ORIGINAL ARTICLE

Overcoming mental disorder stigma: A short analysis of patient memoirs

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Abstract

There is controversy concerning the relationship between stigma and the conceptualization of mental illness as a biomedical disease. Proponents of the biomedical model argue that conceptualizing mental illness as a biochemical disease benefits patients, because it not only enables them to receive medical treatments but also helps them avoid the stigmas associated with mental illness. Opposing this position, others suggest that biomedical causal trajectory further contributes to stigma. When considering individuals' sense of well-being while living with a mental illness, we believe that this debate detracts us from the most important aspects of removing stigma and enabling patients to develop fulfilling lives. Thus, using patient memoirs, we refocus attention on the patient experience itself, searching for how patients' memoirs can illustrate roads to recovery, resilience, and coping. We examine first what facilitates patients to live a fulfilling life and next, what obstacles they identify to a fulfilling life in the face of their encounter with mental illness.

KEYWORDS

medical model, memoir, mental disorder, stigma

1 | INTRODUCTION: MORE THAN THE BIOMEDICAL MODEL

There is continuing controversy concerning the relationship between stigma and the conceptualization of mental illness as a biomedical disease. Proponents of the biomedical model argue that representing mental illness as a biochemical condition enables clinically diagnosed patients benefit from medical treatments and helps them avoid the stigmatization and blame associated with mental illness.[1,2] In opposing this position, other commentators suggest that biogenetic causal beliefs and diagnostic labelling are positively related to prejudice, fear, and desire for distance.[3] Sociological studies frequently suggest that the biomedical model of understanding mental illness reduces blame; however, these studies also show that the biomedical model augments the perception that people with mental illness are out of control and

are likely to behave in unpredictable and/or violent ways.[4-6] Indeed, even proponents of the biomedical model, on the grounds that the biomedical science of mental illness should be taught to the public to provide the "facts" about mental illness, sometimes note how the "disease explanations for mental illness reduced blame but provoked harsher behavior toward an individual with mental illness."[7]

We argue that in and of itself, the biomedical model of mental illness does not remove stigma and nor contribute to patients' ability to create fulfilling lives for themselves. Even if the aetiology of mental illness was entirely uncontroversial (that is to say, that everyone agreed that mental illness is derived from biochemical imbalances in the brain or genetics and could pinpoint the biochemical and or genetic aetiology of specific mental illnesses), this would not address the question of stigma. Moreover—and potentially more importantly to individuals' sense of well-being when living with a mental illness—

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we believe that this debate detracts us from the most important aspects of removing stigma and enabling patients to develop fulfilling lives. Using patients' memoirs of their illness, we hope to refocus attention on the patient experience itself, searching for how these memoirs can illustrate roads to recovery, resilience, or some form of positive outcome. In doing so, we will examine firstly what facilitates such individuals in meeting their desire to live a fulfilling life and secondly, what obstacles they identify to living such a fulfilling life in the face of their encounter with mental illness. In addition, in light of the concerns raised regarding the biomedical aetiology model, we place particular emphasis on how this model interacts with patients' lives as expressed through the memoirs and especially whether the model plays a positive (or negative) role with respect to stigma, as experienced by the memoir writers.

2 | PATIENT MEMOIRS

Given that our objective combines both an interest in examining positive factors that contribute to developing fulfilling lives for individuals with mental illness, alongside an interest in the importance of the biomedical model and stigma, we have analysed these memoirs against a framework suggestive of both recovery and a reduction in stigma. The framework is based upon studies of schizophrenia in developing countries where it has been suggested that there is both a better long-term outcome for individuals suffering schizophrenia in developing countries and a "low level of stigma attached to mental illness" compared with the West.[8] It is worth spelling out the details of these comparative studies. They were initiated as a part of the World Psychiatry Association's programme to challenge stigma associated with schizophrenia in both developed and developing countries. To serve this purpose, the World Health Organization conducted a number of studies, entitled "The International Pilot, Study of Schizophrenia," and conducted follow-ups to validate their results. The International Pilot, Study of Schizophrenia studies conduct large-scale international collaborative transcultural psychiatric investigation of patients in nine countries—Colombia, (former) Czechoslovakia, Denmark, India, Nigeria, China, Union of Soviet Socialist Republics, United Kingdom, and the United States of America. The sample was recruited from successive admissions or referrals to psychiatric facilities in the different centres.[9] The original study and the follow-up studies involved applying standardized interviews in eight different languages. Despite this linguistic diversity, satisfactory interrater reliability was achieved.[9] Studies suggest that patients with characteristic patterns of signs and symptoms, closely corresponding to descriptions of schizophrenia in the most widely used textbooks, were found in each of the settings. Thus, the diagnostic term schizophrenia was applied by the research psychiatrists to those patients whose clinical characteristics were very similar across these centres.[10] These studies have demonstrated a better long-term outcome for schizophrenia in developing countries, particularly in rural regions. These findings generate some professional contention and disbelief, as they challenge assumptions that people generally do not recover from schizophrenia and that the outcomes of Western treatments and rehabilitation must be more effective. However, the results have shown to be remarkably robust, on the

basis of international replications and 15- to 25-year follow-up studies.[11]

Explanations for this phenomenon are still at the hypothesis level; however, a plausible model developed by Alan Rosen suggests that recovery is aided by (1) greater inclusion or retained social integration in the community in developing countries, so that the person maintains a role or status in the society; (2) involvement in traditional healing rituals, reaffirming communal inclusion and solidarity; (3) availability of a valued work role that can be adapted to a lower level of functioning; (4) availability of an extended kinship or communal network, so that family tension and burden are diffused, and there is often low negatively expressed emotion in the family. As manner of shaping the following discussion of memoirs, we believe that these suggestions made regarding recovery and stigma are appealing and applicable to other cultural contexts and for a broad range of mental illnesses. In addition, they avoid entanglement in the etiological question of what causes mental illness and instead, focus attention upon the experiential and cultural basis to recovery. Based on a modified version of these suggestions concerning recovery and reduction in stigma, we have explored the memoirs through the themes of (1) meaningful involvement in society and work, (2) participation in healing rituals, and (3) levels of negative (or positive) expression about the individual with mental illness among family and community.

Psychiatric patients' memoirs offer us plethora of information about living with a mental illness. We learn about the orientational challenges that are associated with having a mental illness such as psychic pain or other symptoms and signs of the illness that patients encounter.[12] We also find out about the sources of their courage and strength in coping with such disruptions in their daily lives. Memoirs also communicate patients' feelings about different treatment methods such as the use of psychotropic medications, receiving professional psychotherapy, and joining support groups. In addition, memoirs provide insight into how patients feel about their interpersonal relationships, how they are treated within the community, and how others react to them as individuals diagnosed with a mental illness.[12]

Let us highlight the epistemological significance of these particular memoirs. Most of the authors of the memoirs we include in this analysis were diagnosed and received treatment for their conditions in North America, while a few are from Western Europe. Their memoirs have been published within the last 20 years. They are educated, have access to publishing industry, and have largely learned to live with their mental illnesses. Most of them in the memoirs note that the support they received from their families and friends was crucial for their well-being. Most of them also note how relieved they felt once they were diagnosed with a mental illness, because they were able to give a name to otherwise puzzling psychic experiences, but they also note how difficult it was to accept that they had these illnesses.[13] The patients we included the memoirs of have been diagnosed with depression, bipolar illness, ADHD, and schizophrenia.

Our analysis is limited, in a sense, because while there are significant similarities between patients' lived experiences with mental illnesses and their treatment, no single story is the same as the other, and we were only able to capture what it is like for these particular

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individuals to be mentally ill. There is no doubt that some of these experiences would be different for an individual from a different social and intellectual background. In addition, there may be epistemological concerns about the status of truth revealed in the first-person accounts of those suffering from mental illness as have been discussed in the literature.[14] We recognize these potential limitations of our analysis, yet we see our contribution as a complementary rather than exhaustive methodology for understanding the complexity of the encounter with mental disorder and stigma that surround it. In addition, another virtue of attending to patient memoirs, despite the above-mentioned limitations, is that they ride close not just to a person's understanding of their condition but also to what is becoming one of the most widely discussed approaches to the individuation of mental illnesses and disorders, ie, the argument that mental disorders are not discrete entities but exist on a continuum, in a network of interacting symptoms.[15] Memoirs illustrate the heterogeneous character of illness experience even when they share the same label, whereas the biomedical model of mental disorders do not capture such heterogeneity. Thus, revealed in the analysis of memoirs below are patients' unique experiences and perspectives on what had worked for *them* in developing a fulfilling life. We find it significant that they echo some of the arguments put forward by Rosen and suggest that the insights they provide may offer resources for those suffer from mental illness as well as care givers and policy makers.

2.1 | Greater inclusion/retained social integration in the community/availability of a valued work role

A major body of literature is available highlighting the importance of maintaining individuals' existing skills and abilities so that they continue to have a recognized role in society. Within Western societies, such is the importance of having a meaningful employment. This merges with availability of a valued work role that can be adapted to a lower level of functioning.[16,17] Several narrative writers reflect upon the maintenance of work status a key to their successful living. Elyn Saks, in her memoir, writes extensively about how studying philosophy and having a job that she loves helped her function and cope with her schizophrenia.[18] Indeed, she states that "[e]veryone has a niche. Of course, resources are heavily skewed against the mentally ill, and the majority never have a chance to realize anywhere near their potential."[18(p334)] In a tacit note towards the point made that the work environment may need to be adapted to a lower level of functioning, Saks writes, "I am not saying that everyone with schizophrenia or psychotic illness can become a successful professional or academic; I am an exception to a lot of rules, and I know that."[18(p334)]

Another patient, Ruth White, an assistant professor in social work, who struggled with ADHD and bipolar illness, referring to the time when she was under serious challenges, suggests that "During all this, I never missed a day of work. It gave me something to look forward to, some sense of normality."[19(p51)]

Mark Atkins, a professor of psychology and psychiatry, who was once diagnosed with schizophrenia and had hallucinatory experiences, tells how he recovered from his condition by getting integrated again with the community through work. After leaving the psychiatric hospital, he volunteers at a local day care centre run by a regional school

district and later gets hired as a classroom aide. Later, he gets a job at the same centre as a lead teacher and takes extension courses on early child education. He says, referring to this transition from hospital to work, "Most remarkably to me, there were no racing thoughts and no depressive episodes or anxiety-laden interactions."[20(p183)]

2.2 | Involvement in traditional healing rituals/ reaffirming communal inclusion and solidarity/ availability of an extended kinship or communal network

Religious and/or spiritual healing rituals (often equated to "traditional" healing rituals) are unlikely to be appropriate locations for healing if the individual themselves and/or their family and community do not share a common spiritual or religious belief. However, if we extend this definition to include contemporary healing environments, it is possible to speak of talk therapy sessions as well as support group meetings, as forms of healing rituals. These also appear to provide an available source of extended kinship or communal network. In one memoir, the writer states that going to an ADHD support group was "the most amazing feeling. First, I was very uncomfortable with being in a group full of 'sick' people. Even though I don't consider ADHD a 'sickness.' But I felt strange being in a support group. But at 8.30 pm, when the meeting was over it was fabulous. To meet all those people who were like me. It was very 'normalizing'."[21(p46)] Other narratives support the view that talking through illness is both successful and significantly more helpful than psychiatric help alone. Thus, a "voice hearer" from the United Kingdom states that "[t]he people in the group knew exactly how I felt. No doctor or nurse could match that, no matter how many degrees they've got hanging on their walls."[16(p26)] Significantly, this writer of the memoir does not see this talking group as curing the illness (and neither did the psychiatric treatment); however, the group was seen as facilitating connection. "Sharing his experiences enabled Jon to carry on his life despite the existence of voices" suggests Gail Hornstein, who had a conversation with Jon about his experience in the support group.[16(p26)] On a similar ground, Saks suggests that "[m]edication has no doubt played a central role in helping me manage my psychosis, but what has allowed me to see the meaning in my struggles—to make sense of everything that happened before and during the course of my illness, and to mobilize what strengths I may possess into a rich and productive life is talk therapy."[13(p331)] Illustrating the benefits of this form of healing ritual, she also states, "[p]eople like me with a thought illness are not supposed to benefit much from this kind of treatment, a talk therapy oriented toward insight and based upon a relationship."[13(p331)] Thus, it is seen through these memoirs, talk therapy and group support meetings offer a form of structured healing ritual and, in addition, a form of extended community. Although it must be noted that this is not necessarily a community experience in the sense of all members of the community participating (such as might be the case when many members of the village attend the same ceremonies), there is little doubt that sense of healing and community are present in these talk-therapy groups. Note here also that Saks does not deny the helpfulness of the medical treatment, a component of the biomedical trajectory of mental illness, but she emphasizes the importance of talk therapy in

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understanding the meaning of her illness, which was necessary to creating a fulfilling life.

2.3 | Levels of negative expression (in the family)

There are a significant number of memoirs that acknowledge and valorize the importance of having had a supportive family in living with a mental illness. For instance, Atkins says "... my parents' and siblings' support ... during those dark ages of psychiatric impairment, provided me with a strong foundation and confidence. There was always a place to return ..."[15(p184)] We can confidently suggest that positive family support was important for these patients in their quest to build fulfilling lives. Some memoirs record high levels of negative expression from both friends and within the psychiatric profession and reflect how these negative expressions create a situation in which the individual is forced to respond to expectations of negative outcome to the diagnosis.

In one respect, negative attitudes are borne out in patients' lived experiences provided in the memoirs. A patient states, "I realized that once people know you're bipolar, they [people generally] think everything you do is because you're bipolar."[22(p276)] Furthermore, being identified with an illness becomes an expectation that your actions are all in relation to that illness—a form of negative re-enforcement. Thus, Mickey de Valda states that "[b]eing called schizophrenic made me feel that I wasn't a regular person, that I was expected to be violent and dangerous. So I became that person."[16] In a significant way, diagnosis appears to suggest that not only persons should expect that their lives should become significantly worse but also they cannot solve or take remedial action to reduce the likelihood of this negative life scenario. Worse still they may feel an implied pressure to act out upon these negative stereotypes. Thus, in addition, patients' orientational challenges come with having to live with a mental illness they are subject to stigma and discrimination in their social lives, which further exacerbating the difficulties in their lives.

With respect to the reaction of friends, in Ruth White's memoir, it is noted that following diagnosis,

"[i]t was too difficult, too, for many of those same friends ... to accept this new diagnosis. They questioned whether I was not simply stressed out from the many changes that had been going on in my life: a new job, a new city, my partner's move, and my new single-motherhood status." Furthermore, the writer notes, "[i]ronically some of my friends thought that I was just being overmedicalized and overmedicated. That angered me. For my friends to think that I was basically being emotionally lazy hurt me deeply. I knew that if I had called to say that I had cancer, the response would have been significantly different. I would have received empathy instead of being challenged on the validity of my diagnosis ... I also understood that the change in diagnosis from ADHD to manic depression made them question the accuracy of my diagnosis, causing them to wonder whether I was just a victim of big pharma."[14(p46)]

Thus, for White, her diagnosis led to a negative reaction from friends who questioned her diagnosis, which in turn, was seen by White as questioning her judgement and moral qualities. Her friends appear to be stuck in a difficult situation—either accepting this diagnosis and see their friend as a form of human alien to others (as discussed above) or not accepting this diagnosis and risking alienating their friend through being unsympathetic. Either way, the diagnosis seems to be accompanied by a strongly negative level of sentiment, as demonstrated in this memoir.

3 | CONCLUSION

Our review of memoirs supports the framework of suggestions offered as to why individuals with mental illness in developing countries have a better prognosis. As would be expected, maintaining social and work status is key element to continuing to live a fulfilling life. Similarly, healing rituals—albeit in a modified form—are associated with positive outcomes in these memoirs. In addition, as expected, positive feedback about one's life from friends and relatives aids recovery, while negative emotional feedback (sometimes associated with the biomedical model) creates a feeling of isolation or stigmatization. We have found that memoir writers frequently see their own recovery in contradistinction as to how they are diagnosed and expected to live. Being integrated within a community where patients feel connected to, as well as respected, despite the immediate orientational challenges associated with their illness, helps them create fulfilling lives. A successful life with illness is described as the negotiation of position whereby one finds a place in society "in the same manner as everyone else." Highlighting this important point, for instance, Saks suggests that it is not recovery that is vital, but finding "the life that's right for you."[13] Furthermore, re-emphasizing that being mentally ill does not turn individuals to categorically different people (something that the biomedical medical labelling system may encourage), Saks states that this challenge of finding a life that is right for you is a "challenge for all of us, mentally ill or not?"[13] Overcoming the distancing effect of living with a mental illness as emphasized in memoirs is seen as key to a successful life with mental illness, a process that is not necessarily facilitated by the search for disease aetiology.

At the beginning of this paper, we criticized the controversy over whether the biomedical model of mental illness augments or reduces on the grounds that there has not been consideration of other important factors. Our intuition is bolstered by patients such as Saks, who benefited from medical treatment but at the same time recognizes that taking medications to alleviate some of the symptoms of illness was only the tip of the iceberg on her quest to create a fulfilling life. Saks writes that seeing the meaning of her struggle with schizophrenia and making sense of everything that happened before and during the course of her illness helped her create a rich and productive life, for which talk therapy was of crucial help.[13]

One may ask whether we can do without diagnoses, given their influence on generating stigma. We believe, however, that not diagnosing someone with a mental illness would not be able to stop stigma from being generated as stigma is more related to the culture of thinking about mental disorders than diagnosis alone. As the memoirs clearly illustrate, receiving a diagnosis of mental illness comes with a number of benefits that help with the treatment of the individual. Let us list a few here: Health care professionals are able to determine a beneficial treatment plan on the basis of diagnosis, the patient receives comfort in being able to label the problems that they are

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having, they can find a community of individuals with similar conditions with whom they can share their experiences, etc. Thus, instead of getting rid of the practice of diagnosis altogether, we must, as a culture, work to remove the stigma associated with mental illness. Analysis of memoirs aids this process, we believe, because they illustrate the ways in which stigma about mental illness is unwarranted: People with mental illness can lead fulfilling lives while making positive contributions to the society they live in, whether it is through work or being a valuable member of the community.

On the basis of our discussion, therefore, we have two recommendations. First, we recommend that further ethnographic study of mental health attitudes and moral treatments outside of the biomedical Western model of mental illness should be undertaken in order to see if we—in the West—can learn more about how individuals live with mental illness and the role of nonbiomedical understandings of such illness.[23] Rosen states such "findings still generate some professional contention and disbelief, as they challenge outdated assumptions that people generally do not recover from schizophrenia and that the outcomes of Western treatments and rehabilitation must be superior."[8] However, this is not to say that we can learn everything about mental illness from "other" cultures. It is impossible to simulate the cultural conditions available that appear to facilitate this recovery —noting, especially that recovery is highest in rural areas—however, it may be possible to distil the essence of what makes a sustainable and fulfilling life possible and appropriate it to the Western cultural environment.

One might point out that such model is already a part of Western societies. For instance, "involvement in traditional healing rituals" takes in our model the form of "talk therapies or support group meetings," which, in the West, as we have suggested, plays a similar role. Attempts to facilitate access to "normal" job positions of people with mental illness are also, to a degree, present in Western cultures. For example, they are now included in the "normal" system of education, while they were excluded and educated in separate schools in the past. Finally, there is more emphasis on the role of the family and community in helping individuals with mental disorders towards recovery; there is more systematic support on families for them to better help their mentally ill family members. If these mechanisms are already present within the society, what else is left to learn from developing countries, one might further ask. While we recognize that such initiatives are already part of Western societies' efforts to aid the treatment and recovery of the mentally ill, they are not consistent across different Western societies and communities (there are significant differences, for instance, between such initiatives in Europe and the United States). When they are available, they are not often pitched as a crucial aspect of treatment and recovery but rather as ancillary ways to supplement various treatment methods. What we are calling for is a change of culture in making sense of mental illness and treatment where the points we addressed are considered as the necessary components of treatment and recovery. Perhaps the way developing countries engage with mental illness and integrate it in their reality is different, and that changes the experience of the ill people too. The whole tradition of approaching mental illness that is typical to these countries and to which the ill people belong thus provides resources for Western societies.

As a corollary to the first recommendation, our second recommendation is that further studies and research on patients' memoirs should be conducted. Patients' own articulation of how they developed resilience in the face of the challenges associated with their illnesses, as well as the social challenges they were subjected to, will help us better understand what patients need in order to create fulfilling lives for themselves. These ethnographic analyses along with memoir analyses will help us understand which features of our current conceptualization of mental illness may help or block progress towards a fulfilling life or even full recovery. In doing so, we may see the heated discussion as a form of distraction from the overwhelming need to facilitate a positive life outcome for individuals with mental illnesses. As demonstrated by the memoirs, of the biomedical model of mental illness is but one small part in facilitating the recovery of mentally ill patients and does not, as it stands, facilitate an improvement to the lives of individuals living with mental illness.

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