Key Challenges and Unmet Needs in Schizophrenia

Bridging the Gap Between Healthcare Professionals and Patients

A Pilot Malaysian Study
WHAT THE REPORT WILL COVER

Executive Summary

Survey Results

- **AWARENESS**
  - Public awareness

- **DIAGNOSIS**
  - Diagnosing a patient

- **TREATMENT**
  - Adherence
  - Consultation
  - Patient-doctor relationship
  - Alternative therapy

- **INFORMATION**
  - Access to information

Conclusion

Appendix: Study Objectives

Appendix: Research Methodology
EXECUTIVE SUMMARY

Levels of awareness and understanding of mental health disorders and treatment in Malaysia are low. This is especially true for mental disorders, such as schizophrenia and bipolar disorder. This situation is exacerbated by the:

- Social stigma placed on people with mental health disorders and cultural barriers
- Lack of adequate infrastructure and resources to deliver required counseling, therapy and patient care to mental health patients
- Under-reporting of mental health disorders in mainstream news media

To date, there is no research-based insight on the challenges in understanding, diagnosing and treating mental health disorders or patients’ perspectives specifically in Malaysia. Hence, this Malaysian-centric study was designed to raise the understanding of one mental health disorder - schizophrenia.

The survey covered four key areas: public awareness; diagnosis; treatment; and access to information.

IMPROVING AWARENESS

Social stigma associated with schizophrenia is considered the most prevalent public attitude in Malaysia (59%). This social stigma doesn’t just apply to the general public. Doctors who attended the Malaysian Psychiatric Association and AstraZeneca Neuroscience Symposium in March 2009 highlighted that people within the medical industry, general practitioners and those from other medical disciplines tend to stigmatise schizophrenia, too.

To overcome this, half of the doctors who responded to the survey regard public health campaigns that aim to reduce discrimination against people with mental health problems as the most practical solution. Many also believe education in schools about mental illnesses will help (35%).

IMPROVING DIAGNOSIS

50% of the doctors surveyed said they take more than a year but less than two years to correctly diagnose a patient. However, there is a disconnect between patients and doctors around diagnosis, as patients’ responses varied from less than one year (26%) to get an accurate diagnosis, to eight years or more (23%).
Doctors insist that family history of schizophrenia does not play a role in a patient seeking help for the condition. However, a third of patients (31%) said they initially sought help because of their family history. Almost all doctors said that patients sought help mainly because they noticed symptoms of psychosis (96%). Patients say they only sought help after being sent to the hospital for behaving abnormally (31%).

Awareness and understanding of schizophrenia is very low. This is evident through the survey where a third of patients are mistakenly motivated to seek treatment because of their own family history. This is further validated by the survey, which showed most patients did not seek help until their behaviour becomes so serious that they had to be hospitalised.

**BETTER TREATMENT**

While a large majority of patients expected medication to cure them (67%), most patients were satisfied with their medication, as it helped them feel better and more relaxed. However, more than half of those surveyed stopped taking their medication, despite knowing that there is a chance of relapse.

Doctors and patients both agreed that the top three reasons patients stop taking their medication were:

1. Feeling better (doctors: 91%, patients: 33%)
2. Forgetting to take medication (doctors: 61%, patients: 13%)
3. Too many side-effects (doctors: 67%; patients 13%)

Hence, doctors suggested the top three ways to encourage compliance:

1. Fewer side effects (doctors: 89%; patients: 40%)
2. Fewer pills to take every day (doctors: 87%; patients: 38%)
3. Medicines that permit a normal life (doctors: 72%; patients: 40%)

While patients were generally satisfied with their doctor-patient relationship, they think doctors could provide more information about schizophrenia (23%) and offer more support in managing their condition beyond merely writing prescriptions (19%).

While doctors believed support groups (89%) and psycho-counseling (78%) are useful in terms of psycho-therapy, patients preferred a holistic approach in addition to psycho-counseling (42%), such as participating in regular exercise (46%), social support groups (38%), as well as faith-based groups (33%).

Key Challenges and Unmet Needs in Schizophrenia – April 2009
BETTER INFORMATION

Doctors believed they provide most of the information to patients (50%) and that patients do not seek information from nurses. However, there is a disconnect; patients said they get information elsewhere (family 37%, newspapers and magazines 15%, general practitioners 15%, web-based resources 12%, pharmacists 10%, nurses 8%). There is a need to educate these other sources of information, where appropriate, to ensure patients get correct and accurate information about their condition.

Patients also relied on the internet to gain more knowledge about their condition (12%). However, the doctors surveyed did not consider the internet at all as a source of information when completing the survey.

In terms of the type of information patients would like, they said information on other things they can do to help themselves (50%), as well as on symptoms of this condition (40%) would be most useful.

Mainstream new media is a powerful form of communication in driving more conversations about schizophrenia. According to additional online research, it is evident that there are also patients and carers who are open to sharing their experiences living with schizophrenia on web-based channels. However, the greatest issue with online sources of information is that they can be inaccurate and inconsistent. It was agreed that Malaysian doctors treating schizophrenia needed to understand what type of information was available online so that they knew the best sites to direct patients and which sites to avoid.
Demographics of respondents

Patients (52 respondents)

![Patient Demographics - Gender](chart.png)
Patient Demographics - Age

- 34%: Below 30
- 10%: 30 to 40
- 35%: 40 to 50
- 11%: Above 50 years
- 10%: Unspecified

Key Challenges and Unmet Needs in Schizophrenia – April 2009

AZM/SQL/GO MISC 01 Nov 09
Doctors (46 respondents)

Doctors' Demographics - sector

- Ministry of Health Malaysia: 55%
- University: 39%
- Private: 4%
- Unspecified: 2%
Doctor's Demographics - years in practice

- Below 5 years: 26%
- 5 to 10 years: 15%
- 10 to 15 years: 15%
- 15 to 20 years: 18%
- More than 20 years: 4%
- Unspecified: 15%
SURVEY RESULTS
AWARENESS

Public Awareness

Doctors say social stigma is the most prevalent public attitude towards schizophrenia

- People make no concessions for patients diagnosed with schizophrenia (15%)
- People actively exclude schizophrenia patients from their social circle (15%)
- People joke about the condition (15%)
- People are embarrassed by schizophrenia and do not talk about it (22%)
- People with schizophrenia in my country do not normally tell others that they have the condition (30%)
- People with a mental health problem are generally stigmatised in my country (59%)
- People have no idea what schizophrenia really is (24%)

Social stigma is still the most prevalent public attitude towards schizophrenia, according to doctors. (59%). Another problem is that people with schizophrenia do not tell others they have this condition (30%). There is also a general lack of knowledge and awareness as to what schizophrenia is (24%).
50% of doctors felt that public health campaigns are key to helping change public attitudes towards schizophrenia. And 35% believed there should be more education in school about mental illness.

DISCUSSION

According to the participants of the Malaysian Psychiatric Association and AstraZeneca Neuroscience Symposium, a significant number of people living with schizophrenia are not getting treatment. Only an estimated 5% of Malaysians with schizophrenia are actually registered on the National Mental Health Registry.
Public health campaigns have to be targeted and on-going. This is to ensure continuity and sustainability. Targeted campaigns mean focusing on specific groups of people when creating awareness programmes about schizophrenia. Examples of target groups include young doctors or medical students, and the news media.

Participants of the conference also suggested that the use of true stories and testimonials was more convincing and easier for others to relate to, such as everyday people, e.g. a doctor living with schizophrenia to talk about mental health issues and coping with life, was important.

The participants agreed that social acceptance needed to start from within. Mental health itself is facing discrimination from within the medical circle. As such, Malaysia Psychiatric Association is starting to target young doctors. This is because colleagues and seniors of young doctors during housemanship ridicule mental health practice. MPA talks about how psychiatry is exciting to encourage young doctors to take up psychiatry.

Not enough has been done to educate the community. Hence, MPA should try and seek support from the government to educate the public.

Doctors should discuss and promote self-care to patients, and doctors should empower patients to work together with them to educate the public on mental illness to fight discrimination.
Approximately 75% of doctors take more than a year before an accurate diagnosis is made. However, the patient responses were varied, with 23% of patients surveyed saying it took eight (8) years or more to get an accurate diagnosis, and another 26% saying it took them less than a year to obtain an accurate diagnosis.
<table>
<thead>
<tr>
<th>Reason</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>I was in a hospital emergency room due to injury resulting from a psychotic episode</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>I was taken to hospital due to my behaviour</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>As a result of a screening test for mental illness</td>
<td>2%</td>
<td>98%</td>
</tr>
<tr>
<td>As a result of a general medical examination</td>
<td>13%</td>
<td>87%</td>
</tr>
<tr>
<td>A family history of schizophrenia</td>
<td>100%</td>
<td></td>
</tr>
<tr>
<td>Symptoms of psychotic</td>
<td>96%</td>
<td>4%</td>
</tr>
<tr>
<td>The insistence of friends and family, or employers</td>
<td>80%</td>
<td>20%</td>
</tr>
</tbody>
</table>
Doctors believed patients initially sought help because they noticed symptoms of psychosis (96%). They also say patients initially went to see them due to the insistence of friends and family or employers (80%). Patients, on the other hand, said they initially sought help because they had a family history of schizophrenia (31%) and also that they were taken to the hospital because of their behaviour (31%).

DISCUSSION

Approximately 75% of doctors take more than a year before an accurate diagnosis is made. There is no shortcut to diagnose patients. So doctors should constantly observe the symptoms and causes of their patient’s condition to ensure quicker diagnosis.

The participants at the conference agreed that engagement with patients and their families is important. Family plays an important role. Hence, family education programmes can assist in engaging the whole family, thereby encouraging appropriate treatment and diagnosis.
The majority of patients expected their medication to cure them (67%), while less than a quarter relied on their medication to ease their symptoms and discomfort (21%).
Almost all doctors were certain that their patients stopped taking medication (98%).
Doctors believed many patients stopped taking their medication because they feel better (91%). Doctors also felt that because of the many side effects (67%), patients stopped taking their medication. 61% of doctors say many forget to take their medication.
62% of the patients admitted they stopped taking their medication. This is despite knowing that there could be a possibility of a relapse (77%)
A number of patients stopped taking their medication because they were feeling better (33%). 13% said they forgot to take their medication. Another 13% said it was because there were too many side effects.
When doctors and patients were asked what would help make it easier for patients to take their medication, both doctors and patients agreed the top three choices would be:

1. Fewer side effects (doctors: 89%; patients: 40%)
2. Fewer pills to take every day (doctors: 87%; patients: 38%)
3. Medicines that permit a normal life (doctors: 72%; patients: 40%)
37% were neither satisfied nor dissatisfied with their medication. About 35% said they were satisfied with their medication. They said it helps them feel better (81%) and more relaxed (69%).
The majority of the doctors surveyed said it took two prescriptions before finding the most appropriate one (72%). Less than a quarter got it right the first time.
Consultation

Average time spent on each visit

<table>
<thead>
<tr>
<th>Duration</th>
<th>Patients</th>
<th>Doctors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unspecified</td>
<td>2%</td>
<td>2%</td>
</tr>
<tr>
<td>Less than 15 minutes</td>
<td>35%</td>
<td>17%</td>
</tr>
<tr>
<td>15 minutes or more but less than 30 minutes</td>
<td>48%</td>
<td>59%</td>
</tr>
<tr>
<td>30 minutes or more but less than 45 minutes</td>
<td>15%</td>
<td>17%</td>
</tr>
<tr>
<td>45 minutes or more but less than 60 minutes</td>
<td>0%</td>
<td>4%</td>
</tr>
<tr>
<td>60 minutes or more</td>
<td>0%</td>
<td>0%</td>
</tr>
</tbody>
</table>

Doctors and patients agreed that the average duration of a consultation is between 15 to 30 minutes (59% and 48%, respectively).
Topics discussed extensively during consultation, according to doctors, include compliance issues (98%), treatment side-effects (96%), symptoms of schizophrenia (93%), and psycho-social issues (93%).

<table>
<thead>
<tr>
<th>Topic</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Symptom recognition, therefore prevention of further episodes</td>
<td>93%</td>
<td>7%</td>
</tr>
<tr>
<td>Treatment side-effects</td>
<td>96%</td>
<td>4%</td>
</tr>
<tr>
<td>Compliance issues</td>
<td>98%</td>
<td>2%</td>
</tr>
<tr>
<td>Psycho-social issues (e.g. family, friends, work, social)</td>
<td>93%</td>
<td>7%</td>
</tr>
<tr>
<td>Treatment choices</td>
<td>87%</td>
<td>13%</td>
</tr>
<tr>
<td>Problems with diagnosis</td>
<td>35%</td>
<td>65%</td>
</tr>
<tr>
<td>The symptoms of schizophrenia</td>
<td>93%</td>
<td>7%</td>
</tr>
<tr>
<td>The aetiology of schizophrenia</td>
<td>59%</td>
<td>41%</td>
</tr>
</tbody>
</table>
Most patients were satisfied with their doctor-patient relationship. More than half (52%) said it is good and that there are no major problems. However, there is still room for improvement. One third said their relationship with their doctor is excellent, because their doctor takes time to understand their situation and goes beyond the call of duty.
When asked what doctors could do better and improve on, 23% said doctors could provide useful information about schizophrenia and its treatment. 19% also said doctors could improve by supporting patients in managing their condition above and beyond just giving prescriptions.
Half of the doctors surveyed said that the best way for patients to help themselves is to come in for regular check-ups (51%). 16% said patients can help themselves by being honest about their own condition and obtaining useful information about schizophrenia and its treatment.
Alternative therapy

Doctors said the best alternative therapy is having a support group (89%) and psycho-counseling (78%). Patients, on the other hand, preferred a more holistic approach, including regular exercise (46%), psycho-counseling (42%), support groups (38%) and faith based groups (33%).

DISCUSSION

Participants at the conference were not surprised that a great number of patients discontinue their medication. They commented that many patients saw their medication as possibly providing a cure, so it was expected they would discontinue medication when they felt better. Doctors should address this issue and educate their patients on the role of medication to their condition.

Doctors should spend time on explaining to patients the role of side effects. Patients experience side effects first before the therapeutic effect takes place. Hence, doctors should educate their patients to anticipate this. This is to avoid from patients stopping their medication.
INFORMATION

Access to information

<table>
<thead>
<tr>
<th>Where do patients get information?</th>
<th>Patient</th>
<th>Doctor</th>
</tr>
</thead>
<tbody>
<tr>
<td>Web-based resources</td>
<td>12%</td>
<td>11%</td>
</tr>
<tr>
<td>Newspaper or magazines</td>
<td>9%</td>
<td>15%</td>
</tr>
<tr>
<td>Patient support group</td>
<td>6%</td>
<td>2%</td>
</tr>
<tr>
<td>Pharmacists</td>
<td>2%</td>
<td>10%</td>
</tr>
<tr>
<td>Nurses</td>
<td>0%</td>
<td>8%</td>
</tr>
<tr>
<td>Psychiatrists</td>
<td>27%</td>
<td>50%</td>
</tr>
<tr>
<td>General Practitioners</td>
<td>7%</td>
<td>15%</td>
</tr>
<tr>
<td>Friends</td>
<td>6%</td>
<td>4%</td>
</tr>
<tr>
<td>Family</td>
<td>26%</td>
<td>37%</td>
</tr>
</tbody>
</table>

While doctors believed psychiatrists provide the most information to patients (50%), patients disagreed and said their family members provide the most information (37%). In addition to psychiatrists (27%), patients also obtained information from a variety of sources, including general practitioners (15%) newspapers and magazines (15%), as well as from pharmacists (10%) and nurses (8%).

Patients are also relying on the internet to gain more knowledge about their condition (12%).
Half of the patients surveyed wanted more information on other things they can do to help themselves (50%). They also would like to see more information on the symptoms of schizophrenia (40%), about schizophrenia itself (37%), and the side effects that come with the medication they take (37%).
Most conversations on the internet related to mental health focused on depression.
Most conversations online about schizophrenia were triggered by mainstream news stories (35%). 14% were on personal experiences shared by schizophrenic patients or people who are related or know someone with schizophrenia.

When people talk about schizophrenia on the internet, what do they say?

1. **Schizophrenia = split personality**
   a. Schizophrenia is generally viewed as a serious medical condition that causes a person to have hallucinations or split personalities.
   b. Symptoms cited include feelings of suspicion, talking to self, feeling trapped.

2. **Medication**
   a. Some antipsychotic drugs were mentioned. Most people discussed side effects when antipsychotic drugs were mentioned.
3. **Schizophrenia wrongly diagnosed as spirit possession**
   
a. In Malaysia, some people mistook hallucinations and delusions from schizophrenia as being possessed by spirits. Hence, they did not seek or receive proper medical treatment. Instead, they resorted to consulting non-conventional and non-medically licensed practitioners.

4. **Food affects mental health**
   
a. Diet and exercise helped make a difference to a person’s mental health. The type of food can worsen or improve a person’s mental health, such as eating Omega-3 found in fish, said to help stabilise moods.

**DISCUSSION**

Discussions online about schizophrenia may not be accurate or true. Hence, doctors should lead patients and their family to the correct web resources or channels to ensure that information obtained is accurate and current.

There is a disconnect between patients and doctors in terms of providing information on schizophrenia. Doctors believed they are the key source of information, but patients think otherwise. Hence, doctors should go beyond oral consultation, providing booklets and leaflets on schizophrenia to reinforce what was said.

**CONCLUSION**

This Malaysian-centric study was conducted to improve understanding and identify key challenges in diagnosing and treating schizophrenia. This study reinforced certain beliefs about schizophrenia and highlighted certain issues and disparities in terms of patient and doctors opinions of this condition, allowing for better understanding of this disorder in Malaysia.
APPENDIX: STUDY OBJECTIVES

The primary objective of this initiative was to better understand challenges from both doctor and patient perspectives about the awareness, diagnosis and treatment of schizophrenia in Malaysia.

This was achieved through a small-scale survey of patients, carers, and doctors supplemented by insight derived from social media conversations.

The study was designed to understand:

- Challenges from both doctor and patient perspectives
- Expectations about treatment and adherence
- Doctor-patient relationship dynamics and communication
- Access to information on schizophrenia
APPENDIX: RESEARCH METHODOLOGY

The research had a two-phased approach:

- Qualitative questionnaire with 52 patients of schizophrenia
  - Collaboration with the Malaysian Psychiatric Association to mobilise member specialists to identify respondents
  - Patients were given questionnaires to completed and return to doctors or nurses
  - Completed survey forms were then returned to Survey Central (Edelman)

- Qualitative questionnaire with 46 health professionals
  - Collaboration with the MPA to gain doctors’ perspective
  - Survey posted on MPA website for doctors who are interested to download and fill up the questionnaire
  - Completed questionnaires were returned to Survey Central by email or fax

- Social media (internet) conversation benchmark audit
  - Social media is the umbrella term to describe primarily Internet- and mobile-based tools for sharing and discussing information among people. These discussions usually take place on blogs, forums and other online social networking sites.
  - This method enables better understanding of the volume, content, discussion topics, and sentiment of conversations related to mental health disorders and schizophrenia amongst Malaysian social media conversationalists.
  - This was important as mental health disorders are under-reported in mainstream news media. Furthermore, due to the social stigma attached to mental health disorders, there was a possibility that people were more likely to speak more freely about the condition on web-based channels as these channels allow people to enquire and speak anonymously.