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The suffering of schizophrenia: stigma, enigma and the search for a cure

Fatima Sheikh

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THE SUFFERING OF SCHIZOPHRENIA: STIGMA, ENIGMA AND THE SEARCH FOR A CURE

This Research Report is submitted to the Faculty of Business Administration as partial fulfillment of Masters of Science in Journalism degree

by

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Dedication

With love and affection, I dedicate this work to my sister, Amber Irfan, and brother, Adil Shaikh – my friends and confidants. They encouraged and motivated me when I needed it most. At one point when I thought to quit, Amber made sure her presence and lifted my spirits. Throughout the whole process of reporting, Adil stood beside me and accompanied me wherever I needed.

I further dedicate my work to all prospective students interested in exploring mental illnesses, their treatment and stigma attached to them.

Acknowledgement

I thank Almighty Allah to enable me completing this work. Besides, I thank my mother, Mamuna, my supervisor, Shahzeb Hashim, and my friend, Rabia Bugti, for helping me throughout the process.

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Abstract

Patients suffering from Schizophrenia, a severe mental illness, firmly believe in their delusions due to a loss of connection with reality and creation of an imaginary world. Generally, diagnosis and treatment of the mental disorder have been ignored due to cultural and social setup in Karachi. Schizophrenia cannot be cured but manageable with lifetime medicines and rehabilitation after each lapse. The purpose of my investigative piece is to highlight the stigma attached to Schizophrenia along with a search for its treatment.

Introduction

Each time she has a relapse, Ayesha Aslam's belief grows stronger that someone is trying to get to her through black magic. "I know these are delusions and I am suffering from schizophrenia," says Ayesha, but she can't help but think otherwise.

Donning a yellow shalwar kameez and dupatta, Aslam was waiting in the female waiting area on the ground floor of the Karachi Psychiatric Hospital (KPH). On and off, she has consulted Dr. Mobin Akhtar, the founder and Chief Executive Officer (CEO) of KPH, every week for the last six years. But on this day, she is waiting for Dr. Akhtar Fareed Siddiqui – another consultant psychiatrist.

Aslam was diagnosed with schizophrenia in 2011. She lived in Hyderabad at the time and believes the triggering moment occurred when one night, she had stayed up to prepare for her final exam for grade nine. "Satan came and I could see him," she reminisces. "He told me to meet him regularly and he would take me back with him," she added, the look of horror evident on her face. Schizophrenia is a mental disorder, whereby the patient firmly believes in their delusions due to a loss of connection with reality and creation of an imaginary world. The patient has no insight of the illness and they are unaware of the deterioration and changes in life. At times, the patient has delusions of being controlled by others and they believe people can read their mind. Other symptoms are auditory hallucinations which can be commanding.

Normally, the symptoms of the illness start appearing from 15 to 45 years of age. Patients suffering from schizophrenia have two types of symptoms; positive and negative. In positive symptoms, new things emerge in a patient's life due to the mental illness. They come in the form of hallucinations and delusions on which a patient firmly believes. For instance, someone wants to harm or hurt him or her; the patient hears voices or sees faces; people are talking about him or her; the patient considers himself or herself superior or inferior; he or she doubts the intentions of others and considers them the enemy; the patient also thinks people are addressing him or her in media. Old things vanish from the patient's life in negative symptoms of schizophrenia. They include social withdrawal, emotional detachment and losing the ability to perform daily chores. Schizophrenia can be genetic or environmental. Chances of genetic transmission of the illness can be reduced by upbringing children psychologically strong and by training them to deal with stress. It is not necessary that children always inherit schizophrenia from their parents. It is possible that

five children inherit schizophrenia from one of the parents suffering from the illness. Another possibility is that parents suffer from schizophrenia but no child inherits it.

Biologically, chemical imbalances in the brain cause schizophrenia. The levels of Dopamine and Serotonin increases and the levels of Glutamate and GABA reduces.

It is a non-gender biased illness. Unfortunately, there are no national statistics of this disease in Pakistan. All over the world, one percent of the population suffers from schizophrenia and the ratio of male to female is almost equal.

Socially, a stigma is associated with mental illness. Lack of awareness about schizophrenia - a severe mental illness - leads patients to spiritual healers. Often patients' families connect schizophrenia with behavioral issues which increases the intensity of symptoms resulting in violence. Private hospitals charge exorbitant amounts where psychologists and psychiatrists treat patients suffering from schizophrenia with old methods of Electro Convulsive Therapy (ECT) and doses of injectable medication.

Treatment at Karachi Psychiatric Hospital (KPH)

Aslam's father noticed her talking to herself at night. After her exam the next day, he immediately took her to a hospital. For a year, she was under treatment of Dr. Kishore Kumar, a psychiatrist. "I felt better under his treatment," remembers Aslam. Dr. Kumar then left for abroad and her treatment discontinued. The same year, her father was posted to Karachi and the whole family moved to the metropolis. Then her treatment started at KPH.

KPH was founded by Dr. Syed Mobin Akhtar in 1970. Patients suffering from bipolar disorder, schizophrenia, depression, anxiety and substance abuse visit the hospital frequently. Built on four stories, the head office of the hospital is located on main Nazimabad Number 3. The hospital has four branches in different areas of Karachi and one in Hyderabad. The branches in Karachi are located at Quaidabad, two branches in North Nazimabad Block B and one at M.A Jinnah road. The branch in Hyderabad is at Latifabad No. 2.

"Mainly, schizophrenia is treated through injections," said Sadia Kareem, a psychologist at the KPH's main branch. On the first floor of the hospital, psychologists may be consulted in the Out Patient Department (OPD).

According to Kareem, the minimum duration of admission for a patient suffering from schizophrenia is a week. The injection is administered once a week but it may be injected twice if patient's symptoms worsen.

“The minimum dose of injection is 25 mg (ml),” she said. (Kareem, 2019)

“Antipsychotic injections (for example fluphenazine) are administered to treat patients suffering from schizophrenia because they don't take medicines and chances of relapses are high,” said Dr. Akhter Fareed Siddiqui, a psychiatrist who conducts OPD on the ground floor of KPH. “Its effects can stay for one or two weeks and sometimes for a month.” (Siddiqui, 2019)

The OPD of KPH is divided on an affordability basis. Psychologists conduct OPDs charging from Rs. 550 to Rs. 750. To consult senior doctors (psychiatrists), patients have to pay a hefty amount which starts from Rs. 1,740 while the fee to meet the founder of the hospital, Dr. Akhter, is more than Rs. 7,000. He conducts OPD twice a week. The hospital administration also offers discounts to needy families to make sure no patient goes untreated.

“Junior doctors (psychologists) on the first floor take patients' histories while senior doctors conduct OPD on the ground floor,” said Hidayatullah Ali, an OPD in charge at the first floor of the hospital. “Dr. Syed Mubin Akhter, Dr. Akhter Fareed Siddiqui and Dr. Salah Uddin Siddiqui are senior doctors at the hospital.” (Ali, 2019)

The administration of KPH admit patients on the advice of psychologists. Admitted patients can choose their consulting doctor depending on the amount they can afford to pay.

Aslam was admitted to the main branch of the KPH while it was under construction. “There was a pungent smell and the ward felt like a jail,” says Aslam, recalling her experience at the female ward located on the third floor of the hospital. “Doctors here prefer to keep patients admitted for a month but my father refused so I was only admitted for a few days in the hospital (she couldn't recall exact number of days).” She had been treated with ECT 25 times.

To a follow-up question, just to be certain of the number of times she was given the electric shock, she responded, “I am not sure about the number but ECT was given to me many times.”

According to Siddiqui, ECT is a speedy and effective treatment for patients suffering from schizophrenia. Medicines take time to improve the symptoms. Patients who have severe symptoms are treated with ECT.

“It is an electrical stimulus given to patients of schizophrenia,” explained Siddiqui. “Anesthesia is already present in the machine. It is administered twice a week up to 10 times

according to the symptoms of patients. After four to five ECTs, the symptoms start alleviating,” said the psychiatrist.

Medicines, injections and ECTs are simultaneously used to treat patients suffering from schizophrenia at the hospital.

Not everyone agrees with Siddiqui over the use of electric shocks though.

“ECT is not recommended in the treatment of schizophrenia except for catatonic schizophrenia which is very uncommon,” said Dr. Majid Ali Abidi, head of the department of psychiatry at the Hamdard College of Medicine and Dentistry, Hamdard University. “When the patient goes in stupor, only then is ECT treatment recommended.” (Abidi, 2019)

Abidi, who has more than 20 years of experience at psychiatry, said that in modern pharmacotherapy, effective, safe and imported medication is available, therefore the need of ECT has reduced.

Then there is the admission criteria of patients. KPH has certain criteria to admit patients suffering from schizophrenia, said Siddiqui. The symptoms of mental illness must be intense and families are unable to handle patients at home. Secondly, those patients are admitted who can be suicidal or homicidal.

But during our conversation with Aslam, it was revealed that the said criteria is rarely followed by the psychologists and psychiatrists at the hospital.

Aslam has been under treatment at KPH for six years but doctors keep changing her medicines on a regular basis. The quantity of her medicines changes too, ranging from 100mg to 300 mg, which is also adversely affecting her health.

“Often, saliva flows out of my mouth, my hands shiver, my menstruation cycle is disturbed, I have gained weight and I feel drowsy,” said Aslam. Whenever she stops medication though, her delusions emerge again, she becomes furious, fights with her family members and abuses them physically.

A number of booklets written by KPH doctors in Urdu are on display in OPD rooms on the first and ground floor of the hospital. These are available at the pharmacy store on the first floor and cost between Rs. 70 and Rs. 300. Ayesha has read about schizophrenia from the same books.

“We can’t educate a patient suffering from schizophrenia in a short span of time so we suggest these booklets (in Urdu) to them,” said Kareem.

‘Expert in social issues’, is another designation written in the list of doctors at the hospital. It catches the attention of patients and their families. According to Siddiqui, KPH provides counselling for all the patients according to their needs. It includes patients’ and families’ counselling, marital counselling and others too.

Sadia Karim and Abdullah Aziz don’t know much about any therapies or counselling conducted at the hospital. They have been working as psychologists at the KPH for a few months.

Cultural issues related to mental illnesses

Cultural norms play an important role in how psychiatric illnesses are perceived in society. Dr. Uzma Ambareen, the vice president of Pakistan Association for Mental Health (PAMH) - a not-for-profit organization which works for mental health awareness, its legislation and other services - believes that in Pakistani society, “unfortunately, due to lack of awareness, mostly the first stop over of patients is not a psychiatrist but a religious or spiritual healer”. Most people consider schizophrenia a manifestation of black magic because of the unusual nature of the illness.

According to Ambareen, it is often the one family member who realizes that the problem is a medical one and brings the patient to a psychiatrist. In most cases, however, family members are torn between whether to approach spiritual healers or consult a psychiatrist.

Spiritual healing is part of our cultural belief system, says Ambareen, which is why she prefers not to challenge patients’ families lest she lose the patient. She even suggests to them to continue the spiritual healing, if they desire, depending on the expenses and provided it entails no physical abuse to the patient.

“Which ever healing (spiritual or medical) works, it is beneficial for the patient,” says Ambareen. (Ambareen, 2019)

Mostly, it is the under-privileged and uneducated who frequently visit faith healers, not only just in cases of mental illness, but for almost every ill fortune that may have befallen them. Be it relationship issues, difficulties in work, children’s health or marriage troubles, for these people, faith healers hold the key to everything.

Then there is another group of people who believe in both faith healer and in the rehabilitation system. It is similar to the group of people who try both homeopathic and allopathic medicine.

For Dr. Farah Naseem Saeed, a psychotherapist by profession, some faith healers heal with Quranic verses while others are ‘fake who have set up their theatres’. “Fortunately or unfortunately, people have firm belief in their healing powers which make their survival possible,” said Saeed.

The shrine of Hazrat Noor Ali Shah Shaheed (Noori Baba) is situated at Jehangir Road near Teen Hatti flyover. The shrine is visited by many people who claim to have been possessed by djinns, evil spirits, affected by black magic and psychiatric illnesses.

“Only 15 percent people who come here are actually ill and need spiritual treatment. Other 85 percent visitors are possessed by doubts,” says Aslam Yaseen, the incharge of the shrine appointed by the department of Sindh Auqaf Department.

In the ladies’ section, grills of the windows are full of locks. Women hold the grill tight, screaming, and moving back and forth, or silently asking Noori Baba to bless them and protect them from black magic.

“The rituals of locks and tightening ropes have no connection with reality, also it is not permissible in religion but visitors are allowed to do it for their satisfaction,” said Yaseen.

Most psychiatric patients who visit the shrine are females. It is often difficult for Yaseen to handle them. At times, he has to tie them with a chain because they can get too violent and harm others.

Yaseen said, “Psychiatric patients continuously recite four Quls in front of Noori Baba’s grave which are also written on the cloth of grave cover.”

Many psychiatric patients come to shrines after not having slept for many days. Yaseen suggests them to visit a psychiatrist because half of the healing is possible by visiting the doctor. “Psychiatric patients should go for medical checkup first. Spiritual healing comes next,” said Yaseen. (Yaseen, 2019)

Mostly patients of schizophrenia come too late to psychiatrists because of easy access to faith healers and difficult access to psychiatrists.

Prisoner patients suffering from schizophrenia

Asad Mateen is a 37-year-old divorced prisoner at Central Jail Karachi who is suffering from schizophrenia. He is convicted for one year for not providing family provisions to his wife and children. He was unemployed since 2014. The case was filed by his in-laws. Initially, he was

completing his sentence in District Jail Malir Karachi but he was transferred to Central Jail Karachi in March 2019.

Mateen is a Hafiz e Quran and has completed a Master's degree. He is aggressive, stubborn, short-tempered and has odd behavior. He doesn't really talk to anyone; doesn't eat or drink much; doesn't care much about his self-hygiene and largely stays ungroomed and unkempt. His symptoms also include social isolation and decreased self-care. Consciously, he speaks English but his speech is irrelevant and coherent.

"His symptoms of self-neglect are typical of schizophrenia," said Dr. Waseem Alvi, a psychiatrist at Central Jail Karachi.

When he was brought to the prison, Mateen was uncooperative. He was neither eating food nor he was drinking water. Alvi spent a whole day with Mateen after which he drank four glasses of water in a go. "A person can be dehydrated or his kidney function can be affected due to non-intake of water. Behavioral issues can be neglected but medical issues arise due to non-intake of food and water. They can't be avoided because of danger of organ failure," said Alvi, who has experience of 15 years in psychiatry.

Mateen's hair was extremely unkempt. He hadn't taken a bath in a long time. In the Central Jail premises, he was last given bath by a pipe and his head was shaved so that he doesn't get lice in his hair, Alvi noted in his register. The prisoner was reluctant to attend the court proceedings, the psychiatrist had observed, adding that he wasn't taking medicines therefore they had to be given to him intravenously. It was only after that that he started eating and drinking.

"It is difficult to give oral medication daily to uncooperative prisoners suffering from mental illnesses therefore they are injected every 21 days," said Alvi. (Alvi, 2019)

Generally, mental illnesses, specifically schizophrenia, is either undiagnosed or kept hidden because it is considered 'a disgrace'. When the symptoms become uncontrollable due to non-treatment, a patient suffering from schizophrenia may become violent and commit a crime. Later in prison, the mental illness is diagnosed.

Cases of Khizar Hayat, Imdad Ali, Kanizan Bibi and Saleem Ahmed are proof of undiagnosed patients suffering from schizophrenia. Khizar Hayat was on death row for the last 16 years. He passed away on March 21 at Jinnah Hospital Lahore where he was admitted after he stopped taking food and medication.

In 2001, Hayat killed his colleague because he insulted Hayat on a monetary issue. After two years, he was awarded death sentence by a trial court. Hayat was diagnosed with schizophrenia in 2008. Lahore High Court and Supreme Court dismissed his review petition and maintained the death sentence. Justice Project Pakistan (JPP) approached president of Pakistan to pardon Hayat but it was unsuccessful.

According to Section 444 of the jail rules, a person with a mental illness cannot be executed, his lawyer argued. To deny him this treatment was an arbitrary abuse of power and a violation of Articles 9, 14 and 25 of the Constitution.

Hayat's mental illness made him the target of abuse and attacks by fellow prisoners. On one occasion, he received near-fatal head injuries severe enough to require surgery. After treatment he was in solitary confinement until his death.

Dr. Umair Ali Khan, a Psychiatric Rehabilitation Practitioner at The Recovery House (TRH), believes that the communication of prisoners suffering from schizophrenia has been halted by isolating them to solitary confinement and their symptoms have doubled.

“Worldwide, conviction of prisoners suffering from mental illnesses follows a specific procedure. The prisoner must be treated in a hospital, then he is sent to a rehabilitation center and then he should be convicted,” said Khan. (Khan, 2019)

The Central Jail Karachi's Alvi said that when a prisoner is imprisoned for the first time, he or she may be in anxiety or depression due to the jail's environment – especially if the person belongs to a well-to-do family. Acute anxiety makes their behavior even more disturbed. “Such prisoners take two to three weeks to adjust in the jail environment,” said Alvi. “For habitual criminals, chances of depression are less.”

In January 2019, former Chief Justice (CJ) Saqib Nisar took notice of Hayat's case. The case was referred to a larger bench and adjourned indefinitely.

Imdad Ali was diagnosed with paranoid schizophrenia by Dr. Itisham ul Haq a year before he fatally shot his religious teacher for causing obstruction in his spiritual knowledge. Haq excused from appearance before the court as a defense witness for Ali. In 2002, Ali was sentenced to death. Jail authorities diagnosed him with schizophrenia after six years in 2008.

The apex court took the mentally ill prisoner's case for granted. In October 2016, the SC rejected Ali's wife's review petition on the grounds of his mental illness. The then CJ wrote in the verdict that schizophrenia is a curable disease and not a permanent mental disorder.

According to Alvi, patients confined in jail cells become irritable in closed environment. There should be open time for prisoners in jail so they may walk and exercise. Their positive energy which is excessively produced by chemicals in the brain needs to be burned.

Treatment of schizophrenia at a government hospital

Nazish Sabeen, 24, is diagnosed with schizophrenia. She was admitted in the psychiatry ward of Jinnah Post Graduate Medical Centre (JPMC). One day Sabeen ran away from the hospital. She demanded Sooper biscuit from her mother, Aasia Bibi. Bibi left her in the care to an unknown person as she went to purchase the biscuit. In return, he asked Bibi to bring Samosas for him. Sabeen pushed the man and ran away after her mother had left. No one at the psychiatry ward noticed that a patient suffering from mental illness leaving the ward without her primary caretaker. Bibi was in panic when she couldn't find Sabeen with the man who was supposed to care for her. She ran from one ward to another in search of Sabeen but couldn't find her. Bibi briefed about Sabeen's appearance and dress to security guards and ambulance drivers at the hospital but they were clueless. In the severe heat of March, Bibi fainted in front of the emergency ward of the hospital due to high blood pressure.

When she regained conscious, Bibi called her son Riaz Ahmed and briefed him about the situation. Ahmed reached the hospital instantly. He started calling her mother names and blamed her for being irresponsible. Ahmed told Bibi to bring back Sabeen even if she had to give birth to her again. Bibi wept as she recalled the incident that shaken her world two days ago.

Ahmed reported Sabeen's disappearance in a nearby police station. Later, he left for home because he received a call from his neighbors that Sabeen was at home. Sabeen told him that she looked for her mother but couldn't find her. She also confessed to her mistake of leaving hospital without informing Bibi.

Sabeen had left the hospital and gone home by bus. She was clueless when the conductor asked for the fare because she had no money. A Baloch man travelling in the same bus gave her fare. They both had same destination. Upon reaching Malir 15, she sat on top of a rickshaw in her neighborhood. A woman neighbor asked her about her illness to which Sabeen assured of her health. Then she entered her home, had a paratha, combed her hair and donned her chaddor.

Sabeen was brought back to the JPMC where she remained admitted for the next three weeks. Bibi decided not to leave her alone even for a second in the hospital.

According to JPMC records, Sabeen has been battling a psychotic illness for the last eight years. Her symptoms worsened eight months ago resulting in aggressive behavior, breaking household stuff, fighting with family members, hitting them and bullying them. Sabeen had also run away from home once.

She had the same symptoms back in 2013. After a year's treatment, her symptoms improved and she stopped taking her prescribed medicine. In 2018, the symptoms resurfaced. Psychiatrists at JPMC consider Bibi the primary caretaker of the patient. They diagnosed her psychotic illness as schizophrenia. Her biological, social and family functions are disturbed but she has never attempted suicide or homicide. Sabeen has no history of psychiatric illness in her family.

Bibi said that Sabeen had lots of complaints regarding her social status. The young patient notices people prospering but her brothers are at the same position. Most of the time, she talked gibberish, shouted for no reason and then she laughed. Once she cried for an hour till her eyes became red. Her friend came and talked to her. Sabeen started laughing in front of her and said, "I don't know who is my enemy." Her friend suggested Bibi to take Sabeen to a psychiatric hospital. In 2018, Sabeen was treated at Al-Syed Centre Quaidabad, Landhi (a branch of Karachi Psychiatric Hospital) for four months. Bibi had no clue about the name of the doctor and the diagnosis of her daughter. "Per visit fees of psychiatrist was Rs. 1000. I beseeched the hospital management to reduce the fee to Rs. 500 which I borrowed from my previous employer," said Bibi

The doctor told Bibi that Sabeen would be treated three to four times to become perfectly healthy. Three courses were successfully completed. During the fourth course, the doctor told Bibi that Sabeen was fine now and Bibi should get her daughter married.

During the fourth course, one day Bibi discovered a pile of medicines behind a box. Sabeen threw all the medicines behind the heavy box in her house which was cleaned fortnightly. When Bibi scolded her for not taking medicines, Sabeen claimed that she has been perfectly alright.

Sabeen refused to visit the hospital and resisted by shouting, crying and calling names. This continued for two days. The next day, she started breaking household appliances and tried to inflict harm on her nephew and other members of the family. She bit her mother on the hand. Niaz Ahmed, her brother, started beating her but Bibi pacified him. Later, Sabeen accused her brother Ahmed of raping her. Hearing the accusation, Bibi scolded her harshly.

On the fourth day, Sabeen pulled up her shirt while the family was having lunch. She did it for two days. On next day she pulled down her trousers. Ashamed, confused and concerned, the next day Bibi brought her to the psychiatry department of JPMC.

“Sabeen came with the symptoms of reduced self-care, self-talking, self-laughing, hearing voices, social withdrawal and emotional detachment,” said Dr. Ayub Khan, a postgraduate trainer at the psychiatric ward of JPMC. He was observing Sabeen’s case.

Medicines take two to four weeks to improve patients’ condition. “One-third of patients suffering from schizophrenia need medicines for one year, the other one-third need medicines for five years and the rest of the patients need medicines for life time,” said Khan

“Patients suffering from schizophrenia aren’t aware of the disease which was why Sabeen ran from the hospital,” said Dr. Mohammad Iqbal Afridi, the Chairperson of Department of Psychiatry at JPMC. “They are unaware of their benefit and loss,” he added.

Cost of medication and consultation

Treatment of schizophrenia is almost out of reach for lower middle social class in our society where private hospitals, such as Karachi Psychiatric Hospital, charge exorbitant fees and patients have less access to or knowledge about free treatment at government hospitals.

Sabeen belongs to a Babchi-speaking lower-middle class family. She lives in Malir 15. Her father died 5 years ago. She is the youngest amongst 5 siblings. Bibi has worked for 25 years as a house maid. Bibi spent almost Rs. 5,000, excluding traveling expenses, in four months on Sabeen’s treatment at Al-Syed Centre Quaidabad, Landhi. She borrowed money from her previous employer for Sabeen’s treatment at the hospital. Riaz Ahmed, Sabeen’s brother, is the only bread winner for the family. He works in a company at night shift for Rs. 11,000 per month. The amount is insufficient to run daily affairs of home therefore Bibi had to often borrow money from her previous employer.

The cost of local medicines of schizophrenia range from Rs. 20 to 100 per day while imported medication costs from Rs. 300 onwards per day.

The pharmacy at psychiatry department of JPMC provides free medication to mentally ill patients for life. Mohammad Ayub, 48, has been working at the pharmacy for 19 years. “Patients can get free medicines from here until their illness continues, until JPMC exists and until this department (of psychiatry) exists,” said the assistant pharmacist.

The pharmacy provides free medication to OPD patients and admitted patients at the psychiatry ward. Those who are discharged from the ward get medication for a week. Ayub mentions on the prescription to follow up with the patient on Monday or Thursday at the OPD. On the advice of psychiatrists at the OPD, free medicines are provided to the patients having prescription of psychiatry department of JPMC.

Lack of psychiatrists and psychologists

Because of lack of awareness about the disease, access to a psychiatrist is difficult in Pakistan. Lack of psychiatrists is another major reason for the unaffordable treatment.

“Worldwide, one psychiatrist is recommended for a population of 0.1 to 0.15 million. Pakistan, a country of 220 million people, has only 400 qualified psychiatrists. So it is difficult for patients to reach a psychiatrist. Qualified psychologists are even fewer in number,” says Abidi. (Abidi, 2019)

Zehni Sehat (Mental Health) Free Clinic

Another less explored free clinic for mental patients is situated at Garden Road III, Karachi. Established and operating under the supervision of Pakistan Association for Mental Health (PAMH), Zehni Sehat (Mental Health) Free Clinic provides free consultation and medication to patients. Mostly under-privileged patients visit the clinic. Free medicines are supported by Zakat, donations and free samples by pharmaceutical companies.

Nadeem Khan, the operator and manager at the clinic, who has been working there for 20 years, said that patients suffering from different mental illnesses often visit the clinic for consultation. Such cases are often messed up by doctors at Karachi Psychiatric Hospital, Civil Hospital and Lyari Hospital.

Dr. Uzma Ambareen, the Vice President and a member of Executive Committee at PAMH, has been working pro bono at the clinic since its inauguration in December 2002.

People suffering from depression and anxiety are more frequent visitors to the free clinic. Out of 30 patients, Ambareen treats 5 to 6 patients suffering from schizophrenia on a regular basis. Ambareen considers family education a vital element for the families of patients suffering from schizophrenia. Family members need to tolerate certain behaviors of patients like anger because it

is a part of schizophrenia. They need to refrain themselves from physical abuse of patients.

According to Ambareen, it is equally important for psychiatrists to work with the family. They need to be educated about their expectations from the medication and patients.

“They (family members) need to be educated about their behavior with the patient and the patient’s behavior too. They need to understand that patients’ actions are part of their illness and not a voluntary act,” said Ambareen.

Psychiatrists at Zehni Sehat (Mental Health) Free Clinic educate patients suffering from schizophrenia after recovery. Ambreen said that at times, patients realize they are suffering from schizophrenia, or they don’t realize their illness at all, or they realize it to the extent of taking medicines.

“It is our belief that if patients can understand their illness, they can manage it well without depending on others,” said Ambareen. (Ambareen, 2019)

Social stigma attached to schizophrenia

Schizophrenia is an illness of youngsters who are either busy in education, involved in a relationship or setting up their lives after marriage. Normally, families of patients connect the symptoms of schizophrenia to either failure in exam, failure to continue a relationship or difficulties in coping up with newly married life. The stresses of real life play a precipitating role in this illness.

There is a stigma attached with mental illness and schizophrenia is seen as a curse or shame therefore it must be kept hidden. A myth prevails in the society that people suffering from schizophrenia are mad and they can never be sane. They should be isolated and no expectations should be made from them. People also think that medicines can’t control schizophrenia; rather it makes them drowsy. Violence is also frequently associated with the patients of schizophrenia.

“A very small percentage of schizophrenia are violent,” clarifies Ambareen. “Mostly, they become victims of violence because they are vulnerable.”

At times families disown patient suffering from schizophrenia. Mostly it depends on the guidance provided to families and medical expenses because the treatment lasts for a long time for many patients. At times, families become tired because of the expenses, taking care of patients, and unemployment of the patients (if they are unemployed).

Role of a psychologist in the treatment of schizophrenia

Psychotherapist or psychologist has an equally important role in controlling, recovery and rehabilitation of schizophrenia. In Pakistan, usually a dichotomy exists between psychology and psychiatry. People think they need either one of them but in reality, both psychologist and psychiatrist are required hand in hand to treat schizophrenia because it has behavioral as well as physiological symptoms. Behavioral symptoms are managed by a psychologist or occupational therapist whereas psychiatrists deal with the physiological symptoms.

At times, many patients become stable with the treatment of psychiatrists. The need of psychologist depends on the prognosis of psychiatrist, symptoms of patient and the time at which the treatment starts.

When the prognosis is treatment resistant, the patient needs a psychologist. Treatment resistant schizophrenia means the brain is not responding to chemicals. In such a situation, a psychologist or an occupational therapist induce things behaviorally in patients.

In mental retardation and drugs usage, a patient suffering from schizophrenia essentially needs psychological intervention to educate them. Learning disability and addiction of drugs are better handled by psychologists. Psychiatrists can treat it but up to a certain level and not beyond because patients are generally unable to understand them.

As a psychotherapist, Dr. Farah Naseem Saeed analyzes the intensity and frequency of symptoms, the coping mechanism and the effects of medicines in recovery of the patients. “Unfortunately, medicines don’t work at all on some patients with severe symptoms (schizophrenia),” she said. “In other cases, a mild doze of antipsychotic and mood stabilizer works well.” (Saeed, 2019)

The patient’s symptoms must be basically managed through medication. For three months, Saeed analyzes the effects of medicines for basic management of symptoms for a patient.

Patients suffering from mental illnesses and experts of psychiatry has drafted a system of rehabilitation, Illness Management Recovery (IMR). Due to negative connotation of the word ‘illness’, it has been renamed Wellness Management Recovery (WMR).

WMR has ten chapters with submodules. It starts with the idea of recovery for mentally ill patients, understanding their symptoms, identifying their illness (schizophrenia, bipolar or chronic depression), and determining the intensity of the disease. In short, a patient is made aware of his or her symptoms.

“The idea of recovery is difficult for those patients who don’t respond to medication. Mostly medication make patients numb,” explained Saeed.

The meaning of recovery is different for each patient suffering from schizophrenia. Patients may come with the idea of impossible recovery. E.g. a patient may think to become well if he could fly an airplane.

“A psychotherapist brings them to reality, make them see the limitations and redefines the form of recovery,” said Saeed. (Saeed, 2019)

The idea of recovery for patients may be to fulfill their basic responsibilities. For instance, to clean their room; if a patient is a full-time mother, she could send her children to school, cook meals, and fulfill the household responsibilities. For a student it may be going back to college. For a professional it may be going back to work, performing on the job consistently and growing in it. “The idea of recovery also depends on the severity of the damage,” said Saeed.

A chapter in WMR briefs about the support system of patient which depends on relationships. A primary caretaker is required for this system. For male patients, the person can be the mother, sister or wife. For female patients, the primary caretaker is vague or inconsistent. It often depends on mothers how much they think of the wellness of their daughters. In a number of cases, female patients suffering from severe mental illnesses have to take care of themselves.

Another chapter in WMR talks about social conduct for patients of severe mental illness (schizophrenia). Social skills means what to say, how to say, what to hear, how to respond, how to sit, whether to disclose or not or be in one’s own thoughts. These skills of an individual deplete when the mental illness is chronic which means a patient has been suffering from schizophrenia for five to seven years.

Saeed said that patients suffering from severe mental illnesses have social phobia or social anxiety.

A severe symptom in schizophrenia is speeding of thoughts. It also affects social skills of the patient. For instance, a patient talks about weather. Instantly he or she shifts on the color of clothes. Then instantly he or she starts talking about food.

“Before initiating the conversation about the first topic, people suffering from mental illnesses (schizophrenia) shift to another topic,” said Saeed.

People suffering from schizophrenia often become silent in social gatherings. People around them wonder about the reason. On the other extreme, such patients have speeding thoughts

which also gets noticed by people in social gatherings. And people also look at the person curiously to ascertain what is happening with them.

“A therapist helps clients in identifying the root cause of speeding thoughts and whether medication helps in reducing the symptoms or not,” says Saeed. They also help identify the symptoms, triggers, efficacy of medication and the relational context or triggers of the overall illness.” (Saeed, 2019)

Social transactions is another area in which a therapist helps patients suffering from schizophrenia. For instance, going to the post office, market, bank or other shopping stuff. Therapists train such patients in purchasing things from shops, what to ask, how to talk when one goes to a bank etc.

How to get the best out of a psychiatrist, primary caretaker and therapist?

Saeed said that patients suffering from severe mental illnesses (schizophrenia) should articulate their needs and feelings to psychiatrists, primary caretakers and therapists. WMR has a chapter focusing on communication methods.

“A patient must disclose to the psychiatrist about the symptoms if medicines are unable to alleviate them. It is a patient’s right to discuss with the practitioner about new symptoms, old ones and effects of medicines on the symptoms,” said Saeed.

Patients suffering from schizophrenia sometimes opt for substance abuse to pacify their symptoms which haven’t been diagnosed. Such patients are dually diagnosed, severe mental illness and substance abuse. Choice of substance abuse for instance, alcohol, cocaine, heroin, hash and others, depends on culture and affordability. Brain of patients suffering from schizophrenia is already compromised. Intake of harmful or brain-altering substances makes it even more compromised, leading to psychosis and the symptoms of schizophrenia also become more acute. Saeed said that illness of such patients are called substance abuse psychosis.

Severe illnesses (including schizophrenia) are a byproduct of traumatic experiences of an individual. They can be physical, emotional or sexual abuse in childhood or in adulthood; it could be loss or death of someone to whom the person is attached. Continuous medication makes the patient numb. By working with a practitioner, a patient gets aware of root causes of the illness.

Saeed said, “According to research if a child loses their parents before 11 years of age, they are bound to have severe mental illness unless they get therapy. Therapy prevents the severity of illness by minimizing the stresses and challenges which are acting as triggers.”

Besides educating about the symptoms, a therapist also prevents patients suffering from schizophrenia from relapses. His role is to look deep into root causes to heal trauma. The expertise of a psychotherapist helps in healing trauma of a patient which decreases the intensity of stresses resulting in reducing the symptoms. It will reduce the form of illness and eventually a patient can manage the life. (Saeed, 2019)

Relationships or support system for the patients suffering from schizophrenia

The dynamics of relationships play major role in severe illnesses. A person doesn't born with schizophrenia. Besides trauma, something triggers to create mental illness. They lose trust. Communication breaks down. If mental disease doesn't get diagnosed for a long time, family members – parents and siblings - term the person as stubborn. They see schizophrenia as behavioral issue. Most of the times, before the diagnosis of schizophrenia, distance has already been created in the relationships. And they have been mutilated. That is why relationships become triggers rather than support for a person suffering from schizophrenia.

Peer groups support system is an effective idea of rehabilitation proposed by WMS. In it patients of mental illnesses with similar symptoms are brought together to work on their depleted skills regardless of the diagnosis.

How the media portrays schizophrenia

Generally, the media is seen to portray an inaccurate depiction of patients suffering from schizophrenia, largely focusing on the violent tendencies. Dramas and movies have given a persona of aggression to the patients suffering from mental health issues. In reality, less than one percent patients of mental illnesses are aggressive. Patients suffering from schizophrenia develop a specific kind of negative thought pattern associated with their loved ones. For instance, a boy associates such patterns with his mother. The symptoms then become out of control and in rare cases there is physical and verbal abuse.

“There is no uncontrolled violence in schizophrenia. There are more chances that patients can be subjected to violence,” said Umair Ali Khan, a psychologist. “Patients suffering from schizophrenia at times are so scared when they come to The Recover House (TRH) that he or she can’t express their anger properly. The reason is fear of physical violence.”

Saeed said that illness or psychosis doesn’t bring aggression. Aggression already exists in a person which becomes the reason for mental illness. “In our society children are oppressed for emotional and anger expressions, freedom and sexual abuse,” said the psychotherapist. “All these factors lead to psychosis and culturally, society is responsible for severe mental illnesses.”

The Recovery House – a rehabilitation center for patients suffering from mental illnesses

Situated at Tipu Sultan Road, Karachi, The Recovery House (TRH) rehabilitates controlled and stable patients of mental illnesses. Amongst the patients at TRH, 90 percent are suffering from schizophrenia. They choose the TRH because of long term hospitalization and rehabilitation. For other mental illnesses like depression and anxiety, a patient rarely needs such treatment. Patients suffering from schizophrenia have no knowledge about their illness. They consider themselves perfectly alright therefore rehabilitation is necessary for them.

Normally patients suffering from schizophrenia come after ten years of the initiation of the disease to the TRH. That is the acute stage and the disease has become worse. Family members usually ignore patients. They consider it either behavioral issues or black magic. In such a situation, the symptoms can’t be managed instantly.

According to experts, the best time to treat a patient is after the first episode, when a simple medicine can control the symptoms. “In our society, mostly the diagnosis is not done at that stage,” said Khan.

Mostly, acute patients come after the third or fourth episode of schizophrenia. In such a condition, chemicals in the brain have been disturbed therefore a combination of medicines is administered which takes time to produce its effects. Patients may have become violent at this stage and a threat of suicide or homicide may be possible due to commanding hallucinations and delusions.

Patients suffering from schizophrenia have three levels namely acute, controlled and stable. In acute level, the symptoms of patients are high. Hospitalization is necessary for such patients because they don't take oral medicines. Psychiatrists treat them on intravenous. One injection works for 15 days as the medicine slowly releases into the body. The injectable medicines have to be repeated because of severe symptoms.

At times it is difficult for family members to handle acute patients of schizophrenia at home because they don't take medicines and it is difficult to administer them through water because the patients don't trust their family members. Hospitalization is a preventive measure because the ability of acute patients to self-harm or inflict harm to others have exceeded.

At the TRH, patients suffering from mental illnesses, whose symptoms are under control, are admitted for rehabilitation where their depleted skills are built. For instance, patients can't take care of self hygiene, they can't follow their daily living routine or they can't manage their anger. The staff at the TRH helps patients to cover the deficit in living, learning and socializing. These include behavioral interventions and cognitive behavioral interventions.

“Psychiatrists monitor medicines, psychologists monitor behavioral issues and nursing staff helps patients in their daily issues,” said Khan

Controlled means a patient is going through a professional intervention. At the TRH, there is a controlled environment which includes his daily routine, nursing staff is monitoring him, psychologists are running him and psychiatrists are monitoring him. He is being given medicine and he takes them because he has no other option. When a patient reminds caretakers at the TRH for his medicine or he informs about going to take shower, it means he is moving towards stability. A patient comes with symptoms on which TRH applies controls and intervention. The more the role of professional intervention started reducing, the patient is moving towards stability.

From three to six months, controlled patients suffering from schizophrenia are treated at the TRH. Later they move to day rehab from 9am to 4pm, five days a week. In the next step, the days are reduced to three days a week and then one day a week. The step down is on the basis of meaningful engagements in the life of a client. It depends on the improvement of his or her quality of life. It also depends on how he is managing his life. Either on the basis of his own skills or through the support of someone else or utilizing the available resources.

When a client reaches to one day rehab a week and doctors feel that he has become stable and his functionality in life exceeds from 50 percent, then the client is transferred to OPD. The

patient has becomes able enough to live with minimal support system. The TRH doesn't provide OPD to non-clients.

In OPD, a patient has to consult psychiatrist in a month, two or three for the side effects of medicines and to maintain dosage. Professional interventions complete after a specific time but medication continues for lifelong. A client may be stepped up from OPD to rehabilitation according to his condition and choice.

“Currently the TRH has two to three clients who have stepped up from OPD to rehabilitation,” said Khan.

Medicines play a vital role in treatment of schizophrenia. Counselling, psychiatric rehabilitation and vocational training comes next. Psychiatrists control the symptoms of the patients suffering from schizophrenia because it is similar to diabetes and high blood pressure which can't be cured but controlled through medication.

“Up till now, all the medication of schizophrenia can control its symptoms and can't cure the illness. A very small percentage of patients suffering from schizophrenia become cured through medication and later they need not to take medicines. Rest of the patients can lead normal life with medication continuing throughout their lives,” said Ambareen, a medical director at the TRH. Schizophrenia is a neurological defect in the brain occurred due to imbalances of chemicals. To maintain the levels of chemicals, pharmaceutical help is permanent. They have to be maintained on a specific dosage for lifelong just like medicines of diabetes, cholesterol or hyper tension.

Early diagnosis of schizophrenia takes less medication and less professional expertise to recover a patient while in late prognosis a patient takes more time to recover. The treatment also becomes complex. Intravenous medication and combination of different formula tablets are required to obtain a specific result.

“Antibiotics for physiological diseases affect patients on fifth day but medication for schizophrenia takes three to four weeks to activate in the body,” said Khan. “Psychiatrists have to wait during the period to analyze the effects of medication. In late prognosis, further four weeks are required to maintain dosage or adjust formula therefore treatment becomes more complex.”

Importance of medical history of patients suffering from schizophrenia

Six months of history is necessary for the patients suffering from schizophrenia. Without the history of patients it is extremely difficult to diagnose the exact illness. Incomplete history of patients also lead to misdiagnosis. At times, family members are not aware of the history and patient is not in the proper condition to narrate about his illness.

Khan said that in the case of absence of history, schizophrenia is mostly confused with bipolar disorder. The medication of bipolar and schizophrenia is almost similar therefore wrong diagnosis doesn't make much difference. But in rare conditions, schizophrenia may be diagnosed as depression or anxiety. Movement disorders are possible due to increased level of serotonin.

For the patients suffering from schizophrenia, mostly people think if the symptoms are not visible, the problem has been resolved. For instance, a patient gets admitted in a hospital for fury. If the symptom disappears, the family thinks he is stable. But they don't notice other symptoms emerging in the patients' life. For instance, he is not talking to any family members. Rehabilitation is necessary for such patients but its awareness is rare in the society.

Family psycho education intervention

Dr. Uzma Ambareen conducts a 12 weeks family training when a patient is in residence at the TRH. 'Family Psycho Education Intervention' is the name of the program. She educates families to understand schizophrenia and try to tackle patients at home.

Khan said, "It is a compulsory training for the families of patients conducted every Thursday for two hours. It includes dealings with patients after residence program; for instance conversation with them, to understand them, and to set their limits. It also includes education about symptoms, relapses and medication." (Ambareen, 2019)

Lapse in schizophrenia

Lapse and relapse in schizophrenia is common but preventive measures can reduce its chances. In rehabilitation, a psychotherapist educates a patient and his or her caretaker of the symptoms therefore in case of lapse or relapse a patient could immediately contact the psychiatrist and brief them about his or her condition.

"Every relapse in severe illness depletes the cognitive area of a patient. To keep it intact, a patient has to prevent relapses," said Saeed, the psychotherapist.

Patients suffering from schizophrenia may lapse if they stop taking medicines. Early diagnosis of a lapse increases the chances of rapid stability. Missing a lapse leads to relapse after which the treatment starts from scratch.

Environmental factors, like agitation and stress, lead to lapse in schizophrenia even for those patients who regularly take medication. A patient may have delusions of people making fun of him or her. When people around the patient actually do so, chances of lapse are high instead of regularly medication. The patient can recover with adjustment of medicines according to the symptoms and therapies.

Families of patients suffering from schizophrenia are educated to be aware of patients' daily routine outside the home. Patients are also educated to understand their triggers and symptoms of stress and with whom they should talk to share their condition.

A crisis management plan is made at the TRH in which patients identify their triggers of agitation. They also identify a person with whom they can talk to in such a situation. It may be a family member, a psychiatrist, a psychologist or anyone else. Patients make this well thought plan in stable condition to prevent chances of lapse.

Schizophrenia – a mental illness of highly intellectual people

Schizophrenia is associated with highly intellectual people. John Forbes Nash, an American Mathematician, was a patient of schizophrenia. He made fundamental contributions to game theory, differential geometry, and the study of partial differential equations. His theories are widely used in Economics. Born in 1928, Nash shared the Nobel Memorial Prize in Economic Sciences with two other game theorists in 1994 while he was serving as a Senior Research Mathematician at Princeton University. In 2015, he also shared the Abel Prize with Louis Nirenberg for his work on nonlinear partial differential equations.

Sylvia Nasar gathered events of Nash's life and compiled them as biography in her book titled 'A Beautiful Mind'. The book later dramatized as a movie in 2001.

If patients suffering from schizophrenia are treated and rehabilitated, they can become highly productive members of society. The IQ level of such patients is higher than common people. "My profession doesn't allow me to call a person mad who has a higher IQ level than me," said Abidi. (Abidi, 2019)

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