What my Grandma’s schizophrenia taught me

Lance Reidenbach, MPH

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Grandma was sitting in her chair in the corner of the living room, and her eyes were wide, filled with fear and suspicion as she glanced between me, Mom, and Papa. “They are out to get me,” she said, slightly frantic. She glanced down at her right hand, fixated on a spot on the dorsum. Gingerly lifting her arm, she angled her hand toward my mom’s face. “You see that? They have been conducting experiments on me. I AM THE QUEEN,” she sobbed, “and you are planning together” she said, directing her attention to Papa and me. In that moment, Grandma was convinced Papa and I were conspiring to assassinate her. It hurt to see my grandmother look at me with genuine fear in her eyes. It was overwhelming to watch her deteriorate from the person I had been accustomed to for most of my life to the paranoid individual shaking in front of me.

This was the first time I had really observed my grandmother experiencing acute psychosis. My mom explained to me at a young age that my grandmother had an illness in her mind. I noticed that compared to other people in my life, my grandmother seemed to express less emotion and changed topics in conversations frequently, but by having an understanding provided by my mother, my brother and I didn’t think much of it; that was just Grandma. She would occasionally talk about her experiences with hearing voices or people on the television talking about her. For the most part, though, she was stable; she was able to carry out cleaning, cooking, and watching her favorite shows.

That was until she turned 65 and started on Medicare for insurance. The government required her to trial a less expensive medication and wanted her family practitioner to adjust the medications she had been on for years. This decision was made by people unfamiliar with my grandmother and her story. As a result, my family struggled alongside Grandma for over a month as she battled hallucinations and labile emotions. Living in rural Ohio, she had no access to a psychiatrist or other mental health professional during this period. The adjustments to her medications, changes in her insurance coverage, and lack of consistent psychiatric care led to a deterioration of her stability. This was the only time in my life that I saw Grandma at a place where she would have needed to be hospitalized if the symptoms lasted much longer. I spent evenings sitting with her in that dark and scary place, listening, sympathizing, and challenging her distortions of reality. This experience laid the foundation for my growing passion for providing care and advocating for people experiencing mental illness. I observed firsthand how the absence of consistent, compassionate, and informed care could lead to psychiatric hospitalization.

Lance Reidenbach, MPH

Mr. Reidenbach is an MD candidate, Northeast Ohio Medical University, Rootstown, Ohio.

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In the past, my grandfather hid my grandmother’s diagnosis from those around them. This approach prevented my uncle from disclosing the same information to my cousins. I observed how they would look at her with confusion and sometimes fear, which was rooted in a lack of understanding. This desire to hide Grandma’s schizophrenia stemmed from the marginalization society imposed upon her. There were sneers, comments regarding lack of religious faith, and expressions that she was not trying hard enough. My grandparents decided together to inform their church of my grandmother’s illness. The results were astounding. People looked at my grandmother not with confusion but with sympathy and would go out of their way to check on her. Knowledge is power, and awareness can break down stigma. Seeing the difference knowledge could have on a church community further solidified my desire to educate not only patients and their family members but also communities.

Access is another huge barrier my grandmother has faced. There is a lack of referring and awareness as well as large geographic disparities of psychiatrists around my hometown. My grandmother has also had struggles with being able to pay for services, medication, and therapy. This shows the desperate need for more mental health professionals who are competent and knowledgeable in how social determinants of health impact outcomes. These factors contributed to my decision to pursue a Master of Public Health degree. I aspire to use this background to prevent what happened to my Grandma from happening to other patients and to be an advocate for enhanced access to services, improving community mental health and awareness, and promoting continuity of care to increase treatment compliance. That is what my Grandma has fostered in me as a future psychiatrist.