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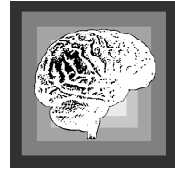
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Personalia

Forty-five years of schizophrenia: personal reflections

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Views about schizophrenia can change dramatically, even within one lifetime. In order to illustrate such changes over the last forty-five years, this article uses the example of 'Mandy', a composite woman patient with a diagnosis of schizophrenia. It shows that, although there have been many advances over this period, understanding of schizophrenia continues to be elusive, and treatments remain imperfect. Therefore, as perspectives shift and the ground moves beneath us, the psychiatric profession needs to anchor itself firmly in the stories our patients tell us.

Keywords: *aetiology; history; outcome; schizophrenia; treatment; USA*

This paper reflects one psychiatrist's personal experience in treating schizophrenia patients over a period of forty-five years. I spent the first five of those years in the USA, training and conducting research studies in a state hospital. Except for one year in England, the rest of my career has been in Canada in an academic environment. Necessarily, my view of the history of schizophrenia reflects the context in which I have practised. My experience and that of my patients would almost certainly have been very different if I had worked in the United Kingdom, in a rural rather than an urban setting, or in a community clinic far from teachers, learners and research experiments. What follows is my subjective view of how concepts of schizophrenia and its preferred treatment have changed. I tell the story as it applies to one patient whom I have called Mandy, but it is really the life story of a composite

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woman patient first diagnosed with schizophrenia in the 1950s, adapting over time to her illness and its treatment in a big city in the USA.

I make the point that, although the stories our patients tell us are listened to differently and interpreted differently and responded to differently at different stages of history, our field, for better or worse, must remain anchored in these stories.

Schizophrenia in the 1960s

My involvement with schizophrenia began in 1961 at the start of my psychiatric residency at the Manhattan State Hospital Research Unit on Ward's Island in New York City's East River. I lived close to the hospital for 5 years, which meant that the 30 women who were inmates of the research unit called New Branch III grew to be, in many ways, my extended family (Seeman, 2004). In 1967 I moved my practice to Toronto, Canada, but, over the 38 years that followed, I have kept in touch by letter, by occasional visits and more recently by e-mail with many of the ex-residents of New Branch III.

Doctors still wore white coats and nurses still wore uniforms when I started my residency. But not long afterwards, the concept of the therapeutic community swept in from across the Atlantic and, in my hospital at least, the hierarchy implicit in white coats and uniforms was shed (Denber, Turns and Seeman, 1968; Jones, 1966; Seeman, 2004). Not only patients, doctors and nurses, but also maintenance and housekeeping staff were asked for input into individual behaviour management. There was a new belief that the organization of institutions influenced recovery (Goffman, 1961). Institutions were seen as malignant. The paternalism associated with total institutions soon began to give way to new views that valued patient autonomy and self-determination. First year residents at Columbia University were taught that human beings were born with equal potential, *tabula rasa* (Petryszak, 1981), and, if mental illness struck some of them in their adult years, the fault must, of necessity, lie within their social environment. Correcting the inner environment of psychiatric hospitals became the mission of the 1960s in much of North America (Goffman, 1961). Since many despaired of ever reforming the poor conditions into which the large psychiatric state institutions had fallen, psychiatric wards began to appear in general hospitals (Garner and Falk, 1967), and community treatment was hailed as the third great revolution in mental health (Rochefort, 1984). (The first revolution was the removal of chains; the second was the discovery of the unconscious.)

Major tranquilizers, as antipsychotic drugs were first called, were being prescribed for schizophrenia, but many American psychiatrists refused to use them. In the 1960s, the majority were convinced that drugs could only lead to symptom substitution – one symptom dissipating but another coming to take its place – unless the conflict from which symptoms arose were first understood (Ayd, 1960). The prevalent practice was for the patient with

schizophrenia to take drugs during the acute stage of illness only, and then to consolidate gains through psychotherapy (Lehmann, 1972).

Mandy

When I met Mandy, she was 25 and had already been in hospital for eight years. Long stays were not unusual at the time. Several salient points about Mandy's history are: three maternal relatives were long-time residents in psychiatric institutions; her mother was not married at the time of her birth; and Mandy had never met her father. Mandy's mother was always on the road, never spending time with her daughter. The child was brought up by her grandfather who abused her sexually for many years. When she was 15, her grandfather hanged himself in the basement of their home, and Mandy was the one who found him. Some years later, Mandy was apprehended by police while walking carelessly between speeding cars on a highway. She wanted to be run over, she told them, 'to prevent capture by the men from Mars'.

Psychiatric residents were expected to do psychological formulations – coherent chronological stories to help them to understand patients' symptoms. Today I would have heavily weighted the genetic component; in 1961 I barely noted it. Though Franz Kallmann was one of our teachers at Columbia and the results of his twin studies in schizophrenia were widely known (Rainer, 1966), genetic determinism, so soon after World War II, was not mentioned in our formulations. The *tabula rasa* concept was favoured. Today I would have focused on the sexual abuse in Mandy's history; back then I would not have thought it important. The shock of finding her grandfather hanging in the basement I would have considered an important precipitant then, as now, but I put most weight in 1961 on what was, in the USA at least, the accepted explanation for schizophrenia symptoms – parents putting children in double bind situations (Bateson, Jackson, Haley and Weakland, 1956; Schuham, 1967; Sluzki, Beavin, Tarnopolsky and Veron, 1967). This is more or less what I would have told Mandy had she asked me why she was sick: 'Your mother expected you to tell her you loved her but she was never there for you and you didn't love her; you hated her. You couldn't admit it, even to yourself; you couldn't escape either, so your way out was to go crazy.' The 'schizophrenogenic mother', a term coined by Frieda Fromm-Reichmann, was enjoying great currency in American psychiatric thinking (Hartwell, 1996; Meyer and Karon, 1967; Neill, 1990).

In the 1960s, to learn how to help patients with schizophrenia, psychiatric residents read *I Never Promised You a Rose Garden* (Greenberg, 1964) by a patient of Fromm-Reichmann and also *Autobiography of a Schizophrenic Girl* by French psychoanalyst, Marguerite de Secheyne (1951). In this book, the cure takes place when the therapist offers the protagonist, Renée, an apple, symbolic of the breast. The idea was, my supervisor told me, to nurture, but only (of course) symbolically. He himself tended not to be overly nurturing.

Whenever I disagreed with him over patient management, he warned me that my rebelliousness would inevitably increase my patients' symptoms – the Stanton Schwartz phenomenon (Denber, 1987), a powerful psychological guilt-making theory that had evolved from the belief that institutional events influence patient recovery. I understood from my supervisor that patients were made sick by their parents (read: mothers) and re-traumatized by trainees who disagreed with their mentors.

Our research unit was engaged in the early screening of antipsychotic drugs. At that point several drugs were already on the market and many more were in field trials. Drug trials in the early 1960s were not what they are today. They consisted of clinical observations. There was no blinding and no randomization. Informed consent was unnecessary. There were no institutional review boards. Initially, there were no rating scales, and results were reported in a narrative fashion (Cleghorn, 1984). But, after 1962 as an aftermath of the thalidomide calamity, rating scales were made mandatory.

Mandy's treatments in hospital

During the day the dormitory of New Branch III was kept locked so patients could not lie abed. Our patients were expected to work during the day, packaging, sorting, assembling (Brooks, Deane and Laqueur, 1970). The profits from work contracts helped the research. One research protocol Mandy took part in was a trial of mescaline, touted for a time as a cure for psychosis (Denber, 1964). When that did not work, she was tried on a variety of new antipsychotics and did best on butaperazine (Bordeleau, Rajotte and Tetreault, 1964–65), a drug we studied under the code number AHR 712, later marketed as Repoise, now abandoned. Mandy was also treated with a combination of insulin coma and family therapy. The latter was a form of psychological regression therapy in which family members were invited to participate so that healthy, clinically supervised 'rebirth' of the patient could begin (Laqueur, 1969). Barbiturates were used for sleep; there were auxiliary therapies of various sorts, including psychodrama, gestalt and token economies (Seeman, 2002).

Due to successful treatment or perhaps to the enactment of new legislation (the Community Mental Health Centers Act; Rochefort, 1984), at age 27 Mandy was released from hospital after a 10-year stay.

Hospital discharge

Many problems faced her when she left the hospital, not unlike those facing newly discharged patients today. One question patients asked, then as now, was: 'How long do I have to continue taking these medications?' The answer we gave to that question, at the time, was: 'Continue medications only while symptoms persist.' A second question was whether or not to live with family

who, the prevailing view having been communicated to the patient, had contributed to the original illness. The advice in those days was to stay away from family whenever possible. A third important issue in the 1960s was how the transition to another therapist could most smoothly be made (I was planning to leave the city before too long). Influential work on separation trauma in schizophrenia had just been published, stressing the need for object constancy (Burnham, Gladstone and Gibson, 1969; Searles, 1965), so this question loomed larger than it would today. Nowadays I am always shocked by the cavalier (in my opinion) fashion with which residents move from one rotation to another, leaving their patients to the ministrations of others without a passing thought to the impact of the discontinuity.

Another issue for Mandy was work. After some deliberation, she was referred to a sheltered workshop. The expectation was that she would eventually move on from there to competitive work. Mandy asked about the prospect of marriage and family, and we discussed the pros and cons. Although residents did not put genetics into psychodynamic formulations, I recall that, as a profession, psychiatrists were not in favour of patients with schizophrenia bringing children into the world. Not that I recall ever discussing contraception with my patients in the 1960s. We talked to them about sexual fantasies involving their fathers, but we seemed to avoid the subject of sexuality in real time.

Ten years later

In 1972 I caught up with Mandy again while visiting New York City. She was on depot medications and was attending an aftercare clinic, relatively standard practice at that time (Lehmann, 1970). She lived in her own subsidized apartment. She had been provided with financial assistance to return to school, had done very well and was now working as a Practical Nurse. Psychotic symptoms were not apparent when I talked to her. Over the course of the ten years since her hospital discharge, she had had several romantic relationships, had become pregnant once and had given the child up for adoption. At that time, this would not have been an unusual step for a single woman to take.

Psychiatry had become the target of labelling theorists in sociology, cultural relativists in anthropology, antipsychiatrists from within the discipline itself, and critical historians of psychiatry (Fabrega, 2001). Revisionism led to the waning of psychological theories about the origins of schizophrenia. Blaming parents for illness was on the way out. Schizophrenia was now commonly spoken about as caused by a 'chemical imbalance' (Ban and Lehmann, 1977; Gallagher, 1977). Social therapies (engaging the patient in work-related activities and social interaction) had nevertheless been shown to decrease relapse rates over and beyond what drugs could accomplish on their own (Hogarty, Goldberg, Schooler and Ulrich, 1974). Drugs plus social rehabilitation were considered optimal treatment. This has not changed.

Twenty years later

Psychiatric diagnoses had now become defined by operational criteria and Mandy's official diagnosis was changed to schizoaffective psychosis. Public confidence in psychiatric classification had been badly shaken over the decade by the Rosenhan study (1973). In this study, pretend patients gained admission to psychiatric hospitals by claiming to hear a voice that said 'empty', 'hollow' or 'thud'. All of them received a psychiatric diagnosis (mainly schizophrenia) even though, once admitted, they no longer complained of any symptom and behaved naturally. In a second part of the study, the hospital staff were informed (falsely) that at some time during the following three months one or more pretend patients would attempt to be admitted. This led to 10% of real patients being suspected of masquerading as pseudo-patients (Rosenhan, 1973). Tightening up diagnosis was an important advance.

Patients had always found the side-effects of drugs hard to tolerate but by 1982 tardive dyskinesia (TD) was widely recognized as a very prevalent and undesirable long-term side-effect (Ezrin-Waters, Seeman and Seeman, 1981; Task Force ..., 1980), especially problematic because it persisted even when drugs were withdrawn and often led to legal suits against psychiatrists. Indeed, when I visited Mandy, her shoulders twitched and she had developed spasms around her mouth. She was no longer working and had started to drink heavily. Drinking was thought of as more a moral flaw than a medical disorder, compared with today, and it was not yet recognized that many individuals with psychotic disorders (almost 50%) drink alcohol to combat the psychophysiological effects of antipsychotic drugs.

Mandy was living with a man considerably younger than herself and, interestingly, had developed a new closeness with her mother. Her mother had joined NAMI, the National Alliance for the Mentally Ill (Howe and Howe, 1987), and had taken up a cause: to debunk the new buzzword in schizophrenia circles, 'Expressed Emotion' (EE). This was a reference to the high levels of criticism and hostility found in a parent's speech when talking about their child, the patient. Levels of EE had been shown to correlate with early relapse in schizophrenia (Leff and Vaughn, 1980). NAMI considered this line of thinking to be anti-parent and did not support the research. For the most part, in the USA and Canada, schizophrenia was considered a form of progressive degeneration or atrophy of neural tissue, starting at adolescence, triggered by stress and developing over time (Barrett, 1998).

Thirty years later

By the 1990s it seemed to me as if an about-face had occurred in the theorizing about schizophrenia. Although social deterioration was evident over the course of time in many patients, longitudinal brain imaging studies did not, on the whole, support brain degeneration. New imaging techniques

confirmed earlier reports (Johnstone, Crow, Frith, Husband and Kreef, 1976) of intracerebral ventricle enlargement indicative of early brain atrophy (Van Horn and McManus, 1992). Since the enlargement was already detectable at the patient's first presentation to hospital and did not appear to worsen over time, it seemed to point to a stable, nonprogressive early deficit. The thinking became that neurodevelopment (not neurodegeneration) was at fault in most instances of schizophrenia, the inhibition or impairment of the formation of well-functioning neural circuits in foetal life (Arnold, 1999) through mechanisms still unknown.

Mandy was 56 and clinically not doing well. Her mother had died. Her man friend had disappeared. Whether from alcohol, from grieving, from menopause or financial concerns, the symptoms of Mandy's illness had rekindled (Seeman, 1998). Despite the stable deficit theory, she now had more symptoms than ever, and they were more severe. She thought enemy agents were following her, slipping powerful drugs into her food, entering her apartment at night, mumbling messages into her ears. Her medication, which had been changed to a low dose 'atypical' antipsychotic because of the TD, was not proving effective. She had several hospital admissions and was once again put on an intramuscular depot. Her TD got worse.

2005

Mandy is now 69. I saw her recently in New York. She is being treated with clozapine, an antipsychotic drug recognized as being effective in about two-thirds of patients classified as 'non-responsive'. Her psychotic symptoms are more stable than they were. Her tardive dyskinesia is thankfully gone. She lives relatively contentedly in a seniors' (retirement) home. She has grown very fat. She suffers from diabetes and also from heart disease. Obesity, diabetes and heart disease are too often associated with the use of clozapine and some of the other 'atypical' antipsychotic drugs (Casey, 2004; Miller and Molla, 2005). During these last 8 years, she has had both breasts removed due to cancer. Antipsychotic drugs have been suspected of raising the risk of breast cancer in women (Wang, Walker, Tsuang, Orav, *et al.*, 2002), although this is not generally believed to be true (Sweeney, Blair, Anderson, Lazovich and Folsom, 2004). Despite health problems, Mandy has been active. She attends a writing workshop where psychiatric patients are encouraged to write their stories in one of three narrative frames: stories of loss, tales of survival and self-discovery, and narratives of the self as a patient (Davies, 2001). She has decided that hers will be a tale of survival.

Because of her family history, Mandy is much sought after now to give blood for genetic testing (schizophrenia is currently thought to result from a small number of yet-to-be identified genes, each probably exerting a small effect; Sanders and Gejman, 2001). Being an only child with no descendants makes Mandy an uninformative subject for family linkage studies, but she

can contribute to association strategies that compare haplotypes of unrelated affected individuals with those of unaffected individuals. There now exist many genetic clues to possible schizophrenia, 'hot' spots in the human genome that have been linked to the illness, but so far, for want of replication and characterization, these clues remain promising (Rutter and Plomin, 1997) but tentative (DeLisi, 2000).

In the current age of molecular medicine, psychiatrists appreciate that mutation in the coding sequence of genes or their promoter regions is not the only way to produce illness (Guttmacher and Collins, 2002). As it adapts to individual experience, the nervous system in early life is remarkably malleable, structurally and functionally. In this sense, schizophrenia is now considered a genomic (the result of a disturbance of gene expression) rather than a genetic (the result of a mutated gene) disorder, secondary to a still mysterious interaction of genes and epigenetic factors, some perhaps protective and some presumably pathologic.

Conclusion

Major shifts in causal attribution have occurred over these last forty-five years (Thaker and Carpenter, 2001). As new data emerge, they tend to disprove some and uphold other theoretical assumptions. The study of the history of psychiatry is salutary. It allows the profession to tolerate the incompleteness and ambiguity and mutability of many of its concepts (Mulder, 1993). The antipsychiatry movement active in the 1970s and 1980s has, for the moment, become less vocal, perhaps because of rekindled optimism about recovery that has helped to remove some of the stigma associated with mental illness (Dain, 1995).

There are some critics of our current classification system (van Praag, 2000) but most would agree that major improvements have been made in nosology over the last forty years: the standardization of data collection; the formulation of operational diagnostic criteria; the multi-axial approach to psychiatric diagnosis; the development of compromise classification systems; the poly-diagnostic approach; and, most importantly, the idea that psychiatric diagnoses are hypotheses to be tested and not validated categories (Katschnig and Simhandl, 1986). Mel Sabshin (1990) has pointed to other major advances: the emphasis on combined pharmacotherapeutic/psychotherapeutic treatment; the alternatives to full inpatient care; and the much improved outcome databases for psychiatric treatments. John Romano (1994) has underscored: the move from a system of involuntary incarceration and forced treatment in public institutions to a voluntary and pluralistic system; the provision of public and private insurance; support for office, outpatient and inpatient psychiatric care; the resurgence of psychopharmacology; the evolution of multiple modes of psychotherapy; and the pursuit of collaborative research in biological and psychosocial fields simultaneously. Although many have

claimed that the new successes of biological psychiatry have made the profession less humane than it used to be (Lipowski, 1989), biological psychiatry per se is not a new departure (Moncrieff and Crawford, 2001).

What is in store for future Mandys? Through shifts in perspective (which will undoubtedly continue) and despite pressures from health economists, from the pharmaceutical industry, from civil libertarians, from health reformists, and from burdened families, psychiatrists need to carry on patiently elucidating and retelling inner experiences of illness, as did Adolf Meyer (1866–1950) and Karl Jaspers (1883–1969) much earlier than forty-five years ago (Huber, 2002; Winters, 1951–2). However the winds shift, our profession needs to rely on individuals like Mandy to share their stories (Kleinman, 1988), whether they be of symptoms, of loss or of survival.

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