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Reflections From the Other Side of Acute Care

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Reflections From the Other Side of Acute Care

Abstract

An occupational therapist of 40 years experiences a traumatic event during her time in an acute care hospital. She journeys through a host of life-altering experiences, including cognitive decline, delusion, paranoia, and an inability to engage in her desired occupations. While on this journey and during reflections following her return home, she is able to see more clearly how an occupational therapist may have assisted with several of the major concerns she was experiencing, thus improving her well-being and quality of life. She is an Assistant Editor for the Open Journal of Occupational Therapy (OJOT) and this is her story.

Keywords

occupation-centered therapy, acute care, ICU-acquired delirium

Credentials Display

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A recent and unexpected event confirmed for me that lifelong learning takes many forms and occurs in unforeseen settings. At the end of February, 2023, I was diagnosed with a sudden and fast-moving case of necrotizing fasciitis of my right leg. Although traumatic and life-altering, this experience left me with a greater understanding and appreciation of the occupational therapy patient experience and insights into the gaps, challenges, and opportunities in our profession in the acute care setting.

The goal of this article is not to imply that all facilities and therapists are the same but to share what I learned through my 38 days as a patient in an acute care hospital. My stay included more than a week of respirator-supported care in the intensive care unit, 12 trips to the operating room for wound debridement and reapplication of a full leg wound vac, and finally, the application of a partial thickness skin graft using my entire back as the donor site. Despite my fairly extensive knowledge of our profession, coupled with 40 years of work in diverse treatment and educational settings, my eyes have been opened. I now have a new perspective and believe that living the experience of a patient in the health care context is the best way to understand what our patients experience. I can also better appreciate how aspects of the occupational therapy scope of practice and targeted occupation-centered interventions can potentially improve the functional, physical, and most importantly, cognitive and psychological well-being of the patient.

A Brief Historical Recap

Occupational therapy has been a part of the medical setting since the first and second world wars (Morrison, 2020). Back then, the belief in the curative properties of crafts and other meaningful activities to address patient factors and skills needed for daily activities was understood by the medical team and highly valued. Hospital stays were longer, measured by weeks instead of hours or days, and discharge was decided by patient readiness versus policy and reimbursement (Howard, 1991).

Before the mid-1960s, occupational therapy was considered a bed-rate intervention, much like nursing, which required no added charge to a patient who received help from the service. The occupational therapist was able to make a plan of care and provide holistic interventions that they felt would best benefit the patient. This fact enabled occupational therapists to do what they needed according to theories of the day without concern for payment or third-party policy.

On July 30, 1965, President Lyndon B. Johnson signed the Medicare and Medicaid Act, also known as the Social Security Amendments of 1965, into law. It established Medicare, a health insurance program for the elderly, and Medicaid, a health insurance program for people with limited income (Congressional Research Service, 2020). Becoming a service paid for by the federal and state governments began the changes to occupational therapy we experience today. Some of these changes were positive; occupational therapists received increased pay, for example. Unfortunately, other changes did not bode as well for the profession.

In 1991, Howard described the impact that changes in reimbursement were having and have had on the profession. A literature review found that the profession had changed the definition, practice, management, ethics, and professional response that could be directly tied to reimbursement (Howard, 1991). In other words, therapists and patients could not decide the course of treatment; third-party payers were setting rules and regulations to do that.

Of course, there are positive aspects to change that may offset some of those that have modified our profession; for example, there is now reimbursement for previously non-reimbursed areas of care, such as functional cognition services. However, bringing these new areas into everyday practice will take

time and motivated occupational therapists who are willing to grow their knowledge and skills and advocate for our role.

According to DeJong (2016), the time has come for health care practitioners to stop focusing on professional territory and procedural codes and focus more on the value that their interventions bring to patients. He foresees a time when valuable outcomes drive payment and service provision, not vice versa. This is not to say that therapies merge into one, but that within their scope of practice, practitioners must advocate for and measure the effectiveness of their interventions, which is important for keeping the cost of health care in check by turning focus to things that work. Outcomes include shorter hospital stays with a focus on home services, a decrease in falls leading to expensive hospital readmissions, and improved activity of daily living (ADL) and cognitive abilities (DeJong, 2016). These areas should excite acute care occupational therapists as they fit perfectly within our framework and scope of practice (AOTA, 2020).

Pritchard et al. (2019) also point to changes in health care policy and payment as underpinning the focus on cost-effectiveness and confirm that focus on the aforementioned areas of patient outcomes is expanding opportunities for occupational therapy, especially in the acute care setting (Pritchard et al., 2019). When the list of quality outcomes is broken down, we see that the areas of patient improvement that will lead them to include interventions, such as discharge planning, including home assessment and modification; fall prevention, which includes attention to medication management and low vision; functional cognition that is needed for safe discharge and independent living; and other quality of life factors. However, it cannot be overstated that the ability to bill for these services and put them into standard practice requires ongoing interest and advocacy on the part of the practitioner, educators, managers, and students, as well as the professional organization.

The Impact of Hospitalization on the Patient

As mentioned, I was not aware of the first week of my hospital stay. I was heavily sedated and intubated for a return trip to the operating room if I needed an emergency procedure or further debridement. When the time came to be extubated, I required a dose of Ketamine to jump-start independent breathing. This is where I mark my first, but not last, experience of hallucinations and delirium, collectively known as ICU-acquired delirium, post-intensive care syndrome (PICS), or hospital-acquired delirium (Davidson, 2013; Vandergrindt, 2022). PICS can cause patients to experience physical, cognitive, and psychosocial deficits (Tobar et al., 2017). Causes are reported to include disengagement from typical habits, roles, and routines, lack of interaction/socialization with others, loss of circadian rhythms, including difficulties completing restful sleep cycles, and, of course, the typical cocktails of medications, including opioids, benzodiazepines, and antipsychotics. Medications each have their own side effects and can also interact with each other in problematic ways (Tobar et al., 2017). Side effects can then increase hospital length of stay and compound the risk of lasting cognitive and functional decline (Tobar et al., 2017). Individuals experiencing PICS have been shown to have a decreased long-term survival rate compared to those not in the ICU (Kotfis et al., 2020).

For me, the hallucinations improved within days, but the delirium, delusions, bothersome lucid dreams, paranoia, and ensuing anxiety were intermittent yet persistent for the duration. Changes and challenges to cognitive function and mental acuity led to significant secondary difficulties, including the inability to express myself to hospital staff accurately. I found that having my needs tended to efficiently and with empathy caused me to be termed a demanding patient by some staff and coddled like a child by others; both responses were confusing and demeaning.

According to Fadoo (2023), patients in a hospital environment present with various deficits and are often in great need of functional cognitive assessment and intervention. Cognitive impairments that I experienced included:

1. Long- and short-term memory loss: Including loss of events occurring when I initially sought medical treatment for leg pain, as well as many events occurring after extubation.
2. Attention: I could not sustain attention to an activity or interaction with a person for more than a few moments.
3. Safety awareness: during nighttime hours, I tried to get out of bed when my right leg was attached to a wound vac, and I was unable to stand/ambulate independently.
4. Organization: including writing coherently. I was unable to compose emails and text messages to friends and family.
5. Problem-solving: unable to contribute to conversations with family and doctors about issues that arose and unable to complete familiar tasks and activities.

One illustration of my cognitive difficulties involved an attempt to complete a craft activity. Before my hospitalization, I was working on simple potholders/trivets to sell at local seasonal festivals. The first step in this process was to convey to my husband the whereabouts of the supplies in our home so he could bring them to me. As expected, I had a great deal of difficulty articulating this information, partly because I could not recall the exact location of the looms and loops in my craft nook and partly because I could not adequately convey to him the exact components I needed. This became a source of frustration for both me and my spouse, especially when he brought me the wrong items.

Once I received the necessary materials, I tried to create a simplistic potholder/trivet using random loop colors and a simple over/under weaving design. After an hour of trying to complete this typically quick project, I considered it impossible, had a good cry, and put it down for 3 weeks. Once I re-attempted the project, I completed the weaving component, although it took twice the amount of time it should have. I was still unable to use my crotchet hook to remove the piece from the loom but eventually did so after my return home.

Motor abilities and the completion of ADLs were affected by my infection and subsequent medical interventions. Several of my fingers had a moderate level of numbness, leading to difficulties opening containers on food trays, closing fasteners on clothing, manipulating the nurse call bell, and typing on an iPad and smartphone. This numbness was likely because of positioning during intubation and the tightly applied “mittens” that kept me from pulling out my breathing tube. Immobilization of my ankle, generalized weakness, and a lack of proper equipment contributed to difficulty transferring to the bathroom commode; dressing the lower body, including socks and shoes; an inability to bathe in a tub or shower; and to walk with a walker more than 5 feet without significant pain and fatigue.

The most ubiquitous concern was generalized anxiety and panic attacks. These were likely the result of myriad underlying causes, including pre-disposition, ICU delirium, side effects, a combination effects of medications, and possibly post-traumatic stress disorder. Despite attempts at targeted medications and the assurances of family and hospital staff that improvements were being made in my health, this part of the hospital experience was one of the most concerning aspects of my 38-day stay. The feeling of constant panic and dread seemed to eat away at my soul and my self-identity, further diminishing hope and optimism for the future.

Once I could process all that was happening, I realized that in addition to PICS, I was likely dealing with occupational deprivation (OD). According to Whiteford (2000), OD is the outcome of being prevented or precluded from engaging in occupations and activities that are necessary or meaningful. OD can have profound consequences as it reduces abilities and diminishes health, well-being, and quality of life. I have learned much through this unexpected experience.

A Patient of Occupational Therapy

My acute care stay occurred in a Level II trauma center owned and operated by a for-profit company. My understanding through reading about the facility is that they believe occupational therapists only use exercise and skill training to help people with ADLs and IADLs. This is not how I view my profession.

Although minimally, I did interact with an occupational therapist during my stay. My first encounter was an evaluation at bedside in the ICU shortly before I was transferred to a surgical floor. The assessment primarily focused on sitting balance and future-facing questions about my home situation (caregivers, location of bedroom, stairs, etc.). When I asked about other aspects of my current functioning, including ambulation and cognitive and psychosocial interventions, it was explained that I could see a physical therapist or an occupational therapist for functional ambulation but that acute care occupational therapists did not work on cognitive or psychosocial interventions. I have since learned that rehabilitation in this facility is primarily focused on movement and that cognitive interventions provided by speech-language pathology are reserved for those who have experienced a stroke.

The six additional treatment sessions I had were provided by either an occupational therapist or a physical therapist; they worked on the same functions: sitting and standing and ambulation to a chair or bathroom using a walker. I only knew the difference in professional training of the therapists based on reading name tag credentials. The interventions were exactly as reported in the rehabilitation description above.

Because of the swelling in my leg, lack of skin, presence of wound vac, and fast-developing ankle contracture, I was certainly concerned with future ambulation abilities. However, when I asked about specific and effective ankle exercises or manual joint mobilization, I was only encouraged to actively rotate my foot and passively stretch my ankle into dorsiflexion using a leg lifter that I bought from Amazon during my stay.

Additional adaptive and exercise equipment were not supplied to me at bedside, as it was unavailable to acute care therapists. For example, I was interested in having a long handle reacher to assist with ADLs and a set of hand weights to augment the AROM exercises that the occupational therapist recommended I do with my (functional yet deconditioned) shoulders and elbows. Of course, being an occupational therapist, I compensated by having ever-present family members retrieve and position items for me and using small cans of pineapple juice and chicken noodle soup as hand weights.

As discharge approached, I began thinking about my home setup and what durable medical equipment (DME) would be needed to enable some level of independence and reduce the burden on my husband. I planned for entry into the home, bathing, and toileting. One day, when an occupational therapist covered my treatment, I asked if we could discuss ideas and any recommendations for DME she may have. She listened and agreed with my thoughts on equipment and, without further discussion, recommended that I share my plan with the unit discharge planner.

The Gaps

There are approximately 180,000 occupational therapists in the U.S. If we consider how many patients receive help from occupational therapy interventions in a given day, regardless of the diverse treatment settings in which occupational therapists work, we can assume there are thousands of therapist and patient interactions. Despite this, I posit that there are very few opportunities for reflection by the therapist or other team members about the breadth of the interventions and the unspoken needs of the patient.

Although a therapist will always be measuring the impact of intervention during each session and completing assessments and reassessments at various times during the episode, I have seen several gaps between patient needs and what ultimately become the therapist and facility goals. I am not speaking about attention to walking to the bathroom and transferring to a bedroom chair for endurance enhancement, but rather about gaps in mental functions and patient factors and cognition, the ability of a hospital patient to complete occupations and activities requiring executive cognitive function, the ability of the patient to maintain power over their lives and the semblance of an identity, as well as to work through the effects of PICU. According to a 1916 article by Emily Haines, the power of occupational therapy is such that:

Patients may become gradually vitalized with interest, the dull monotony of their days alleviated, and they are sent on the path towards recovery... [Occupation] presents a fair horizon, towards which many may wander, and by various paths to the desired goal of peace and restoration (Haines, 1916, p. 611).

The part of this excerpt that resonates the most is the section stating that “occupations present a fair horizon, towards which many may wander.” To me, this means that occupations are innately motivating and that people will naturally seek them out and eventually get to a place of interest despite their travels being characterized as a slow *wander*. The next section reminds us “and by various paths to the desired goal of peace and restoration.” Which, to me, highlights the fact that to get more precisely where people want/need to be, they must follow a specific or guided path. Perhaps this is through the support and intervention of the occupational therapist.

My thoughts have now turned to reflect on what I expect(ed) from my profession when in the complex role of patient. I cannot speak to every aspect of what occupational therapy should be in every acute care setting, but I have landed on the belief that we can do better.

For me, the most frightening aspect of my stay was my loss of cognitive function. I certainly believe that it is the role of the physical therapist to address ambulation training, endurance, and sit-to-stand transfers with a walker, out of the context of an activity; this is their role. The gap for me was the occupational therapist doing the exact same treatment as the physical therapist when meaningful and interesting activities and tasks could have been provided that would not only impact my gross motor functions but also my emotional and cognitive states as well. It is understood that in an acute care setting, activities and occupations can be difficult to plan and execute; however, if the occupational therapist is motivated and allowed by the setting to be creative and patient-focused, this becomes much easier, especially for acute care long-timers, according to the National Institute of Health (2023), the average acute care stay is 5 ½ days.

In most hospitals, there are areas for family members to rest or wait for patients undergoing procedures; there are also lobbies with chairs on each floor or at the main entrance. When a patient feels

isolated, is confined to a dark hospital room, and cannot recall how to compose a text message because of deficiencies in executive functions, it would seem feasible that an occupational therapist recommends a trip to one of these communal areas. The patient could wash their face, brush their hair, don a robe, stand, walk as able, use a wheelchair when needed, transfer to a standard chair, talk with the therapist, smile at other people, see the sunlight, and enjoy being in a large communal space. This can be more therapeutic for the patient and address more skills and performance patterns than one can imagine. For example, adding other tasks, such as eating a protein snack after opening containers, can address fine motor strength and encourage the ingestion of nutrition for wound healing.

The patient and therapist could compose a text or email message to a work colleague or concerned friend hoping for a status update. The occupational therapist can provide helpful cues for a successful paragraph and offer feedback as needed for problem-solving on how to operate the phone. Following this highly interactive 30-min visit to the atrium, the patient can be instructed to find the way back to their room.

In my case, this multifaceted occupational therapy treatment would have been ideal. My passwords to my personal social media accounts and work email were changed by my family. Their aim was to keep me from inadvertently sending incoherent messages, which was important. But at the same time, a part of my independence and identity as a high-functioning adult was taken away.

An occupational therapy visit focused on self-care ADLs, including dressing, cleaning the upper body, and dental care, would have been very much appreciated. In the hospital environment where I was a patient, nursing care was limited because of staff shortages. I was seldom (perhaps twice) asked if I wanted a full bath or would like help to change my pajamas or wash my hair. Perhaps a bit personal to share, but these are the experiences that our patients are having and gaps that can be filled by occupational therapy that is in our scope of practice and represent occupations that we know to be powerful. I am not suggesting that occupational therapists give a bath or brush a patient's teeth, I am suggesting that sometimes a patient needs cues, guidance, and adaptations to re-learn how to do for themselves in an often restricting and gloomy environment.

Let us revisit my previous example of cognitive and sensory impairment limiting my ability to complete a simple craft activity. An occupational therapist who adopts an occupation-based or occupation-focused practice in an occupation-centered paradigm (Fisher, 2014) could have used pot holder weaving as an excellent way to help me problem-solve, recall facts and procedures, and offer assistance and advice/adaptation for numb fingers that would enable me not only to exercise my brain but let me know there is hope and that the fog will indeed pass in time. Of course, there is always that endurance building of sitting in a chair, walking to the chair, and transferring stand-to-sit and sit-to-stand that also support physical therapy goals.

The work of occupational therapy in acute care, especially for long-timer patients, must be more than replicating the work of physical therapy or believing that occupational therapy and physical therapy are interchangeable. I am sad that my patient experience of our profession showed me that this type of reductionism exists. According to Reightler (2022), occupational therapy services are supported by 2021 guidelines released by The Society of Critical Care Medicine when describing the importance of early and ongoing intervention for ICU patients. According to the guidelines, occupational therapy services should begin as soon as ICU patients are medically stable and when using clinical judgment and communication with the interprofessional team (Pohlman et al., 2010). Occupational therapists can address autonomy, psychosocial demands, cognition and delirium, and early engagement in occupations and mobility within

the ICU. In addition, when performing their evaluation, occupational therapists can assess patients at risk for PICS and may start management of immediate symptoms, such as delirium and weakness (Reightler, 2022). Unfortunately, the literature reveals that therapists find several barriers to using occupations in the acute care setting. Some of these, as highlighted by Asiello and Craven (2023), include:

- Lack of time to practice incorporating occupations into treatments
- Lack of time to complete occupations during sessions
- Space and equipment
- Confidence and skills
- Patient perception of what intervention should include/look like
- Team attitudes about OT using occupations such as games or crafts.
- Medical model focus of hospital
- Treatment restrictions/protocols/billing.

I have mentioned several of these perceived barriers throughout this paper. Some may be valid concerns, and all can be remedied through an understanding of and belief in the profession and advocating for what we know is best for our patients.

Looking Forward

Articles and textbooks that outline the value of OT in the acute care setting are plentiful. By intention, this article is unique in that it provides a look at the lived experience of an occupational therapist enduring an extended stay as an acute care patient; it is unclear if my prior knowledge was a help or hindrance in this case.

I have laid out my medical journey and the effects thereof, as well as how the profession has changed over the years from one of reliance on activities and occupations as holistic and curative entities to current times where, despite opportunities for the profession to grow into new focus areas, there are gaps in best practice because of reimbursement guidelines, facility mission, and therapist choice.

Through reading the literature and my firsthand observation of the standard of occupational therapy care in this one facility, I believe that there are huge opportunities for our profession that will serve to benefit acute care patients who are struggling. My hope is that if the gaps and needs of the patient are brought to light, therapists will advocate for the profession within hospitals to ensure a strong future for OT. The truth of the matter is that patients need help, and it does not appear that there are other professions looking at cognitive and emotional issues in the function-based and evidence-supported manner of occupation therapy.

As the fog has lifted for me, I am left with memories of a very unhappy time in my OT life. I was not able to call on my own profession for help with my cognitive and emotional issues or create a discharge plan but instead learned to rely on what knowledge and skills I could recall to assist myself in getting better and going home.

I will close with words from a few of our best and brightest colleagues who agree that OT must reclaim the profession that we know is effective, distinct, and necessary.

- Occupational therapy practitioners should collaborate with patients to find activities they perform routinely and incorporate them into intervention plans (Cahill, 2022, p. 36).

- We cannot defend our scope of practice if we do not practice what we preach. We need to reclaim what we do and realize that nobody does occupation better than we do (Gillen, 2013, p. 644).
- The responsibility to increase awareness of our profession belongs to us Our strength is situated in our commitment to engagement in meaningful occupation and how what we do helps patients achieve that engagement. Our focus on occupation is essential to the lives of our patients and essential to our competence (Cohn, 2019, p. 2).

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