

Opinion

A Molecule from Madness: An Exploration into Patients' Illnesses through West Texas Polio

Jonathan Kopel 

School of Medicine, Texas Tech University Health Sciences Center, Lubbock, TX 79430, USA; jonathan.kopel@ttuhsc.edu

Abstract: Neurology holds a unique perspective that embodies the art of capturing a patient's story. Despite medical advancements, many neurological conditions leave patients permanently impaired. This sudden loss of independence can be demoralizing and, in most cases, directly changes a person's identity. It is therefore a necessary part of a neurologist's trade to know their patient's history—their story. Their tales reveal intimate details of their personality changes, memory loss, sensory deprivation, and movement disorders. A true neurologist is a person that remains vulnerable through their willingness to take a history—the story of their patient—and remain curious, vulnerable, and compassionate through their journey to heal and comfort the patient. To understand the patient's illness experience in neurology, the underlying themes of patient recovery (compassion, determination, and patience) are explored with regard to the neurological patient's experience. These themes are then expanded to include the neurology patient's mental perceptions of themselves, and their illness' influences over their identity, recovery, and daily life. In addition to the patient's experience, the neurologist's awareness and emotional response to the patient's illness experience can provide an opportunity to develop a strong therapeutic bond with their patient and improve patient outcomes. Given that their neurological impairment causes a loss of independence and control over their identity and self-worth, neurologists can incorporate the patient's experience into their management and treatment, to better address their emotional and spiritual needs as they come to terms with their identity.

Keywords: neurology; illness experience; perception; identity; story; emotion therapy; patient–physician relationship



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“Sir William Osler was an internist in addition to being a pathologist, and so he had plenty of live patients as well as dead ones. He is reputed to have said (and he may have been restating Hippocrates here): ‘It is much more important to know what sort of a patient has a disease than what sort of a disease a patient has’. To me, this is an excellent working definition of empathy”—Dr. Danielle Ofri [1].

1. Introduction

Despite technological advances, the fundamental component of medicine is embodied within the confines of the physician relationship. Despite the rise of artificial intelligence (AI), patients overwhelmingly desire to have direct physical interactions with their physicians and other healthcare staff [2–7]. According to the Pew Research Center's study, Americans are generally very uncomfortable with the thought of using artificial intelligence (AI) in their own healthcare. Only 39% of United States (U.S.) citizens say that they would feel comfortable if their own healthcare practitioner used artificial intelligence to diagnose illnesses and suggest treatments [2–7]. In addition, a sizable majority of U.S. consumers are reluctant to use an AI chatbot for their personal mental health assistance [2–7]. There appears to be a deep-seated belief in the benefit and power of the physician–patient relationship that AI simply cannot fully replicate. Fundamentally, the physician–patient

relationship requires a consensual relationship between both parties [8–11]. As Fallon Chipidza explained,

“At its core, the doctor-patient relationship represents a fiduciary relationship in which, by entering into the relationship, the physician agrees to respect the patient’s autonomy, maintain confidentiality, explain treatment options, obtain informed consent, provide the highest standard of care, and commit not to abandon the patient without giving him or her adequate time to find a new doctor. However, such a contractual definition fails to portray the immense and profound nature of the doctor-patient relationship. Patients sometimes reveal secrets, worries, and fears to physicians that they have not yet disclosed to friends or family members. Placing trust in a doctor helps them maintain or regain their health and well-being” [12].

As Fallon Chipidza wrote, the physician–patient relationship encompasses four key elements: mutual knowledge, trust, loyalty, and regard [12]. Mutual knowledge refers to the doctor and patient’s understanding of one another. Trust includes both the patient’s confidence in the doctor’s skill and compassion and the doctor’s confidence in the patient’s ability to truthfully report their symptoms. When a patient is loyal, they are prepared to overlook any inconveniences or errors made by their doctor, and they trust that their doctor will not leave them. These four components form the basis of the doctor–patient connection and imply that the patient believes that the doctor loves and respects them as a person first, rather than simply a patient [12]. Despite the increase in imaging and other technologies, neurology is one of the few fields where the history and physical exam within the physician–patient relationship remain an important component of the treatment and healing of patients.

Neurology holds a unique perspective that embodies the art of capturing a patient’s story. Unlike a surgeon, whose tools are the scalpel and suture, the neurologist gains an intimate understanding of their patient by collecting their stories and linking them with their keen eye for observation and clever use of the neurological exam. Even with advances in neuroimaging, neurologists remain dependent on the history and neurological exam. As with an artist, a neurologist becomes intimately familiar with their patient’s illness. Despite medical advancements, many neurological conditions leave patients permanently impaired. This sudden loss of independence can be demoralizing and, in most cases, directly changes a person’s identity. As a result, neurologists traverse the depths of their patient’s consciousness, where the physical and immaterial aspects of human existence collide. It is therefore a necessary part of a neurologist’s trade to know their patient’s history—their story. Their tales reveal intimate details of their personality changes, memory loss, sensory deprivation, and movement disorders. It is through this lens that neurologists learn, as Dr. Sara Manning aptly wrote, that “we are each just a molecule away from madness” [13]. Most medical training has focused on the physical aspects of disease and the use of scientific skills to help with treatment. The personal elements, feelings, emotions, struggles, and changes to a patient’s identity are rarely emphasized. However, reading the stories of neurology patients provided me with a glimpse into the remarkable beauty that my patients’ stories offer, contributing to my growth as a human being and as a healer. To become a great doctor, one must become a loving and remarkable human being, and the only way to do so is through a willingness to remain as vulnerable and open as one’s patients—to be fully human. As Leonore Buckley wrote,

“Illness affects not only the life of the patient, but also the broader circle of caregivers, including family and friends. Willingness to see is the beginning. The next part is recognition: communicating what is seen in a way that helps people to hold their own, because that is much of what living with suffering is, holding one’s own. Recognition is based on a simple, three-part message: I see your suffering; I honour your living with this suffering; I respect that it is an achievement to live as you must, with your illness” [14].

A true neurologist is a person that remains vulnerable through their willingness to take a history—the story of their patient—and remain curious, vulnerable, and compassionate through their journey to heal and comfort their patient. To understand the patient's illness experience in neurology, the underlying themes of patient recovery (compassion, determination, and patience) are explored with regard to the neurological patient's experience. These themes are then expanded to include the neurology patient's mental perceptions of themselves, and their illness' influence on their identity, recovery, and daily life. In addition to the patient's experience, the neurologist's awareness and emotional response to the patient's illness experience can provide an opportunity to develop a strong therapeutic bond with their patient and improve patient outcomes. Given that a patient's neurological impairment can cause a loss of independence and control over their identity and self-worth, the neurologist can incorporate the patient's experience into their management and treatment, to better address their emotional and spiritual needs as they come to terms with their identity.

2. Compassion, Determination, and Patience—Themes from Neurology Patients

Neurology patients face unfathomable hurdles due to their physical limitations and the loss of control and confidence in their own mind and body [15,16]. Curiously, some patients view the experience as enlightening. Dr. Jill Bolte Taylor described her stroke as an enlightening experience involving new sensations and feeling dissociated from the limitations of her body. Upon waking on the morning of her stroke, Dr. Taylor wrote,

“Stepping out of the shower, my brain felt inebriated. My body was unsteady, felt heavy, and exerted itself in very slow motion. What is it I’m trying to do? Dress, dress for work. I’m dressing for work. I labored mechanically to choose my clothes and by 8:15 am, I was ready for my commute. Pacing my apartment, I thought, Okay, I’m going to work. I’m going to work. Do I know how to get to work? Can I drive? As I visualized the road to McLean Hospital, I was literally thrown off balance when my right arm dropped completely paralyzed against my side. In that moment I knew. Oh my gosh, I’m having a stroke! I’m having a stroke! And in the next instant, the thought flashed through my mind, Wow, this is so cool! I felt as though I was suspended in a peculiar euphoric stupor, and I was strangely elated when I understood that this unexpected pilgrimage into the intricate functions of my brain actually had a physiological basis and explanation. I kept thinking, Wow, how many scientists have the opportunity to study their own brain function and mental deterioration from the inside out? My entire life had been dedicated to my own understanding of how the human brain creates our perception of reality. And now I was experiencing this most remarkable stroke of insight!” [17].

Initially, Dr. Taylor mused that her stroke was almost a form of enlightenment, in which her mind was dissociated from the physical limitations of her body. In fact, she felt that it was almost a relief to be outside of her body. Compared to most neurology patients, it is quite odd to hear a patient marvel at their loss of sensation and movement and their dissociation from their body. However, Dr. Taylor's initial sense of wonder transitioned into a fearful realization that her sense of self and identity were slipping away. Her feeling of liberation became a searing reminder that her body was not her own as her awareness diminished.

“I felt tired. I felt vulnerable and completely fragmented as I sat there waiting. Although I was consistently distracted by an enveloping sense of being at one with the universe, I was desperate to carry out my plan to get help. Within my mind, I rehearsed over and over again what I needed to do, and what I would say. But keeping my mind tuned in to what I was trying to do was like struggling to hang on to a slippery fish. Task one, hold the thought in mind; task two, execute the internal perception in the external world. Pay attention. Hold on to the fish.

Hold on to the understanding that this is a phone. Hold on. Hold on for the next functional moment of clarity!" [17].

The loss of identity, as Dr. Taylor observed, strikes at the heart of why neurological disorders can be devastating. It is not the physical but the emotional scars of losing oneself to a disease that one cannot control. There is a lack of stability or sense that one's identity will remain tomorrow. What seemed previously to be a stable element of reality for the patient comes to resemble a fractured wall within their mind. The stable sense of identity that a patient requires for healing becomes unreliable. In a sense, the person's own being becomes untrustworthy. This feeling of vulnerability can be overwhelming without support. Through Dr. Taylor's recovery, she observed three underlying themes common to neurology patients who successfully recover from their illnesses: (1) compassion for the patient and their problems, no matter how troubling or desperate; (2) determination that the problems can be solved, no matter how complex or daunting; and (3) patience, recognizing that time is a factor and success will come in increments.

2.1. A—Compassion

During Dr. Taylor's recovery, she repeatedly observed the difficulty of having family, friends, and healthcare staff understand and empathize with her condition. Even among her neurologists, the physical exam could become an obstacle, focusing on the physical symptoms rather than her emotional needs. A small improvement in her mental status was viewed as relief despite her worries about her recovery. However, her experience with physicians who could listen and empathize was refreshing. As Dr. Taylor wrote during one day in the hospital,

"Eventually my doctor understood enough of my message to comprehend who I was and what I needed. She directed me, "Get to Mount Auburn Hospital." As she spoke, although I could hear her words, I could not grasp their meaning. Feeling despondent, I thought to myself, If only she would speak more slowly and enunciate more clearly, perhaps I could get it, perhaps I could understand. With hope in my heart, I pleaded in a semi-intelligible way, "Again?" With concern, she slowly repeated her directive, "Get to Mount Auburn Hospital." Yet again, I could not comprehend. With patience and genuine compassion for my obvious neurological breakdown, she repeated her directive. Repeatedly, I could not connect meaning to the sounds and make sense of what she said. Feeling exasperated by my own inability to understand her simple language, I primed my vocal pump again and somehow communicated that help was on its way and we would call her back" [17].

Empathy, or the capacity to relate to and comprehend another person's experience, is a necessary component of most human relationships [14,18]. If a doctor has personally experienced the effects of disease, either directly or through a close relationship, this is one factor that predicts whether they behave in an empathic manner [14,18]. A person who is hospitalized becomes a patient, someone who is distinct from others and from the person whom they have always been, thanks to the hospital setting and the plain robe that they wear. They are denied access to the basic objects that give them comfort and serve as reminders of who they are. The hospitalist, a new doctor with whom the patient typically has no prior history, frequently provides care for the hospitalized patient. The hospitalist may feel under pressure to diagnose, treat, and release patients as soon as possible, so spending time getting to know the patient as a person may seem superfluous. Time, therefore, prevents empathy from developing [14,18].

However, the lack of empathy, as it slowly disappears during medical training, is, in large part, related to the structure and socialization process in medicine. The physician Harold Morowitz wrote,

"I suppose that over the past 30 years I have counseled over 500 students wishing to discuss a career in medicine. No one has ever asked, "Do I have enough

empathy to be a health professional?" Hundreds have asked, "Do I have high enough grades in organic chemistry or high enough MCATs to get into medical school?" [14,18].

Within the medical profession, great importance is given to endurance and the capacity to work long hours during practice and training. Empathy is not encouraged by fatigue. Overworked or harried doctors only attempt to complete the bare minimum [14,18]. Most medical students and residents fail to observe the gradual loss of empathy in their patient encounters throughout their training. The personal relationships between doctors and patients that once fostered empathy have been diluted by the complexity of modern healthcare. In most workrooms, physicians are gathered around computers, ordering tests and analyzing data. There is not much time spent in connecting with patients [19]. The team approach to care raises the level of knowledge and monitoring for several physicians. With diffuse care across several specialists, this can impede our ability to empathize with our patients [14,18]. Furthermore, physicians have different attitudes towards chronic illnesses than their patients. In contrast to the general population, medical students and residents are self-motivated individuals that come from the upper-middle to upper class portions of society, with greater access to education, money, and personal support. They are engaged in planning and anticipating their future lives. However, many patients, particularly those who have not had access to the same resources and opportunities, lead lives over which they have little control. The fragility, loss of control, and incapacity to make plans are all worsened by serious and/or chronic illnesses [14,18].

However, empathy underlies the traits of the humanistic doctor and should guide all physicians. How, then, do we foster empathy given these challenges? Simply, it is through conversation. As Dr. Howard Spiro reflected, in his own career as a physician dealing with the pressures and struggles of caring for patients, "Conversation helps to develop empathy, for it is here that we learn of shared experience and feelings " [14]. Many physicians believe that close connections with their patients—through discussions about their families and goals, shared laughs, and anguish over losses—keep them interested in medicine and prevent them from becoming burnt out. These brief exchanges combine over years of practice to create a composite that paints a more complete image of the patient as a person similar to them. In a period of growing bureaucracy and technology, the insights that emerge through connections with patients offer practice, purpose, and intrigue everyday.

2.2. B—Determination

In my experience, neurological illnesses can be emotionally challenging. The brain is not a fixed clock. Some people's brains recover quickly, while other brains need long stretches of time to heal properly. Seeing the same result continuously, over many days, can be demoralizing for both physicians and patients. The urge to quit or give up hope of any healing or recovery becomes almost irresistible. However, Dr. Taylor noted that determination, no matter how long a person's brain takes to heal, is paramount for not only healing but encouragement, for both patients and physicians. In her own recovery, Dr. Taylor wrote that

"Recovery, however you define it, is not something you do alone, and my recovery was completely influenced by everyone around me. I desperately needed people to treat me as though I would recover completely. Regardless of whether it would take three months, two years, 20 years, or a lifetime, I needed people to have faith in my continued ability to learn, heal, and grow. The brain is a marvelously dynamic and ever-changing organ. My brain was thrilled with new stimulation, and when balanced with an adequate amount of sleep, it was capable of miraculous healing" [17].

Time must pass before one can become accustomed to the new realities of living with a disease, yet once a major sickness is diagnosed and while receiving treatment, time passes agonizingly slowly [14]. People often feel as though life is moving slowly when they are

waiting for test results, recovering from surgery, dealing with treatment side effects that make them feel nauseous or exhausted and prevent them from enjoying a family meal, or simply sitting at home for hours without being able to do anything. One of the greatest obstacles is simply getting through each day. Recovery ultimately begins with the capacity to simply move on, to put one foot in front of the other and live each day. Hope underpins the resolve to move on—hope that a cure or treatment will one day be discovered, hope that a respectable life can be rebuilt, and hope that, in the absence of a successful treatment, family, friends, and medical professionals will do everything in their power to preserve a patient’s quality of life and dignity. Throughout sickness, hope is the driving force that propels individuals onward. Without it, it is difficult to persuade patients to adhere to therapy and cope with the hardships that contemporary medical care entails [14].

2.3. C—Patience

It is safe to say that patience is not a virtue of many physicians. We live in a world of rapid results, learning, and responding to different problems—a never-ending cascade of requests and problems to handle, with little control over when or where. As such, our approach to patients can be demanding, even if we do not acknowledge it directly. This can be manifested in our inability to listen and move through our mental scripts of the day’s to do lists. Dr. Taylor noticed this through an interaction she had with a medical student whom she called the “energy vampire”. She wrote, rather annoyed, that

“I awoke early the next morning to a medical student who came rushing in to take a medical history. I thought it curious that she had not been informed that I was a stroke survivor who could not speak or understand language. I realized that morning that a hospital’s number one responsibility should be protecting its patients’ energy levels. This young girl was an energy vampire. She wanted to take something from me despite my fragile condition, and she had nothing to give me in return. She was rushing against a clock and obviously losing the race. In her haste, she was rough in the way she handled me, and I felt like a detail that had fallen through someone’s crack. She spoke a million miles a minute and hollered at me as if I were deaf. I sat and observed her absurdity and ignorance. She was in a hurry, and I was a stroke survivor—not a natural match! She might have gotten something more from me had she come to me gently with patience and kindness, but because she insisted that I come to her in her time and at her pace, it was not satisfying for either of us. Her demands were annoying, and I felt weary from the encounter. I realized that I would have to protect my precious energy with keen caution” [17].

Perhaps our impatience as doctors renders us “energy vampires”: we demand, ask, and expect patients to act, be, and respond in a certain way to our interactions. It is a great irony in medicine that our long track to become and remain proficient physicians produces people who lack patience. In moments of frustration, we often find ways to demean and justify our impatience. As Dr. McGovern emphasized regarding my frustration and annoyance during my training, an important aspect of life is learning to let go of our “intellectual sledgehammer”, remain in the present moment, and appreciate how our presence can be a source of healing. When we define our ability to heal with action, the more benign moments of medical care seem to be hurdles to the next major event towards our next great victory. However, it is by embodying patience that we learn to develop our presence as physicians, which sets the tone for healing and recovery. It is through this process that we become aware of our own biases and struggles, without projecting them onto our patients. It is rather curious that physicians who have experienced illness appreciate the power of patience much more than when they started practicing medicine. As Dr. Harvey Mandell wrote after his surgery,

“At first my illness and surgery gave me more patience with patients who were frightened or couldn’t wait a reasonable time for laboratory and imaging tests

to come back, but eventually that wore off and I guess in the long run I was not more affable than before. For a while it made me better with people who acted in unpleasant ways or who seemed hostile at first meeting. It gave me pause to wonder if their behaviors were governed at least in part by something they weren't sharing with me. I did develop permanently more feeling and understanding for those who failed to get the same sort of support from their spouses that I did." [14].

3. Neurology Patients' Illness Narratives

Discussions about the patient experience frequently and prominently revolve around the patient's perspective or impression of the medical care that they receive [20–22]. Healthcare professionals that try to comprehend the patient's point of view of their experience learn more about the patient's experience. Therefore, it is crucial to remember that a patient's general health and experience with an illness begin long before they access the healthcare system. Although the patient experience varies considerably, patients move through three primary stages from an individual to a patient. First, a patient begins as a unique individual absent of disease or illness. Each person embodies a complex combination of physical, psychological, social, and spiritual backgrounds that are manifested in the context of their family and respective community. Once a person becomes sick, they transition to become a patient. During this process, patients with chronic illnesses can develop anxiety, fear, and suffering associated with their illnesses. As their disease progresses or relapses, these patients begin using healthcare resources and meet healthcare professionals. Through this process, a patient remains deeply embedded in their physical, psychological, social, and spiritual backgrounds. However, patients can feel dissociated or cast out of the "healthy tribe" that they used to easily associate with. As Dr. Susan Sontag described,

"Illness is the night-side of life, a more onerous citizenship. Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick. Although we prefer to use only the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place" [14].

This tension underlying a neurology patient's desire to enter society as a healthy or stable person is related to four primary ways in which a disease impacts one's life: (1) the impact of illness on identity, (2) the emotional response to serious illness, (3) coping and renewal, and (4) life after illness.

3.1. A—*The Impact of Illness on Identity*

A patient's self-image and self-esteem may be severely damaged by an illness that alters their appearance. A patient may have a sense of loss of identity due to the physical effects of their condition. Amputations, colostomies, and other surgical operations, such as mastectomies, attack the body suddenly and alter one's bodily identity. Even more upsetting for patients is the fact that medical professionals frequently fall short of adequately preparing them for the bodily changes that occur along with a serious disease and treatment. In response to these experiences, patients often feel powerless and scared, as these issues are frequent, unanticipated, and beyond their control. Patients are forced to observe, wait, and worry, which can be disheartening. This tension can be seen with Huntington's Disease (HD) patients waiting for their genetic testing results.

"During [genetic] counseling the range of test results is described, including clearly normal, clearly abnormal, and the so-called gray range, where one may or may not develop symptoms of HD. The pros and cons of testing are discussed. A negative (normal) test may relieve anxiety. A positive (abnormal) test may worsen anxiety. A positive test does not affect the ability to obtain health insurance, but it could adversely affect the ability to obtain life, disability, or long-term care insurance. Remember, a positive test result in this context means the laboratory

has identified the DNA variant or mutation associated with HD. It does not mean the person has symptoms of HD, nor can the result accurately predict when symptoms will develop. It only means the individual has inherited the HD-associated variant (mutation) from one of the parents” [23].

As patients learn to live with their illnesses, their ability to work or support others can be disrupted. The inability to perform their routines and activities with their families, friends, and coworkers can be isolating and demoralizing. Although it may appear that being sick would relieve patients of their responsibilities, this suspension of their regular duties comes at a cost. Dr. Arthur Frank described this dilemma, arguing that “Illness excuses people from their normal responsibilities, but the cost of being excused is greater than it appears at first. An excuse is also an exclusion” [14]. Not surprisingly, neurology patients experience similar disruptions and vulnerability in their sense of identity. Given the fact that our sense of identity and self is associated with proper neurological functioning, the feeling that one’s sense of self is “slipping away” can be unbearable. One of Dr. Oliver Sack’s stroke patients described this sensation aptly in his own book, *The Mind’s Eye*:

“When I awoke the next morning in the hospital, I was totally (globally) aphasic. I could understand vaguely what others said to me if it was spoken slowly and represented a very concrete form of action. . . . I had lost completely the ability to talk, to read and to write. I even lost for the first two months the ability to use words internally, that is, in my thinking. . . . I had also lost the ability to dream. So, for a matter of eight to nine weeks, I lived in a total vacuum of self-produced concepts. . . . I could deal only with the immediate present. . . . The part of myself that was missing was [the] intellectual aspect—the sine qua non of my personality—those essential elements most important to being a unique individual. . . . For a long period of time I looked upon myself as only half a man” [24].

3.2. B—Emotional Response to Serious Illness

The three greatest obstacles due to a major disease that patients must face are vulnerability, uncertainty, and a lack of control. Many of the emotional reactions to sickness are rooted in this trio. Individuals are concerned that everything significant to them in life, including their work, physical independence, relationships with their spouses, children, and friends, and maybe even life itself, could be lost or altered. The stakes are great, and the future is unknown. The body is not dependable due to relapses, exacerbations, and the consequences of sickness and therapy. Patients are uncertain as to whether they will continue to live the life that they have been living and, if so, whether it will ever be the same again. Every facet of standard medical care eventually results in a loss of control. Hours are spent waiting, either in line to be seen or on hold while speaking with a medical practitioner to discuss an issue, acquire test results, schedule an appointment, or seek a referral. These feelings were perfectly described by a patient, Amelia, who was diagnosed with HD:

“Entrenched in the same anxiety that had struck her mother—a feeling she now learned could be a predecessor to the movement symptoms of Huntington’s disease—Amelia once again decided to change course. She wanted to know if she had inherited her mother’s genetic mutation. If she had, she would prepare her mind and her muscles to be the strongest they could be when the disease eventually took over. She would travel, witnessing the world while she could still talk to strangers and board buses. Perhaps, she thought, she would adopt children. Pacing around her apartment one morning, Amelia spoke to a nurse at Huntington’s disease clinic. She described images from her mother’s demise and explained why she wanted to be tested for the gene that haunted her. She went into a clinic and talked with a psychiatrist, a neurologist, and a genetic counselor. She spat into a clear plastic tube and watched as the saliva was tucked away into

an envelope to be sent to a laboratory in another state, where her future would be decoded" [13].

Finding comfort amid the pain that results from losing the life that the patient had planned to live is difficult, particularly if the patient believes—correctly or incorrectly—that it might have been avoided. Many people are persuaded that their disease is directly related to what they have done or have not done. Many individuals are immobilized by their frustration with a healthcare system and insurance programs that are not set up to be responsive to their requirements. Patients often become upset with friends and coworkers who do not provide adequate support or who completely disappear. Patients may endure several difficulties and setbacks that, despite their best efforts, they have little control over, and they are more prone to burnout or giving up. Many patients can give up, especially if they are physically weak or worn out, or have expended all their personal and financial resources. Due to their social environment, financial constraints, or a lack of education, people who have had little control over their personal lives frequently approach illness more passively from the beginning and are less likely to be hopeful that anything they do in terms of treatment will affect the outcome. Ultimately, patients may see suicide as the last resort to take control of their situation. As Dr. Bird wrote regarding one of her HD patients,

"Robert would not be in the room to discuss genetic testing. Forty-five years old, he was from a small farming community about 150 miles away from the clinic. His father had died with HD. Robert came to the clinic with his wife. He was calm, articulate and determined to proceed with testing. His neurological exam was normal but his genetic test revealed the HD mutation. He accepted his positive result with a nod of his head and a shrug of his shoulders. He said he wasn't too surprised and was resigned to the outcome. Unfortunately, what he meant by "resignation" was unexpected. He returned home and a few days later killed himself with a shotgun. This came as a complete shock. He had given no clue to his family or to our clinic team that this was his intention" [23].

3.3. C—Coping and Renewal

After the diagnosis of a serious or life-threatening disease, patients undertake the difficult work of managing their everyday stress and uncertainty, rearranging their lives and relationships, and continuing on to find happiness in a new, often physically more constrained life [14]. They must try to find purpose, calm, and enjoyment in their daily lives, as well as to sustain or repair their connections throughout time. Whilst few people claim to have encountered God during their sickness, patients frequently find great comfort in their relationships with God, as well as in their relationships with the clergy and others in their religious communities. Religious ideas about the purpose of life, pain, and the afterlife provide comfort to individuals who are suffering. Their isolation and vulnerability diminish as they discuss their connections with God in prayer [14]. Even those without strong religious convictions can find comfort and solace in their spiritual lives as a method to cope with uncertainty, worry, and grief. Many people find calm and comfort in nature's stillness and beauty when they spend time outside.

After fully recovering from a catastrophic illness, some people return to their previous lives, generally with new insights [14]. It is difficult for patients to give up the dream of returning to their previous life, job, family obligations, and interests. Finding the drive to continue forward may be much more challenging. Returning to work is a key component of rehabilitation for those who are well enough, since it is a significant component of our identities [14]. Although relying on disability allowances while unable to work is initially desirable, it may be discouraging. Returning to work or reestablishing a regular pattern that gives the day direction and purpose might take years. For patients with permanent impairments, finding a job is made much more difficult by a lack of resources, access to transportation, and education. Throughout sickness, relationships with family and friends can undergo significant upheaval [14]. However, there is no other period in life in which intimate connections are more crucial. Relationships provide patients with mental and

physical support, allowing others to be with them, listen, comfort, assist, laugh, and divert their attention. Frequently, these connections become stronger over time. However, feelings of isolation can be exacerbated by disappointment with friends, family members, and coworkers. Time must pass before one can become accustomed to the new realities of living with a disease, yet, once a major sickness is diagnosed and while receiving treatment, time passes agonizingly slowly [14]. Recovery ultimately begins with the capacity to simply move on, to put one foot in front of the other and live each day.

3.4. D—Life after Illness

The pace of life is slowed down by illness, along with the exhaustion, physical limitations, and time away from home and work required for testing and treatment [14]. Patients are forced to change their usual routines. The absence of regularity can be unsettling, but it also presents an opportunity for leisurely reflection and time to consider the fundamental aspects of life that contribute to happiness and purpose. While very few people claim that their sickness has changed them completely, it often changes one's perspective on life. Many individuals develop greater levels of tolerance, reflection, and gratitude for the little things while they reevaluate their ideals and relationships [14]. As a patient returns to their prior life, they are frequently not the same person. Patients often develop a more pessimistic outlook on life. Patients may develop frustration at the failure of their body to function as they anticipated it would [14]. Even when the illness is in remission or has been healed, anxiety and sadness can prevent patients from reestablishing connections and a daily routine, returning to work, or making future plans. The deconditioning brought about by disability might make anxiety and insomnia worse [14].

4. Emotions and Empathy of Physicians towards Patient Illness

Empathy is made easier when one can relate to someone and regard them as similar to oneself. As Dr. Leonore argued,

“One of the hard things to learn in medicine, even harder to teach, is what it feels like to be a patient. In the old days, when serious illness was a more commonplace experience, shared round by everyone, the doctor had usually been through at least a few personal episodes on his own and had a pretty good idea of what it was like for his patient. A good many of the specialists in pulmonary disease who were brought up in the early years of this century had first acquired their interest in the field from having had tuberculosis themselves. Some of the leading figures in rehabilitation medicine had been crippled by poliomyelitis. And all physicians of those generations knew about pneumonia and typhoid at first hand, or at least once removed, in themselves or their immediate families” [14].

In addition, the environment in which physicians offer care is one with significant institutional impediments to empathy. Doctors are more likely to perceive their patients as whole people—in all of their roles—and to be familiar with their families in small areas where they live and regularly interact with their patients. Nonetheless, because of the complexity of medical practice and the need for efficiency, treatment is usually provided in centralized locations. Many physicians rarely develop a perception of the patient as a person in these situations. As a result, a patient's emotional concerns are frequently effectively concealed. Furthermore, the training of most physicians emphasizes a version of stoicism embodied by Sir William Osler. As Danielle Ofri explained,

“Despite this, the conventional stereotype that doctors are fairly emotionless continues to maintain its hold. Many trace this back to the eminent Canadian physician Sir William Osler, often considered the father of modern medicine for such revolutionary ideas as whisking medical students out of the staid classroom and bringing them to the bedside to learn medicine by examining actual patients. The current educational system of clinical clerkships and residency training is largely attributed to Osler, as are hundreds of snappy quotations. His continuing

influence is apparent in the scores of diseases, endless libraries, and numerous medical buildings, hospital wings, societies, and awards that bear his name" [1].

Sadly, there are many obstacles to patients and clinicians discussing psychological difficulties [14]. Some doctors feel uncomfortable addressing emotional concerns with patients and are unsure of what to say or do to aid them, either due to personality issues or a lack of training. Others believe that if it was not included in their training, it should not be included in their duties. Many patients, however, prefer to speak with a doctor whom they already know and trust, who is familiar with them. Many patients find it far more acceptable to discuss psychological difficulties with their doctor, rather than a counselor or social worker. When a doctor appears to be busy, a patient may be hesitant to discuss particularly personal matters. In the bustle of daily practice, the indirect indicators of a patient's misery—missed appointments, noncompliance, signs of worry, melancholy, irritation, or apathy—are disregarded or used as an excuse. Consequently, where should we start? The task is difficult because of the complexity and uniqueness of each person's condition, personality, personal support (or lack thereof), finances, religion, and cultural background. However, showing an interest and curiosity in the patient as a person can make a difference. Dr. Leonore described a story from one of her students regarding this idea. She wrote,

"A fourth-year medical student told me about the approach of a neurologist she admired who specialized in the treatment of multiple sclerosis. 'The first thing he did when he took a new patient history', she said, 'was to ask the person questions about their life. Where were they from? How many children did they have? Any children still at home? What kind of work were they in? What were their hobbies?'" That initial conversation allowed him to personalize the conversation later. If he did confirm the diagnosis of MS in the subsequent history and physical examination, that discussion was facilitated by the relationship he had already begun to establish. His interest in the patient as a person led them to trust him. Patients felt like they were talking to someone who knew them and appreciated them as a person" [14].

There are few questions that disclose the specifics of the patient's life, despite the fact that we spend a lot of time in medical school becoming familiar with the "script" of their history taking and physical exam [14]. The social history portion of the exam is typically framed as a questionnaire regarding the patient's job, marital status, and habits (smoking, drinking, drugs, and sexual activity), whereas the family history is often restricted to questions about disease and death (how often, with whom, and how). Despite their importance, these questions only reveal a portion of the patient's story. By asking them, we separate the patient from the person and the disease from the ailment [14]. However, unscripted questions about a patient's family, favorite sports teams, employment, hobbies, and interests bring the conversation back to the subject at hand. Furthermore, these questions establish a respect towards the patient that makes it easier for the doctor and the patient to establish a relationship. The ability to empathize with the patient and value them as a person inspires the doctor to be a better communicator, educator, counselor, and advocate. Moreover, they give the impression to the patient that they value their input and their background enough to spend additional time getting to know them [14]. Conversations about personal matters are considerably more likely to occur after this kind of friendship has been developed.

Both patients and physicians naturally tend to look away or rapidly change the subject in order to spare the individual from humiliation or pain when confronted with negative emotions or topics that touch on death and/or suffering [14]. However, when a doctor looks away or turns away, it suggests that the subject is improper or that they are uneasy or indifferent. Regrettably, most physicians have, at one time or another, been harsh or insensitive while delivering information that might change someone's life, regardless of whether they mean to or not. Physicians occasionally hasten or become sidetracked by the

hundreds of pieces of data that need to be gathered, examined, and used on the day to decide on a course of therapy. Furthermore, physicians digest so much information that they can easily lose sight of its significance and the individual effects that the blunt delivery of medical information can have on a patient. As Dr. Ofri surmised in her assessment of physicians that do or do not address their emotions or respond to their patients' emotions,

“But no matter how it's portrayed, and no matter how many high-tech tools enter the picture, the doctor-patient interaction is still primarily a human one. And when humans connect, emotions by necessity weave an underlying network. The most distant, aloof doctor is subject to the same flood of emotions as the most touchy- feely one. Emotions are in the air just as oxygen is. But how we doctors choose—or choose not—to notice and process these emotions varies greatly. And it is the patient at the other end of the relationship who is affected most by this variability” [1].

Physicians often make the error of talking about illness as an intellectually stimulating topic, rather than as a serious occurrence that disrupts their patients' lives. Doctors discuss disease in terms of pathophysiology and therapy throughout training and in their professional lives daily. This is done using technical terminology that speeds up the discussion and separates the knowledge from its emotional implications for the patient. This type of communication is suitable for interactions between doctors and other healthcare professionals. However, it becomes an issue when we neglect to alter the discourse when speaking with patients about their illnesses. What, then, is the secret to presenting information to patients in order to foster the appropriate emotional and therapeutic support? Simply, physician communication regarding difficult topics should focus on the humanity of the patient, rather than focusing solely on the illness itself—in other words, framing the disease within the context of the person, rather than the person in the context of the disease.

“Paying attention to emotions within the doctor-patient interaction doesn't guarantee healing, no doubt. But ignoring them surely makes it less likely. Thirty-six years after Dr. Osler's “Aequanimitas” speech, Dr. Francis Peabody gave another commencement address to another graduating class of eager medical students. He summed up his ideas in this now famous phrase: ‘The secret of the care of the patient is in caring for the patient’. In this deceptively simple axiom, he encompassed compassion, empathy, and human connection, along with all the medical technologies and therapeutic modalities that a doctor can offer to a patient. Beyond curing, this is what offers the possibility of healing” [1].

5. West Texas Polio—Lessons from a Post-Polio-Syndrome Patient

Through the stories of neurology patients' illnesses, I was fortunate to learn the valuable lessons that a patient's story can provide in understanding and appreciating the human spirit. Working with neurology patients and their families solidified my passion for this specialty. In the clinic, I became close friends with a post-polio-syndrome patient who struggled with the progressive loss of lower extremity function despite recovering from polio during the Great Depression. His appreciation for my willingness to listen and help to guide his care goals left an indelible mark on my life. Through our interactions, I learned more about his story and the impact that polio had on the lives of patients in West Texas.

Polio outbreaks were a common occurrence in postwar America, and it often spread fear across both rural and urban regions of the United States [25,26]. Communities and families attempted, with varied degrees of success, to cope with the condition. Before World War II, polio outbreaks were a common occurrence, particularly during the summer months. Despite the fact that polio had been present in the American population for decades, an event occurred in the mid-1940s that caused it to spread more rapidly than in previous years [25,26]. As Americans grew more mobile after WWII, these areas often witnessed fast expansion and became considerably less isolated from the rest of the globe. This supports the theory that the polio outbreaks in the 1940s and 1950s were connected to

postwar economic expansion, which coincided with a massive increase in polio cases [25,26]. Patients and clinicians struggled to learn how to cope with and treat polio due to a lack of reliable knowledge of the disease's etiology and course at the time. Meanwhile, community leaders looked for and tested a variety of prevention techniques to avoid new outbreaks. This was particularly the case in cities located in rural regions, such as San Angelo in the West Texas region [25,26].

San Angelo was a peaceful, largely isolated West Texas stock-raising area before WWII. It was largely an army garrison and a way stop on livestock drives heading for railheads further north in the previous century [25,26]. San Angelo saw a devastating outbreak of polio in the summer of 1949, causing widespread alarm and demonstrating the hysteria that a significant polio epidemic may produce in a city. Some residents responded well, overcoming their anxieties to assist in the handling of an uncontrollable disaster [25,26]. Others allowed their reasonable concern to overcome them. Some even regarded the polio pandemic as a commercial opportunity. San Angelo had the highest polio rate in the country in 1949, with 420 recorded cases and 28 fatalities. Similar outbreaks occurred throughout the West Texas region [25,26].

By the mid-1950s, polio immunization began to expand rapidly in the United States and became ubiquitous by the mid-1960s. Success arrived rapidly. Iron lungs were quickly mothballed and subsequently dumped by hospitals that had had wards full of them. However, those afflicted by the previous polio outbreaks experienced periods of temporary or permanent paralysis that affected their daily lives. Those who seemingly recovered later developed a resurgence of their polio symptoms, known as post-polio syndrome. In this work, one West Texas polio survivor with post-polio syndrome, Dewain Collins, was interviewed to discuss his experience with polio during the mid-1950s and subsequent years into his retirement. His story provides insights into the unique challenges and impacts of the polio pandemic on communities and families, as well as the lessons that it provides for the management of neurology patients in the 21st century.

6. Interview with Dewain Collins in West Texas

"The Scottish Rite Hospital for Children in Dallas, Texas, will be 100 years old in this year. It was established by the Masons (Masonic Lodge) to do charitable work for children in need of Treatment for the dreaded Infantile Paralysis (POLIO) that was raging at the time. The medical Community didn't know where it came from, what caused it, how to treat it, etc. I was a patient beginning in 1937. Born in September 1936 and just learning to walk in 1937. We had a farm, 160 acres, and lived 17 miles from Weatherford, Texas. This was the 1930's during the depression and times were tough. We raised cotton, corn, and peanuts; we also had cattle, hogs, and chickens. We had food to eat but no money. We had a car but put it up in blocks so the tires would not rot because we couldn't afford gasoline. This farm was on the county line between Parker & Hood counties, and we farmed with a team of horses.

About August 1937 my dad hooked a team to a wagon and mother, dad, and sister (who was about 9 years old), we went down the road about 2 miles to a neighbor's house for Sunday dinner. Sometime that afternoon I began to get sick. We returned home and I laid around for three or four days. Home remedies were the thing at the time, but my family decided they had to take me to the doctor in Weatherford, 17 miles of dirt road. We asked a neighbor to take us. The doctor diagnosed the problem right away and said, 'This child has infantile paralysis'.

I was paralyzed from the waist down. My legs would blow in the wind like a leaf on a tree. The doctor mentioned to find a few Masons and get their signature to get him into the Scottish Rite Hospital for Crippled Children in Dallas [27].

In 1921 the Masons in Dallas were looking for some charitable something they could do and there was only one Orthopedic Surgeon in Dallas. They wanted to build a hospital to treat these children and they asked him if they built a hospital would he practice there. That was the beginning of the Scottish Rite Hospital and the doctor's name was Dr. Carroll.

I don't know how we got there the first time but when we checked in, the hospital told my folks you can see this child from 2–4 p.m. on Sunday but it would be best if you didn't come to see him at all because of his age and he would want to go home with you. They couldn't afford to come on Sunday anyhow. The first thing they did was strap me to a board. There are three types of (POLIO), muscular, respiratory, and spinal, and not much was known about the disease and they were afraid I might have spinal, which causes a curvature of the spine.

My folks went back home and with no electricity or telephones they couldn't even call to check on me. When school started in September the school wouldn't let my sister go to school. They were afraid she might be a carrier as not much was known about it. The rural mail carrier ran every day except Sunday and the hospital wrote a letter and said come and get me. Always in the letter were two train tickets (round trip) from Weatherford to Dallas and back. We still had to get to Weatherford to catch the train.

When we went to the hospital, we never knew whether I would have to stay or not. Sometimes I would have to stay for 6 or 8 weeks. The school at Dennis would let me make up the classes I had missed. Once after an operation they put walking casts on my legs and I was supposed to walk on them, but I couldn't. I'll never forget that the doctors kept trying to get me to walk without my crutches, but I wasn't interested. For with them I could keep up with the other children on the farm and without them I was limited. But somewhere about age 10 or 12, I quit using them all the time and only used them when I had to do a lot of walking.

As a child I remember that once we were going to go to town, Weatherford, which we didn't get to go very often. As usual a child does more crawling than walking, I wore braces on my shoes and wore a hole in the toe of one shoe. I was embarrassed about the hole, so I took an old newspaper and stuffed into the hole and then polished it and the shoe with shoe polish. It didn't look that much better, but I felt better about it. My school was taken to the state fair and I got separated from the rest of the class and was standing there on crutches crying. A man walked up and wanted to know what was wrong. I told him I couldn't find my class and he said something like, "Don't worry, you'll find them". He gave me around 50 cents; a few moments later, someone else walked by and gave me a quarter, and then another and another. First thing I knew I had a \$1.75 and I found the others in my class. I bet I didn't have over 50 cents to start with.

I finished high school and had no idea what I wanted to do. My family said I should go to college. I stayed with my aunt & uncle during the week, and I would ride with her to school and catch the school bus back to her house in the afternoon. On Friday, I would pack a suitcase and leave it in her car. After school I would walk a few blocks, get the suitcase, and walk out on the highway and hitchhike home, most of the way on a dirt road. At College, I learned a big lesson. Most students had a job, a car, and a girlfriend, and I had nothing. When that year was over, I went home and told my mother I was leaving in the morning. "Where are you going", and I told her somewhere in West Texas. My father had left us many years ago and lived in Levelland. He was always talking about the opportunities in the Oil field. My brother was working on a ranch near Weatherford and was using the only car we had, and I asked him to take me to the highway the next morning.

On his way to work I would hitchhike to Levelland. We didn't know our dad very well. We would see him once or twice a year for an hour or so, but I knew where he lived. I showed up on his doorstep and he said, 'What are you doing', and I said, 'Looking for a job'. 'Well, we'll help you find one'.

I found a job with Halliburton, which was in Eunice, New Mexico. My dad didn't have any money, so I hitchhiked home to borrow some money. Mother said, 'Honey I don't have any money', and I knew she didn't. I said, 'Let's go to the bank', but she knew they wouldn't loan money for a job. She finally went with me to the bank, and they were not impressed that I had a job. They finally agreed to loan me \$100.00 if she would co-sign.

She said she would take me to the bus station the next morning but a bus ticket to Levelland was less than \$10 and I knew I might need that money before I got paid. Again, I

hitchhiked back to Levelland. On Sunday my dad took me to Eunice, and I found a place to live. I got that job, then a car, and then a girlfriend, married now for 60 years. I spent 2 years with Halliburton in Eunice and Lovington, and, like a dumb kid, I quit and moved back to Texas. I went to work for the Texas Department of Public Safety as a Dispatcher, then became Supervisor, and stayed 40 years. Retirement didn't fit me so now I work for Allen Butler Construction. I gave them up and walked without them for 60+ years. After I got old (84 years old now) I use them again. What was a devastating blow in my young life, God put the opportunities there for a full rich life".

7. Conclusions

As Dewain's story illustrates, the polio pandemic caused significant disruption to the childhoods and young adulthoods of millions of Americans [27]. Leg braces and iron lungs, which were prevalent prior to the announcement of the Salk vaccination, are now considered historical artifacts. The massive cylindrical devices were medical marvels because they allowed individuals to breathe again after polio had devastated their respiratory muscles. They were, nevertheless, also sources of dread. Parents envisaged their polio-affected children being confined to iron lungs simply to keep alive. Dewain's story embodies the true courage and bravery that neurology patients must summon in order to face their illness and still live meaningful and exciting lives.

Neurology patients face many challenges on the road to recovery. Several neurological conditions leave patients permanently impaired. This sudden loss of independence can be demoralizing and dramatically impacts a patient's perception of their identity and self-worth. Through the narratives of neurology patients, neurologists can incorporate the patient's experience into their management and treatment to better address the emotional and spiritual needs of their patients as they come to terms with their identities. As Dr. Buckley wrote,

"So, the challenge as you start practice is to make sure that there is enough quiet time in your professional career for you to have a chance to notice, listen, wonder, and maybe even write about the important things that happen every week. This peaceful time to clear your mind and reflect about people, society, values, and your own actions and reactions will help you to keep the important things in perspective, and will allow you to be the physician you hope to be" [14].

In the final analysis, we are "all a molecule away from madness". The denial of our shared humanity with our patients is a fundamental flaw in modern medicine. When we objectify a patient's experience in physical terms, we lose our capacity to respond and interact with the patient's identity and story. Human beings are ultimately a reflection of society and the narratives that it presents. In this context, patients are reflections of ourselves and the stories that we chose to embody in our pursuit of healing and truth. What we need is not more knowledge. What we need is courage. Without the uncertainty that patients force us to confront, it is my assessment that we will never truly understand what being a physician is unless we learn to confront the truth that lies in front of us. As the historian Sven Lindqvist wrote,

"Everywhere in the world where knowledge is being suppressed, knowledge that, if it were made known, would shatter our image of the world, and force us to question ourselves-everywhere there. You already know that. So, do I. It is not knowledge we lack. What is missing is the courage to understand what we know and draw conclusions" [28].

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