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Crawling Out from Under: A Physical Therapist's Celebration of the Power of Occupational Therapy

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Abstract

Isaacs' syndrome, also known as Acquired Neuromyotonia, is a rare condition caused by continuous firing of the motor units, leading to twitching muscles and cramping that will persist even during sleep. The medical treatment of Isaacs' syndrome is nondescript and arbitrary. Because of the rare incidence of the disorder, very few studies have been conducted to help determine the appropriate intervention for individuals with this affliction. This paper is a narrative case-study that offers a first-person account of a physical therapist with Isaacs' syndrome and her journey through rehabilitation with her occupational therapist. The progress of this individual over time supports the use of occupational therapy services at every stage of her rehabilitation. It also supports the strength of participation and positive social interaction as tools to propel an individual through the rehabilitative process.

Comments

The author declares that they have no competing financial, professional, or personal interest that might have influenced the performance or presentation of the work described in this manuscript.

Keywords

Isaacs' syndrome, neuromyotonia, occupational therapy, participation

Cover Page Footnote

I have to thank my family of caregivers: My incredible parents, Pauline and Rudy Norman; my wonderful kids, Heather M. Slaughter, Thomas M. Housel, and Tiffany R. Ganley, as well as Austin Michaels and Alexandra Michaels (who earned her COTA in 2021), Deata Slaughter, and Kat Housel; my advisor and mentor, Dr. Marcella Kysilka; my early neurologist, Dr. Edward Davis; my early rheumatologist, Dr. Frank Vasey; my early internist, Dr. Stephen Zellner; my current primary care physicians, Drs. Christopher Holloway and Jonathan Lee; my phone buddy, "Sarah;" my neurologist and friend through the tough times, Terri Edwards-Lee; my patient, persevering, and lovable husband, Rick Michaels; and the reason for this paper, my angel, occupational therapist extraordinaire, Bonnie Jean Clancy.

Credentials Display

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Available evidence-based treatment interventions for extremely rare conditions are often limited. Such is the case with Isaacs' syndrome, a rare chronic neurological condition of peripheral nerve hyperexcitability (Isaacs, 1961; Maddison, 2006). Isaacs' syndrome, also known as Acquired Neuromyotonia (NMT), is characterized by the continuous firing of the motor unit, leading to muscle twitching and cramping that can persist even during sleep or under anesthesia (National Institute of Neurological Disorders and Stroke, 2023). Symptoms of Isaacs' syndrome include excessive night sweating, pseudomyotonia, weakness, and myokymia (Alessi, 2000). There is also muscle stiffness that is more severe in the limbs and trunk, although cranial muscles, speech, and breathing might also be affected. It has been suggested that Isaacs' syndrome is an autoimmune-mediated disorder affecting the potassium channels in the peripheral nerves (Newman-Davis & Mills, 1993). Voltage-gated potassium channels (VGKCs) are important as part of the line of transmission for signals in the peripheral and central nervous system (Maddison, 2006). It is believed that autoantibodies block the potassium channels at the distal motor nerve terminals (Bady et al., 1991). These potassium channels typically stabilize the potential difference at the membrane, but when these areas blocked by autoantibodies, they are left vulnerable (Bady et al., 1991; Sinha et al., 1991).

Even though the current literature does not associate Isaacs' syndrome with the involvement of the central nervous system (CNS), the fact that this syndrome is accompanied by a decreased ability to maintain balance in response to being startled (2021), similar to a Moro reflex, has led this author to question if the CNS may also be involved. There are still no precisely defined criteria for electromyographic readings with NMT, but it is suggested that the presence of doublet, triplet, or multiplet discharges from a single motor unit might indicate neuromyotonic or myokymic discharge (Maddison, 2006). More recently, Isaacs' syndrome has been associated with paraneoplastic syndrome, depicting a potential for an underlying neoplasm, but this has not been found in all cases (Rana et al., 2012). It was found that roughly half of all cases of patients with NMT also have another associated autoimmune disorder (Maddison, 2006). It has been proposed that there may even be two types of peripheral nerve hyperexcitability (PNH), immune-mediated PNH and non-immune mediated PNH, that would possibly be the result of toxins, neuronal degeneration, or genetic disorders (Hart et al., 2002).

Treatment interventions typically consist of anti-seizure medications that block sodium channels, immunoglobulin infusions, and possibly immunosuppressants (Alessi et al., 2000; Maddison, 2006). The author of this article received all of the above-mentioned interventions at various points of rehabilitation but feels that the interventions that focused on enhancing occupational engagement and social participation were critical and, perhaps, even more beneficial. The International Classification of Functioning, Health, and Disability (ICF) model stresses the importance of activity and participation, as does the *Occupational Therapy Practice Framework: Domain and Process* (AOTA, 2020). The literature is filled with many well-written research papers supporting the use of participation as an imperative form of rehabilitation (Berger et al., 2013; Chan & Chan, 2007; Schaaf et al., 2015), but when you live through it, the story takes on a totally different color, smell, taste, touch, and feel.

There has been a great deal of discussion in the literature regarding the value of lived experience (Frechette et al., 2020; Koenders et al., 2020; Petitmengin et al., 2019; Sundler et al., 2019). This is often evaluated through descriptive or interpretive phenomenological analysis (Frechette et al., 2020; Sundler et al., 2019) and has been found to provide valuable information about the patients seen in the health care environment (Koenders et al., 2020; Sundler et al., 2019). Although this paper does not apply the rigorous concepts mentioned above, it does provide a candid narrative. It has been noted in the literature that

narrative or storytelling is related to identity and social co-construction (Eggly, 2009; Strong and Shadden, 2020). This is my narrative about the power of occupational therapy (OT).

My Story

I was working in a room with 20 people seated at a large round table in a chilly, stark conference room that doubled as our break room and copy area. You could feel the tension in the air as the reviewer from the Joint Commission on Accreditation of Health Care Organizations began asking us questions regarding our Home Health Department. As the Director of Rehabilitation for Home Health, I was prepared to describe a storyboard depicting a problem we resolved over the preceding 6 months. I tried hard to hide my nerves as I presented, noticing that my hands were trembling in a way I had never seen before. After giving my presentation and receiving accolades for a job well done, I expected the tremors to subside. However, when they persisted over the course of the next 2 days, accompanied by pain and cramping, I decided to call a psychologist. I believed it was the result of stress, but the psychologist disagreed and sent me to a neurologist.

That is how it started. Over the next 3 months, I went from being an active mother of three and successful rehabilitation home health director to a shaking, pain-ridden woman in a wheelchair. I stopped working in October of 1998. My oldest daughter was 9 years of age, and the twins were 6 years of age. This was not in the preconceived plans for my time as a young mother and physical therapist.

My doctor eventually gave me a possible diagnosis of Amyotrophic Lateral Sclerosis or Lou Gehrig's Disease. I was devastated and fell apart later that evening while watching my youngest daughter trying to tie her shoes. I wondered if I would live long enough to see her actually accomplish this feat. What about her graduation from high school? Her wedding? Her first child? I became choked up with tears and ran from the room to cry.

I called my doctor the next morning to ask for a second opinion. I had been up late the night prior looking online for a possible alternative diagnoses. I believe this is the bargaining stage of Kubler-Ross (Tyrrell et al., 2022). Then, I found Isaacs' syndrome and happily presented this possibility to my physician, who said, "Natalie, you are in denial, and you have a better chance of winning the lottery than having Isaacs' syndrome." So, he sent me to a specialist in Miami the following week.

Sitting in the specialist's office after an extensive evaluation and waiting for his return to discuss my condition felt like an eternity. When he re-entered the room, my stomach lurched. He looked across his massive desk at me and said gravely, "I have some bad news. You have Isaacs' syndrome." I jumped up to hug him. I was so happy. As he shook me off, he asked, "Why are you happy, Isaacs' syndrome is a lifetime of pain and suffering." I said, "Yeah, but it's a LIFETIME of it!!!" I now knew that I had to fight, but how?

Submission

The day I reluctantly listened to my doctor and stopped working at my awesome job was terrifying. My career was a huge part of my identity. It was raining outside, and a hurricane was approaching. I had just finished making phone calls to help to place patients who resided in mobile homes in safe locations while my colleagues frantically wrapped up paper medical records in a heavy plastic material as per our hurricane protocol. After I finished, I took a deep breath and with the help of colleagues, wheeled out of my office in my new folding wheelchair to my car. I was scared, but not of the approaching hurricane. I was afraid of the pain and the absence of distractions to help me through the long days after I stopped going to work. I was afraid to leave the stability and safety of my work environment, and the looming hurricane felt like an omen of things to come. But, I needed time to learn how to deal with this excessive

discomfort, and I could not do that without first eliminating some distractions and resting, even for a little while.

After I got home, I went to bed. No one tells you that with Isaacs' syndrome, the less you move, the more rigid you become. No one told me because, at the time, no one knew. I went to bed as instructed. At first, it felt wonderful. But after the kids left the house for school, without the distractions, the pain became intense. Most of the time, sleep was not possible, and moving around became more and more difficult. I felt horrific. The pain was a deep-down body ache, like having a fever of 104 degrees. The inside ache that you cannot access with massage or any topical treatments because it is so deep inside you, as though the inside of your bones hurt. My 9-year-old daughter, Heather, helped with her 6-year-old twin siblings, Tommy and Tiffany. Friends visited a lot at first, then slowly stopped. My wonderful mother, thank goodness, came over to help care for the kids and cook meals. My husband at the time tried to do his best, but he simply did not know how to deal with me. We gradually grew apart.

The Rehabilitation Team

I was visited by many wonderful physical therapists who strengthened me but could only help me to a point because of the limitations caused by my severe pain. They tried pain-relieving interventions, but this did not touch the depression I felt after hitting that "point" of being unable to progress further and consistently to do things with my family. One of the physical therapists requested an OT referral.

Imagine your mother happily coming into your bedroom to say that we were all going out to dinner and that they "found a restaurant with a wheelchair-accessible bathroom, and everyone is so excited, so we'll help you get ready. Let's go!" You say, "No, Mom. You all go and have fun. I'll be fine. I don't really want to go. Thanks for asking, but really, you go and have a good time." You say this, but you do not mean it. You want to go so badly it aches, but the last thing you want is for your family to have to care for you all evening. You are certain that this will ruin their good time. You insist they go without you and take the kids because you know they will love it. Finally, they leave, and you lie in bed and cry. Then, an angel appears at your door: your friend Bonnie Clancy, an amazing occupational therapist. She says, "Oh, stop this. There are so many things you can still do."

The Occupational Therapist

In her inaugural address, Stoffle (2014, p. 629) stated that "attitude colors what people do, and how they approach everyday life situations." I desperately needed a more positive outlook, and Bonnie helped whisk away the negativity in me, aligning with what I call "the Stoffle Modus Operandi," through her authenticity and actions. She brought me tonic water. I know this probably sounds like a small act, but it was the first gift from a non-family member in such a long time, and I was really touched. She asked if I had made many phone calls to friends and if I had returned emails. Of course, I said "No." Then I remembered that I did make one phone call. I had recently been accepted as a student at the University of Central Florida (UCF) for my doctorate in curriculum and instruction, and I had called them to say that I could no longer do this. I was sick! Bonnie insisted that I look at my emails just to get back into the socialization process. I did this, and I found an email from Dr. Marcella Kysilka at UCF. She said she was sorry to hear about my situation, but wondered if I would like to be one of the school's first online distance students. I thought that this would be impossible but was thrilled to be considered. I called her back thanked her, but said, "No." She said she would set it up for me anyway (just for my prerequisites), and if I felt like it, I could go online and try. The first day, I looked at the computer. On the second day, I sat on the edge of my bed. On the third day, I got out of bed and went over and sat in the desk chair, still not turning on the PC. I took several days before I actually logged into the class. With Bonnie's

encouragement, I was soon online, and I was able to do this in real-time, to observe the teacher, interact, and ask questions. It was amazing. I started aching to do more.

The Fight to Crawl Out from Under

The first thing I needed was a way to remain seated in the chair in front of the computer without losing my trunk control. Again, enter Bonnie, who brought me special seat cushions for support and taught me exercises to allow my hands to type with a fewer typos, and my endurance to improve slowly. But, the more you do with Isaacs' syndrome, the more you hurt. Yet, the sensations of pain that we typically see as a warning to stop an activity really mean nothing with Isaacs' syndrome. If you push through this pain, you more than likely are not injuring yourself (or, so you hope), except for the problems with heart rate and blood pressure that arise when you do too much too quickly (because this pain really takes your breath away). So pacing myself became an issue, but this was again an issue addressed by Bonnie. She taught me ways to calmly get in touch with the sensations of pain in my body without overdoing it, but also without babying myself too much.

I looked up my disorder on the National Organization for Rare Diseases (NORD) website. At the time, there were only eight people listed with the disorder, but you could request contact information for the others who had given permission. I received this list, and I called the one female on the list besides me. We will call her "Sarah." She and I began talking frequently. She was awesome. One day, when I was feeling extremely rambunctious, I told her I believed that this severe pain might have a ceiling. Since the pain means virtually nothing, if I could find the point where the pain stops increasing, maybe I can learn to tolerate that level of pain and somehow get on with my life. I put her on speakerphone while I got out of bed and began to walk around my bedroom. She was mortified. What if something happened to me? I asked her not to worry, but that if something happened, she should just hang up and call 911 on my behalf. I believe I made her a nervous wreck.

The first day was a walk around the room, the second was a walk out of my room, and so on until I was on an exercise bike (this took about a month), crying from the pain but realizing that I finally found the ceiling. I was laughing and grinning with tears in my eyes! This is nuts! I was not sure I could possibly train myself to handle that level of pain; but eventually, I learned. It was hard but much easier to do as I began moving more. Every step of the way, Bonnie was there to offer encouragement and to provide me with assistive devices that I would use until I could somehow find a way to outgrow them. Her positive energy and encouragement made me believe in myself, the first step in any endeavor. Soon, I was leaving the house with my awesome father's help to attend satellite classes on the Florida Gulf Coast University Campus (FGCU). Three years later, I was walking across the stage to receive my doctorate. Albeit I was using a quad cane, but I was doing it! I took my first adjunct teaching job with a leg catheter and a quad cane. Eventually, with biofeedback therapy (again suggested by Bonnie), I was able to get off the catheter, and this offered more possibilities.

Nine years later, as a single mom teaching full time and finally using a straight cane, I was out and about on a regular basis. I stopped at a local coffee shop on the way to work, and it was there that my life changed dramatically. I met Rick. Well, I actually spilled coffee on the man (accidentally), and he bought me another cup. After a few weeks of dating, he asked me about my disorder. I proudly told him my story and the gradual rehabilitation to this point where only a cane was needed. His response was, "Why did you stop?" I became irate. "Did you hear what I've been telling you at all? Don't you realize how far I've come?" He smiled and said, "Next time I take you out, I want you to go without the cane." I said, "I can't.

I'll fall." He smiled and answered, "As long as you're with me, you'll never fall." I started using the cane less and less, and I danced in stilettos at our wedding. He was right; with him, I have never fallen.

The Present

So, I called Bonnie a few months ago and told her I wanted to write a paper about her. She was a bit shocked, and we laughed, but I told her I was serious. I will always feel the pain from Isaacs' syndrome, but I do not have to be slammed under a rock, afraid to move and afraid to live. I am a physical therapist who now teaches as a full professor in one of the best OT programs in the country, proof that a person can psychologically crawl out from under the weight of a physically limiting disorder. I believe that regardless of my physical limitations, this amazing occupational therapist would have found some way to help make my life psychologically meaningful.

I am not saying that hard work, dedication, and perseverance will help everyone to overcome adversity, although it certainly cannot hurt. And I cannot overlook all the resources I have had at my disposal, resources with which few people are blessed. This is simply my lived experience of how a special individual was able to help me participate in life again. The participation might be a bit different, but no less fulfilling. As Stoffle (2014, p. 629) so beautifully stated, OT is the health profession that "facilitates reflection on what makes a life worth living and focuses on getting to the work of helping people live their life to its fullest;" the "Stoffle Modus Operandi."

Some have asked what theories or models of practice affected Bonnie's clinical reasoning with respect to my care. Although Bonnie's frame of reference was typically patterned after the *Model of Human Occupation* (Keilhofner & Burke, 1980), her focus for my care was more in-line with the *Occupational Therapy Intervention Process Model* (Fisher, 1998). Bonnie used a very client-centered approach, listening to my concerns and taking a keen interest in my personal goals, including my living situation, family, culture, and desire for more social interaction. There was always an undercurrent of mutual respect, and it was easy to be candid with her about my worries and fears. She worked hard to learn more about my diagnostic condition and then began her top-down approach, identifying my strengths, as well as the things that might hinder my occupational performance. After analyzing my performance, she explained the specific actions that I needed to perform more efficiently. Because there was so much added purpose for each exercise, my motivation skyrocketed, and therapeutic occupation became a central theme toward my occupational goals. I feel very lucky to have had such a powerful intervention.

Conclusion

Here is my testimonial to a wonderful profession and the person who took the time to care and who had the skill to accomplish great things by seeing the diamond in the rough so easily missed by others. OT is a profession that seeks to support "health and participation in life through engagement in occupation" (AOTA, 2020, p. 2). Occupational therapists focus on the application of science toward the goal of motivation and encouragement of patients to actively pursue their most meaningful life. I am forever grateful, and I am honored to be a part of the education of individuals who will one day give so much to so many.

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