Behind the Medical File

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Patty knows exactly what the truck coming down the street means. As a child, she would spot her father's truck turning onto their road and calculate, in the seconds she had left, whether there was time to disappear. He was a belt user. The fear was constant — and, as Patty eventually figured out entirely on her own at age 68, that relentless childhood stress is almost certainly part of why her nervous system has been in a state of revolt for the past two decades (Patty, 2026). Her doctors never made that connection. A Facebook researcher at the Mayo Clinic did. That says something.

For this interview project, I spoke with Patty across two recorded sessions using Arthur Kleinman's (1988) eight-question explanatory model of illness as a guide. I should be transparent: Patty is my partner's mother. I walked into her house already knowing she had fibromyalgia, that she was stubborn in the best viable way, and that she would talk for as long as I had recording space. What I did not know — and had no idea I was about to learn — was the full architecture of two decades of chronic pain, medical indifference, pharmaceutical gaslighting, and hard-won survival. This paper argues that Patty's narrative reveals a fundamental gap between how fibromyalgia is managed medically and how it is actually lived — a gap built from dismissal, unexamined trauma, the stigma of invisible illness, and a body of experiential knowledge her healthcare providers never thought to ask about (Patty, 2026). Kleinman's (1988) explanatory model makes that gap clinically visible. Patty's story makes it impossible to look away from.

Summary of the Interview

Rather than marching through Kleinman's (1988) eight questions in order like a checklist — which, with Patty, would have lasted approximately one question before she redirected the

conversation — I used them as a flexible framework and let her lead. The picture that emerged was of a woman who had spent twenty years teaching herself what fibromyalgia was doing to her body, because the people paid to do that never did. She follows a Mayo Clinic researcher she calls “Dr. Fibromyalgia” on Facebook, she learned about the seven-stage classification system from her online support group, and she recently began using a $10 jar of magnesium glycerin cream on a neighbor’s advice — noticing measurable improvement within four days (Patty, 2026). Her rheumatologist of fifteen years recommended none of it.

On causation, Patty assembled a history no single appointment had ever pieced together. She cited her grandfather’s lupus as a likely genetic thread — lupus and fibromyalgia share immune dysregulation and chronic pain pathways (Clauw, 2014) — and described childhood symptoms dismissed as growing pains: “My mom used to come in the bedroom and literally lay on my legs with her whole body weight to calm my body down so I could sleep” (Patty, 2026). Her years as a flight attendant, before a head injury changed everything, were actually her healthiest: “I didn’t hurt. It was like anything that could bother my body went away for those few years” (Patty, 2026). Away from stress, she was essentially symptom-free. Then came the head injury, then 9/11, then a brutal job — and the body remembered all of it. Most significantly, Patty connected her childhood trauma to her onset entirely on her own, at 68: “My father was very brutal. He was a belt user. All of those times of being afraid — that’s constant stress. And children should not have to deal with that stuff” (Patty, 2026). When I mentioned that her mother had also claimed fibromyalgia symptoms, Patty was succinct: “Bullshit. It came from the Briley side” (Patty, 2026).

In describing what fibromyalgia does to her body daily, Patty was precise where medicine is often vague. Her hips are the primary site — tendon pain, not bone pain, a distinction

she makes firmly, contrasting her condition with Randall's hip replacements for bone pain (Patty, 2026). Flares run on a three-week cycle — preceded by migraines and arriving, as Patty described it, "almost like a period." She wakes most nights at 2:30 a.m. and migrates to the couch — one of those invisible management routines that chronic illness demands and no one bills for. She leans on the grocery cart for support on bad days. She recently learned she is at Stage 6 out of 7. Her reaction was characteristically dry: "I did not even know fibromyalgia had stages." Then, after a beat: "I don't think they know" (Patty, 2026). Her rheumatologist, Dr. T, spent fifteen years dictating notes into a microphone rather than speaking to her, and never forwarded documentation to her primary care doctor (Patty, 2026). Prescribed pharmaceuticals clouded her cognition so badly that "people thought I was crazy, because I stammer" (Patty, 2026); when she eventually stopped taking them, her brain fog lifted. She now manages with magnesium cream, cannabis, daily bike rides, and prayer. Her goal is not a cure but continued movement — including, one day, boarding Randall's sailboat, which requires the hip rotation her injury has not yet permitted (Patty, 2026).

The social costs of fibromyalgia have been, in some ways, as disabling as physical ones. Friendships have ended over it: "I've had people tell me, if you're going to live like that, I'm not your friend anymore" (Patty, 2026). Her late husband Jack told her to stop talking about her fibromyalgia in public; his brother Charlie, to his credit, pushed back: "Even if you don't understand, give a little courtesy" (Patty, 2026). That external silencing eventually became internal: "I have this fear that I have to keep quiet about it because I do not want to lose somebody else close to me. It is a made-up fear in my head, but that is what I think about a lot" (Patty, 2026). She and Randall have also chosen not to marry — in part because the financial penalties of legal marriage would make both their lives materially harder — a structural

consequence of chronic illness that appears in no clinical note, on no treatment plan, and presumably in no microphone dictation (Patty, 2026).

Analysis

Kleinman (1988) drew a foundational distinction between disease — the biomedical pathology a clinician can name and code — and illness — the lived, meaning-laden experience of suffering embedded in an actual human life. Illness encompasses "the personal and social meaning the patient gives to the disorder" and "how the illness affects his relationships and social roles" (Kleinman, 1988, p. 4). On paper, Patty's disease is a central sensitization disorder (Clauw, 2014). Her illness is the truck coming down the street, the husband's command to be quiet at the dinner table, the sailboat she cannot yet board, and a body that finds neither sitting nor standing tolerable for long. Häuser et al. (2011) documented significantly elevated rates of childhood emotional, physical, and sexual abuse among fibromyalgia patients, and Clauw (2014) identified central sensitization as a state that chronic early-life stress can initiate and perpetuate. That Patty assembled this connection at 68, via a Facebook page rather than a physician, is not a footnote to her care history. It is the headline. As Kleinman and Benson (2006) argued, genuine cultural competency requires attending to the patient's own framework of meaning — a practice that was, by Patty's account, almost entirely absent across two decades of treatment.

Mishler (1984) described the central dynamic of clinical encounters as the "voice of medicine" systematically suppressing the "voice of the lifeworld" — the patient's narrative of how illness fits within an actual life (p. 91). Dr. T, with his fifteen-year microphone habit, is essentially a case study for this. He talked in the room; Patty talked to a doctor who was not listening to her. Buchbinder (2010), drawing on Kugelmann (1999), described the "genre of complaint" as a narrative appeal for moral recognition of suffering that has gone

unacknowledged (p. 117). Patty has been making that appeal for an exceptionally long time. She has also moved, with characteristic practicality, from complaint to advocacy: when she meets newly diagnosed women, she tells them that the "new" drug is the same compound with one letter changed — clinical knowledge she earned the hard way, free of charge (Patty, 2026). Randall's sustained optimism has genuinely helped; perceived social support is one of the strongest modulators of fibromyalgia symptom severity (Clauw, 2014). Prayer works alongside that: "I give it to God. It gives me calm, it gives me peace" (Patty, 2026). Kleinman and Benson (2006) argued that cultural competency requires attending to the patient's spiritual life as well — a dimension clinical encounters routinely ignore. Frank (1995) identified the "quest narrative" as the form a story takes when someone transforms suffering into something that can be passed on to others (p. 115). Patty is doing exactly that: "I'll be glad to answer whatever question I can to help you find your way" (Patty, 2026).

Conclusion

I admit that I came into this interview thinking I had a reasonable sense of who Patty was warm, direct, occasionally profane in an endearing way, and navigating a chronic illness with considerable grace. I was wrong in almost every direction. I did not know the architecture of her pain — built from a childhood spent flinching at the sound of a truck, shaped by a head injury at 40,000 feet (about 12.19 km), and managed for fifteen years by a doctor who found his microphone more interesting than his patient (Patty, 2026). I did not know her healthiest years were spent as a flight attendant, that she has been her own clinical researcher for two decades, or that the thing she fears most is not the wheelchair but the ongoing social pressure to stay quiet about her pain. I did not expect her answer when I asked how she wanted to be remembered: "Dignity. I pushed through. I came out the other side and kept on going" (Patty, 2026).

The gap between a textbook description of fibromyalgia — widespread pain, fatigue, cognitive disruption (Clauw, 2014) — and the life Patty described is exactly the gap Kleinman (1988) argued the explanatory model exists to close. Her illness is the truck, the 2:30 a.m. couch, the sailboat she cannot yet board, the friend who walked away, and the brother-in-law who still calls on Mother's Day to ask how her body is doing. The explanatory model surfaces all of it — the biological, biographical, relational, and structural dimensions that Häuser et al. (2011) and Kleinman and Benson (2006) have identified as inseparable from effective, humane care. Patty spent twenty years assembling this picture herself because no clinician ever thought to ask. Kleinman's model insists on the question: not just what is wrong with the body, but what does this mean to you, in your life, on your terms. All the healthcare system has to do is ask — and then, critically, stop talking into the microphone long enough to actually listen.

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