Key Challenges and Unmet Needs in Bipolar Disorder

*Bridging the Gap Between Healthcare Professionals and Patients*

A Pilot Malaysian Study

March and April 2010
WHAT THE REPORT WILL COVER

Executive Summary

Survey Results

- **AWARENESS**
  - Public awareness

- **DIAGNOSIS**
  - Diagnosing a patient

- **TREATMENT**
  - Adherence
  - Alternative therapy

- **INFORMATION**
  - Access to information

Conclusion

Appendix: Study Objectives

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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 – bipolar disorder.

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

IMPROVING AWARENESS

Social stigma associated with bipolar disorder is considered the most prevalent public attitude in Malaysia (59%). In addition, there is a general lack of understanding of what this condition is, from symptoms to how it affects patients.

To overcome this, more than 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.

IMPROVING DIAGNOSIS

37% of the doctors surveyed said they take two (2) years or more, but fewer than four (4) 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 (27%) to get an accurate diagnosis, to eight years or more (27%).
Mis-diagnosis is a prevalent problem. According to doctors, mis-diagnosis happens ‘often’ (51%). This is backed up by 64% of the patients surveyed claiming they were wrongly diagnosed when they first saw the doctor. In most cases, patients were wrongly diagnosed with depression before they were correctly diagnosed. However, problems with diagnosis are least discussed during consultation.

The people around patients (family and friends) play an important role in the initial diagnosis. This is evident through the survey where doctors surveyed say that patients seek help mainly because of the insistence of friends and family, or employers (59%). 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**

Doctors say the most challenging part of treating bipolar patients is getting them to comply with treatment. However, only slightly less than one-third of the patients surveyed stopped taking their medication, despite knowing that there is a chance of relapse.

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

1. Feeling better (doctors: 90%, patients: 9%)
2. Forgetting to take medication (doctors: 59%, patients: 9%)

Hence, doctors and patients believe the top three ways to encourage compliance:

1. Fewer side effects (doctors: 88%; patients: 64%)
2. Fewer pills to take every day (doctors: 85%; patients: 64%)
3. Medicines that permit a normal life (doctors: 73%; patients: 64%)

While doctors believed psycho-counseling (78%) and support groups (63%) are useful in terms of psycho-therapy, patients preferred a holistic approach in addition to support groups (55%), such as participating in regular exercise (55%), psycho-counseling (27%), as well as faith-based groups (27%).
BETTER INFORMATION

Doctors believed they provide most of the information to patients (46%) and that patients do not seek information from nurses. However, there is a disconnect; while patients do get information from their psychiatrist (45%), they also obtain information elsewhere (family 36%, newspapers and magazines 9%, general practitioners 18%, web-based resources 9%, nurses 9%). There is a need to educate these other sources of information, where appropriate, to ensure patients get correct and accurate information about their condition.

In terms of the type of information patients would like, they said information about bipolar itself (45%), as well as the side effects of medication (45%) would be most useful.

According to additional online research, it is evident that there are little or almost no information on bipolar disorder on the internet here in Malaysia. Hence, doctors were urged to contribute more information on bipolar online (E.g. blogs, forums, twitter). Doctors also play a role in leading patients and their family to the correct web resources or channels to ensure that information obtained is accurate and current.
Demographics of respondents

Patients (11 respondents)

![Pie chart showing gender distribution among patients]

**Patients' Demographics - Gender**

- Female: 45%
- Male: 55%
Patient Demographics - Age

- 73%: 30 to 40 years
- 18%: 40 to 50 years
- 9%: Above 50 years
- 3%: Less than 30 years
Doctors (41 respondents)

Doctors' Demographics - Sector

- University: 44%
- Ministry of Health Malaysia: 56%
Doctors' Demographics - Years in practice

- Less than 5 years: 24%
- 5 to 10 years: 44%
- 10 to 15 years: 10%
- 15 to 20 years: 10%
- More than 20 years: 7%
- Unspecified: 5%
SURVEY
RESULTS
Doctors say social stigma is the most prevalent public attitude towards bipolar disorder (63%). But patients feel that mostly people just don’t have any idea what bipolar really is (64%).
59% of doctors felt that public health campaigns are key to helping change public attitudes towards bipolar disorder. And another 59% believed there should be more education in schools about mental illness.
An overwhelming majority of patients (91%) say the people around them who know about their condition are supportive and understanding.
DISCUSSION

According to the survey results, a significant number of people either stigmatise bipolar or have no idea what the condition is. However, friends and family of patients who do know about their condition are supportive and understanding.

Hence, doctors believe that public health campaigns are important to raise the levels of awareness of this condition. Doctors also believe education in schools is important to improve understanding of bipolar disorder and reduce the levels of discrimination amongst the public.

Not enough has been done to educate the community. The MPA should try to seek support from the government to educate the public.
More than half (53%) of the patients rate their relationship with their doctor as ‘good’
Approximately 37% doctors say they take two (2) years or more, but fewer than four (4) years, to correctly diagnose a patient. However, patients say it took either eight (8) years or more (27%), or less than a year (27%), before they were accurately diagnosed.
More than half of the doctors surveyed say that patients seek help mainly because of the insistence of friends and family, or employers (59%). Doctors also believed patients initially sought help because they noticed symptoms of psychosis (41%). Patients say they were first taken to the hospital due to their behavior (45%). Hence, it is the people around patients who play an important role in the initial diagnosis.
Doctors: *How often does misdiagnosis happen?*

- Rarely: 5%
- Frequently: 2%
- Sometimes: 42%
- Often: 51%
Majority of the doctors surveyed said that mis-diagnosis happens ‘often’ (51%). About a third of patients surveyed (64%) say they were wrongly diagnose when they first saw the doctor.
45% of the patients revealed that they were wrongly diagnosed for depression before they were correctly diagnosed with bipolar.
Doctors say compliance issues and psycho-social issues are most discussed during consultation; problems with diagnosis least discussed

**DISCUSSION**

Approximately 37% of doctors take more than two (2) years 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. However, patients feel it takes either eight (8) years or more (27%) or less than a year (27%) before they were accurately diagnosed.

According to doctors, mis-diagnosis happens ‘often’ (51%). This is backed up by 64% of the patients surveyed claiming they were wrongly diagnose when they first saw the doctor. In most cases, patients were wrongly diagnosed with depression before they were correctly diagnosed. However, problems with diagnosis are least discussed during consultation. One possible way to reduce mis-diagnosis is to thoroughly discuss symptoms and problems with diagnosis during consultation.

More than half of the doctors surveyed say that patients seek help mainly because of the insistence of friends and family, or employers (59%). Patients say they were first taken to the hospital due to their behavior (45%). Hence, it is the people around patients who play an important role in the initial diagnosis. Family education programmes can assist in engaging the whole family, thereby encouraging appropriate treatment and diagnosis.
How long, on average do you spend with your patient on each visit?

- Less than 15 minutes: 12%
- 15 minutes or more but less than 30 minutes: 68%
- 30 minutes or more but less than 45 minutes: 20%

68% of doctors say the average duration of a consultation is between 15 and 30 minutes.
Patients say the one thing doctors could do better for them is to spend more time with them (36%)
A large majority of doctors (60%) prescribe two types of medication before finding the most appropriate one.
Doctors say the most challenging part of the management of bipolar is getting patients to adhere to treatment (41%).
Half of the patients surveyed (50%) understand that medication helps them cope day-to-day but more than one-third expect the medication to cure them.
Slightly less than one-third of patients (27%) surveyed have stopped taking their medication and a minority (27%) are not aware that if they stop, there will be a relapse.
Doctors believed many patients stopped taking their medication because they feel better (90%). Doctors also felt that because of the many side effects (59%), patients stopped taking their medication. 59% of doctors say many forget to take their medication.
Patients: Why did you stop taking your medication?

<table>
<thead>
<tr>
<th>Reason</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Other reasons</td>
<td>0%</td>
<td>32%</td>
</tr>
<tr>
<td>Forgot to take medication</td>
<td>9%</td>
<td>24%</td>
</tr>
<tr>
<td>Too many side effects</td>
<td>3%</td>
<td>29%</td>
</tr>
<tr>
<td>Made them feel worse</td>
<td>0%</td>
<td>32%</td>
</tr>
<tr>
<td>No difference in outcome</td>
<td>6%</td>
<td>26%</td>
</tr>
<tr>
<td>Feeling better</td>
<td>9%</td>
<td>24%</td>
</tr>
</tbody>
</table>

Patients (9%) agree that the reason they stop taking medication is that they felt better. They also stopped because they tend to forget to take their medication (9%).

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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: 88%; patients: 64%)
2. Fewer pills to take every day (doctors: 85%; patients: 64%)
3. Medicines that permit a normal life (doctors: 73%; patients: 64%)
According to 40% of doctors, the one thing patients can do to help themselves is to come in for regular checkups.
Doctors say the best alternative therapy is psycho-counseling (78%) and support groups (63%), but patients say support groups (63%) and regular exercise (55%) helps.

**DISCUSSION**

Doctors say the most challenging part of treating bipolar patients is getting them to adhere to treatment. Doctors should address this issue and educate their patients on the role of medication to their condition.

The top two ways to help patients comply to medication:
1. Fewer side effects (doctors: 88%; patients: 64%)
2. Fewer pills to take every day (doctors: 85%; patients: 64%)
3. Medicines that permit a normal life (doctors: 73%; patients: 64%)
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.

Patients are seeking a holistic approach when it comes to alternative therapies such as support groups and regular exercise. Doctors can address this need by directing and recommending patients to the right alternative therapies suitable.
INFORMATION

Access to information

Doctors believed psychiatrists provide the most information to patients (46%), 45% of patients agreed. However, patients also regarded their family members as a key source of information (36%). In addition, patients also obtained information from a variety of sources, including general practitioners (18%) newspapers and magazines (9%), as well as from nurses (9%) and friends (9%).

Patients are also relying on the internet to gain more knowledge about their condition (9%).
73% of patients still trust psychiatrists the most. However, family (55%), friends (45%) and general practitioners (45%) play an important role.
Patients would like to have more information on bipolar itself (45%), as well as the side effects of the medication they’re taking (45%).
CONVERSATIONS ON THE INTERNET

Depression is searched more online than other mental health condition. Most searches come for Petaling Jaya.

**Subregions**
1. Selangor, Malaysia
2. Wilayah Persekutuan Kuala Lumpur, Malaysia
3. Pahang, Malaysia

**Cities**
1. Petaling Jaya, Malaysia
2. Kajang, Malaysia
3. Kuala Lumpur, Malaysia
Most conversations on the internet related to mental health focused on depression.

**DISCUSSION**

Psychiatrists are the key source and the most trusted source of information for patients. Hence, doctors should go beyond oral consultation, providing booklets and leaflets on bipolar disorder to reinforce what was said.

Bipolar disorder is rarely discussed online in Malaysia. Usually, online conversations focus more on general mental health issues as opposed to specific conditions, such as bipolar. Therefore, doctors should contribute more information on bipolar online (e.g. blogs, forums, twitter). Doctors can also help by directing patients and their family to the correct web resources or channels to ensure that information obtained is accurate and current.

**CONCLUSION**

This Malaysian-centric study was conducted to improve understanding and identify key challenges in diagnosing and treating bipolar disorder. This study reinforced certain beliefs about bipolar disorder 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 bipolar disorder 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 bipolar disorder
APPENDIX: RESEARCH METHODOLOGY

The research had a two-phased approach:

- Qualitative questionnaire with 11 patients of bipolar disorder
  - Collaboration with the Malaysian Psychiatric Association to mobilise member specialists to identify respondents
  - Patients were given questionnaires to complete and return to doctors or nurses
  - Completed survey forms were then returned to Survey Central (Edelman)

- Qualitative questionnaire with 41 health professionals
  - Collaboration with the MPA to gain doctors’ perspective
  - 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 bipolar disorder among 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.