited her to collaborate with me on what I mistakenly thought would be limited ethnographic research of the relationship of her childhood occupations to her experience of recovery. Having been interested in developing my friendship with Penny, I had visited her many times over the course of her recovery. Informed by occupational science concepts, I had invited her to do activities that I thought would give her a sense of connection with her former self: a lecture by the sculptor J. Seward Johnson that celebrated ordinary activity as captured in art, an elegant lunch at the Four Seasons Hotel, a swim in a large 1940s vintage swimming pool in the women's gymnasium at USC, an occupational science symposium that featured the physicist Stephen Hawking as keynote speaker. I also encouraged her to attend lectures and social gatherings at which I would be present. As I had hoped, our friendship developed over time. When I invited her to collaborate on this project, she, a bit reluctantly, said yes, so that something good might come out of her awful experience.

We began our work on October 11, 1992, but, as the ethnography evolved, it soon became clear that I had begun to function as her occupational therapist, through encouraging her to tell her story and by helping her to imagine new possibilities. Nature had stripped Penny of many aspects of her old self, but fate had worked to assemble in her world people who were committed to helping and supporting her. Most individuals with disability probably do not develop to their full capacity because the development of human potential is, like identity, also contingent on circumstance. It is unlikely that most survivors of stroke possess the resources of an upper middle-class family, have a retired mother positioned to dedicate her life to caregiving, and, on top of this, just happen to have a friend who is an occupational therapist. I began to view my role as similar to that of the coach of an elite athlete or ballet student, for, unlike most people who only develop a fraction of their ability, Olympic athletes, and persons with disability must push themselves to the edge of their capacity and therefore need someone to coach them along the way. Perhaps, in part, it is because traditional occupational therapy is now so constrained by place and time, so decontextualized from the person's real life, that the statistics on independence of persons with disability are not more encouraging (Bergmann, Kuthmann, Ungern-Sternberg, & Weismann, 1991; Cavazos, 1989; Dombovy, Sandok, & Basford, 1986; Howard, Till, Toole, Matthews, & Truscott, 1985; Kraus & Stoddard, 1991; Schaffer & Osberg, 1990).

I will now give a sort of coda of how occupational therapy unfolds when it is grounded in occupational science, and the progression through which I became a therapist-coach. This analysis can only capture the highlights of the process as they were interpreted by Penny, me, and our research assistant. Soon after we had begun the interview process, Penny realized that the sessions were therapeutic because they gave her a chance to reflect on her situation "with another person who has insights of her own into this, who is well-read, intelligent, and sympathetic . . . but not someone who pities me or just feels sorry for me or is trying to change me."

As time went on, Penny's view of how the sessions came to be therapeutic was further crystallized:

One of the reasons I enjoy our conversations is because I put things into words . . . . and then they become intentions and I have this sort of an emerging plan towards things that I am going to do, that I just think up on the spot, and then I think about them afterwards and I think OK . . . yeah, get on with it, Penny.

At one point I asked her how I might approach teaching my colleagues how to do this form of occupational therapy. She responded by saying, "I think you can say, well [during clinical practice], pretend this is a research project and that you are going to take them [the survivors] through this exercise because it ends up being very therapeutic." Penny now saw our process as an investigation of my status and it gives me something interesting to think about. It has given me some new ways, all of which have had, the thing in common is that it has put me in charge, it has made me get to direct, conduct, if you like, my life.

We agreed that recomposition, modifying a term used by Bateson (1990), best captured what had been going on. The conversations were very free-flowing; they built one upon the next, and themes would emerge and then be recycled in modified forms in the next transcript, much as certain motifs unify the movements of a symphony.
time. The discourse could be classified as Occupational Storytelling and Occupational Story Making.

Occupational Storytelling

Occupational science assumes that adult character and competence are shaped through childhood occupations (Clark et al., 1991; Primeau, Clark, & Pierce, 1989; Yerxa et al., 1989).

Another way of describing the process, based on the work of the French philosopher, Foucault (cited in Rabinow, 1984), is to think of the self as formed, in part through its history of activities and conduct. It is not enough, he believed, to focus on the symbolic systems, the person is “constituted in real practices—historically analyzable practices” (p. 368). A crucial element of the recomposition process was to ground the work in Penny’s occupational historicity. One interview had been focused almost entirely on tales of her childhood occupations and her experience in the world of adult activity. I have already presented much of the content of this interview in Movement 1, the Allegro Spiruoso of this paper. Interpretation of these stories gave me a feeling for Penny’s spirit and a sense of her values. I came to respect her moral stances. Simply stated, I learned what she cared about, about the things that had always mattered in her life. Horseback riding symbolized independence and creativity; adventures with Judy Christmas, exciting opportunities for risk-taking; and the stories of Chancellor Farm, literary celebrations of nature, animals, and the cultural collisions of urban and pastoral life styles.

I was struck by how hard working, organized, and imaginative she had been as a child. She had not simply fantasized BBB episodes; she also took the time to write about them and nearly everything else of significance in her life. Horseback riding symbolized independence and creativity; adventures with Judy Christmas, exciting opportunities for risk-taking; and the stories of Chancellor Farm, literary celebrations of nature, animals, and the cultural collisions of urban and pastoral life styles.

Occupational Story Making

The second type of clinical reasoning Mattingly (1991) described is story making, which involves the therapist and survivor creating stories that are enacted in the future, rather than telling them. I think it is fair to classify the second practice in this therapeutic approach as occupational story making. I knew that when Penny and I began the project, we would find ourselves in the middle of an unfolding story about her as an occupational being, but I had no idea how the subplots would evolve.

As it turns out, upon coding, I realized that this form of therapy departed from customary practice in that no mention was made of diagnostic categories, strengths or weaknesses, or assets or liabilities. Also, neither Penny nor I, nor both of us collaboratively, set goals for her. Instead, she identified the problematiques (a word borrowed from Foucault cited in Rabinow, p. 343) that were most disturbing in her life, and then she would search for and eventually enact solutions. For Foucault, problematiques are things in relation to which one feels threatened or endangered; they are not quite the same as bad things. He maintained that if things were dangerous, one would “always have something to do” (p. 343).

Through the interview process, Penny identified the overarching problematique in her life at the time: the moral imperative to fight against consignment to a disability role. Although she was now able to walk with a walker and was independent in activities of daily living, she was still fighting bouts of depression, the disclosure of which she believed threatened her social acceptability. She felt walled off, divided from the world of persons without disabilities, ignored, and disempowered. In one session she admitted that, like “Bret Rabbit he lay low,” she was resorting to “hiding” as much as she could in the many work and social situations in which she felt threatened. Interestingly, before the Big A, she had been able to envision herself in the future as an active, nature-loving senior citizen, but she could no longer do this; she felt she had been “frozen over.” It seemed that Penny was longing to move on by attacking this overarching problematique. She then broke it down into several more finely graded problematiques: a more manageable state in which she was able to invent solutions. The process by which she began to resolve two of these more finely graded problematiques is discussed below.

Problematic 1: How can I build an image of myself that bridges the old and the new me? After I had verbally painted some pictures to her of persons with disability who transcended stereotypes, Penny began to realize that she had the power to recompose her identity into one with which she would be comfortable; she simply did not have to allow herself to be slotted into the status of disabled, at least not entirely. In another interview, I drew parallels between aging and disability, giving Penny a sense of the ways in which disability overlapped with a process that we all undergo. On her own, she decided that one solution to this problematique would be to wean herself from the walker, which clanked and
seemed to be a physical barrier to others; this solution inspired her to push herself to become competent using a cane. Recycling the motif of hiking (what Jackson [in press] would call recycling a theme of meaning), Penny began what she called "cane hiking." It occupied her every evening, and soon she was able to shed the clunky walker, a stigmatizing piece of orthopedic paraphernalia she had detested, for a cane. Initially, she was exceedingly proud of this accomplishment, but soon she needed to move on. The chrome cane with the orange rubber handle was a small, but still obvious, emblem of disability. In a conversation during which she told a dear friend of this milestone, the friend pointed out that in Britain the cane is a fashion accessory, and that she might like to take a trip to London (another occupation) to buy a cane at a shop in which the proprietor had gathered more than 13,000 canes. When Penny told me this story, I thought it was fabulous, and shared with her that Margaret Mead had used a cane and, as legend has it, would shake it at her students. Penny's friend, it turned out, had also mentioned that canes were wonderful because you could shake them at people.

This simple telephone conversation had a snowballing effect on our image-building process. The idea of the cane led us to play with the idea of building her new image around that of the British academic woman, as she continued to cane hike to further develop her ambulation. She now wanted to shop for clothes through which to embody this new image. In this way, the solutions to a problematique inspired new occupations. One day Penny called me ecstatically to tell me that she had forgotten both her walker and her cane on that day's shopping excursion, so she had taken the risk and walked without either all afternoon (see Figure 1)! To celebrate, we had an ice cream party, and several weeks later we went shopping in Los Angeles for an elegant British cane, the symbol of her new persona. She was no longer the person slinking around in the shadows. She was no longer hiding. She next moved on to the project of getting a driver's license. She contacted Rancho Los Amigos Medical Center and enrolled in the driving program. She described the occupational therapist as wonderful as they worked jointly on Penny's new project. Her brother Steve was delighted to take Penny for practice driving sessions in which she could perfect driving strategies she had begun to master in occupational therapy.

Problematique 2: How can I begin to take command in my world of social relationships when I feel so rejected? Interestingly, the process of image reconstruction inadvertently served as a partial solution to this problematique. During her cane hikes, Penny would encounter her neighbors who lived in the condominium complex. Just as she had once classified individuals as city slickers and country hicks, she divided condominium residents into those who were comfortable with her condition and those who were not. She then invented a kind of game of converting people into what she called "condo comrades" through handling discourse in a variety of clever, engaging, and humorous ways. This was her application of an idea that I had expressed, that wherever I went, I would search out the people who could be therapeutic for me. "Cando hiking" became a bridge to a world of social support and led to reincorporation into the social world from which the Big A had separated her.

Other solutions to this problematique led to an even richer round of occupations. The image of the British academic inspired Penny to buy a pair of season tickets to the opera. She had always loved opera and now planned to invite friends to join her in this occupation, which was a symbol of her past cultural situation and a medium through which she could give to others. She also decided to enroll in a gourmet cooking class and comically envisioned inviting friends to home-cooked gourmet meals: if they did not like the food, she would shake her cane at them. This was a particularly surprising solution since she
had not been to a supermarket for nearly 4 years.

In summary, through occupational storytelling and occupational story making, Penny identified the problematiques of her immediate experience. To these she found solutions that resulted in engagement in a wide array of occupations; occupations that joined the old self and the new self that she was recomposing. We collaborated in the process. She had provided me with a sense of her historicity and identified the problematiques that were most pressing and their solutions. I helped her to do that by reminding her of her progress, making suggestions, probing her values, reflecting my interpretations of our discourse back to her, and listening in a way that conveyed my profound interest in her story. I also spent a good amount of time sharing my knowledge about the power of occupation in life recomposition, to give her a framework for how to use occupation in her recovery process. In the end, she moved into the world of activity, not as a disabled person lurching in the background, trying to be invisible, but as a slightly lame sort of British aristocrat in full command of her destiny. She had possessed her life in a new way.

Conclusion
I have presented results of work that is in the genre of interpretive occupational science. Donald Polkinghorne’s book Narrative Knowing and the Human Sciences, along with his guidance, gave me the courage to develop a paper of this kind and provided an overall framework for this narrative interpretation. The methodology also combined elements of life history ethnography (Frank, 1979, 1984; Mandelbaum, 1973), ethnomethodology (Garfinkel, 1967), narrative analysis (Briner, 1989, 1990a; Polkinghorne, 1988; Rosaldo, 1989) and the naturalistic approach used to study professional practice by Mattingly (1989) and Schön (1983). My colleague Michael Carlson and I (1991) suggested several years ago that innovative and unique methods would need to be developed to tackle the research questions posed by occupational science. I believe that the methodology used in the present study, which draws on the various qualitative approaches I have listed, is an example of one uniquely designed for occupational science inquiry.

My colleague, the anthropologist Gelva Frank, who pioneered use of the rich anthropological tradition of life history method with a woman who had a severe disability, in a dyadic context, wrote that the methods for which she is known can “offer images of the lives over time of persons with disabilities in their natural circumstances and settings, against which clinical practice can be reflected” (1984, p. 640). In another paper (Frank, 1979), she distinguished life histories from autobiographies. Unlike the latter, she pointed out, life history represents a collaboration of the investigator and the informant and reflects the consciousness of both. I believe that the method that Penny and I created for the present study also possesses these qualities that Frank described.

My mentor, Elizabeth J. Yerxa (1991), has presented compelling ethical and epistemological arguments for why qualitative methods are highly suited for occupational science. Her thinking is congruent with that of Geertz (1973), the renowned anthropologist, who stated that “Man is an animal suspended in webs of significance he himself has spun. I take culture to be one of those webs, and the analysis of it to be therefore not an experimental science in search of laws, but an interpretive one in search of meaning” (p. 5). If the concept of culture requires an interpretive science, so too does the narrower cultural construct of occupation.

This lecture has demonstrated how interpretive occupational science research speaks to practice, not by discovery of general laws or principles, but by providing thick descriptions of actual cases that practitioners can refer to as they submerge themselves in practice. I believe Penny Richardson’s story can inform practice in the way that a series of relationships might inform a future decision about a mate. Just as we learn from each of the previous relationships, so too can we learn by collecting thickly described stories, grounded in an epistemology that respects subjectivity. Palmer (1987) has argued that all epistemologies end in a set of ethics: “Every way of knowing tends to become a way of living” (p. 22). He has written that objectivism “breeds intellectual habits” that “destroy a sense of community,” making objects of one another and “the world to be manipulated for our own private ends” (p. 22). Unlike objectivism, which leans toward promoting competitive individualism, subjectivism, when handled sensitively, encourages friendship, rapport, and equality. Because I was her friend, Penny shared her story, and soon I became a sort of Judy Christmas in her adulthood. However, our stories were less about the BBBs—they were more directly about Penny Richardson as an occupational being.

In occupational science, occupations are defined as chunks of daily activity that fill the stream of time and can be named in the lexicon of the culture (Clark et al., 1991; Yerxa et al., 1989). As cultural phenomena they have been celebrated in the legacy of artists and craftsmen throughout history. Just as each civilization invented culturally specific occupations as solutions to their issues of lifestyle and survival, people place occupations within the framework of their lives. A crucial role for the occupational therapist, therefore, is to help survivors define their problematiques and find solutions. Occupational therapists cannot be expected to do detailed and time-consuming ethnographies in the clinic, but they can make occupational storytelling and occupational story making the core of their clinical reasoning as a way to nurture the human spirit to act.
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References


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Occupational Therapy Treatment Goals for the Physically and Cognitively Disabled

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