

## Reactions to symptoms of mental disorder and help seeking in Sabah, Malaysia.

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### Statement of relevance:

This article is of relevance to any practicing psychiatrist that works with people with strong spiritual beliefs. It offers a new model of help seeking, which is different to the models from Western societies. Understanding the decision making process when people become unwell will help us design services which are more appropriate for people with strong spiritual beliefs. This study demonstrates the need to work collaboratively with religious authorities to improve access to evidence based treatments and to help patients and families integrate spiritual and biomedical explanatory models.

### Abstract

**Background:** the average duration of untreated psychosis in Malaysia is over two years. **Aims:** to understand how systems interact and decisions are made regarding help seeking. **Method:** Interviews were carried out with patients, carers, healthcare staff, religious authorities, traditional healers and community members. **Results:** Four stages of help seeking were identified: 1) noticing symptoms and initial labelling as abnormal, 2) collective decision making, 3) spiritual diagnoses and treatment, 4) psychiatric diagnosis and treatment. Patients are generally brought to the hospital as a last resort if the symptoms are unmanageable. **Conclusions:** Spiritual diagnoses had the advantage of being less stigmatising, giving meaning to symptoms and were seen to offer cure rather than just symptom control. Patients and carers need help to integrate different explanatory models into a meaningful whole. Collaborative working with religious authorities will help healthcare staff to perform this function better as well as leading to earlier use of evidence based treatments. **Declaration of interest:** none.

### Introduction

The reactions to psychological symptoms can have a significant effect on the outcome. For example, critical or hostile reactions from family members<sup>1</sup>, stigmatising reactions from society or receiving medical treatment late, all leading to less favourable outcomes in psychosis<sup>2-4</sup>. Understanding reactions to psychological symptoms is important if we wish to improve outcomes, but most research on pathways to care is based in higher income countries and Western societies<sup>5</sup>. Goldberg and Huxley's model describes how patients go through various "filters" in order to reach care, including community help, primary care and secondary mental health services<sup>6</sup>. In non-Western cultures supernatural beliefs about mental disorders are common and traditional or religious healing is a large part of the response<sup>7-9</sup>. Western models of treatment seeking, cannot be considered typical and cannot easily be generalised to other cultures.

Sabah is one of the East Malaysian states on the island of Borneo. The population is mainly Muslim or Christian, but also has prominent animist/pagan beliefs. The health services in Sabah are under-resourced, with the psychiatric services under particular strain<sup>10</sup>. Most psychiatric disorders are not treated or treated very late, with one study in health clinics in the capital, Kota Kinabalu showing that over 90% of people with mental illness in primary care clinics are not diagnosed or treated<sup>11</sup>. The psychiatric system mainly treats psychotic illness. Depression and anxiety are rarely treated, mainly because symptoms of these disorders are normalised<sup>12</sup>. In Malaysia, religious authorities and *bomoh* (traditional healers) are a large component of the response to mental disorder<sup>13-15</sup>. *Bomoh*

are traditionally believed to have supernatural powers and are found all over Indonesia, Malaysia and Brunei<sup>16,17</sup>. The duration of untreated psychosis in Malaysia is more than two years<sup>18</sup> and part of the reason was believed to be that people seek traditional or spiritual help before they seek medical help<sup>14</sup>. However, recent studies have shown that the duration of untreated psychosis is not significantly different for patients that seek traditional treatment first, and that traditional healers are frequently advising patients to seek treatment in the hospital<sup>19</sup>.

Psychological symptoms are responded to by several different systems, (eg the family, the village, the traditional healthcare system, the psychiatric system) and we need to better understand how these systems interact with each other in order to improve collaboration and access to evidence based healthcare. We also need a better understanding of how patients, families and communities make the decision about which system to use for help seeking.

## Methods

The study applied an action research approach, directed towards finding ways of improving collaboration across the different systems. Semi-structured individual and group interviews were conducted in Bahasa Malaysia and English. The interviews were analysed in their original language using n-vivo software with a grounded theory approach<sup>20</sup>. Highly detailed codes reflecting all possible meanings were generated first, before higher order codes were created. Reflexivity was built into the process by having two people with different cultural and professional backgrounds coding together, having regular discussions, using memos and a reflective diary. The study was approved by the Ministry of Health ethics committee and all respondents gave written informed consent. Member checking to ensure acceptability of the results was done by asking for feedback of our findings from key informants.

## Results

A total of 130 people were interviewed in 27 individual interviews and 26 focus groups of two or more people. This included 62 mental health care staff, 20 patients, 11 family members, 8 village heads, 5 school and college counsellors, 5 primary healthcare staff, 5 district hospital staff, 4 members of NGOs and 7 religious authorities and 3 *bomohs* (traditional healers). First episodes of mental illness were described by all groups of respondents, with staff and community members describing episodes in several people. Nearly all descriptions from patients, carers and staff were of psychotic illness.

The typical pathway to psychiatric services involves four steps (see table 1), although these four steps were not followed in all cases. Steps were sometimes missed or not followed in a linear order.

### 1. Initial labelling and response.

The symptoms of mental disorder described by participants were nearly all external phenomena, such as changes in behaviour. The most common changes were anger, violence against others and hearing voices. These symptoms were noticed by people around the patient, rather than the patient themselves in nearly all accounts. The families were the first to respond to the change. The first response included labelling the problem as abnormal, eg "attitude problem", "lazy", "aggressive" and "weird". Patients and families described a number of emotional reactions when the patient started to behave abnormally, which were predominantly anger, shame and fear. Initial management strategies included prayer, advice, trying to find a reason, trying to hide the problem, attempts to control the person and punishment:

Carer 1 (brother of patient): "Maybe because she was being beaten by the family she felt stressed by them. She was beaten when she fought back. She was different to other girls, she didn't want to do housework, didn't wash her clothes and that was what made my mother angry."

Community participants also gave accounts of people with symptoms of common mental disorders such as anxiety and depression, but they did not label these as "mental disorder".

School counsellor D: "I do not have any mental disorder student because in school we just focus about their motivation, problem of learning, discipline, social problems and drug taking or smoking."

These symptoms were managed by patients, families, schools and communities using the initial management strategies described above. They did not proceed to the next stage of help seeking if the symptoms were contained.

## 2. Collective decision making regarding what is causing the problem and what should be done

Respondents described family discussions, during which hypotheses will be formed about what is causing the problem and a decision taken about what to do. The family and others around the patient attempt to find a reason for the problem. This discussion may include extended family or people such as village leaders.

Ward carer R (husband of patient on ward): "before this we didn't discuss..but after this her own family members noticed and felt it was weird... her changes.. her way of talking.. then we discussed with her family."

Explanations for symptoms at this stage are mainly psychological (eg too much thinking), spiritual or environmental in nature. Sometimes all elements are in the explanation (eg relationship problems lead to mental weakness, which allowed spiritual attack).

Village head 2: "Regarding mental illness, there are two types of mental illness. The first type is stress. The second is where a curse is put on someone and we can see they are truly sick".

The family has to make a decision about where to seek help. In most cases the family decides to rule out spiritual causes first. Family members and patients sometimes described feeling pressured to try treatments from the *bomoh* first by other family members, even if they didn't believe in them. Scepticism towards *bomoh's* was seen in most hospital staff, and many patients and carers. Some believed in spiritual causes, but saw mystical healing from *bomohs* as a form of heresy or felt afraid of it.

Ward Carer C (Husband of patient on ward): "maybe she got possessed or something else, such as a curse. But I wasn't brave enough to get mixed up with these things. Because this type of illness, when they get it, sometimes he gets... how to explain... sometimes it gets worse."

In contrast, uncertainty of religious authorities was not expressed and respondents (including hospital staff) appeared confident in their explanations and were satisfied with their treatments.

In most cases the hospital is seen as the last resort, after other options have been tried. Reasons for this was the community perception of the hospital, which was described by one school counsellor as "like a jail for crazy people". The hospital was seen as a repository where the patients were held

without any hope of treatment. Some patients described how they were surprised when they came to the hospital that they offered treatment.

Patient 2: "I thought [the hospital] is a place for mad people. I didn't know that you could get treatment here. No-one told me."

Pastor 2: "I mean psychiatry in this country has not been well developed. And the mental hospital is viewed as a one way ticket, like you go in there and you get locked up forever."

This was sometimes based on experience of people they know going to the hospital and not being cured.

*Bomoh* 3: "It is proven that a lot of cases that we refer to the doctors are not fully cured, so in the end it will be advised to meet with us."

### 3. Spiritual diagnosis and treatment.

Most patients and carers reported going to *Bomohs* or religious authorities for spiritual diagnosis and treatment.

#### ***Spiritual diagnosis***

*Bomoh's* and religious authorities described a diagnostic process, parallel to the diagnostic process used in medicine. They will take a history and formulate an aetiology, which is based on the likely precipitants for the illness. These precipitants include issues in relationships, emotional issues and spiritual issues. *Bomohs* and religious authorities differed in the degree to which they believed that behavioural and psychological symptoms can be attributed to spiritual problems. Some believed that nearly all behavioural and psychological symptoms are spiritual in nature. Some had integrated the different explanations, for example using biomedical language, but attributing spiritual causes.

Ustaz (Islamic religious teacher): "So they hear voices that others can't hear, in the language of the hospital it is schizophrenia. But there are two categories: the first one is the *Jin* (a kind of spirit) inhabiting the body through a medium using a curse, the second is the *Jin* inhabiting the body without us realising it.."

Some respondents distinguished between spiritual problems and mental disorders and some distinguished psychological problems as a separate category. Ways that they distinguished a mental disorder from a spiritual diagnosis included the voice or appearance changing, the person becoming stronger, fainting or unusual movements, such as the person acting like an animal. If the problem is spiritual, the patient will react when prayers or holy texts are read:

Pastor 1: "for example, when I ask the person to say the prayer, if the person with no problem, he says the prayer, then it is not a possession. Because normally the spirit will not allow the person to say the prayer."

Spiritual diagnoses included *saka* (spiritual inheritance), curses and heresy. *Saka* was mainly described by Islamic respondents and is where someone befriends or makes a deal with a spirit, who inhabits them. When the person dies the spirit is passed onto their descendants. The background history is important for spiritual diagnosis, in that someone with a spiritual problem may have a history of not practising the religion appropriately, practising black magic, failing to keep an agreement with a *Jin*, having conflict with someone who may be responsible for a curse, or having an ancestor who also had a *saka*.

### ***Spiritual treatment***

Treatments from religious authorities normally include reading a Holy Text or prayer, which may be specific to the diagnosis. The patient is sometimes advised to change their lifestyle to avoid future attack. Faith in God is seen as important to recovery. Treatment may involve psychological elements, such as counselling.

Outpatient discussion group patient K: “.. they pray according to the illness. Like for me, I have a mental illness, they have a special prayer for it.”

Treatments from *bomohs* also normally includes reading Holy texts and prayers. *Bomohs* that provide services with elements in line with Holy texts are more likely to be seen as legitimate by Muslim respondents. Treatment from *bomohs* can also include spells and physical elements, such as sprinkling water, pulling or pushing or slapping parts of the body and removing objects (eg needles, eggs) from the body. They may ask the client to drink things, (eg special water, a lime and onion mixture).

If the treatment is not effective, some *bomohs* and religious authorities advise the patient to seek treatment from another religious or spiritual healer with more specialised knowledge in spiritual disturbance or from psychiatric services:

Patient 1 (outpatient): “after meeting [the *bomoh*] then they told me to get the treatment here in [the hospital].”

Others may treat the illness for many years.

Imam: “Yes for cure it can take many years, and until now there are people who have not been cured yet. The reason is that Saka is slow to be cured. Saka is hereditary, dangerous and hard to become normal again.”

#### 4. Psychiatric diagnosis and treatment.

Sending the patient to the hospital usually happens during a crisis, when the family can't stand the behaviour any longer. Families generally sent patients to the hospital directly, sometimes with police assistance, but usually bypassing primary care. One of the main factors that appeared to influence sending to the hospital was contact with someone who worked in the health services.

Ward Carer A (Mother of patient on ward): “It was like I couldn't stand it because I couldn't control her. My daughter was in the house for three days, three nights. Every door was locked. I can't let her go out. I can't sleep any more. She couldn't sleep. She slept for a while and when she awoke, she started throwing things. After that..she was possessed...so I called the Church. They came to persuade her and there is one hospital worker, related to the church, who said it is better to go to the hospital”.

After attending psychiatric treatment, decisions still need to be made about whether to take biomedical treatment when in the community. Patients and carers rarely gave biological explanations and retained spiritual explanations after psychiatric diagnosis. Some patients and carers gave several different explanations for the illness, either assimilating the explanations or accommodating them without any integration or assimilation.

Ward Carer A (Mother of patient on ward): “When she is stressed or depressed, her spirit is weak, and that is when the bad spirits can enter.” (assimilation of explanations)

Some patients fully rejected biomedical explanations, but still attended hospital appointments. Patients and carers were more likely to use social labels, such as “mad” than biomedical labels, such as schizophrenia. Some patients described themselves as “mad”. Others used these terms to describe other patients in the hospital, from whom they differentiated themselves.. The way that they differentiated themselves from the other “mad” people in the hospital was by showing that their illness was explainable, not permanent or not severe. The label of madness was normally applied when the decision is made to bring them to the hospital. “Mental” was used as a synonym for madness, and also had connotations of permanence, being unexplainable and severe. Decisions about whether to follow medical advice was sometimes collective, going back to steps two or three.

Ward carer B (husband of patient on the ward): “For me, before I make any decision, whatever the doctor's advice is, I will meet with my closest family and ask for opinion or permission.. if they say OK I will follow. Because in the village I will meet with the village head.. family, then village head.”

## Discussion

The pathways to care in this study were different from pathways to care in studies from Western societies. Primary care was absent for most people interviewed, decisions are made collectively and spiritual diagnosis and treatment are a significant part of the response to mental illness. The subjects interviewed in this study had a range of beliefs about illness. The decision about which system of care to use is determined by beliefs about the cause of illness, beliefs about the acceptability and perceived efficacy of treatment options and potential stigmatising effect that any label might have. It was not only the patient's beliefs, but also the beliefs of their family and community that lead to treatment seeking decisions. The spiritual explanations are generally preferred to the biomedical explanations and seeking help from psychiatric services is last resort. Kleinman<sup>21</sup> described five processes which are performed by health systems, including lay and traditional healthcare systems: 1. Social construction of the illness experience; 2. establishment of general criteria to guide help seeking; 3. Managing specific illness episodes through labelling and explaining; 4. healing activities; 5. management of outcomes, including management of chronic illness, or treatment failure. The first three functions were all performed more by the spiritual system of care than the biomedical system. For some respondents, the fourth function: healing, is performed only by the alternative and religious healers. The psychiatric system is only performing the fifth function: managing the symptoms after the real healing activity has failed.

It is clear from the interviews that the label of mental disorder is more stigmatising than the spiritual explanations. Attribution theory<sup>22,23</sup> helps to give some explanation for this. Attribution theory describes how searching for cause and meaning behind events is a fundamental part of human behaviour and influences motivation for action. Attribution theory gives three dimensions which affect the way illnesses are stigmatised<sup>24</sup>: *locus*, *control* and *causal stability*. *Locus* is whether the problem is in the person themselves, or something external to the person. Spiritual explanations have a more external locus, in that the problem is not the within the person themselves, but the spirit. *Control* is about whether the person can control the illness or is to blame. The perception of control for both mental disorders and spiritual disorders varies between respondents and different diagnoses. For example, the patient is not normally seen as being responsible for *saka* or curses, but is to blame if the cause is heresy. *Causal stability* is about whether the problem will persist or improve. Spiritual causes were mainly seen as something that could be recovered from. In contrast, mental illness was seen as a “one-way street” that can't be recovered from. Initial labels (eg lazy) were also more stigmatising than spiritual labels, in that they normally had an internal locus and control and described enduring personality traits.

Some subjects simultaneously held a mixture of biomedical, psychological and spiritual illness beliefs. Patients and carers sometimes had spiritual beliefs about causation, but were still receiving biomedical treatment. Spiritual and religious healers were also assimilating spiritual with biomedical beliefs and many said they referred to health services. Good<sup>25</sup> described how patients and families used a network of semantic systems to label and explain symptoms. These systems are often conflicting and contradictory, but when faced with symptoms most people pragmatically use whatever explanatory system gives rise to relevant treatment options. Osman described similar conflicts in Malay culture, between pre-Islamic, Islamic and modern scientific belief systems<sup>16</sup>. This study also shows these conflicts when the decision is made to seek help from either the Bomoh, the religious authorities or the hospital.

If mainstream evidence based medical practitioners wish to collaborate with religious and alternative healers, we need to understand who they are treating. From the descriptions given by religious and alternative healers, many of the people that they heal have symptoms that are not typical of psychotic illness or other mental disorders. If we were to use a psychiatric label for this group, it would most likely be dissociative disorder. Religious authorities are also likely to be treating people with common mental disorders (such as anxiety and depression), through faith based and psychological treatments. The people that are diagnosed as *saka* may have some overlap with schizophrenia. Hearing voices is one of the main symptoms and it is clear from the descriptions that it is considered to be chronic, requiring many years to heal. Working with religious authorities and alternative healers may allow this group to be treated earlier.

Further study is needed to better understand the outcomes of people given spiritual diagnosis rather than psychiatric diagnosis. The spiritual explanatory models have a clear advantage in that the stigma is less and so they are accepted by the people around them. The spiritual treatments are perceived as offering cure, rather than just offering symptom control. The spiritual explanations give meaning to symptoms, which is now accepted as one of the most important aspects of recovery from illness<sup>26,27</sup>. When the symptoms are understandable and not seen as permanent, patients are able to differentiate themselves from the label of madness. However, the biomedical models means that medication and other evidence based treatments are given.

## Conclusions

As healthcare providers we need to be aware of the deficits of the illness models that we are using and understand how other healthcare systems can fill those holes. Biomedical models failed to perform some of the essential functions needed by a healthcare system, particularly failing to provide meaningful and acceptable labels and explanations. We need to help people assimilate explanatory models that are apparently competing, rather than encouraging people to drop spiritual models in favour of biomedical models. Patients need help to integrate their different systems of understanding to construct labels and explanations that are meaningful and acceptable to them. If we want to increase the number of people receiving medication and other evidence based treatments, patients need to integrate biomedical elements into their existing explanatory models in a meaningful way. Meaning-making needs to be a central component of healthcare provision and working with practitioners from other systems of care will allow us to do this better.

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Table 1: Stages in pathway to psychiatric treatment

	<b>1. Initial labelling and response</b>	<b>2. Collective decision making</b>	<b>3. Spiritual diagnosis and treatment</b>	<b>4. Psychiatric diagnosis and treatment</b>
<b>Labelling and explanation</b>	Initial labelling: <i>eg</i> weird, aggressive, attitude problem, angry, amok.	Hypothesis formation: spiritual, psychological, environmental or mixed.	Spiritual diagnosis and formulation: spiritual, psychological, environmental or mixed.	Psychiatric diagnosis together with social labelling: <i>eg</i> mad, mental.
<b>Psychological reactions of patient and family</b>	Anger, shame, blame, fear, confusion, minimising, trying to understand and find a reason.	Trying to understand and find a reason, hope, trying to help. Anger, shame, blame, fear and confusion reduce.	Trying to understand and find a reason, hope. Strengthening or weakening of spiritual beliefs.	Pity, anger, shame, blame, fear, loss of hope, distancing. Relief, hope, acceptance. Accommodation, assimilation or rejection of biomedical model.
<b>Management</b>	Prayer, advice/ counselling, trying to hide the problem, punishment.	Decision to seek treatment with Bomoh, religious authority or hospital	Faith based treatments, psychological treatments, physical treatments/spells or advice to seek help elsewhere.	Hospitalisation and medication (seen as offering containment of symptoms rather than cure).